

Six lives: the provision of public services to people with learning disabilities

Part one: overview and summary investigation reports

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Second report

Session 2008-2009

Presented to Parliament pursuant to
Section 14(4) of the Health Service Commissioners Act 1993

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-I
London: The Stationery Office
£64.15

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ISBN: 9 78 010295 8577

Foreword

I am laying this report before Parliament under section 14(4) of the *Health Service Commissioners Act 1993* (as amended).

The report relates to six investigations which I have conducted as Health Service Ombudsman for England, three of them jointly with the Local Government Ombudsman, Jerry White, in accordance with the powers conferred on us by amendments to our legislation due to *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007*.

The complaints were made by Mencap on behalf of the families of six people with learning disabilities, all of whom died between 2003 and 2005 while in NHS or local authority care.

The complaints were made following Mencap's report, *Death by indifference*, published in March 2007, which led to the setting up of the Independent Inquiry into Access to Healthcare for People with Learning Disabilities by Sir Jonathan Michael MB BS FRCP (Lond) FKC, commissioned by the then Secretary of State for Health. The Inquiry's report, *Healthcare for All*, was published in July 2008.

The complaints were made against a total of 20 public bodies. They all concerned the quality of care which was provided and the majority of them also included concerns about the way in which subsequent complaints about the quality of that care had been handled at local level, and by the Healthcare Commission.

The report is in eight Parts (or volumes).

Part 1 provides an overview of the work we have undertaken, identifies the themes and issues arising from our work, and makes some general recommendations to address those issues. Part 1 also contains a summary of each of the individual investigation reports.

Parts 2 to 7 are the full reports of the six investigations.

Part 8 is an easy read version of Part 1.

Note: Unusually, the summary reports and the full investigation reports are not fully anonymised. This is because some of the names of the complainants are already in the public domain as a result of Mencap's earlier report; and because Mencap have confirmed that the families are content to be named in the published reports. We have taken into account the public interest and the interest of the complainants and the other people affected by our reports and consider that it is necessary in that context to include the names of the complainants.

Our findings

Our investigation reports illustrate some significant and distressing failures in service across both health and social care, leading to situations in which people with learning disabilities experienced prolonged suffering and inappropriate care.

Our investigations found maladministration, service failure and unremedied injustice in relation to a number, but not all, of the NHS bodies and local councils involved. In some cases we concluded that there had been maladministration and service failure for disability related reasons. We also found in some cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality.

Our findings contrast markedly with the first Principle of the recently published *NHS Constitution for England and Wales*, which says that '*The NHS provides a comprehensive service, available to all irrespective of gender, race, disability, age, sexual orientation, religion or belief. It has a duty to each and every individual it serves and must respect their human rights*'.

A similar contrast is evident for social care. *Independence, Well-being and Choice*, published by the Department of Health in March 2005, set out a vision for adult social care and established a standard for social care which was endorsed by the white paper *Our Health, Our Care, Our Say* in January 2006. It says that '[Social care services] should treat people with respect and dignity and support them in overcoming barriers to inclusion... They should focus on positive outcomes and well-being and work proactively to include the most disadvantaged groups'.

The wider context

This report is timely in a number of respects.

On 19 January 2009 the Department of Health published *Valuing People Now: a new three-year strategy for people with learning disabilities*, which reaffirms the commitment to the principles of equality, dignity, rights and inclusion set out in *Valuing People: A New Strategy for Learning Disability for the 21st Century*, published by the Department of Health in 2001. The strategy places strong emphasis on leadership at all levels through the public sector from central government, through regions, to health and local authorities.

On 1 April 2009 a new regulator, the Care Quality Commission, comes into being and from April 2010 a new registration system will come into effect for all health and social care providers.

Finally, this report is laid before Parliament at a time of imminent change in the complaint handling landscape for both health and social care which will take effect from 1 April 2009. I welcome those changes and the opportunity to remind public bodies of the value of dealing with complaints promptly and effectively and, where complaints are justified, offering appropriate remedies.

Together with my Local Government Ombudsman colleague, I am also committed to ensuring that the learning from complaints is fed back to those responsible for the design and delivery of public services so that they can use that feedback to improve those services for the future. There is much to learn from the findings of these investigations, and much to improve. I hope that all NHS bodies and local authorities, together with the relevant regulators and the Department of Health, will respond positively to the recommendations in this report and demonstrate a willingness to learn from it, and that this might provide some small consolation to the families and carers of those who died.



Ann Abraham
Parliamentary and Health Service Ombudsman

March 2009

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Overview summary

Introduction

In March 2007 Mencap published a report, *Death by indifference*, which set out case studies relating to six people with learning disabilities. Mencap believe that they died unnecessarily as a result of receiving worse healthcare than people without learning disabilities.

On behalf of the families involved, Mencap asked the Health Service and Local Government Ombudsmen to investigate complaints about all six cases, three of which span both health and social care. Summaries of each of the investigation reports follow this Overview and the full reports of each individual investigation are published as Parts 2 to 7 of this report.

The investigation reports illustrate some significant and distressing failures in service across both health and social care. They show the devastating impact of organisational behaviour which does not adapt to individual needs, or even consistently follow procedures designed to maintain a basic quality of service for everyone. They identify a lack of leadership and a failure to understand the law in relation to disability discrimination and human rights. This led to situations in which people with learning disabilities were treated less favourably than others, resulting in prolonged suffering and inappropriate care.

The issues range from a complaint about the care provided in a single hospital to complaints about service failures which involve the whole system of health and social care, including the ability of organisations to respond appropriately to complaints. A total of 20 organisations were involved, including 3 councils and 16 NHS bodies. Complaints about the Healthcare Commission's handling of complaints were made in 5 of the 6 cases.

Our reports look at the experiences of:

- **Mark Cannon**
- **Warren Cox**
- **Emma Kemp**
- **Edward Hughes**
- **Martin Ryan**
- **Tom Wakefield**

All of these people died between 2003 and 2005, in circumstances which Mencap alleged amounted to institutional discrimination.

We did not uphold all of the complaints and it should be noted that complaints were not upheld against many of the public bodies involved. In particular, none of the complaints against GPs were upheld. We did see some examples of good practice.

This does not mean we have always been uncritical of the public bodies concerned. There were a number of examples where health professionals in particular could have been more proactive, acted on the advice and information that was given to them by the families or care staff who knew the person best, or adjusted their practice to better meet the needs of the individuals concerned.

In one case we concluded that the death of the person concerned occurred as a consequence of the service failure and maladministration identified. In another case the Health Service Ombudsman concluded that it was likely the death of the person could have been avoided, had the care and treatment provided not fallen so far below the relevant standard. In two cases, although we upheld complaints of service failure and maladministration, we could not conclude that the person's death was avoidable. Mencap have asked us to say that, whether the death could have been avoided or not, this should not detract from the

unacceptable standard of care and treatment that was experienced in those cases. We agree and have no difficulty in doing so.

In four of the six cases we upheld the complaint that the person concerned was treated less favourably, in some aspects of their care and treatment, and in the services of some of the bodies about which complaints were made, for reasons related to their learning disabilities. We also found in four of the six cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality.

Role of the Ombudsmen

The Health Service Ombudsman is empowered to carry out independent investigations into complaints made by, or on behalf of, people who have suffered injustice or hardship because of poor treatment or service provided by the NHS. The Local Government Ombudsman has a similar remit in respect of services provided by councils, which include social care.

Both Ombudsmen look thoroughly at all the circumstances surrounding a complaint and try to resolve it in a way which is fair to all concerned. Where the complaint is justified we look to the public bodies involved to provide an appropriate and proportionate remedy for the injustice or hardship suffered by complainants.

In 2007 a Regulatory Reform Order amended our legislation to give new powers to the Ombudsmen to work together more effectively in investigating and reporting on complaints which cross our respective jurisdictions. These new powers have been relevant in three of the six cases we have investigated. It has enabled us to produce joint investigation reports in those three cases and this joint Overview.

Relevant policy and good practice guidance

Each of the individual investigation reports sets out in detail the relevant legal, policy and administrative framework for the NHS, for social care services commissioned or provided by councils in the three reports where this is relevant, and for arrangements for co-operation between the two. The individual reports also describe the relevant standards and guidance, including professional standards which were in existence between 2003 and 2005, at the time when these deaths occurred.

Of particular relevance is *Valuing People: A New Strategy for Learning Disability for the 21st Century* (Valuing People) issued in 2001, which requires public services to treat people with learning disabilities as individuals with respect for their dignity. Other general guidance, in particular the professional standards set out by the General Medical Council and the Nursing and Midwifery Council, stresses the importance of looking at the individual, of personal accountability, the interests of patients and the need for co-operative working.

One of the most distressing features of our investigations has been the evidence in some cases that these fundamental principles were not being consistently upheld, to the extreme detriment of the individuals concerned.

Treating people as individuals

The *Disability Discrimination Act 1995* makes it unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified. It is also unlawful for service providers to fail to make reasonable adjustments for people with disabilities, where the existence

of a physical barrier, practice, policy or procedure makes it impossible or unreasonably difficult for a person with a disability to use the service provided, unless such a failure is justified.

Equality for people with disabilities does not mean treating them in the same way as everyone else. Sometimes alternative methods of making services available to them have to be found in order to achieve equality in the outcomes for them. The focus is on those outcomes.

In many of the organisations whose actions we investigated it did not appear that this level of understanding of the need to make reasonable adjustments had become embedded, even at the most senior levels, despite the legislation and the extensive guidance available. Our investigations uncovered a lack of understanding of how to make reasonable adjustments in practice, which suggests there may be a need for further training on the practical implementation of the *Disability Discrimination Act 1995*.

When the UK Government introduced the *Human Rights Act 1998* it said that its intention was to create a new 'human rights culture'. A key aspect of that culture is the observance of the core human rights principles of fairness, respect, equality, dignity and autonomy for all. Our investigation reports demonstrate that an underlying culture which values human rights was not in place in the experience of most of the people involved.

Doing the basics well – an issue of leadership

Guidance on standards of practice across a range of health and social care functions is regularly issued and sets out a broad and consistent approach which should be familiar to all professionals in

these fields. These standards will, if observed consistently, offer many of the safeguards essential to ensuring that the needs of people who are vulnerable for any reason are addressed, and appropriate adjustments made to their care.

On many occasions in the lives of the people concerned, basic policy, standards and guidance were not observed, adjustments were not made, and services were not co-ordinated. There was a lack of leadership and in some situations it appeared that no one had a real grasp of what was happening.

The full investigation reports give details of the various complex factors which led to failure to offer good care to individuals in very vulnerable situations. It is this complexity which in itself requires strong leadership to maintain a focus on the experience of and outcomes for people with learning disabilities and, in all probability, many other people with complex needs.

The areas of concern included:

- Communication
- Partnership working and co-ordination
- Relationships with families and carers
- Failure to follow routine procedures
- Quality of management
- Advocacy.

Complaint handling

Most of the complaints which we investigated had been reviewed first by the NHS or council complaints systems. The families told us that their experiences of these systems had left them drained and demoralised and with a feeling of hopelessness.

They gave repeated examples of failures to understand their complaints, with little effort made to clarify matters with them; confused and fragmented systems; poor investigations with little rigorous testing of evidence; defensive explanations; a failure to address the heart of the complaint; and a reluctance to offer apologies. Our investigations generally confirmed this picture.

Complaints against NHS bodies at the time of these events followed a second stage review process by the Healthcare Commission. The families who asked the Healthcare Commission to review their complaints said they had hoped that the Healthcare Commission's review would give them the explanations they sought. In practice, they experienced many of the same problems of delay, lack of contact, poor specification of complaints and a lack of clarity about the process that they had experienced at the first stage of the process. Clinical advice was not always appropriately sourced, explanations were inadequate and the families remained unclear as to what had changed as a result of their complaints. Again, our investigations generally confirmed this picture.

For the most part the NHS bodies and the councils concerned, and the Healthcare Commission, have subsequently acknowledged and apologised for the failings in their complaint handling and have provided information on improvements they have made to their services and to their complaint handling arrangements.

Nonetheless, it remains the case that poor complaint handling compounded the distress which resulted from the failures in service experienced by the families of those who died. These families should not have had to wait so long and fight so hard for the explanations and apologies to which they were entitled.

From 1 April 2009 changes introduced by the *Health and Social Care Act 2008* will implement a single comprehensive complaints process across health and social care, focused on resolving complaints locally with a more personal and comprehensive approach. The Healthcare Commission will be removed as the second tier complaint handler and the Ombudsmen will provide the second and final tier of the new system across health and adult social care. The changes in the system provide an excellent opportunity for health and social care organisations to review their systems and to put in place good arrangements for the future handling of complaints.

Remedy

The unremedied injustice which the Ombudsmen concluded had resulted from the maladministration and service failure identified include:

- An avoidable death and a death which was likely to have been avoidable.
- Unnecessary distress and suffering for the aggrieved.
- Unnecessary distress and suffering for the families of the aggrieved, in particular about those failings which occurred for disability related reasons.

- Distress at unanswered questions of what difference would have been made if there had been no service failure or maladministration. Would the person concerned have lived longer? Could there have been some improved enjoyment in the last period of their life?
- Distress compounded by poor complaint handling leaving questions unanswered.
- Distress arising from a failure to live up to human rights principles.

The remedies which were provided by the councils and NHS bodies concerned, prior to the Ombudsmen's investigations, included:

- Senior level personal apology and offer of meetings.
- Offer to involve family in planning services.
- Actions to address failings and to minimise risk of reoccurrence; action plan notified at Board level and to the regulator.
- Commitment to learn lessons from the investigations, and to work openly and collaboratively with local and central bodies.
- Identification of lessons learnt.

The further remedies recommended and secured by the Ombudsmen include:

- Further personal apologies and offers of meetings.
- Public apologies through the published investigation reports.
- Financial compensation for distress ranging from £5,000 to £40,000.

Conclusion and recommendations

We do not extrapolate from these cases to suggest that all health and social care in respect of people with learning disabilities is poor. Nevertheless, the recurrent nature of the complaints across different agencies leads us to the view that understanding of the issues is at best patchy and at worst an indictment of our society.

In writing this report we have been motivated by the desire to bring positive change from the experiences of these people and their families, which could in itself provide some redress for all those concerned. We are not looking to '*make this a priority for 2009*', but to change underlying attitudes and behaviour on a lasting basis. We do not underestimate the challenges involved.

We have made individual recommendations to address the specific unremedied injustice we have found in the cases where we have upheld the complaints (and for the most part these individual recommendations have been accepted by the public bodies concerned).

However, the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities.

We have thought long and hard about what general recommendations we could properly and usefully make in the light of our investigation findings, and the themes and issues we have identified in this Overview. We are Ombudsmen, not regulators and we do not seek to usurp their role. Nonetheless, we are committed to ensuring that the learning from complaints investigated by us is fed back to those responsible for the design and delivery of public services so that they can use that feedback to improve those services.

We see no point in repeating the detailed recommendations of Sir Jonathan Michael's Independent Inquiry into Access to Healthcare for People with Learning Disabilities, *Healthcare for All*, although we do not disagree with those recommendations.

We welcome the simplified complaint handling arrangements for health and social care which are being introduced from 1 April 2009 and therefore make no specific recommendations for improvements in the complaint handling system.

We have not found any shortage of policy and good practice guidance on the planning and provision of health and social care services for people with learning disabilities; on making reasonable adjustments in order to comply with the requirements of the *Disability Discrimination Act 1995*; or on observing the core human rights principles of fairness, respect, equality, dignity and autonomy for all. We have noted the very recent publication by the Department of Health of *Valuing People Now: a new three-year strategy for people with learning disabilities*. So we make no recommendations for further guidance.

Nonetheless, we are still left with an underlying concern that similar failures to those identified in the investigations will occur again – and indeed may be occurring today in services provided or commissioned by NHS bodies and councils across the country. We believe it is legitimate, in the light of the very serious findings of our investigations, to ask all NHS bodies and councils with social services responsibilities to satisfy themselves that is not the case.

As we have said above, we have concluded that the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities. This is not a question that we, as Ombudsmen with a very specific remit, can or should answer but it is, we suggest, a question which those responsible for commissioning and providing health and social care services should ask themselves; which those responsible for the regulation of health and social care services should ensure is addressed in their regulatory frameworks and performance monitoring regimes; and about which the Department of Health should properly be concerned. Our recommendations are therefore addressed to the leaders of those bodies.

We recommend:

First, that all NHS and social care organisations in England should review urgently:

- the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas;

and

- the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities;

and should report accordingly to those responsible for the governance of those organisations within 12 months of the publication of this report.

Secondly, that **those responsible for the regulation of health and social care services (specifically the Care Quality Commission, Monitor and the Equality and Human Rights Commission)** should satisfy themselves, individually and jointly, that the approach taken in their regulatory frameworks and performance monitoring regimes provides effective assurance that health and social care organisations are meeting their statutory and regulatory requirements in relation to the provision of services to people with learning disabilities; and that they should report accordingly to their respective Boards within 12 months of the publication of this report.

Thirdly, that the **Department of Health** should promote and support the implementation of these recommendations, monitor progress against them and publish a progress report within 18 months of the publication of this report.



Ann Abraham
Parliamentary and Health Service Ombudsman



Jerry White
Local Government Ombudsman

March 2009

Overview report

Introduction

In March 2007 Mencap published a report, *Death by indifference*, which set out case studies relating to six people with learning disabilities. Mencap believe that they died unnecessarily as a result of receiving worse healthcare than people without learning disabilities. Following that publication, Sir Jonathan Michael MB BS FRCP (Lond) FKC, was invited by the then Secretary of State for Health to chair an Independent Inquiry into Access to Healthcare for People with Learning Disabilities. Sir Jonathan's report, *Healthcare for All*, published in July 2008, found significant gaps between the law, policy and the delivery of effective services for people with learning disabilities. He made ten recommendations designed to strengthen the systems for assuring the quality of health services at all levels.

Following the publication of *Death by indifference*, Mencap, on behalf of the six families involved, asked the Health Service and Local Government Ombudsmen to investigate complaints about all six cases, three of which span both health and social care. Summaries of each of the investigation reports are included at the end of this Overview and the full reports of each individual investigation are published as Parts 2 to 7 of the report.

The investigation reports illustrate some significant and distressing failures in service across both health and social care. This is despite extensive policy and guidance published over a number of years concerning the quality and nature of services which should be available to everyone, including people with learning disabilities. It is also despite the expressed commitment of professionals to meeting the needs of individuals. They show the devastating impact of organisational behaviour which does not and apparently cannot adapt to individual needs, or even consistently follow procedures designed

to maintain a basic quality of service for everyone. They identify a lack of leadership and a failure to understand the law in relation to disability discrimination and human rights. This led to situations in which people with learning disabilities were treated less favourably than others, resulting in prolonged suffering and inappropriate care.

Taken together, the investigation reports demonstrate an urgent imperative for organisational and cultural change coupled with individual leadership and commitment. Central government and professional organisations have set out clear expectations in policy and guidance for many years. However, our investigations have found clear evidence of instances in which implementation of these basic requirements was at best patchy and at worst entirely lacking. It seems to us unlikely that these are isolated cases and that they are likely to be indicative of a wider problem. In this situation, the overarching questions arising from our work are to ask what action is required, and by whom should it be done, to ensure that, no matter what their situation, everyone receives the care and support they need in a timely and effective way.

We have investigated six cases in which people with learning disabilities have died. In describing them as 'cases' we are using a shorthand expression to represent information about them, their families and all their personal circumstances. The use of the term is not intended in any way to diminish their individuality and relationships or the grief and distress of their families at their loss.

The issues range from a complaint about the care provided in a single hospital to complaints about service failures which involve the whole system of health and social care, including the ability of organisations to respond appropriately to complaints. A total of 20 organisations were involved, including 3 councils and 16 NHS bodies.

Complaints about the Healthcare Commission's handling of complaints were made in 5 of the 6 cases.

We did not uphold all of the complaints and it should be noted that complaints were not upheld against many of the public bodies involved. In particular, none of the complaints against GPs were upheld. We did see some examples of good practice.

This does not mean we have always been uncritical of the public bodies concerned. There were a number of examples where health professionals in particular could have been more proactive, acted on the advice and information that was given to them by the families or care staff who knew the person best, or adjusted their practice to better meet the needs of the individuals concerned.

The brief illustrative examples given in this Overview highlight the issues but are no substitute for a thorough reading of each of the investigation reports. Our reports look at the experiences of:

- **Mark Cannon** aged 30, a smiling and mischievous young man with a fine sense of humour. He enjoyed activities, social events and outings with his family but also liked just lazing around and relaxing. He had a particularly close relationship with his sister.
- **Warren Cox** aged 30, a happy and contented young man, who was usually quiet but had a great sense of humour and love for everyone. His parents, with whom he lived, described him as very fit.
- **Emma Kemp** aged 26, described by her mother as a 'party animal' who was caring, friendly and sociable and liked dancing, bowling, television and computers. She was lively and active and could understand people who used simple direct language.

- **Edward Hughes** aged 61, who was a quiet, private man who spent much of his life in care. He had been settled in a care home for some time, where he enjoyed the ordinary routines of daily living.
- **Martin Ryan** aged 43, described by his family as a charming, strong and energetic man who took time to get to know people but lived happily in his care home.
- **Tom Wakefield** aged 20, a sociable young man who liked music – particularly Robbie Williams, Blue and Jools Holland. He also enjoyed barbecues and football matches.

All of these people died between 2003 and 2005, in circumstances which Mencap alleged amounted to institutional discrimination. We have undertaken detailed separate investigations into what happened to each one of them. This Overview draws out overarching themes and lessons and makes general recommendations, in addition to the specific recommendations arising from the individual investigations.

We have not upheld all the complaints, but the very nature of our thorough and impartial investigations serves only to heighten the sense of outrage at the treatment received by most of the people involved.

In one case we concluded that the death of the person concerned occurred as a consequence of the service failure and maladministration identified. In another case the Health Service Ombudsman concluded that it was likely the death of the person could have been avoided, had the care and treatment provided not fallen so far below the relevant standard. In two cases, although we upheld complaints of service failure and maladministration, we could not conclude that the person's death was avoidable. Mencap have asked us to say that, whether the death could have been

avoided or not, this should not detract from the unacceptable standard of care and treatment that was experienced in those cases. We agree and have no difficulty in doing so.

In four of the six cases we upheld the complaint that the person concerned was treated less favourably, in some aspects of their care and treatment, and in the services of some of the bodies about which complaints were made, for reasons related to their learning disabilities. We also found in four of the six cases that the public bodies concerned had failed to live up to human rights principles, especially those of dignity and equality.

We believe these outcomes are a shocking indictment of services which profess to value individuals and to personalise services according to individual need.

Role of the Ombudsmen

The Health Service Ombudsman is empowered to carry out independent investigations into complaints made by, or on behalf of, people who have suffered injustice or hardship because of poor treatment or service provided by the NHS. The Local Government Ombudsman has a similar remit in respect of services provided by councils, which include social care. We usually investigate only after the complaint has already been reviewed by the relevant public body and, currently in the case of complaints about NHS bodies, by the Healthcare Commission as well. Our investigations include consideration of the way in which complaints about services have been handled during earlier stages of the process, and the reasonableness of decisions and actions taken in the light of the law and of good practice in existence at the time of the actions concerned.

Both Ombudsmen look thoroughly at all the circumstances surrounding a complaint and try to resolve it in a way which is fair to all concerned. Where the complaint is justified we look to the public bodies involved to provide an appropriate and proportionate remedy for the injustice or hardship suffered by complainants.

Our approach uses the following *Principles of Good Administration*:¹

- Getting it right
- Being customer focused
- Being open and accountable
- Acting fairly and proportionately
- Putting things right
- Seeking continuous improvement.

These Principles, and the outcomes which they provide, are of great relevance to the cases under consideration and are reflected in the individual reports for each person. Above all we have been concerned, in recognising that we cannot in these situations put things right, to secure positive remedies for the families concerned, when we have upheld complaints.

In 2007 a Regulatory Reform Order amended our legislation to give new powers to the Ombudsmen to work together more effectively in investigating and reporting on complaints which cross our respective jurisdictions. These new powers have been relevant in three of the six cases we have investigated. It has enabled us to produce joint investigation reports in those three cases and this joint Overview.

¹ *Principles of Good Administration* is available at www.ombudsman.org.uk

Relevant policy and good practice guidance

Each of the individual investigation reports sets out in detail the relevant legal, policy and administrative framework for the NHS, for social care services commissioned or provided by councils in the three reports where this is relevant, and for arrangements for co-operation between the two. The individual reports also describe the relevant standards and guidance, including professional standards, which were in existence between 2003 and 2005, at the time when these deaths occurred.

Of particular relevance to all of these cases is the guidance issued by the Chief Inspector of Social Services in 2001 concerning the provision and planning of services for people with learning disabilities.

HSC 2001/016 and LAC (2001) 23: Valuing People: A New Strategy for Learning Disability for the 21st Century: implementation

This document required councils and primary care trusts to have in place by April 2002 a quality framework to improve service quality amongst all agencies with particular attention to people with complex needs. Its intention was that *'All public services will treat people with learning disabilities as individuals, with respect for their dignity'*. Funding was provided that year to help healthcare providers develop appropriate skills, especially in primary and secondary care. Objectives included:

- *'2.2 All public services will treat people with learning disabilities as individuals with respect for their dignity and challenge discrimination on all grounds including disability.'*
- *4.4 Making sure that all agencies work in partnership with carers, recognising that carers themselves have needs which must be met.'*

- *5.2 Enabling mainstream NHS services, with support from specialist learning disability staff, to meet the general and specialist health needs of people with learning disabilities.'*
- *5.16 Carers should be treated as full partners by all agencies involved.'*

Other documents set out the requirement to assess an individual's health and social care needs and to draw up plans to meet those needs, to focus on the fundamentals of good nursing care, to benchmark practice in this area, to establish principles of good practice in discharging people from hospital, and to involve individuals and their families at every stage in the planning of care.

In addition to this, both the General Medical Council and the Nursing and Midwifery Council set out professional standards on how doctors and nurses should approach their work. Of particular relevance to most of our investigations are:

- Paragraphs 5 and 36 of the General Medical Council's *Good Medical Practice 2001*, which say:
 5. *'The investigation and treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age or social or economic status to prejudice the treatment you give.'*
 36. *Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide.'*

And:

- The Nursing and Midwifery Council's *Code of Professional Conduct*, published in April 2002, which says:
 - 1 *'You are personally accountable for your practice. This means that you are answerable for your actions and omissions regardless of advice or directions from another professional.*
 - 2.4 *You must promote the interests of patients and clients. This includes helping individuals and groups gain access to health and social care, information and support relevant to their needs.*
 - 4.1 *The team includes the patient or client, the patient or client's family, informal carers and health and social care professionals in the NHS, voluntary and independent sectors.*
 - 4.2 *You are expected to work co-operatively within teams ... You must communicate effectively and share your knowledge, skills and expertise with other members of the team as required for the benefit of patients and clients.'*

None of the above is intended solely for specialists in working with people with learning disabilities. Instead, it sets standards for the quality of services to be provided for everyone. The statements are fundamental to the values of the professions and should underlie the behaviour and actions of individuals at all times. One of the most distressing features of our investigations has been the evidence in some cases that these fundamental principles were not being consistently upheld to the extreme detriment of the individuals concerned.

Following a stroke in November 2005, Mr Ryan was admitted to a busy general ward run by a Hospital Trust. Although prevailing policy and guidelines did not require trusts to have a specialist stroke unit (and this Trust did not have such a unit) the guidelines did require trusts to organise stroke services so that patients were admitted under the care of a specialist team for acute care and rehabilitation. At the time Mr Ryan was admitted, services at the Trust for stroke patients were fragmented and fell short of professional and national expectations for stroke care set out in policy and guidelines.

There was no special team of experts skilled in management of the needs of stroke patients, for example doctors, nurses, dieticians and speech and language therapists, who could identify and meet Mr Ryan's basic needs, including his nutritional needs.

Neither the Consultant nor the Ward Sister provided effective clinical leadership, either for their professional group or the ward team as a whole. Despite speech and language therapy assessments that Mr Ryan would need alternative feeding (such as feeding him by a tube through his nose or abdominal wall into his stomach), the medical team did not make a decision about alternative feeding until Mr Ryan had been in hospital for 18 days. Soon after that, Mr Ryan became too ill to undergo the procedure to insert a feeding tube.

Mr Ryan died 26 days after admission.

Treating people as individuals

The *Disability Discrimination Act 1995* makes it unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified. It is also unlawful for service providers to fail to make reasonable adjustments for people with disabilities, where the existence of a physical barrier, practice, policy or procedure makes it impossible or unreasonably difficult for a person with a disability to use the service provided, unless such a failure is justified.

Equality for people with disabilities does not mean treating them in the same way as everyone else. Sometimes alternative methods of making services available to them have to be found in order to achieve equality in the outcomes for them. The focus is on those outcomes.

In many of the organisations whose actions we investigated it did not appear that this level of understanding of the need to make reasonable adjustments had become embedded, even at the most senior levels, despite the legislation and the extensive guidance available. Our investigations uncovered a lack of understanding of how to make reasonable adjustments in practice, which suggests there may be a need for further training on the practical implementation of the *Disability Discrimination Act 1995*.

Valuing People explained that the Government's intention was that:

'all public services will treat people with learning disabilities as individuals with respect for their dignity.'

The objective was to:

'enable people with learning disabilities to access health [and social care] services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary.'

The *Human Rights Act 1998* came into force in England in October 2000. It was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. It requires public authorities to act in a way which is compatible with the Convention.

Of particular relevance to the delivery by a public authority of health and social care for people with disabilities are the following rights contained in the Convention:

Article 2 The right to life.

Article 3 The prohibition of torture or inhuman or degrading treatment.

Article 14 The prohibition of discrimination.

When the UK Government introduced the *Human Rights Act 1998*, it said that its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new 'human rights culture' among public authorities and among the public at large.

A key component of that human rights culture is the observance of the core human rights principles of fairness, respect, equality, dignity and autonomy for all.

Despite the fact that ten years have elapsed since the introduction of the *Human Rights Act 1998*, our investigation of these complaints demonstrates that an underlying culture which values human rights was not in place in the experience of most of these people. The lack of respect for these principles spread across many organisations. The absence of understanding of individual needs, empathy for the situation in which individuals were placed, and a basic concern for them as people, led to prolonged suffering and inappropriate care. This happened in a context within which professionals pride themselves on caring for others.

When Mr Hughes, following an operation, was transferred to a ward, the nurses made entirely inadequate attempts to assess his needs, or plan or deliver care for him. Mr Hughes was medically fit to be discharged but it was not safe to discharge him. The Trust's staff failed to enact even the most basic principles of good discharge as set out in the prevailing local and national policies. They did not engage with community staff to ensure that a multi-agency plan was in place. This service failure was at least in part for disability related reasons.

In the investigations which we have undertaken we have found several examples of very poor service which have resulted in shocking outcomes for the people concerned. Sir Jonathan Michael's report, *Healthcare for All*, highlights the important effect of professional misperceptions, in which illness is overlooked and its symptoms attributed to the disability of the person concerned, despite information from carers to the contrary. We have found evidence of this in some of our investigations. On one occasion it appeared that some professionals were seeking to move someone, whose needs they found difficult to address, out of their service with no regard for the interests of the person concerned.

We were shocked that such events should have occurred and that on these occasions, and possibly on a much wider basis, the policy intentions of government set out in the *Human Rights Act 1998*, the *Disability Discrimination Act 1995* and in *Valuing People* were frustrated and appear not to have been understood. Or, if understood, they were not regarded as important enough to be put into practice. Taken together, they set out an inspirational culture which underlies everyday practice and places a value on the life of every human being.

While we are concerned here with the experience of a number of people with learning disabilities, we are well aware that there may be other vulnerable groups who are similarly affected and who would equally benefit from a change in culture. Such a change will come about only through strong leadership at all levels in the Department of Health, the NHS and local government. We make recommendations to the organisations concerned designed to focus on the understanding and practical implementation of values stated and restated, over several years, and to the regulators of those bodies to ensure that this time lessons are genuinely learnt and change occurs.

Table 1: Overview of upheld complaints

Body complained about	Decisions on upheld complaint
Buckinghamshire Hospitals NHS Trust	<ul style="list-style-type: none"> • Inadequate care and treatment including inadequate attempts to assess, plan and deliver care by nursing staff and inadequate discharge arrangements which were unsafe. • These failures were for disability related reasons. • In some areas the Trust failed to live up to human rights principles of dignity and equality. • Failure to inform patient’s family of significant events in his care. • Poor complaint handling.
Gloucestershire County Council	<ul style="list-style-type: none"> • Arrangements for transition from residential school to adult care fell significantly below a reasonable standard. • Some of this maladministration was for disability related reasons. • The Council failed to live up to human rights principles of dignity and equality. • Poor complaint handling.
Cheltenham and Tewkesbury Primary Care Trust (now Gloucestershire Primary Care Trust)	<ul style="list-style-type: none"> • Shortcomings in fulfilling of responsibilities with regard to planning for the health needs of people with profound and multiple learning disabilities. • This service failure was for disability related reasons. • The PCT failed to live up to human rights principles of dignity and equality. • Poor complaint handling.

<p>Gloucestershire Partnership NHS Foundation Trust (now 2gether NHS Foundation Trust for Gloucestershire)</p>	<ul style="list-style-type: none"> • Service failure in care and treatment including nursing care and arrangements for discharge to an adult care home. • Some of this service failure was for disability related reasons. • The Trust failed to live up to human rights principles of dignity and equality. • Poor complaint handling.
<p>Gloucestershire Hospitals NHS Foundation Trust</p>	<ul style="list-style-type: none"> • Failures in care and treatment including the co-ordination and supervision of care, poor record keeping, inadequate observations, failure to properly report and record highly significant incidents, failures in nursing care, poor care planning, failures in communications with the patient’s family about prognosis and imminent death. • Many of the failures in care and treatment were for disability related reasons. • The Trust failed to live up to human rights principles of dignity and equality.
<p>Kingston Hospital NHS Trust</p>	<ul style="list-style-type: none"> • Had service failure not occurred it is likely the patient’s death could have been avoided. • Service failure in care and treatment including failure in stroke care, clinical leadership, communication and multidisciplinary working and a failure to feed the patient. • In many respects the service failure occurred for disability related reasons. • The Trust failed to live up to human rights principles of dignity, equality and autonomy. • Poor complaint handling.

London Borough of Havering	<ul style="list-style-type: none"> • Contributed to public service failure which resulted in an avoidable death. • Failure to provide and/or secure an acceptable standard of care and consequently the care home resident's safety was put at risk. • Less favourable treatment for reasons related to disability. • The Council failed to live up to human rights principles of dignity equality and autonomy. • Poor complaint handling.
Barking, Havering and Redbridge Hospitals NHS Trust	<ul style="list-style-type: none"> • Contributed to public service failure which resulted in an avoidable death. • Service failure in care and treatment including failures in pain management, post-operative monitoring, discharge arrangements and nursing care. • Some of these service failures were for disability related reasons. • The Trust failed to live up to human rights principles of dignity equality and autonomy. • Poor complaint handling.
Royal Berkshire NHS Foundation Trust	<ul style="list-style-type: none"> • Poor complaint handling.
Healthcare Commission	<ul style="list-style-type: none"> • Poor complaint handling.

Doing the basics well – an issue of leadership

The individual investigation reports for each of the people concerned set out the standards of practice to be observed across a range of everyday functions in health and social care. Such guidance is issued on a regular basis and covers matters such as communication, record keeping, partnership working, working with carers, transition

and discharge planning, and the use of advocates among others. Some might say there are too many good practice documents to enable them to be assimilated, but they set out a broad and consistent approach which should be familiar to all professionals across health and social care, not just to those who specialise in working with people with disabilities. In fact, the standards in place for normal professional practice across all areas will, if observed consistently, offer many of

the safeguards essential to ensuring that the needs of people who are vulnerable for any reason are addressed, and appropriate adjustments made for their care.

Again, on many occasions in the lives of these people, basic policy, standards and guidance were not observed, adjustments were not made, and services were not co-ordinated. There did not appear to be any understanding of the impact that this failure in service was having, nor any empathy for the suffering caused. Above all, what was evident was a lack of leadership. In some situations it appeared that no one had a real grasp of what was happening. No one took responsibility for sorting out organisational difficulties, which were impacting adversely upon standards of care. No one took a proactive approach in owning and resolving problems by making reasonable adjustments and seeking urgent solutions. It is this aspect of the quality of the service they experienced that Mencap described as 'indifference', and it is unacceptable.

The poor practice which was evident in many situations across these investigations covered a wide range of day-to-day care and administration and did not always amount to service failure or maladministration. In this Overview we highlight some of the most prominent issues which had significant impacts on the care given to individuals, but this short section is by no means a definitive list of examples. We commend the full investigation reports to readers wishing to gain an understanding of the various complex factors which led to failure to offer good care to very vulnerable individuals. It is this complexity across widely varying situations which itself requires strong leadership to maintain a focus on the experience of and outcomes for people with learning disabilities, particularly when they are unable to communicate their own needs.

- **Communication** – it is clear that professionals who were not specialists in learning disabilities were not always familiar with legislation and guidance, which had been in existence for some years, and did not have it at the forefront of their minds. This raises questions which were not part of our investigations about how information is disseminated within organisations and the training and support available to assist implementation. However, there is another highly relevant issue concerning the passing of information accurately between professionals, and between professionals and the family, and then acting upon it.

Mr Ryan himself was unable to communicate his needs. There was evidence that various professionals, including the community team and the speech and language therapists, were very concerned about Mr Ryan and tried to raise their concerns, particularly about nutrition, with the medical and nursing teams. But they could not make themselves heard and nothing happened to help Mr Ryan. Nobody took any action to feed him.

- **Partnership working and co-ordination** – in some of the cases we have investigated there was clear evidence that professionals were not working together to make use of the skills and expertise of different disciplines in the interests of the individual. The example above concerning Mr Ryan demonstrates this in a multidisciplinary health team but, sadly, this was even more evident on occasions across the boundaries of health and social care. Guidance on transition planning for children moving into adult services, and in discharge planning for those leaving hospitals, is intended to ensure that the needs of individuals at a time of change and risk are fully assessed, resources are appropriately targeted and plans are in place to meet those needs, but in situations in which individuals were at greatest risk this co-ordination and planning was entirely absent. It was not clear that in these complex situations a designated professional had been appointed formally as co-ordinator to ensure effective planning and implementation.

Tom Wakefield spent much of his early life in a residential school but at the age of 19, when he should have moved to suitable adult accommodation, no appropriate place had been found or commissioned for him. He remained at the school where his behaviour and health deteriorated. There was no proactive planning for Tom's future needs between the Council and the Primary Care Trust and no formal co-ordinated transition plan.

- **Relationships with families and carers** – in 2001, as part of the supporting documents for Valuing People, the Department of Health published *Family Matters*, a report highlighting the perspective of family carers for people with learning disabilities. It acknowledges:

'Families have an important and unique contribution to the discussion of the future direction of services for men and women with learning disabilities. They are the only people who will have a continuous relationship with the person with a learning disability from childhood to adulthood. This contribution needs to be acknowledged, valued, listened to and acted upon.'

However, they also state that: *'in many services a culture has developed that sees families as a problem and difficult to work with ... The reality is that services need to find constructive and positive ways to work with families in the best interest of people with learning disabilities'*.

In some of the situations which we considered, the importance of listening to family members, recognising their particular knowledge of the person concerned, and often their ability to communicate and to understand responses, was not acknowledged. Families, and on occasions residential care workers, were not treated as part of the team. Valuable contributions, which only they were able to make, were lost. This led them to feel excluded and ignored and greatly added to their distress.

- **Following routine procedures** – there are many documents which set out standard good practice and processes, some of which we have quoted in this Overview, which would have improved the experience of and outcomes for these people, and are in fact designed to support the professional management of complex situations. However, it appeared in our investigations that it was in exactly these situations that standards and guidance were not followed, significantly increasing the risk to vulnerable individuals. We have already described the impact for Tom Wakefield of the lack of transition planning, and for Mr Hughes of the lack of a proper discharge plan.

- **Quality of management** is important in ensuring that routine good practice and established procedures happen on a regular and consistent basis, and in taking ownership and responsibility for the needs of individuals. Part of this management is an understanding of personal accountability in taking a proactive and sustained approach to addressing poor practice, and challenging inadequate systems. We found a few examples of people who had indeed tried to do this but who appeared either to give up easily in the face of an unresponsive system or resistance from others, or had no senior support for their efforts. We have already described how the attempts of the community team and speech and language therapists to raise their concerns about Mr Ryan were not heard.
- **Advocacy** – a final issue in identifying the basics which need to be done consistently well is notable for its absence in all of our investigations. The strategy set out in Valuing People in 2001 included investment of significant amounts of money in the following years to develop advocacy services to support people with learning disabilities. We have seen no evidence of the use or availability of independent advocates for any of the people involved in these six cases until the stage at which Mencap became involved. While parents and families undoubtedly advocated strongly on behalf of their family members, it is possible that independent advocates might have provided the people concerned and their families with additional support, or even have affected some of the outcomes. We have no way of knowing whether this is the case, but the use of independent advocates could have provided an additional safeguard for the rights of a very vulnerable group of people. We cannot speculate on the reasons why they did not have this opportunity.

We asked ourselves what would change the attitudes and culture which resulted, in these cases, in a failure to follow basic good practice. More guidance will not help since detailed and appropriate guidance has been in existence for many years. Reminders and refreshers for staff across all disciplines, perhaps coupled with the lessons learnt from these investigations, may be helpful, and the implementation of good management processes would also assist. Above all, changes in this area depend on strong leadership, at all levels in organisations, from people who recognise the hallmarks of good quality services in everyday practice and have a real empathy for and understanding of the situations of others – particularly those who cannot easily communicate, and are prepared to challenge consistently the acceptance of poor outcomes. The focus must always be on the best possible outcomes for individuals. Current standards in place for normal professional practice will, if observed, offer many of the safeguards essential to ensuring that the needs of people with learning disabilities are addressed. The investigation reports show that basic standards and guidance in a range of general services, such as care planning, nutrition and pain management, were often not observed and that this disproportionately disadvantaged and discriminated against the people concerned. There is nothing ‘specialist’ about this.

Complaint handling

Most of the complaints which we considered had been reviewed first by the NHS or council complaints systems. The families told us that their experiences of these systems had left them drained and demoralised and with a feeling of hopelessness.

They gave repeated examples of failures to understand their complaints, with little effort made to clarify matters with them, confused and fragmented systems, poor investigations with little rigorous testing of evidence, defensive explanations, a failure to address the heart of the complaint and a reluctance to offer apologies. Our investigations generally confirmed this picture.

Complaints against NHS bodies at the time of these events followed a second stage review process by the Healthcare Commission. The families who asked the Healthcare Commission to review their complaints said they had hoped that the Healthcare Commission's review would give them the explanations they sought. In practice, they experienced many of the same problems of delay, lack of contact, poor specification of complaints and a lack of clarity about the process that they had experienced at the first stage of the process. Clinical advice was not always appropriately sourced, explanations were inadequate and the families remained unclear as to what had changed as a result of their complaints. Again, our investigations generally confirmed this picture.

For the most part the NHS bodies and the councils concerned, and the Healthcare Commission, have subsequently acknowledged and apologised for the failings in their complaint handling and have provided information on improvements they have made to their services and to their complaint handling arrangements. We have included this information in the individual investigation reports.

Nonetheless, it remains the case that poor complaint handling compounded the distress which resulted from the failures in service experienced by the families of those who died. Even in one case where the complaint of service failure was not upheld, poor complaint handling added to the distress of losing a much loved family member. In most cases, the distress to families could have been reduced by effective investigation and empathetic and timely responses to complaints. These families should not have had to wait so long and fight so hard for the explanations and apologies to which they were entitled.

The White Paper *Our Health, Our Care, Our Say*, published in January 2006, made a commitment to implement a single comprehensive complaints process across health and social care, focused on resolving complaints locally with a more personal and comprehensive approach.

From 1 April 2009 changes introduced by the *Health and Social Care Act 2008* will remove the Healthcare Commission as the second tier complaint handler and the Ombudsmen will provide the second and final tier of the new system across health and adult social care. The changes in the system provide an excellent opportunity for health and social organisations to review their systems and to put in place good arrangements for the future handling of complaints.

Remedy

Our investigations found that in some of the cases there was unremedied injustice which we concluded had resulted from the maladministration and service failure we identified. Table 2 below gives an overview of the injustice we found.

Table 2: Overview of injustice found

- One avoidable death and one death which was likely to have been avoidable.
- Unnecessary distress and suffering for the aggrieved.
- Unnecessary distress and suffering for the families of the aggrieved, in particular about those failings which occurred for disability related reasons.
- Distress at unanswered questions of what difference would have been made if there had been no service failure or maladministration. Would the person concerned have lived longer? Could there have been some improved enjoyment in the last period of their life?
- Distress compounded by poor complaint handling leaving questions unanswered.
- Distress arising from a failure to live up to human rights principles.

Table 3 gives an overview of the remedies which were provided by the councils and NHS bodies concerned prior to our investigations.

Table 3: Overview of remedy provided prior to the Ombudsmen's investigations

- Senior level personal apology and offer of meetings.
- Offer to involve family in planning services.
- Actions to address failings and to minimise risk of reoccurrence; action plan notified at Board level and to the regulator.
- Commitment to learn lessons from the investigations, and to work openly and collaboratively with local and central bodies.
- Identification of lessons learnt.

The summary investigation reports which follow detail our findings in relation to the public bodies concerned and set out the remedies we have recommended and secured for the injustice we found. They include apologies and explanations to the families, financial compensation and extensive action plans to ensure that others do not experience similar injustice in future.

Table 4: Overview of remedy secured by the Ombudsmen

- Further personal apologies and offers of meetings.
- Public apologies through the published investigation reports.
- Financial compensation for distress ranging from £5,000 to £40,000.

Conclusion and recommendations

Many of the issues highlighted by our investigations have been evidenced by previous inquiries, yet people with learning disabilities continue to live with them day by day. We do not extrapolate from these cases to suggest that all health and social care in respect of people with learning disabilities is poor. Nevertheless, the recurrent nature of the complaints across different agencies leads us to the view that understanding of the issues is at best patchy and at worst an indictment of our society.

In writing this Overview we have been motivated by the desire to bring positive change from the experiences of these people and their families, which could in itself provide some redress for all those concerned. We are not looking to '*make this a priority for 2009*', but to change underlying attitudes and behaviour on a lasting basis. We do not underestimate the challenges involved.

We have made individual recommendations to address the specific unremedied injustice we have found in the cases where we have upheld the complaints (and for the most part these individual recommendations have been accepted by the public bodies concerned).

However, the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities.

We have thought long and hard about what general recommendations we could properly and usefully make in the light of our investigation findings and the themes and issues we have identified in this Overview. We are Ombudsmen, not regulators and we do not seek to usurp their role. Nonetheless, we are committed to ensuring that the learning

from complaints investigated by us is fed back to those responsible for the design and delivery of public services so that they can use that feedback to improve those services.

We see no point in repeating the detailed recommendations of Sir Jonathan Michael's Independent Inquiry into Access to Healthcare for People with Learning Disabilities, *Healthcare for All*, although we do not disagree with those recommendations.

We welcome the simplified complaint handling arrangements for health and social care which are being introduced from 1 April 2009 and therefore make no specific recommendations for improvements in the complaint handling system.

We have not found any shortage of policy and good practice guidance on the planning and provision of health and social care services for people with learning disabilities; on making reasonable adjustments in order to comply with the requirements of the *Disability Discrimination Act 1995*; or on observing the core human rights principles of fairness, respect, equality, dignity and autonomy for all. We have noted the very recent publication by the Department of Health of *Valuing People Now: a new three-year strategy for people with learning disabilities*. So we make no recommendations for further guidance.

Nonetheless, we are still left with an underlying concern that similar failures to those identified in the investigations will occur again – and indeed may be occurring today in services provided or commissioned by NHS bodies and councils across the country. We believe it is legitimate, in the light of the very serious findings of our investigations, to ask all NHS bodies and councils with social services responsibilities to satisfy themselves that is not the case.

As we have said above, we have concluded that the findings of our investigations pose serious questions about how well equipped the NHS and councils are to plan for and provide services tailored to the needs of people with learning disabilities. This is not a question that we, as Ombudsmen with a very specific remit, can or should answer but it is, we suggest, a question which those responsible for commissioning and providing health and social care services should ask themselves; which those responsible for the regulation of health and social care services should ensure is addressed in their regulatory frameworks and performance monitoring regimes; and about which the Department of Health should properly be concerned. Our recommendations are therefore addressed to the leaders of those bodies.

We recommend:

First, that all NHS and social care organisations in England should review urgently:

- the effectiveness of the systems they have in place to enable them to understand and plan to meet the full range of needs of people with learning disabilities in their areas;

and

- the capacity and capability of the services they provide and/or commission for their local populations to meet the additional and often complex needs of people with learning disabilities;

and should report accordingly to those responsible for the governance of those organisations within 12 months of the publication of this report.

Secondly, that those responsible for the regulation of health and social care services (specifically the Care Quality Commission, Monitor and the Equality and Human Rights Commission) should satisfy themselves, individually and jointly, that the approach taken in their regulatory frameworks and performance monitoring regimes provides effective assurance that health and social care organisations are meeting their statutory and regulatory requirements in relation to the provision of services to people with learning disabilities; and that they should report accordingly to their respective Boards within 12 months of the publication of this report.

Thirdly, that the Department of Health should promote and support the implementation of these recommendations, monitor progress against them and publish a progress report within 18 months of the publication of this report.



Ann Abraham
Parliamentary and Health Service Ombudsman



Jerry White
Local Government Ombudsman

March 2009

Summary investigation reports

Summary report of a joint investigation by the Health Service Ombudsman and the Local Government Ombudsman of a complaint made by Mencap on behalf of Mr Allan Cannon and Mrs Anne Handley in relation to their late son, Mr Mark Cannon.

Complainants:

Mr Allan Cannon and Mrs Anne Handley

Aggrieved:

Mr Mark Cannon (late son of Mr Allan Cannon and Mrs Anne Handley)

Representative:

Mencap

Complaint against:

London Borough of Havering (the Council)
Barking, Havering and Redbridge Hospitals
NHS Trust (the Trust)
The New Medical Centre, Romford (the Practice)
Healthcare Commission

Introduction

This complaint was investigated jointly by the Local Government Ombudsman for England and the Health Service Ombudsman for England in accordance with the powers conferred by amendments to their legislation due to *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007*. With the consent of the complainants, Mr Allan Cannon and Mrs Anne Handley, the two Ombudsmen agreed to work together because the health and social care issues were so closely linked. A co-ordinated response, consisting of a joint investigation leading to a joint conclusion and proposed remedy in one report, seemed the most appropriate way forward.

Background

Mr Cannon was a 30 year old man with severe learning disabilities. He also suffered from epilepsy. He had very little speech but was able to communicate with his family and he was particularly close to his sister. He was able to walk unaided but often needed support when he was feeling unsteady on his feet. Mr Cannon was smiling and 'mischievous' with a fine sense of humour. He enjoyed participating in activities, social events and outings with his family and carers, but he also liked lazing around and relaxing in an easy chair or bean bag. Mr Cannon lived at home with his mother, stepfather and sister. He attended a day centre five days a week with occasional stays at the Grange (the Care Home) owned by the Council.

In June 2003 Mr Cannon was at the Care Home and he broke his thigh bone, in circumstances which remain unclear. He was admitted to the Trust, the broken bone was repaired and he was discharged to his mother's home. However, four days later his GP arranged for him to be readmitted to the Trust because he was in pain and it was difficult to persuade him to eat or drink. After about a week, Mr Cannon was discharged again.

In early August 2003 Mr Cannon's GP made a home visit, diagnosed an infection and prescribed antibiotics. Despite this treatment, Mr Cannon's condition deteriorated and a few days later he was taken to the Accident and Emergency Department (A&E) at the Trust. He was admitted to a medical admission ward but he deteriorated further and was transferred to the Intensive Therapy Unit (the ITU). A couple of days later his condition had stabilised and he was transferred to the High Dependency Unit (the HDU). However, Mr Cannon collapsed, suffered a cardiac arrest and returned to the ITU. Around a fortnight later, almost three weeks after he had been admitted

as an emergency, Mr Cannon's family agreed with doctors that there was no hope of recovery and Mr Cannon died.

The Coroner found that Mr Cannon's broken leg was caused by a fall and that his death was as a result of bronchopneumonia. He recorded a verdict of accidental death.

The complaint

Mr Cannon's parents complained that their son should not have died. They said that if staff at the Care Home, the Trust and the Practice had acted differently, he would have survived. They believed their son had been treated less favourably for reasons related to his learning disabilities.

Mr Cannon's parents were also dissatisfied with the way their complaint against the NHS had been handled by the Trust and the Healthcare Commission, and with the way the circumstances of Mr Cannon's injury had been investigated by the Council. They felt the NHS and Council complaints processes had failed them, and they asked for answers to their questions about the service provided for their son.

What should have happened

The staff who looked after Mr Cannon should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework, and the professional standards relevant to the events in question.

In Mr Cannon's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard.

Mr Cannon's care should have been organised within the legal and policy framework for integrated health and social care as set out in key documents including the *National Health Service and Community Care Act 1990*, the *National Assistance Act 1948* and the *Care Standards Act 2000*.

In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies. Mr Cannon's care and treatment at the Trust should have met national and professional standards regarding nursing care and discharge arrangements.

The responses to Mr Cannon's parents' complaint about the Trust should have followed the procedures set out in the *Directions* (1996 and subsequent amendments) produced by the Secretary of State for Health, and the Healthcare Commission should have reviewed that complaint in line with the *National Health Service (Complaints) Regulations 2004*. The complaint about the Council should have been handled in line with the *Complaints Procedure Directions 1990*.

How the Ombudsmen investigated

The investigator met Mr Cannon's parents to gain a full understanding of their complaint. It was important to carefully consider their recollections and views. Evidence about what happened to Mr Cannon and how his parents' complaints about NHS and Council services were handled was considered. Enquiries were also made of the Coroner who conducted the inquest into Mr Cannon's death. All the bodies complained about provided additional information in response to specific enquiries.

Several professional advisers provided expert clinical advice to the Ombudsmen. They were: an A&E nurse; a community nurse; an orthopaedic nurse; a learning disability nurse; an A&E consultant; an ICU consultant; an orthopaedic consultant; and a GP.

Mr Cannon's parents, their representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

What the Ombudsmen found and concluded

The Local Government Ombudsman's investigation of the complaint against the Council

Mr Cannon broke his leg when he was in respite care at the Care Home. His parents complained that their son was provided with inadequate care by the Council and this led to his injury and death. They said the Council failed to keep their son safe as a result of poor planning, poor supervision, weak management and inadequate staffing. They

also said the Council repeatedly failed to properly investigate the circumstances of Mr Cannon's injury or take responsibility for the part their failings played in his injury and subsequent death.

The Local Government Ombudsman concluded that the Council failed to provide and/or secure an acceptable standard of care for Mr Cannon and, as a result, his safety was put at risk. That failure constitutes maladministration.

The Local Government Ombudsman also concluded that there was maladministration in the way the Council investigated Mr Cannon's parents' complaint. He found complaint handling during the early stages of the complaints process was extremely confusing, the complaints were poorly considered, responses were unsympathetic and the whole process was unreasonably delayed.

Therefore, the Local Government Ombudsman upheld the complaint against the Council.

The Health Service Ombudsman's investigation of the complaint against the Trust

Mr Cannon was admitted to the Trust three times between June and August 2003. During the first admission he underwent surgery to repair his broken leg. Subsequent admissions were because his condition deteriorated while he was at home.

Mr Cannon's parents complained that on each occasion that Mr Cannon was admitted the Trust failed to provide him with adequate care and treatment or to plan and put in place proper arrangements for his discharge. They were happy with his care in the ITU but they said failings elsewhere at the Trust led to a decline in his condition and his death. They were also dissatisfied with the way their complaint was handled.

The Health Service Ombudsman found failings in key aspects of the care and treatment provided for Mr Cannon.

- Management of Mr Cannon's pain was inadequate. His urgent need for pain relief was not met and assessment and planning for ongoing pain management was not of a reasonable standard. This failure meant Mr Cannon was left in severe pain and great distress for prolonged periods of time.
- Assessment, observation, monitoring and recording of Mr Cannon's condition was inadequate particularly during his three admissions to A&E, during the days immediately following his operation and when he was admitted to a ward on his third admission.
- Management of Mr Cannon's epilepsy was inadequate because his seizures and medication levels were not properly monitored and his medication was not always given as prescribed. This failure may have increased the frequency of Mr Cannon's seizures and increased his agitation.
- On two occasions discharge arrangements did not meet the standards set out in national guidelines. Mr Cannon was discharged without due concern for his safety and community healthcare providers were not fully aware of his condition or the level of support he would need. Staff did not properly consider his needs and his mother was left to care for him and arrange help as best she could.
- On one occasion junior doctors made a decision that Mr Cannon should not be resuscitated if he collapsed. Their decision was not appropriate and did not conform with legal and professional guidance.

The Health Service Ombudsman found shortcomings in the way in which the Trust handled Mr Cannon's parents' complaint. For instance, the Trust failed to properly investigate the complaint and failed to take opportunities to offer full explanations and appropriate apologies.

The Health Service Ombudsman concluded there was service failure in the care and treatment provided for Mr Cannon by the Trust and that this was at least in part for disability related reasons. She also found maladministration in the way the Trust handled his parents' complaint.

The Trust told the Health Service Ombudsman about actions it had taken subsequently to address the failures in the service provided for Mr Cannon.

The Health Service Ombudsman concluded that, had the Trust provided appropriate and reasonable care and treatment, according to prevailing standards and guidance, it is likely Mr Cannon's suffering would have been less and it is possible that he would have survived. Furthermore, his family would have suffered less anxiety and distress. These findings represented unremedied injustice.

Therefore, the Health Service Ombudsman upheld the complaint against the Trust.

The Health Service Ombudsman's investigation of the complaint against the Practice

Mr Cannon's parents had not previously complained about the Practice, but to ensure they had a full picture of their son's care and treatment during the final months of his life, the Health Service Ombudsman used her discretion to investigate their complaint.

Mr Cannon's parents complained that the Practice failed to provide their son with adequate care and that more could have been done to diagnose his illness following his discharge from hospital. In particular, Mr Cannon's parents believed that a GP who examined their son only a few days before he was readmitted had not acted properly and should have done more to help him.

The Health Service Ombudsman did find some shortcomings in the actions of the GP who visited Mr Cannon prior to his final admission to hospital. However, she decided that these shortcomings did not amount to service failure.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Practice.

The Health Service Ombudsman's investigation of the complaint against the Healthcare Commission

Mr Cannon's parents were dissatisfied with the way their complaint was handled by the Healthcare Commission.

The Health Service Ombudsman found maladministration in the way the Healthcare Commission reviewed Mr Cannon's parents' complaint against the Trust because it was not based on appropriate or adequate clinical advice. This meant its decision was unreliable and unsafe. Furthermore, the Healthcare Commission's review did not cover key aspects of Mr Cannon's parents' complaint and the report of the review contained significant factual inaccuracies. The Health Service Ombudsman concluded the Healthcare Commission's response was superficial, incomplete and not evidence-based. Mr Cannon's parents were denied a proper independent review of their complaint against the Trust and this caused them unnecessary uncertainty and distress.

Therefore, the Health Service Ombudsman upheld the complaint against the Healthcare Commission.

Was Mr Cannon treated less favourably for reasons related to his learning disabilities?

The Health Service Ombudsman concluded that failures in the care and treatment provided for Mr Cannon by the Trust were in part for reasons related to his learning disabilities. Staff did not make reasonable adjustments to the way in which they organised and delivered care to meet his complex needs. She concluded that in some significant respects the service failures at the Trust were for disability related reasons.

The Local Government Ombudsman concluded that some of the failures by the Council represented failure to make reasonable adjustments to meet Mr Cannon's needs, and resulted in him being treated less favourably for reasons related to his learning disabilities.

The Ombudsmen concluded that there was no evidence of any positive intention to humiliate or debase Mr Cannon. Nevertheless, by omitting to provide and/or secure proper care for Mr Cannon, public services failed to have due regard to his dignity and status as a person, and the need to observe the principle of equality.

Was Mr Cannon's death avoidable?

The Ombudsmen considered Mr Cannon's death could not be attributed to one specific incident or action. That said, they concluded that the Council and the Trust had failed Mr Cannon. The injury suffered by Mr Cannon might well have been avoided. In any event he should not have died as a consequence of that injury. On that basis, the Ombudsmen found that Mr Cannon's

death arose in consequence of service failure and maladministration they identified. Therefore, they concluded his death was avoidable.

The Ombudsmen's recommendations

The Ombudsmen recommended that Mr Cannon's parents should receive apologies and compensation totalling £40,000 from the bodies against which complaints were upheld. The compensation was in recognition of the injustice suffered in consequence of service failure and maladministration identified.

In response to these recommendations the Trust acknowledged its failings and apologised to Mr Cannon's parents. It also agreed to pay its share of the compensation recommended. The Healthcare Commission agreed to apologise to Mr Cannon's parents. The Council did not accept the recommendations.

The complainant's response

Mr Cannon's parents welcomed the Ombudsmen's report, saying it was *'tough and hard hitting'*. Nevertheless, they were particularly disappointed that the Health Service Ombudsman did not uphold their complaint against the Practice because they believed their son did not receive a reasonable standard of care from the GPs there. Mr Cannon's father, although welcoming the Health Service Ombudsman's findings regarding the Trust, expressed continuing concerns about specific aspects of the care and treatment it provided for his son.

Summary report of an investigation by the Health Service Ombudsman of a complaint made by Mencap on behalf of Mr and Mrs Cox in relation to their late son, Mr Warren Cox.

Complainants:

Mr and Mrs Cox

Aggrieved:

Mr Warren Cox (Mr and Mrs Cox's late son)

Representative:

Mencap

Complaint against:

Harold Road Surgery (the Surgery)

A GP employed by South East Health Ltd
(the Out of Hours GP)

East Sussex Hospitals NHS Trust (the Trust)
Healthcare Commission

Background

Mr Warren Cox was a 30 year old man with severe learning disabilities. His parents described him as a very happy and contented young person with a great sense of humour and a love for everyone. He lived at home with his parents who were his carers. Mr Cox had very little speech, but he could make himself understood to his family.

In September 2004 Mr Cox became unwell with abdominal pain. He had difficulty sleeping and had a bad epileptic seizure. His parents contacted their local Surgery, and the GPs who visited Mr Cox and spoke to his parents on the telephone diagnosed a viral infection. Around 1.30am on 25 September 2004 Mr Cox's parents became increasingly anxious about their son because his abdomen was very swollen and they telephoned the Out of Hours GP. He visited and said Mr Cox

should go to hospital for an X-ray. Mr Cox's parents were reluctant to take Mr Cox to hospital at that time of night because they were worried they would have to wait until the X-ray department opened and this would make it hard for them to care for their son properly. Subsequently, Mr Cox's parents telephoned the Out of Hours GP again and he arranged for an ambulance to take Mr Cox to hospital urgently.

At the Trust an intestinal obstruction was diagnosed. Various examinations and tests were performed and Mr Cox had an X-ray of his abdomen. Shortly after he returned from the X-ray department, around 90 minutes after he reached the Trust, Mr Cox vomited and unexpectedly his heart stopped and he stopped breathing. Sadly, attempts to resuscitate him were unsuccessful.

A post mortem showed that Mr Cox had died from inhaling vomit into his lungs and that his bowel had stopped working due to inflammation of the lining of his abdomen.

The complaint

Mr Cox's parents complained that their son should not have died. They said that if the GPs from the Surgery, the Out of Hours GP and staff at the Trust had acted differently and with more urgency, he would have survived. They believed their son had been treated less favourably for reasons related to his learning disabilities.

Mr Cox's parents were also dissatisfied with the way their complaint had been handled by the Surgery, the Trust and the Healthcare Commission. They felt the NHS complaints process had failed them and they had not had answers to their questions about the service provided for their son.

What should have happened

The NHS staff who looked after Mr Cox should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Mr Cox's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard. In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies.

The responses to Mr Cox's parents' complaint should have followed the *National Health Service (Complaints) Regulations 2004*.

How the Health Service Ombudsman investigated

The investigator met Mr Cox's parents to gain a full understanding of their complaint. It was important to carefully consider their recollections and views. Evidence about what happened to Mr Cox and how his parents' complaint had been handled was considered. Further enquiries were made of the Surgery, the Out of Hours GP and the Trust.

Several professional advisers provided expert clinical advice to the Health Service Ombudsman. They were: two GPs; a consultant gastroenterologist; a consultant surgeon; an accident and emergency consultant; a hospital nurse; and a learning disability nurse.

Mr Cox's parents, their representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

What the Health Service Ombudsman found and concluded

The investigation of the complaint against the Surgery

Mr Cox's parents complained that GPs at the Surgery failed to diagnose their son's condition and failed to carry out further investigations when it was clear he was in pain and distress. They said the GPs did not listen to them when they expressed concern about Mr Cox's condition and when they suggested he had appendicitis. They believed the GPs treated their son less favourably for reasons related to his learning disabilities. Mr Cox's parents were also dissatisfied with the way the Surgery handled their complaint.

The Health Service Ombudsman was advised that diagnosing acute appendicitis is very difficult, especially when a person is unable to communicate the detail about their symptoms. Also, she was advised that although the GPs did not reach a definitive diagnosis this did not necessarily mean their actions were unreasonable. She found that, although the GPs could have considered more proactive management, they were not at fault for

taking a conservative approach to Mr Cox's care and treatment. The Health Service Ombudsman found that, in the circumstances, the GPs acted reasonably in their responses to Mr Cox's parents' concerns about their son and in their examinations of him.

The Health Service Ombudsman concluded that no one could say for certain whether different or more urgent action by the GPs would have resulted in a different outcome for Mr Cox. However, she found no evidence of service failure by the GPs and no evidence that they treated Mr Cox less favourably for reasons related to his learning disabilities. Also, she found no maladministration in the way the Surgery handled Mr Cox's parents' complaint.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Surgery.

The investigation of the complaint against the Out of Hours GP

Mr Cox's parents had not previously complained to the Out of Hours GP. However, the Health Service Ombudsman exercised her discretion and accepted their complaint for investigation because it was important to consider the whole story about Mr Cox's care and treatment.

Mr Cox's parents complained that the Out of Hours GP who saw their son on the night he died did not tell them how seriously ill he was and delayed calling an ambulance. They believed that, had he acted more urgently, their son might not have died. They said the Out of Hours GP did not listen to what they had to say and treated their son less favourably for reasons related to his learning disabilities.

The Health Service Ombudsman found that the Out of Hours GP provided a good standard of care, took appropriate note of Mr Cox's parents' concerns and acted promptly and appropriately when he heard that Mr Cox had deteriorated.

Mr Cox's parents thought the ambulance took too long to arrive. However, the Health Service Ombudsman found that the Out of Hours GP had called for an urgent ambulance immediately after he had spoken to them for the second time and the ambulance had arrived within half an hour. Furthermore, it was clear that the Out of Hours GP could not have predicted Mr Cox's rapid deterioration and, therefore, his actions were appropriate in the circumstances. The Health Service Ombudsman found no evidence that the Out of Hours GP treated Mr Cox less favourably for reasons related to his learning disabilities.

The Health Service Ombudsman found no evidence of service failure by the Out of Hours GP and, therefore, she did not uphold the complaint against him.

The investigation of the complaint against the Trust

Mr Cox's parents complained that their son should have been treated with greater urgency when he reached the Trust. They were dissatisfied with specific aspects of his care and treatment, including the actions of doctors, nurses and a radiographer. Mr Cox's parents felt strongly that inappropriate action by the staff meant they were denied the opportunity of being with their son when he died. They said he had received less favourable treatment for reasons related to his learning disabilities. They were also dissatisfied with the way the Trust handled their complaint.

The Health Service Ombudsman found that doctors and nurses at the Trust had acted reasonably in the way they assessed Mr Cox. Staff performed appropriate examinations, arranged appropriate tests and investigations, and instigated appropriate treatment. She found staff could not have predicted that Mr Cox's heart would stop and he would stop breathing because there was no indication that he would collapse so suddenly. Also, in the circumstances, staff acted appropriately and in line with professional guidelines in asking Mr Cox's parents to leave the area where he was being resuscitated.

The Health Service Ombudsman found no reason to believe that Mr Cox would have survived if different or quicker treatment had been provided by staff at the Trust. She identified some areas where the care and treatment provided could have been better, for example the management of pain and communication with Mr Cox's family, but found the overall standard of care and treatment was in line with prevailing standards. She found no evidence that staff at the Trust treated Mr Cox less favourably for reasons related to his learning disabilities. Furthermore, she found no maladministration in the way the Trust handled Mr Cox's parents' complaint.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Trust.

The investigation of the complaint against the Healthcare Commission

Mr Cox's parents were dissatisfied with the way their complaint was handled by the Healthcare Commission.

The Health Service Ombudsman found failings in the way the Healthcare Commission reviewed Mr Cox's parents' complaint. She concluded that these failings amounted to maladministration

which led to an injustice because the Healthcare Commission had denied Mr Cox's parents a proper independent review of their complaint and unreasonably delayed resolution of the complaint.

The Health Service Ombudsman upheld the complaint and recommended that the Healthcare Commission should apologise to Mr Cox's parents for the failings identified. The Healthcare Commission accepted this recommendation.

Was Mr Cox treated less favourably for reasons related to his learning disabilities and was his death avoidable?

The Health Service Ombudsman found no evidence that Mr Cox was treated less favourably by any of the bodies complained about for reasons related to his learning disabilities. She found no service failure or maladministration relating to the care and treatment Mr Cox received from any of the bodies complained about. On that basis she found that Mr Cox's death did not arise in consequence of any service failure or maladministration. Therefore, she could not conclude that his death was avoidable.

The Health Service Ombudsman said that in reaching her conclusions she had seen nothing in any of the evidence which suggested that Mr Cox's parents were in any way to blame for the death of their son. She said she had no doubt that at all times they acted in what they understood and believed to be his best interests.

The complainants' response

Mr Cox's parents were dissatisfied with the outcome of the investigation. They expressed their strong belief that the actions of the GPs at the Surgery led to delay in diagnosing their son's condition and that the Out of Hours GP failed him.

Summary report of an investigation by the Health Service Ombudsman of a complaint made by Mencap on behalf of Mrs Jane Kemp in relation to her late daughter, Miss Emma Kemp.

Complainant:

Mrs Jane Kemp

Aggrieved:

Miss Emma Kemp (Mrs Kemp's late daughter)

Representative:

Mencap

Complaint against:

NEWDOC GP out of hours service
Falkland Surgery
Eastfield House Surgery
Royal Berkshire NHS Foundation Trust (the Trust)
Healthcare Commission

Background

Miss Kemp was a 26 year old woman with severe learning disabilities who lived in a residential care home. Mrs Kemp described her daughter as a *'party animal'* who was caring and friendly and loved dressing nicely to go out with her family and friends. She had many interests including dancing, bowling, television and computers. Mrs Kemp said there was not a day in the week when her daughter was not doing something. She was lively, active and always up early, eager to go out. Miss Kemp could understand what people said to her as long as they used simple direct language and she liked talking to people about her activities. She regularly spent time with her mother and grandparents.

In late April 2004 Miss Kemp became unwell and over the following month she was seen by several GPs and community nurses. In late May 2004 she was admitted as an emergency to the Trust and a

doctor found a previously unnoticed lump in her groin. Over the next two weeks she underwent various tests before she was discharged to her mother's home. In mid-June 2004 Mrs Kemp was told by two of the Trust's cancer specialists (Consultants R and S) that the lump was a non Hodgkin's lymphoma (a malignant tumour of the lymph system, which is the system that helps the body fight infection). Within days Miss Kemp was readmitted to the Trust because her GP was concerned she was not eating or drinking properly.

Mrs Kemp was dissatisfied with the care and treatment her daughter was receiving at the Trust and she instructed solicitors to ensure the Trust's actions were in Miss Kemp's best interests. Mrs Kemp was told by Consultant R that the likelihood of successful treatment of Miss Kemp's cancer was less than 10%. A second opinion was obtained from a third consultant, Consultant T, which confirmed Consultant R's view. Mrs Kemp then agreed with the consultants' proposal that chemotherapy was not in her daughter's best interests. At the end of June 2004 Miss Kemp was transferred to a specialist facility for palliative care (care which focuses on controlling symptoms, such as pain and discomfort, rather than cure). She died there in July 2004.

The complaint

Mrs Kemp complained that her daughter should have received cancer treatment and that she should not have died. She said the GPs should have diagnosed her condition earlier and staff at the Trust did not act in her best interests when planning and delivering care and treatment. She believed her daughter had been treated less favourably for reasons related to her learning disabilities.

Mrs Kemp was also dissatisfied with the way her complaint had been handled by the Trust and the Healthcare Commission. She felt the NHS complaints process had failed her and she wanted answers to her questions about the service provided for her daughter.

What should have happened

The NHS staff who looked after Miss Kemp should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Miss Kemp's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard.

In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies. Miss Kemp's care and treatment should have met national and professional standards regarding management of cancer patients, general nursing care and discharge arrangements as well as the Trust's own discharge and consent policies. In addition, NHS staff caring for Miss Kemp should have acted in accordance with the law and professional standards for managing patients who lack capacity to consent to investigations and treatment.

The responses to Mrs Kemp's complaint should have followed the *National Health Service (Complaints) Regulations 2004*.

How the Health Service Ombudsman investigated

The investigator met Mrs Kemp to gain a full understanding of her complaint. It was important to carefully consider her recollections and views. Evidence about what happened to Miss Kemp and how her mother's complaint had been handled was considered. The Trust also provided additional information in response to specific enquiries and investigators met key Trust staff.

Several professional advisers provided expert clinical advice to the Health Service Ombudsman. They were: a professor of oncology; a hospital nurse; a learning disability nurse; and a GP.

Mrs Kemp, her representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

What the Health Service Ombudsman found and concluded

The investigation of the complaint against the GPs

Mrs Kemp had not previously complained about the GPs. However, the Health Service Ombudsman exercised her discretion and accepted the complaint for investigation because it was important to consider the whole story about Miss Kemp's care and treatment.

Mrs Kemp complained that the various GPs who saw her daughter in the month before her cancer was detected did not recognise that Miss Kemp's symptoms meant she was seriously ill. She said they should have admitted Miss Kemp to hospital for investigation and their inaction resulted in delayed diagnosis and treatment.

The Health Service Ombudsman found that the GPs had no reason to refer Miss Kemp to hospital sooner or to suspect she had cancer. She concluded that there was no reason to criticise the service provided by the GPs. Their actions were in line with national and professional standards and they made reasonable adjustments in their practice with regard to Miss Kemp's learning disabilities. There was no evidence that they treated her less favourably with regard to her learning disabilities.

Therefore, the Health Service Ombudsman did not uphold the complaint against the GPs.

The investigation of the complaint against the Trust

Mrs Kemp was dissatisfied with the organisation of investigations, with nutrition, hydration, pain relief and discharge planning, and with the standard of accommodation and facilities. Mrs Kemp said her daughter's condition had deteriorated and she became critically ill because of the poor care she had received and because staff did not act in her best interests.

The Health Service Ombudsman found that the time taken to investigate and diagnose Miss Kemp's cancer was reasonable and during a biopsy of the lump and a CT scan key staff tried to adapt their practice to meet her needs. She found that on the whole, tests and examinations were carried out in a reasonable way and best interest principles were appropriately applied.

The Health Service Ombudsman found that more could have been done to meet Miss Kemp's nutrition, hydration and pain relief needs. For example, Trust staff could have made more effective use of the knowledge of Miss Kemp's family and carers to help them assess her pain. However, the Health Service Ombudsman found no evidence that at any point during either admission to the Trust Miss Kemp's condition was seriously compromised by lack of fluid or food. Neither did she find that her need for pain relief was ignored or that she was denied pain relief.

Miss Kemp was discharged from hospital to her mother's home after her first admission when preliminary tests to establish the nature of the lump in her groin had been completed. The Health Service Ombudsman found shortcomings in the Trust's approach to managing Miss Kemp's discharge. However, staff did take some action to try and ensure she was safely discharged. On balance, the Health Service Ombudsman did not conclude that discharge arrangements fell significantly below a reasonable standard in the circumstances.

The Health Service Ombudsman found that when Miss Kemp was admitted to the Trust on the second occasion the standard of accommodation and facilities was not ideal. No single room was available on the cancer ward. However, a single room was found close by the specialist ward and in the circumstances the Health Service Ombudsman did not consider this was unreasonable.

Mrs Kemp's key complaint was that the decision not to treat her daughter's cancer was made solely because Miss Kemp had learning disabilities. Miss Kemp had a high grade B cell lymphoma for which the usual treatment would be a series of cycles of specialist chemotherapy known as R-CHOP. This involves giving four different drugs intravenously over a period of about six months.

The treatment can have serious side-effects, including infection.

During the course of the investigation it became clear that even eminent experts in cancer treatment held different views about whether or not treating Miss Kemp's cancer was in her best interests. However, it was not for the Health Service Ombudsman to have a clinical opinion about whether or not Miss Kemp should have received treatment for her cancer. The question she asked was whether or not Miss Kemp received a reasonable standard of care and treatment.

The Health Service Ombudsman found that Consultants R and T did act in line with relevant ethical, legal and professional guidance on how they should act when a patient lacks the capacity to consent to treatment. She found they consulted with a wide range of colleagues, weighed up the risks and benefits of treatment and involved Mrs Kemp in their decision. She also found that in the circumstances the decision taken by Consultants R and T was not unreasonable.

The Health Service Ombudsman found no evidence that in making their decision Consultants R and T treated Miss Kemp less favourably with regard to her learning disabilities. That is not to say that if Miss Kemp had not had learning disabilities the decision in relation to her best interests would have been the same. Rather, that they considered the challenges that existed as a result of her learning disabilities and the adjustments that could reasonably be made to address those challenges and concluded that the risk of harm and distress that was likely to be caused by the treatment outweighed the benefit that was likely to be obtained. In different circumstances those assessments of risk and benefit might well have been different, but these were the circumstances that Consultants R and T were faced with in Miss Kemp's case.

The Health Service Ombudsman found no service failure in the care and treatment provided for Miss Kemp by the Trust. Therefore, she did not uphold this aspect of the complaint against the Trust.

The investigation of complaint handling by the Trust

Mrs Kemp was dissatisfied with the way the Trust handled her complaint and the Health Service Ombudsman found the Trust failed to comply fully with the applicable regulations. In particular, the Trust's actions did not accord with principles of good administration and it did not provide an appropriate or adequate remedy.

The Health Service Ombudsman concluded these failings amounted to maladministration but that this did not occur for disability related reasons. She upheld this aspect of Mrs Kemp's complaint but made no recommendation for further remedy because the Trust had apologised and taken appropriate action to address the failings she identified.

The investigation of the complaint against the Healthcare Commission

Mrs Kemp was dissatisfied with the way the Healthcare Commission reviewed her complaint. She said the review took too long and did not provide her with the answers she sought.

The Healthcare Commission reviewed this complaint twice because Mrs Kemp was dissatisfied with the first review. The Health Service Ombudsman found that the Healthcare Commission's first review was flawed because it did not take advice from a suitably qualified clinician. This rendered its decision unreliable

and unsafe and was maladministration. However, overall the Healthcare Commission's second review was reasonable and in line with the applicable standard. The Health Service Ombudsman did not find maladministration with regard to delay. She concluded that any injustice arising from the maladministration relating to the Healthcare Commission's first review was remedied by the second review and there was no service failure in the Healthcare Commission's complaint handling.

Therefore, she did not uphold the complaint against the Healthcare Commission.

Was Miss Kemp treated less favourably for reasons related to her learning disabilities?

The Health Service Ombudsman found no evidence that Miss Kemp was treated less favourably by the GPs or the Trust for reasons related to her learning disabilities.

Was Miss Kemp's death avoidable?

The Health Service Ombudsman found no service failure or maladministration relating to the decision not to treat Miss Kemp's cancer. On that basis, her finding was that Miss Kemp's death did not arise in consequence of any service failure or maladministration. Therefore, she did not conclude that Miss Kemp's death was avoidable. It will never be known whether Miss Kemp would have survived had she received chemotherapy, or whether the intensive treatment which this involved or the side-effects of that treatment would in fact have hastened her death, but that was not the subject of the Health Service Ombudsman's investigation.

The complainant's response

Mrs Kemp was dissatisfied with the outcome of the investigation. Mrs Kemp said she strongly believed that Miss Kemp did not receive a reasonable standard of care, that she should have been treated with chemotherapy and that the decision not to treat her cancer was for reasons related to her learning disabilities.

Summary report of a joint investigation by the Health Service Ombudsman and the Local Government Ombudsman of a complaint made by Mencap on behalf of Mrs Iris Keohane in relation to her late brother, Mr Edward Hughes.

Complainant:

Mrs Iris Keohane

Aggrieved:

Mr Edward Hughes (Mrs Keohane's late brother)

Representative:

Mencap

Complaint against:

Buckinghamshire Hospitals NHS Trust (the Trust)
Tower House Surgery (the Surgery)
Buckinghamshire County Council (the Council)
Healthcare Commission

Introduction

This complaint was investigated jointly by the Local Government Ombudsman for England and the Health Service Ombudsman for England in accordance with the powers conferred by amendments to their legislation due to *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007*. With the consent of the complainant, Mrs Keohane, the two Ombudsmen agreed to work together because the health and social care issues were so closely linked. A co-ordinated response, consisting of a joint investigation leading to a joint conclusion and proposed remedy in one report, seemed the most appropriate way forward.

Background

Mr Hughes was a 61 year old man with severe learning disabilities who had lived in care for most of his adult life. For many years he had lived at a care home in High Wycombe (the Care Home) which was managed by the Council. Mrs Keohane told us her brother had been born in difficult circumstances during World War II and that as a result he suffered damage to his brain at birth. He also suffered from dementia, schizophrenia and heart problems. His verbal communication was limited to a few words and his behaviour could be challenging.

In May 2004 Mr Hughes was admitted to the Trust because he could not pass urine. He had an operation on his prostate but deteriorated after the surgery and was admitted to the Intensive Care Unit (the ICU). After nine days in the ICU he was transferred to a ward and two days later he was discharged to the Care Home. Staff at the Care Home were concerned about him and the following day they asked a GP to visit. The GP decided Mr Hughes did not need to be readmitted to hospital. Later that day Mr Hughes suddenly collapsed and he was taken to the Accident and Emergency Department (A&E) at the Trust, but he could not be resuscitated and died.

The Coroner found that Mr Hughes had died because he had been aspirating (inhaling fluids and solids which should have passed into his stomach) over a period of time and that he had also suffered an acute episode of aspiration.

The complaint

Mrs Keohane complained to the Ombudsmen that her brother should not have died. She said that if the Trust, the GP and the Care Home staff had acted differently, he would have survived. She believed her brother had been treated less favourably for reasons related to his learning disabilities.

Mrs Keohane was also dissatisfied with the way her complaint had been handled by the Surgery, the Trust and the Healthcare Commission. She felt the NHS complaints process had failed her and she asked the Ombudsmen to find answers to her questions about the service provided for her brother.

What should have happened

The staff who looked after Mr Hughes should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Mr Hughes' case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard.

In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies. Mr Hughes' care and treatment at the Trust should have met national and professional standards regarding nursing care and discharge arrangements and the Trust's own discharge policy.

The responses to Mrs Keohane's complaint about NHS services should have followed the *National Health Service (Complaints) Regulations 2004*.

How the Ombudsmen investigated

The investigator spoke to Mrs Keohane to gain a full understanding of her complaint. It was important to carefully consider her recollections and views. Evidence about what happened to Mr Hughes, how his sister's complaint about NHS services had been handled, and the internal investigations conducted by the Trust and the Council were considered. These bodies provided additional information in response to specific enquiries. Enquiries were also made of the Coroner who conducted the inquest into Mr Hughes' death.

Several professional advisers provided expert clinical advice to the Ombudsmen. They were: a professor of cardiology; a surgical consultant; a consultant anaesthetist with experience of work in ICU; a GP; a speech and language therapist; a hospital nurse; and a learning disability nurse.

Mrs Keohane, her representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

What the Ombudsmen found and concluded

The Health Service Ombudsman's investigation of the complaint against the Trust

Mrs Keohane was satisfied with the care and treatment her brother received before he left the ICU at the Trust. She complained about the service provided for Mr Hughes from the time he left the ICU to the time he was discharged two days later. In particular, she said staff on the ward did not take sufficient account of his needs as a person with learning disabilities and his discharge was premature and poorly planned. Mrs Keohane said her brother was '*pushed out*' from the Trust because staff '*did not want him there because he was more difficult*'. Mrs Keohane also complained that Trust staff did not communicate properly with her about her brother's condition and that the Trust's response to her complaint was inadequate.

The Health Service Ombudsman found that Mr Hughes was assessed thoroughly and appropriately by doctors who put in place an appropriate plan for management of his medical care, in particular his heart problems. She also found the Trust's speech and language therapists acted reasonably when assessing Mr Hughes' ability to swallow.

However, the Health Service Ombudsman found nurses on the ward made entirely inadequate attempts to assess Mr Hughes' needs or plan or deliver care for him. Nurses seemed to have little idea of how to look after Mr Hughes or how to make reasonable adjustments so they could manage his needs. They did not act in accordance with professional standards.

Mr Hughes was medically fit to be discharged because he no longer needed specialist medical care and because a plan to manage his heart condition had been put in place by Trust doctors. However, the Health Service Ombudsman found it was not safe to discharge him. She found the team responsible for ensuring Mr Hughes was safely discharged (including nurses, doctors and therapists) failed to enact even the most basic principles of good discharge as set out in the prevailing local and national policies. She was critical of the failure of Trust staff to engage with community staff to ensure that a multi-agency plan was in place for Mr Hughes' discharge. She found that in this respect, neither doctors nor nurses acted in accordance with professional standards.

The Health Service Ombudsman found that when Mr Hughes was in the ICU, Trust doctors had told his family that they thought he had suffered a heart attack. However, she found no evidence that staff communicated with his family after he left the ICU. They did not inform his family, as they should have done, that he had fallen on the night before he was discharged or even that he was due to be discharged.

The Health Service Ombudsman concluded that the Trust failed to: provide a reasonable standard of nursing care; make reasonable adjustments to meet Mr Hughes' needs; discharge him safely; or communicate adequately with his family. She also concluded that this service failure was at least in part for disability related reasons.

The Health Service Ombudsman found many shortcomings in the way in which the Trust handled Mrs Keohane's complaint. For instance, the Trust failed to: recognise or address the most serious issues complained about; conduct an appropriate investigation; or acknowledge and apologise for poor care and treatment. She concluded that this was maladministration.

The Trust informed the Health Service Ombudsman of actions it had taken to address shortcomings in its care and treatment of Mr Hughes and its handling of Mrs Keohane's complaint. It also offered further apologies for failings identified during the investigation. The Health Service Ombudsman found these actions were appropriate and reasonable. However, she also concluded that Mrs Keohane still had reason to be aggrieved by the failings in the Trust's care and treatment of her brother, and in particular those failings which occurred for disability related reasons. Furthermore, partly due to failings at the Trust, Mrs Keohane had to wait four years for answers to her questions which flowed from the maladministration and service failure identified. These findings represented unremedied injustice.

Therefore, the Health Service Ombudsman upheld the complaint against the Trust.

The Health Service Ombudsman's investigation of the complaint against the Surgery

After around three weeks in the Trust, including a period in the ICU, Mr Hughes was discharged to the Care Home at short notice without an agreed discharge plan to guide staff caring for him in the community.

Mrs Keohane complained that the GP did not respond quickly enough to a request from Care Home staff to visit Mr Hughes on the day he died. She said the GP did not examine her brother properly and should have admitted him to hospital. She said the GP treated Mr Hughes less favourably for reasons related to his learning disabilities. She was also dissatisfied with the way the Surgery handled her complaint.

The Health Service Ombudsman appreciated why Mrs Keohane found it difficult to accept that the GP examined Mr Hughes properly and made reasonable decisions about his care and treatment when, later that day, he collapsed and died. However, she found no reason to criticise the GP. She found no evidence of service failure by the Surgery and no evidence that Mr Hughes was treated less favourably for reasons related to his learning disabilities. Furthermore, she found no evidence of maladministration in the way the Surgery handled Mrs Keohane's complaint.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Surgery.

The Local Government Ombudsman's investigation of the complaint against the Council

Mrs Keohane did not complain to the Local Government Ombudsman about the actions of staff at the Care Home until October 2007. By this time the NHS components of the complaint had already been accepted for investigation by the Health Service Ombudsman. Therefore, with the aim of providing a timely integrated response, the Local Government Ombudsman decided he would exercise his discretion and accept the case for investigation.

Mrs Keohane complained about the care and treatment provided by staff at the Care Home when Mr Hughes was discharged and when he collapsed. In particular, she wanted to know whether appropriate arrangements were made for her brother's dietary needs.

The Local Government Ombudsman's review of different sources of evidence showed the story about what had happened to Mr Hughes after his last meal had become distorted over time and he was able to set the record straight on this point. Evidence clearly showed that Mr Hughes' evening meal had been prepared broadly in line with imprecise instructions given by the Trust and that he had collapsed and vomited around 20 minutes after eating his meal. The Local Government Ombudsman found no evidence that the actions of Care Home staff in preparing this meal and other drinks and meals had any influence on Mr Hughes' subsequent collapse and death.

The Local Government Ombudsman was concerned to find that Care Home staff did not have up-to-date first aid training which would have helped them respond appropriately when Mr Hughes collapsed. However, he was persuaded that they acted reasonably in the circumstances and he found no evidence of maladministration.

Therefore, the Local Government Ombudsman did not uphold the complaint against the Council.

The Health Service Ombudsman's investigation of the complaint against the Healthcare Commission

Mrs Keohane was dissatisfied with the way her complaint was handled by the Healthcare Commission.

The Health Service Ombudsman found maladministration in the way the Healthcare Commission reviewed Mrs Keohane's complaint against the Trust because the Healthcare Commission made no effort to follow up its recommendations to the Trust. Furthermore, it took too long to review the complaint and did not keep Mrs Keohane updated on progress. This

resulted in an injustice to Mrs Keohane in that she did not receive a proper review of her complaint. Therefore, the Health Service Ombudsman upheld this aspect of the complaint against the Healthcare Commission. However, she found no maladministration in the way the Healthcare Commission handled the review of Mrs Keohane's complaint against the Surgery and, therefore, she did not uphold this aspect of her complaint.

Was Mr Hughes treated less favourably for reasons related to his learning disabilities? The Health Service Ombudsman's conclusion

The Health Service Ombudsman concluded that failures in the Trust's care and treatment of Mr Hughes were in part for reasons related to his learning disabilities. Staff did not make reasonable adjustments to meet his complex needs. His behaviour, which was linked to his impairment, made him difficult to manage and staff discharged him unsafely.

The Health Service Ombudsman also concluded that the Trust's actions and omissions constituted a failure to live up to human rights principles, especially those of dignity and equality. By discharging Mr Hughes prematurely and without sufficient regard to his care, the Trust failed to have due regard to the need to safeguard his dignity and wellbeing in his future care by the Care Home, and to the observance of the principle of equality in the delivery of his care. There was no evidence of any positive intention to humiliate or debase Mr Hughes. Nevertheless, the standard of service provided did raise the question of whether the Trust's actions constituted a failure to respect Mr Hughes' dignity. In these respects, the Trust's service failure touched upon and demonstrated inadequate respect for Mr Hughes' status as a person.

Was Mr Hughes' death avoidable?

Mrs Keohane asked whether the Ombudsmen could find any additional information about the reason why Mr Hughes collapsed and died. The Ombudsmen were clear that it was not possible to establish beyond doubt why Mr Hughes collapsed. They found no evidence which pointed directly to a cause for his collapse. There was no post mortem evidence which showed that he collapsed due to any of the most common causes of collapse for a person of his age. That said, in the light of the advice from the advisers, it seemed possible that he collapsed due to a sudden change in his heart rhythm which led to the other events associated with his death. The advisers said the likelihood that Mr Hughes would survive such an event, even in hospital, would have been low.

The Ombudsmen did not conclude that Mr Hughes' death occurred in consequence of any maladministration or service failure which they found during the investigation and, therefore, they did not conclude that his death was avoidable.

The Health Service Ombudsman's recommendations

The Health Service Ombudsman recommended that Mrs Keohane should receive an apology and compensation of £10,000 from the Trust and an apology from the Healthcare Commission. The compensation was in recognition of the injustice suffered in consequence of the service failure and maladministration identified.

In response to these recommendations the Trust acknowledged its failings, apologised to Mrs Keohane and offered information about improvements in service since Mr Hughes' death. It also agreed to pay the compensation recommended. The Healthcare Commission agreed to apologise to Mrs Keohane.

The complainant's response

Mrs Keohane said trying to find out what had happened to her brother had been a '*long, frustrating and distressing time*'. She said the investigation was thorough and at last enabled her family to have a better understanding of what happened to Mr Hughes. She said it was a comfort to her to have the story clarified and presented so clearly. She also found comfort in the information provided about the standard of care in the Care Home.

However, Mrs Keohane did not accept the advisers' suggestion about the reason for her brother's collapse, or the conclusion that there was no service failure by the GP. Mrs Keohane said she strongly believed that Mr Hughes was prematurely discharged from the Trust and the GP should have readmitted him.

Summary report of an investigation by the Health Service Ombudsman of a complaint made by Mencap on behalf of Mrs Vera Ryan in relation to her late son, Mr Martin Ryan.

Complainant:

Mrs Vera Ryan

Aggrieved:

Mr Martin Ryan (Mrs Ryan's late son)

Representative:

Mencap

Complaint against:

Kingston Hospital NHS Trust (the Trust)

Background

Mr Ryan was a 43 year old man with severe learning disabilities, Down's syndrome and epilepsy who lived in a residential care home. Mr Ryan's family described him as a charming, strong and energetic man who, before his stroke, was living happily with his carers. They said it took Mr Ryan a while to get to know people and it took people a while to get to know him. They thought this was probably because he could not communicate verbally and because his behaviour was different.

In November 2005 Mr Ryan suffered a stroke and was admitted to a general ward at the Trust. Over the following weeks his care and treatment was the responsibility of a multidisciplinary team including doctors, nurses, physiotherapists and speech and language therapists. For most of the time he was in hospital, carers from his residential home were with him and he was visited occasionally by specialist community nurses. However, throughout his stay he was given no nutrition. The primary causes of

his death were recorded on his death certificate as pneumonia and a stroke.

The complaint

Mr Ryan's mother accepted that the Trust had acknowledged many failings in its care of her son and that it had taken action to try and remedy those failings. However, she remained dissatisfied and complained to the Health Service Ombudsman that her son should not have died. She said that if staff at the Trust had acted differently, he would have survived. In particular, she said she had thought her son would be *'in good hands'* at the Trust. Instead he had *'starved to death'*. She believed her son had been treated less favourably for reasons related to his learning disabilities.

Mrs Ryan was also dissatisfied with the way her complaint had been handled by the Trust. She felt the NHS complaints process had failed her and she asked the Health Service Ombudsman to find out the answers to her questions about the service provided for her son.

What should have happened

The NHS staff who looked after Mr Ryan should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Mr Ryan's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998* and *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) were especially relevant to the overall standard. In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies.

Mr Ryan's care and treatment should have met the prevailing specific national and professional standards for management of stroke patients, especially the *National Clinical Guidelines for Stroke* (1st edition 2000 and 2nd edition 2004) issued by the Royal College of Physicians and the *National Service Framework for Older People* (2001). These documents set out expectations including: standards for developing specialist stroke units; guidelines for testing and investigating stroke patients; and requirements for multidisciplinary working. By April 2004 the government required all hospitals caring for stroke patients to have developed a specialised stroke service. Furthermore, Mr Ryan's care should have met the Trust's own standards, in particular its Eating and Drinking Policy.

The responses to Mrs Ryan's complaint should have followed the *National Health Service (Complaints) Regulations 2004*.

How the Health Service Ombudsman investigated

The investigator met Mr Ryan's family to gain a full understanding of Mrs Ryan's complaint. It was important to carefully consider their recollections and views. Evidence about what happened to Mr Ryan and how his mother's complaint had been handled was considered. The Trust also provided additional information in response to specific enquiries.

Several professional advisers provided expert clinical advice to the Health Service Ombudsman. They were: a consultant physician specialising in stroke care; a speech and language therapist; a hospital nurse; and two learning disability nurses.

Mr Ryan's family, their representative and others involved in the events complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

What the Health Service Ombudsman found and concluded

The basic facts about Mr Ryan's stay at the Trust were revealed by the Trust's internal inquiry. However, Mrs Ryan asked the Health Service Ombudsman to look further into two specific aspects of her son's clinical care – the failure to feed him and the failures in communication between different members of Trust staff. In particular, she wanted to know whether malnutrition had led to her son's death. The Trust had told Mrs Ryan that the failures in her son's care were not for disability related reasons and that he had not died from malnutrition and starvation.

The Health Service Ombudsman found that the key failings in Mr Ryan's care and treatment could be grouped into three main areas: failings in stroke care; failings in clinical leadership; and failings in communication and multidisciplinary team working.

Stroke care

The Trust had not responded to national and professional recommendations about stroke care. Although prevailing policy and guidelines did not require trusts to have a specialist stroke unit (and this Trust did not have such a unit) the guidelines

did require trusts to organise stroke services so that patients were admitted under the care of a specialist team for acute care and rehabilitation. The Health Service Ombudsman found that at the time Mr Ryan was admitted, services at the Trust for stroke patients were fragmented and fell short of professional and national expectations for stroke care set out in policy and guidelines. There was no special team of experts skilled in management of the needs of stroke patients, for example doctors, nurses, dieticians and speech and language therapists, who could identify and meet Mr Ryan's basic needs, including his nutritional needs.

Clinical leadership

The Health Service Ombudsman found that neither the Consultant nor the Ward Sister provided effective clinical leadership, either for their professional group or the ward team as a whole. Neither of the lead professionals had set up effective systems of organising care and treatment. Nursing shift patterns did not encourage continuity of care and medical cover was fragmented with no effective arrangements at weekends. Neither lead professional recognised that the basic standard of care which doctors and nurses in their charge were providing for a very ill man was inadequate.

Mr Ryan could not swallow due to his stroke and the Health Service Ombudsman found that the medical team, under the leadership of the Consultant, was primarily responsible for deciding on a plan for feeding Mr Ryan. Despite speech and language therapy assessments that Mr Ryan would need alternative feeding (such as feeding him by a tube through his nose or abdominal wall into his stomach), the medical team did not make a decision about alternative feeding until Mr Ryan had been in hospital for 18 days. Soon after that, Mr Ryan became too ill to undergo the procedure to insert a feeding tube.

The Health Service Ombudsman found that the Ward Sister did not take the lead, as she should have done, in monitoring and managing Mr Ryan's condition. She did not put in place arrangements to guide or support members of her nursing team in caring for Mr Ryan's needs. It was clear she was not aware of failings in her team: for example, assessments were poor, care plans were inadequate and the delivery and evaluation of nursing care was below a reasonable standard in the circumstances. There was no evidence of nursing actions aimed at meeting Mr Ryan's nutritional needs.

Communication and multidisciplinary team working

National, professional and local policy and guidelines stressed the importance of multidisciplinary team working in stroke care. However, poor communication and team working between professionals meant the approach to Mr Ryan's care, including his nutrition, was fragmented, unplanned and ineffective. For instance, there were no multidisciplinary team meetings. This meant there was no forum for professionals involved in Mr Ryan's care and treatment, such as the community nurses, the speech and language therapists and the physiotherapists, to discuss integrated plans for his care.

There was evidence that various professionals, including the community team and the speech and language therapists, were very concerned about Mr Ryan and tried to raise their concerns, particularly about nutrition, with the medical and nursing teams. But they could not make themselves heard and nothing happened to help Mr Ryan. Nobody took any action to feed him.

Malnutrition and starvation

Mrs Ryan believed her son '*starved to death*'. He was not fed for 26 days and it is an indisputable fact that people need food to live and that without sufficient food people weaken and die.

The Health Service Ombudsman was advised that Mr Ryan had suffered a significant stroke. However, she was also advised that had he been cared for in a Trust where stroke services were organised according to policy and guidelines, he would have had a better chance of survival, albeit with long-term mental and physical problems. However, the Health Service Ombudsman's medical adviser said that prolonged starvation would have made it less likely that Mr Ryan would have survived because he would have been more susceptible to infection and less able to combat infection when it occurred.

The Health Service Ombudsman concluded that she could not say for certain whether Mr Ryan would have survived if he had been fed. However, what she did say was that the failure to feed him for 26 days undoubtedly placed him at considerable risk of harm. She said that although it was impossible to prove that malnutrition and starvation contributed to or caused Mr Ryan's death, it was likely that the failure to feed him for a prolonged period was one of a number of failings which led to his death.

The Health Service Ombudsman concluded that the Trust's failures in its arrangements for stroke patients, clinical leadership, communication, multidisciplinary working and nutritional care were service failure which was at least in part for disability related reasons.

Complaint handling

Mrs Ryan was dissatisfied with the way her complaint was handled by the Trust and she believed her complaint had not been properly dealt with for reasons related to her son's learning disabilities.

The Health Service Ombudsman found shortcomings in the way the Trust handled Mrs Ryan's complaint. For instance, the Trust failed to recognise the seriousness of the matters complained about, failed to investigate properly and failed to provide appropriate responses which were accurate and consistent. She concluded that the Trust's complaint handling was maladministrative but that the failings in complaint handling were not for disability related reasons.

Was Mr Ryan treated less favourably for reasons related to his learning disabilities?

The Health Service Ombudsman concluded that the failings in care and treatment could not be separated from the fact that Trust staff did not attempt to make any reasonable adjustments, as they should have done, to the way in which they organised and delivered care and treatment to meet Mr Ryan's complex needs. She concluded, therefore, that in some significant respects the Trust's service failures were for disability related reasons.

The Health Service Ombudsman also concluded that the Trust's actions and omissions constituted a failure to live up to human rights principles, especially those of dignity, equality and autonomy. By failing to care properly for Mr Ryan, in particular by not feeding him, the Trust failed to have due regard to his status as a person, to the need to avoid the infringement of his dignity and wellbeing

that would arise from a lack of attention to his needs, in particular his need for food, and to observance of the principle of equality in the way these rights were to be protected. There was no evidence of any positive intention to humiliate or debase Mr Ryan. Nevertheless, the standard of service did at the very least constitute a failure to respect Mr Ryan's human dignity.

Was Mr Ryan's death avoidable?

In considering whether to make a finding about avoidable death the Health Service Ombudsman assessed whether the injustice complained about (in this case Mr Ryan's death) arose in consequence of the service failure or maladministration she had identified. She concluded that it was impossible to say for certain whether Mr Ryan would have survived if he had been fed. However, while she could not categorically say that Mr Ryan died because he was not fed, she was not persuaded that the Trust could categorically say that this was not the reason for his death.

The Health Service Ombudsman concluded that, had the care and treatment Mr Ryan received not fallen so far below the relevant standard, it is likely that his death could have been avoided.

Injustice

The Trust put forward evidence about changes which had occurred since Mr Ryan was a patient there, and the Health Service Ombudsman found the Trust had taken reasonable action to address the shortcomings identified by its own inquiry and service failure and maladministration identified in her investigation. That said, Mr Ryan's parents still had reason to be aggrieved by the failings in the Trust's care and treatment of their son and, in

particular, those failings which the Health Service Ombudsman concluded occurred for disability related reasons. Furthermore, they should not have had to wait for an investigation by the Health Service Ombudsman to fully establish the facts about the service provided for their son. Partly due to failings at the Trust, Mr Ryan's parents had to wait over two years for answers to their questions. These findings represent unremedied injustice.

Moreover, in discovering that their son's death could probably have been avoided, had the care and treatment not fallen so far below the relevant standard, Mr Ryan's parents suffered an injustice which can never be remedied.

Therefore, the Health Service Ombudsman upheld Mrs Ryan's complaint against the Trust.

Recommendation

The Health Service Ombudsman recommended Mr Ryan's parents should receive apologies and compensation of £40,000 from the Trust. This compensation was in recognition of the injustice suffered in consequence of the service failure and maladministration identified.

In response to the recommendations the Trust's Chief Executive acknowledged the failings, apologised to Mr Ryan's parents and agreed to pay the compensation.

The complainant's response

Mr Ryan's family and Mencap have said the outcome of the investigation is that *'justice has been done'* because the Health Service Ombudsman's report exposes the very serious failures that led to Mr Ryan's death. They also welcomed the conclusions that some of the failures in care and treatment were for disability related reasons. They said they believe the report will have a positive impact on future care of people with learning disabilities. They welcomed action by the Trust aimed at preventing a similar occurrence. In particular, they have said that the report shows how *'proper care, using multidisciplinary working, personalised care planning and good communication within teams and with families and carers would greatly improve the outcome for people with a learning disability in our hospitals'*.

Summary report of a joint investigation by the Health Service Ombudsman and the Local Government Ombudsman of a complaint made by Mencap on behalf of Mr and Mrs Wakefield in relation to their late son, Mr Tom Wakefield.

Complainants:

Mr and Mrs Wakefield

Aggrieved:

Mr Tom Wakefield (Mr and Mrs Wakefield's late son)

Representative:

Mencap

Complaint against:

West Street Surgery (the Surgery)
Gloucestershire County Council (the Council)
Cheltenham and Tewkesbury Primary Care Trust –
now Gloucestershire Primary Care Trust (the PCT)
Gloucestershire Partnership NHS Foundation
Trust – now 2gether NHS Foundation Trust for
Gloucestershire (the Partnership Trust)
Gloucestershire Hospitals NHS Foundation Trust
(the Acute Trust)
Healthcare Commission

Introduction

This complaint was investigated jointly by the Local Government Ombudsman for England and the Health Service Ombudsman for England in accordance with the powers conferred by amendments to their legislation due to *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007*. With the consent of the complainants, Tom's parents, the two Ombudsmen agreed to work together because the health and social care issues were so closely linked. A co-ordinated response, consisting of a joint investigation leading to a joint conclusion and

proposed remedy in one report, seemed the most appropriate way forward.

Background

Tom Wakefield was a sociable young man with profound and multiple learning disabilities and kypho-scoliosis (progressive curvature of the spine which caused problems with his posture). Since he was an infant he had had gastrointestinal problems for which he had undergone surgery as a child. Tom's posture and gastrointestinal problems gave him pain which appeared to have been well controlled by medication until 2001. He could understand speech and was able to communicate using facial, hand and arm movements. He had a history of self-harming behaviour.

From the age of 6 years Tom attended Penhurst School (the Residential School). In July 2003, when he was 19 years old, he should have been transferred to suitable adult accommodation, but no place had been found for him so he remained at the Residential School. His behaviour and health deteriorated and the school felt unable to accommodate him. In November 2003 he was admitted to an NHS Assessment Unit managed by the Partnership Trust, where he spent 3 months until he moved to an adult care home. By that point his health had deteriorated further and in April 2004, shortly after moving to the Care Home, he was admitted to the Acute Trust where he died a few weeks later, aged 20. His death certificate records the causes of his death as aspiration pneumonia, reflux oesophagitis, scoliosis and cerebral palsy.

The complaint

Tom's parents complained to the Ombudsmen that their son should not have died. They said that if staff at the Surgery, the Council, the Partnership Trust, the PCT and the Acute Trust had acted differently, he would have survived. They believed their son had suffered unnecessarily and had been treated less favourably for reasons related to his learning disabilities.

Tom's parents were also dissatisfied with the way their complaint about NHS services had been handled by the Surgery, the Partnership Trust, the PCT and the Healthcare Commission. They were also dissatisfied with the way the planning and provision of their son's care had been investigated by the Council. They felt the NHS and Council complaints processes had failed them and they asked the Ombudsmen to find out the answers to their questions about the service provided for their son.

What should have happened

The staff who looked after Tom should have been mindful of the overall standard governing their work. This standard is made up of two components: the general standard which is derived from general principles of good administration and, where applicable, public law; and the specific standard which is derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

In Tom's case, legislation and policy about disability and human rights, in particular the *Disability Discrimination Act 1995*, the *Human Rights Act 1998*, *Valuing People: A New Strategy for Learning Disability for the 21st Century* (2001) and *Once a Day: A Primary Care Handbook for people with learning disabilities* (1999) were especially relevant to the overall standard.

Tom's care should have been organised within the legal and policy framework for integrated health and social care as set out in key documents including the *National Health Service and Community Care Act 1990* and the *Care Standards Act 2000*.

In terms of professional standards, the doctors and nurses should have followed the standards set out by their regulatory bodies. Tom's care and treatment at the Partnership Trust and the Acute Trust should have met national and professional standards regarding nursing care and discharge arrangements.

The responses to Tom's parents' complaint about NHS services should have followed the *National Health Service (Complaints) Regulations 2004* and their complaint about the Council should have been handled in line with the *Complaints Procedure Directions 1990*.

How the Ombudsmen investigated

The investigator met Tom's parents to gain a full understanding of their complaint. It was important to carefully consider their recollections and views. Evidence about what happened to Tom and how his parents' complaints about NHS and Council services were handled was considered. The bodies complained about provided additional information in response to specific enquiries, and specific clinical staff involved with Tom's care were contacted.

Several professional advisers provided expert clinical advice to the Ombudsmen. They were: a hospital nurse; a learning disability nurse; two consultant gastroenterologists; a consultant psychiatrist; a professor of pharmacy; and a GP.

Tom's parents, their representative and the bodies complained about had the opportunity to comment on the draft report, and their comments were carefully considered before the final report was issued.

What the Ombudsmen found and concluded

The Health Service Ombudsman's investigation of the complaint against the Surgery

Tom's parents complained that the care and treatment provided by the Surgery was inadequate. In particular, they said the Surgery failed to deal appropriately with their son's pain and weight loss and failed to act on medical advice from a hospice to refer him for an endoscopy (an examination of the gullet and stomach using a telescopic instrument) and prescribe morphine for his pain. Tom's parents were also dissatisfied with the way the Surgery handled their complaint.

The Health Service Ombudsman could appreciate why Tom's parents found it difficult to accept that the Surgery offered reasonable care and treatment to their son during his last years at the Residential School, given that it appears he was in pain and losing weight at this time. However, she found that the care and treatment provided by the Surgery, including the management of Tom's pain and weight loss, and the decision not to refer him for an endoscopy did not fall significantly below a reasonable standard in the circumstances.

The Health Service Ombudsman found no evidence of service failure by the Surgery and no evidence that Tom was treated less favourably by the Surgery for reasons related to his learning disabilities.

Furthermore, she found no maladministration in the way the Surgery handled Tom's parents' complaint.

Therefore, the Health Service Ombudsman did not uphold the complaint against the Surgery.

The Local Government Ombudsman's investigation of the complaint against the Council

Tom was still living in the Residential School when he was 19 years old and should have been living in adult accommodation.

Tom's parents complained that the Council had failed to plan for, or commission, new provision for their son or to deal appropriately with his transition into adult accommodation. They said a Social Worker failed to pass on information about an offer of a suitable permanent placement for Tom. They also said the Council failed to investigate their concerns adequately or respond properly to their complaint.

The Local Government Ombudsman found that the Council's arrangements for Tom's transition to adult accommodation fell significantly below a reasonable standard in the circumstances. He found there was no commissioning strategy in place, there were gaps in plans for people with profound and multiple learning disabilities and challenging behaviour, and transition arrangements, including communication, had been poor. He also found that in relation to finding a placement for Tom, Social Services did not work on a person-centred basis. Rather, they worked in an unplanned and unstructured way. They failed to liaise or communicate properly with colleagues and Tom's family about a potentially suitable placement which became available. Furthermore, the Council did not respond appropriately to Tom's parents'

complaint or provide adequate reassurances about changes in practice. The Local Government Ombudsman concluded that these failures in service provision and complaint handling amounted to maladministration.

The Local Government Ombudsman said it will never be known if, had appropriate arrangements been in place, Tom would have lived longer or if he could have had more enjoyment from his life in his last year. He found that the Council's actions contributed to the injustice suffered by Tom and his family and concluded that some of the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons.

Therefore, the Local Government Ombudsman upheld the complaint against the Council.

The Health Service Ombudsman's investigation of the complaint against the PCT

Tom's parents complained that the PCT failed to liaise appropriately with the Council in planning their son's transition to adult accommodation and did not provide a reasonable response to their complaint.

The Health Service Ombudsman found there were shortcomings in the way the PCT fulfilled its responsibilities with regard to planning for the health needs of people with profound and multiple learning disabilities. She concluded that these shortcomings amounted to service failure which was for disability related reasons.

She also found maladministration in the way the PCT handled Tom's parents' complaint.

The Health Service Ombudsman recognised the Council had lead responsibility for planning for Tom's transition to adult care and took into account improvements the PCT had made since the events complained about. Nonetheless, she concluded that it was impossible to know what difference it would have made to Tom and his family in terms of his transition to adult accommodation if the PCT had fulfilled its responsibilities in this regard. This unanswered question was an injustice which remained a cause of distress for Tom's parents. Furthermore, maladministration in the way the PCT handled Tom's parents' complaint led to further delay and distress for them.

Therefore, the Health Service Ombudsman upheld the complaint against the PCT.

The Health Service Ombudsman's investigation of the complaint against the Partnership Trust

The Residential School decided it could no longer care for Tom because he was an adult and because his behaviour was becoming more challenging. The Residential School served Tom with notice to leave the home where he had lived for 13 years and the Partnership Trust arranged for him to be admitted to an Assessment Unit.

Tom's parents complained that their son's admission to the Assessment Unit was inappropriate. They said his care and treatment there was inadequate, he was at risk because the environment was poor and his discharge to the Care Home was badly managed. They were also dissatisfied with the way the Partnership Trust handled their complaint.

The Health Service Ombudsman found that it had been appropriate for Tom to go to the Assessment Unit for assessment for an onward placement.

However, she found that the environment was not suitable for Tom's needs and the care and treatment he received fell significantly below a reasonable standard in the circumstances. In particular, a good plan was developed for Tom's care, but this was not implemented. Furthermore, the standard of nursing care was poor and the way in which Tom was discharged to the Care Home was not in line with national guidelines on discharge. The Health Service Ombudsman concluded there was service failure in the care and treatment provided for Tom at this time which was at least in part for disability related reasons.

The Health Service Ombudsman found shortcomings in the way the complaint was handled, for example, some aspects were inadequately investigated and the approach and tone of some responses was inappropriate. She concluded that, overall, these shortcomings amounted to maladministration.

The Partnership Trust told the Health Service Ombudsman about actions it had taken to improve services for people with learning disabilities. However, at the time Tom needed help from the Partnership Trust he did not receive a reasonable standard of service. We cannot know whether the outcome for Tom would have been different had he been provided with better medical treatment and social and nursing care. This service failure contributed to the injustice of unnecessary distress and suffering for Tom and his family. Moreover, partly due to failings in the Partnership Trust's complaint handling, Tom's parents had to wait four years to learn the truth about his care and treatment in the Assessment Unit. This undoubtedly contributed to their distress which remained an unremedied injustice.

Therefore, the Health Service Ombudsman upheld the complaint against the Partnership Trust.

The Health Service Ombudsman's investigation of the complaint against the Acute Trust

Tom's condition was already deteriorating when he moved from the Assessment Unit to the Adult Care Home. It was soon after this move that he became so ill that he was admitted to the Acute Trust.

Tom's parents had not previously complained about the Acute Trust, but to ensure they had a full picture of their son's care and treatment during the final months of his life, the Health Service Ombudsman used her discretion to investigate their complaint. They complained that Tom's care and treatment at the Acute Trust, particularly pain management, hydration and nutrition, were inadequate.

It was clear that given Tom's complex health needs, poor nutritional state and disabilities, providing him with appropriate care and treatment represented a significant challenge for the Acute Trust. Tom's condition had deteriorated to a point where his recovery was unlikely.

Nonetheless, the Health Service Ombudsman found significant failings in the care and treatment the Acute Trust provided. In particular: medical co-ordination and supervision of his care fell below prevailing standards; nursing assessments, planning and interventions were inadequate; arrangements for managing Tom's medication were inadequate; incident recording and reporting were poor; and it seemed Tom's parents were not made fully aware of his prognosis. The Health Service Ombudsman found that staff did not act in line with prevailing professional standards and they did not know how to make reasonable adjustments in their practice to meet Tom's needs. This was service failure for disability related reasons.

This service failure contributed to the injustice of unnecessary distress and suffering for Tom and was an unremedied injustice.

Therefore, the Health Service Ombudsman upheld the complaint against the Acute Trust.

The Health Service Ombudsman's investigation of the complaint against the Healthcare Commission

Tom's parents were dissatisfied with the way their complaint was handled by the Healthcare Commission.

The Health Service Ombudsman found maladministration in the way the Healthcare Commission reviewed Tom's parents' complaint. The Healthcare Commission did not look at the NHS services as a whole and failed to address significant aspects of the complaint. Also, the clinical advice it obtained was inappropriate and inadequate which meant its decisions were unreliable and unsafe. Furthermore, the Health Service Ombudsman found the Healthcare Commission did not explain its decision adequately and did not keep in touch with Tom's parents during the review. These shortcomings resulted in an injustice to Tom's parents in that they did not receive the standard of review to which they were entitled and their experience fell far short of their reasonable expectations.

Therefore, the Health Service Ombudsman upheld the complaint against the Healthcare Commission.

Was Tom treated less favourably for reasons related to his learning disabilities?

From the evidence she received the Health Service Ombudsman concluded that the failings in the service provided for Tom by the PCT, the Partnership Trust and the Acute Trust were at least in part for disability related reasons. Similarly, the Local Government Ombudsman's consideration of the actions of the Council led him to conclude that the maladministration he found had been for disability related reasons.

The Ombudsmen concluded that the service failure and maladministration identified at the different organisations constituted a failure to live up to human rights principles, especially those of dignity and equality. They also concluded that there was no positive intention to humiliate or debase Tom. However, they considered the standard of service he received did raise the question of whether the actions of the Council, the PCT, the Partnership Trust and the Acute Trust constituted a failure to respect Tom's dignity. Maladministration and service failure touched upon and showed inadequate respect for Tom's status as a person.

Furthermore, the Health Service Ombudsman concluded that service failure by the Partnership Trust and the Acute Trust resulted in unnecessary suffering for Tom in the final months of his life.

Was Tom's death avoidable?

Tom's parents said that had Tom received appropriate and reasonable service from the bodies they complained about his death could have been avoided. They said they accepted Tom had a life-limiting illness but not that his condition was life-threatening. They said doctors did not give them any indication their son was likely to die.

The Ombudsmen found there was public service failure by the Council and NHS bodies and that those combined failures resulted in significant unremedied injustice for Tom and his parents. Tom's parents will never know if, had appropriate arrangements been in place for their son's transition to adult care, his life would have been longer or if he could have had some extra enjoyment in his last year of life.

However, on balance the Ombudsmen could not say that Tom's death was in consequence of the service failure or maladministration we identified. Rather, they saw evidence that Tom's condition had been declining for many years and that this decline began before the events complained about. Therefore, they could not conclude that Tom's death was avoidable.

The Ombudsmen's recommendations

The Ombudsmen recommended that Tom's parents should receive apologies and compensation totalling £30,000 from the various bodies against which complaints were upheld. This compensation was in recognition of the injustice suffered in consequence of service failure and maladministration identified.

In response to these recommendations all of the bodies acknowledged their failings, apologised to Tom's parents and offered information about improvements in service since Tom's death. They also agreed to pay the compensation recommended. The Healthcare Commission agreed to apologise to Tom's parents.

The complainants' response

Tom's parents were dissatisfied with the outcome of some aspects of the investigation. In particular, they disagreed with the Health Service Ombudsman's decision not to uphold their complaint against the Surgery. They said they believed that the *'actions of the GP were pivotal'* to what happened to Tom. Furthermore, they strongly disagree with the decision regarding avoidable death. They believe Tom's death was avoidable and they do not accept that their son was at the end of his life.

PHSO-0006

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office

ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.

Six lives: the provision of public services to people with learning disabilities

Part two: the complaint made by Mr Allan Cannon and Mrs Anne Handley

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Second report

Session 2008-2009

Presented to Parliament pursuant to
Section 14(4) of the Health Service Commissioners Act 1993

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-II
London: The Stationery Office
£64.15

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ISBN: 978 0 10 295857 7

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Section 1: introduction and summary

- 1 This is the final report of our joint investigation into complaints made by Mr Cannon's parents against: the London Borough of Havering (the Council); Barking, Havering and Redbridge Hospitals NHS Trust (the Trust); the New Medical Centre, Romford (the Practice); and the Healthcare Commission. The report contains our findings, conclusions and recommendations with regard to their areas of concern.
- 5 Mr Cannon was unwell after he was discharged. He was in pain and not sleeping, and it was difficult to persuade him to eat or drink. On 8 July 2003 he was seen by his GP who arranged for him to be readmitted to the Trust. He was discharged to his mother's home on 14 July 2003.

The complaint

- 2 Mr Cannon was a 30 year old man with severe learning disabilities. He also suffered from epilepsy which was difficult to control. He had very little speech but was able to communicate with his family and he was particularly close to his sister, Jane. He was able to walk unaided but often needed support when he was feeling unsteady on his feet. Mr Cannon was smiling and 'mischievous' with a fine sense of humour. He enjoyed participating in activities, social events and outings with his family and carers, but he also liked lazing around and relaxing in an easy chair or bean bag.
- 3 At the time of the events complained about, Mr Cannon lived at home with his mother, stepfather and sister. He attended a day centre five days a week with occasional stays at the Grange, a Council owned care home.
- 4 In June 2003 Mr Cannon was at the Grange while his mother was on holiday. At some point during the night of 26/27 June 2003, in circumstances which remain unclear, he fractured his upper femur (the thigh bone) and was admitted to the Trust on 27 June 2003. After surgery to repair the fracture Mr Cannon was discharged to his mother's home on 4 July 2003.
- 6 On 6 August 2003 Mr Cannon was seen at home by his GP who diagnosed an infection and prescribed antibiotics. Over the next few days his condition deteriorated, he suffered many seizures and developed a high temperature.
- 7 On 10 August 2003 Mr Cannon was taken to the Accident and Emergency Department (A&E) at the Trust with dehydration, malnutrition and renal failure. He was admitted to the Receiving Room (a medical admission ward), but his condition did not improve and on 11 August 2003 he was transferred to the Intensive Therapy Unit (ITU). His condition stabilised and on 13 August 2003 he was moved to the High Dependency Unit (HDU). There his condition deteriorated and he suffered a cardiac arrest. He was resuscitated and transferred back to the ITU. However, after discussion with his family, it was agreed that there was no hope of recovery and treatment was withdrawn. Mr Cannon died on 29 August 2003.
- 8 The Coroner asked the police to investigate the circumstances of Mr Cannon's injury at the Grange. Two pathologists carried out separate post mortems and both concluded it was likely that Mr Cannon's fracture was caused by a fall and that his death was a result of bronchopneumonia. An inquest was held and the Coroner recorded a verdict of accidental death.

- 9 Mr Cannon's parents said they were appalled by what happened to their son. At one point in the complaints process they said:

'All of Mark's 30 years had been a struggle for equal rights to health care, support and services within the society he lived. We battled continuously with virtually no progress.'

- 10 Mr Cannon's parents have given permission for Mencap to act as their representative.

The overarching complaint

- 11 Mr Cannon's parents believe their son's death was avoidable and he received less favourable treatment for reasons related to his learning disabilities. We have called this aspect of the complaint 'the overarching complaint'.

Complaint against the Council

- 12 Mr Cannon's parents complain that:

Complaint (a): their son was provided with inadequate care by the Council and this led to his injury and, ultimately, his death. They believe the Council failed in its duty to keep their son safe while he was in its care as a result of poor care planning, poor supervision, weak management and inadequate staffing, including training and induction. They also believe the Council repeatedly failed to properly investigate the circumstances of their son's injury or to take any responsibility for the part its failings played in his injury and subsequent death.

Complaint against the Trust

- 13 Mr Cannon's parents complain that:

Complaint (b): during each of his admissions, the Trust failed to provide their son with adequate care and treatment or to properly plan his discharge and aftercare. They believe these failures led to the decline in Mr Cannon's health and his death.

Complaint (c): the Trust has failed to investigate the family's complaint about their son's care properly or to apologise for the many shortcomings which they believe occurred.

Complaint against the Practice

- 14 Mr Cannon's parents complain that:

Complaint (d): the GP Practice failed to provide their son with adequate care and that more could have been done to diagnose the reasons for the deterioration in his condition following his discharge from hospital. They believe that if the Practice had taken action sooner their son might have received the care he needed and might not have died.

Complaint against the Healthcare Commission

- 15 Mr Cannon's parents complain about:

Complaint (e): the way the Healthcare Commission handled their complaint. They say the Healthcare Commission failed to properly investigate their complaints against the Trust or take appropriate action where they identified serious shortcomings. They also say the Healthcare Commission's review took too long.

16 Mr Cannon's parents believe they have not had answers to all their questions and they hope the Ombudsmen's investigation will provide them with those answers. They hope other people will not go through the same experiences as their family.

The Ombudsmen's remit, jurisdiction and powers

General remit of the Health Service Ombudsman

17 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In the exercise of her wide discretion she may investigate complaints about NHS bodies such as trusts, family health service providers such as GPs, and independent persons (individuals or bodies) providing a service on behalf of the NHS.

18 When considering complaints against an NHS body, she may look at whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the body, a failure by the body to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.

19 Failure or maladministration may arise from action of the body, a person employed by or acting on behalf of the body, or a person to whom the body has delegated any functions.

20 When considering complaints against GPs, she may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Again, such action may have been taken by the GP himself or herself, by someone employed by or acting on behalf of the GP or by a person to whom the GP has delegated any functions.

21 The Health Service Ombudsman may carry out an investigation in any manner which, to her, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as she thinks fit.

22 If the Health Service Ombudsman finds that service failure or maladministration has resulted in an injustice, she will uphold the complaint. If the resulting injustice is unremedied, in line with her *Principles for Remedy*, she may recommend redress to remedy any injustice she has found.

Remit over the Healthcare Commission

23 By operation of section 3(1E) of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints about injustice or hardship in consequence of maladministration by any person exercising an NHS complaints function. As the Healthcare Commission is the second stage of the NHS complaints procedure set out in the *National Health Service (Complaints) Regulations 2004*, it is within the Health Service Ombudsman's remit.

Health Service Ombudsman – premature complaints

- 24 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Ombudsman generally may not investigate any complaint until the NHS complaints procedure has been invoked and exhausted, and this is the approach she takes in the majority of NHS complaints made to her.
- 25 However, section 4(5) makes it clear that if, in the particular circumstances of any case, the Health Service Ombudsman considers it is not reasonable to expect the complainant to have followed the NHS route, she may accept the case for investigation notwithstanding that the complaint has not been dealt with under the NHS complaints procedure. This is a matter for the Health Service Ombudsman's discretion after proper consideration of the facts of each case.
- 26 In this instance, Mr Cannon's parents had not previously complained to the Practice. However, in their complaint to the Health Service Ombudsman they make clear their concern that the Practice had failed to provide adequate care and treatment to their son when he was cared for at home by his mother after his injury at the Grange. They say they had become exhausted by the complaints process and had felt unable to pursue this matter previously. However, they consider there were shortcomings in the care provided by the Practice and they say that if these are not explained and examined they would still not fully understand what had happened to their son. Taking these matters into account, the Health Service Ombudsman exercised her discretion to investigate the complaint against the Practice under the provisions of the Act which governs her work.

General remit of the Local Government Ombudsman

- 27 Under the *Local Government Act 1974 Part III*, the Local Government Ombudsman has wide discretion to investigate complaints of injustice arising from maladministration by local authorities (local councils) and certain other public bodies. He may investigate complaints about most council matters, including Social Services and the provision of social care.
- 28 If the Local Government Ombudsman finds that maladministration has resulted in an injustice, he will uphold the complaint. If the resulting injustice is unremedied, he may recommend redress to remedy any injustice he has found.

Powers to investigate and report jointly

- 29 *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007* clarified the powers of the Health Service Ombudsman and the Local Government Ombudsman, with the consent of the complainant, to share information, carry out joint investigations and produce joint reports in respect of complaints which fell within the remit of both Ombudsmen.
- 30 In this case, the Health Service Ombudsman and the Local Government Ombudsman agreed to work together because the health and social care issues were so closely linked. A co-ordinated response consisting of a joint investigation leading to the production of a joint conclusion and proposed remedy in one report seemed the most appropriate way forward.

The investigation

³¹ During the investigation, our investigator met Mr Cannon's parents and their representatives to ensure that we had a full understanding of their complaint. Mr Cannon's health records, the Trust's complaint file and legal file relating to the Coroner's inquest, the Healthcare Commission's file and the Council's complaint file were examined. Mr Cannon's family also submitted papers setting out their complaint. Papers were also obtained from HM Coroner for the Eastern District of Greater London including her summing up and verdict. Interviews were conducted with the Council's Learning Disabilities Service Manager and with the Council's Complaints Manager at the time of the events complained about. All of the bodies under investigation also provided additional information in response to our specific enquiries.

³² We obtained specialist advice from a number of professional advisers (the Professional Advisers):

- Ms L Etherington, a nurse specialising in A&E nursing (the A&E Nursing Adviser).
- Dr T Malpass, a consultant physician specialising in A&E Medicine (the A&E Medical Adviser).
- Mr J Albert, an orthopaedic surgeon (the Orthopaedic Surgical Adviser).
- Dr J Skoyles, a consultant anaesthetist with expertise in medical care in high dependency and intensive care settings (the Anaesthetic Adviser).

- Mr B Lucas, a nurse specialising in the care of patients in an orthopaedic setting (the Orthopaedic Nursing Adviser).
- Ms E Onslow, a nurse with expertise relating to discharge planning and community nursing (the Community Nursing Adviser).
- Ms A Kent, a nurse with expertise relating to the care of patients with learning disabilities (the Learning Disability Nursing Adviser).
- Dr J Rasmussen, a general practitioner (the GP Adviser).

In addition, Dr T Owen (a general practitioner) and Mrs S Lowson (an experienced acute nurse and a Lead Clinician at the Office of the Health Service Ombudsman) provided further professional advice in respect of the complainants' response to the draft report.

³³ The Professional Advisers are specialists in their field and in their roles as advisers to the Ombudsmen they are completely independent of any NHS body, local government body and the Healthcare Commission. Their role is to help the Ombudsmen and their investigative staff understand the clinical aspects of the complaint.

³⁴ In this report we have not referred to all the information examined in the course of our investigation, but we are satisfied that nothing significant to the complaint or our findings has been overlooked.

Our decisions

- 35 Having considered all the available evidence related to Mr Cannon's parents' complaint, including their recollections and views and their response to our draft report, and taken account of the clinical advice we have received, we have reached the following decisions.

Complaint against the Council

- 36 The Local Government Ombudsman finds that the Council failed to provide and/or secure an acceptable standard of care for Mr Cannon and that, as a result, his safety was put at risk. That failure constitutes **maladministration** by the Council. The accident suffered by Mr Cannon might well have been avoided if the failures identified in the report had not occurred. The Local Government Ombudsman also finds that the Council did not respond to the complaint made by Mr Cannon's parents in an appropriate way and that this caused further distress to his family. That, too, was **maladministration**. The maladministration found by the Local Government Ombudsman caused **injustice** to Mr Cannon's parents.

Complaint against the Trust

- 37 The Health Service Ombudsman finds that the Trust failed to provide Mr Cannon with a reasonable standard of care and treatment. In particular, pain management, post-operative monitoring, discharge arrangements and nursing care were inadequate. This was **service failure** which was in many respects for disability related reasons. She also concludes that the Trust's acts and omissions constituted a failure to live up to human rights principles of dignity, equality and

autonomy. The failures on the part of the Trust added to Mr Cannon's suffering and lessened his chances of recovery. The Trust's complaint handling was also poor. This **maladministration** compounded the **injustice** and caused further distress to Mr Cannon's family. The Health Service Ombudsman **upholds** the complaint against the Trust.

Complaint against the Practice

- 38 The Health Service Ombudsman finds the service provided to Mr Cannon after he was discharged from hospital on 14 July 2003 did not fall significantly below a reasonable standard in the circumstances. She considers the failings identified **did not amount to service failure**. The Health Service Ombudsman **does not uphold** the complaint against the Practice.

Complaint against the Healthcare Commission

- 39 The Health Service Ombudsman finds **maladministration** in the way the Healthcare Commission reviewed Mr Cannon's parents' complaint against the Trust. This led to **injustice** because they did not receive the robust review of their complaint to which they were entitled. The Health Service Ombudsman **upholds** the complaint against the Healthcare Commission.

The overarching complaint

- 40 We conclude that maladministration by the Council and service failure by the Trust meant Mr Cannon was treated less favourably for reasons related to his learning disability. Furthermore, the acts and omissions of the Council and the Trust constitute a failure to live up to human rights principles of dignity, equality and autonomy.
- 41 We also conclude that Mr Cannon's death occurred in consequence of the maladministration and service failure which we identified and, therefore, that his death was avoidable.
- 42 In this report we explain the detailed reasons for our decision and comment on the particular areas where Mr Cannon's parents have expressed concern to the Ombudsmen.

Section 2: the basis for our determination of the complaints

Introduction

- 43 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, the Ombudsmen generally begin by comparing what actually happened with what should have happened.
- 44 So, in addition to establishing the facts that are relevant to the complaint, we also need to establish a clear understanding of the standards, both of general application and which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. We call this establishing the overall standard.
- 45 The overall standard has two components: the general standard which is derived from general principles of good administration and, where applicable, of public law; and the specific standards which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.
- 46 Having established the overall standard we then assess the facts in accordance with the standard. Specifically, we assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard. If so, we then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

- 47 The overall standard which we have applied to this investigation is set out below.

The general standard

Principles of Good Administration

- 48 Since it was established the Office of the Parliamentary and Health Service Ombudsman has developed and applied certain principles of good administration in determining complaints of service failure and maladministration. In March 2007 the Parliamentary and Health Service Ombudsman published these established principles in codified form in a document entitled *Principles of Good Administration*.
- 49 The document organises the established principles of good administration into six Principles. These Principles are:
- Getting it right
 - Being customer focused
 - Being open and accountable
 - Acting fairly and proportionately
 - Putting things right, and
 - Seeking continuous improvement.
- 50 We have taken all of these Principles into account in our consideration of Mr Cannon's parents' complaints and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:¹

¹ *Principles of Good Administration* is available at www.ombudsman.org.uk

'Getting it right' means:

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

'Being customer focused' means:

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

'Being open and accountable' means:

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.

- Stating criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for actions.

'Acting fairly and proportionately' means:

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

'Putting things right' means:

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

‘Seeking continuous improvement’ means:

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Principles for Remedy

- 51 In October 2007 the Parliamentary and Health Service Ombudsman published a document entitled *Principles for Remedy*.²
- 52 This document sets out the Principles that we consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how we think public bodies should put things right when they have gone wrong. It also confirms our own approach to recommending remedies. The *Principles for Remedy* flows from, and should be read with, the *Principles of Good Administration*. Providing fair and proportionate remedies is an integral part of good administration and good service, so the same principles apply.
- 53 We have taken the *Principles for Remedy* into account in our consideration of Mr Cannon’s parents’ complaints.

The specific standard

Disability discrimination

Legal framework

Disability Discrimination Act 1995

- 54 The sections of the *Disability Discrimination Act 1995* most relevant to the provision of services in this complaint were brought into force in 1996 and 1999 respectively. Although other parts of the *Disability Discrimination Act 1995* were brought into force in 2004 and further provisions added by the *Disability Discrimination Act 2005*, these changes either post-date or are not directly relevant to the subject matter of this complaint.
- 55 Since December 1996 it has been unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified.
- 56 Since October 1999 it has in addition been unlawful for service providers to fail to comply with the duty to make reasonable adjustments for disabled people where the existence of a practice, policy or procedure makes it impossible or unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.
- 57 It has also been unlawful since October 1999 for service providers to fail to comply with the duty to make reasonable adjustments so as to provide a reasonable alternative method of making the service in question available to disabled people where the existence of a physical feature makes it impossible or

² *Principles for Remedy* is available at www.ombudsman.org.uk

unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

- 58 Since October 1999 it has been unlawful for service providers to fail to comply with the duty to take reasonable steps to provide auxiliary aids or services to enable or facilitate the use by disabled people of services that the service provider provides, unless that would necessitate a permanent alteration to the physical fabric of a building or unless such failure is justified.

Policy aims

- 59 The *Disability Discrimination Act 1995* recognises that the disabling effect of physical and mental impairment will depend upon how far the physical and social environment creates obstacles to disabled people's enjoyment of the same goods, services and facilities as the rest of the public.
- 60 The key policy aim behind the legislation is to ensure that as far as reasonably possible disabled people enjoy access not just to the same services, but to the same standard of service, as other members of the public. In other words, those who provide services to the public, whether in a private or public capacity, are to do whatever they reasonably can to eradicate any disadvantage that exists for a reason related to a person's physical or mental impairment.
- 61 The critical component of disability rights policy is therefore the obligation to make 'reasonable adjustments', which shapes the 'positive accent' of the *Disability Discrimination Act 1995*. This obligation recognises that very often equality for disabled people requires not the same treatment as everyone else but different treatment. The House of Lords made explicit what this means in a case (*Archibald v Fife Council*, [2004] UKHL 32, judgment of

Baroness Hale), which although arising from the *Part 2* employment provisions of the *Disability Discrimination Act 1995*, has bearing on the *Part 3* service provisions also:

'The 1995 Act, however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment.'

- 62 As the Court of Appeal has also explained, specifically in respect of the *Part 3* service provisions of the *Disability Discrimination Act 1995* (*Roads v Central Trains* [2004] EWCA Civ 1451, judgment of Sedley LJ), the aim is to ensure 'access to a service as close as it is possible to get to the standard offered to the public at large'.

Policy and administrative guidance

Disability Rights Commission Codes of Practice

- 63 Between April 2000 and October 2007 the Disability Rights Commission had responsibility for the enforcement and promotion of disability rights in Britain. In that capacity, and by virtue of the provisions of the *Disability Rights Commission Act 1999*, it had a duty to prepare statutory codes of practice on the law. These statutory codes of practice, although not legally binding, are to be taken into account by courts and tribunals in determining any issue to which their provisions are relevant.
- 64 Before the establishment of the Disability Rights Commission in April 2000, the relevant Secretary of State, on the advice of the National Disability Council, published a statutory code of practice on the duties of service providers under

Part 3 of the *Disability Discrimination Act 1995* entitled *Code of Practice: Goods, Facilities, Services and Premises* (1999), itself a revision of an earlier code of practice published in 1996.

- 65 On its establishment in 2000 the Disability Rights Commission consulted on a further revised code of practice, which came into force on 27 May 2002 as the *Disability Discrimination Code of Practice (Goods, Facilities, Services and Premises)*. The revised code of practice not only updated the previous codes but anticipated the changes to the law that were due to come into effect in 2004, in particular with respect to the duty to remove obstructive physical features.
- 66 The 2002 code made it clear that a service provider's duty to make reasonable adjustments is a duty owed to disabled people at large and that the duty is 'anticipatory':

'Service providers should not wait until a disabled person wants to use a service which they provide before they give consideration to their duty to make reasonable adjustments. They should be thinking now about the accessibility of their services to disabled people. Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.'

- 67 It also drew attention to the pragmatic strain of the *Disability Discrimination Act 1995*. For example, in respect of the forthcoming 'physical features' duty, the code says:

'The Act does not require a service provider to adopt one way of meeting its obligations rather than another. The focus of the Act

is on results. Where there is a physical barrier, the service provider's aim should be to make its services accessible to disabled people. What is important is that this aim is achieved, rather than how it is achieved.'

Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)

- 68 In 2001 the Department of Health published a White Paper, explicitly shaped by the relevant legislation (including the *Disability Discrimination Act 1995* and the *Human Rights Act 1998*), with a foreword written by the then Prime Minister, outlining the Government's future strategy and objectives for achieving improvements in the lives of people with learning disabilities.
- 69 The White Paper identified four key principles that it wanted to promote: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion (in the sense of being part of mainstream society and being integrated into the local community).
- 70 As the White Paper explained, the intention was that *'All public services will treat people with learning disabilities as individuals, with respect for their dignity'*.
- 71 The fifth stated objective of the Government was to *'enable people with learning disabilities to access health services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary'*.
- 72 The Department of Health also published in 2001 two circulars aimed jointly at the health service and local authorities, focusing on the implementation of Valuing People and including detailed arrangements for the establishment

of Learning Disability Partnership Boards:
HSC 2001/016 and *LAC (2001) 23*.

- 73 The Department of Health has published a series of reports to help the NHS meet its duties under the *Disability Discrimination Act 1995*.

Signposts for success in commissioning and providing health services for people with learning disabilities (1998)

- 74 This was published by the Department of Health and was the result of extensive consultation undertaken with people with learning disabilities, carers and professionals with the aim of informing good practice. It was targeted at the whole NHS and emphasises the need for shared values and responsibilities, respecting individual rights, good quality information and effective training and development. It also encourages the use of personal health records. The accompanying executive letter *EL (98)3* informs chief executives of the availability of the guidance.

Doubly Disabled: Equality for disabled people in the new NHS – access to services (1999)

- 75 This Department of Health report, also aimed at the whole NHS, contains a specific section on learning disability. It provides guidance for managers with specific responsibility for advising on access for disabled patients to services and employment. It also provides information for all staff on general disability issues. The accompanying circular *HSC 1999/093* emphasises the purpose of the document saying:

‘... it will be essential for service providers to ensure that they have taken reasonable steps to ensure that services are not impossible or unreasonably difficult for disabled people to use.’

Once a Day: A Primary Care Handbook for people with learning disabilities (1999)

- 76 This was issued jointly by the Department of Health and the Royal College of General Practitioners, and was specifically aimed at primary care services. It draws attention to the interface between primary care and general hospital services and sets out actions which healthcare providers should take to facilitate equal access to health services for people with learning disabilities. The overall purpose of the handbook was described in the accompanying circular *HSC 1999/103* which says:

‘The purpose of this guidance, for GPs and primary care teams, is to enhance their understanding, improve their practice and promote their partnerships with other agencies and NHS services.’

In practice

- 77 The practical effect of the legal, policy and administrative framework on disability discrimination is to require public authorities to make their services accessible to disabled people. To achieve this objective they must take all reasonable steps to ensure that the design and delivery of services do not place disabled people at a disadvantage in their enjoyment of the benefits provided by those services.
- 78 Failure to meet this standard will mean not only that there is maladministration or service failure, but that there is maladministration or service failure for a disability related reason. This does not require a deliberate intention to treat disabled people less favourably. It will be enough that the public authority has not taken the steps needed, without good reason.

- 79 To be confident that it has met the standard, a public authority will need to show that it has planned its services effectively, for example, by taking account of the views of disabled people themselves and by conducting the risk assessments needed to avoid false assumptions; and that it has the ability to be flexible, for example, by making reasonable adjustments to its policies, practices and procedures, whenever necessary; and by reviewing arrangements regularly, not just when an individual disabled person presents a new challenge to service delivery.
- 80 It should also be noted that a failure to meet the standard might occur even when the service in question has been specially designed to meet the needs of disabled people. This might be because, for example, the service design meets the needs of some disabled people but not others, or because good design has not been translated into good practice.
- 81 It is not for the Ombudsmen to make findings of law. It is, however, the role of the Ombudsmen to uphold the published *Principles of Good Administration*. These include the obligation to ‘get it right’ by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsmen will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving disabled people, such considerations are so integral to good administration and service delivery that it is impossible to ignore them.

Human rights

Legal framework

Human Rights Act 1998

- 82 *The Human Rights Act 1998* came into force in England in October 2000. The *Human Rights Act 1998* was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. To that extent, the *Human Rights Act 1998* did not so much create new substantive rights for UK citizens but rather established new arrangements for the domestic enforcement of those existing substantive rights.
- 83 It requires public authorities (that is, bodies which exercise public functions) to act in a way that is compatible with the *European Convention on Human Rights*; it requires the courts to interpret statute and common law in accordance with the *European Convention on Human Rights* and to interpret legislation compatibly with the *European Convention on Human Rights* wherever possible; and it requires the sponsors of new legislation to make declarations when introducing a Bill in Parliament as to the compatibility of that legislation with the *European Convention on Human Rights*.
- 84 Of particular relevance to the delivery of healthcare to disabled people by a public authority are the following rights contained in the *European Convention on Human Rights*:

Article 2 Right to life

Article 3 Prohibition of torture, or inhuman or degrading treatment

Article 14 Prohibition of discrimination.

Policy aims

85 When the UK Government introduced the *Human Rights Act 1998*, it said its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new ‘*human rights culture*’ among public authorities and among the public at large.

86 A key component of that human rights culture is observance of the core human rights principles of Fairness, Respect, Equality, Dignity and Autonomy for all. These are the principles that lie behind the *Human Rights Act 1998*, the *European Convention on Human Rights* and human rights case law, both in the UK and in Strasbourg.

87 These principles are not new. As the Minister of State for Health Services remarked in her foreword to *Human Rights in Healthcare – A Framework for Local Action* (2007):

‘The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.’

88 The policy implications for the healthcare services are also apparent as one aspect of that aim of using human rights is to improve service delivery. As the Minister of State also observed:

‘Quite simply we cannot hope to improve people’s health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an

opportunity to make real improvements to people’s lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.’

89 At the time of the introduction of the *Human Rights Act 1998* in October 2000, the importance of human rights for disabled people was recognised. Writing in the Disability Rights Commission’s publication of September 2000 entitled *The Impact of the Human Rights Act on Disabled People*, the then Chair of the Disability Rights Commission noted that:

‘The Human Rights Act has particular significance for disabled people ... The withdrawal or restriction of medical services, the abuse and degrading treatment of disabled people in institutional care, and prejudiced judgements about the parenting ability of disabled people are just some of the areas where the Human Rights Act may help disabled people live fully and freely, on equal terms with non-disabled people.’

In practice

90 The practical effect of the legal, policy and administrative framework on human rights is to create an obligation on public authorities not only to promote and protect the positive legal rights contained in the *Human Rights Act 1998* and other applicable human rights instruments but to have regard to the practical application of the human rights principles of Fairness, Respect, Equality, Dignity and Autonomy in everything they do.

- 91 Failure to meet this standard will not only mean that the individual has been denied the full enjoyment of his or her rights; it will also mean that there has been maladministration or service failure.
- 92 To be confident that it has met the requisite standard, a public authority will need to show that it has taken account of relevant human rights principles not only in its design of services but in their implementation. It will, for example, need to show that it has made decisions that are fair (including by giving those affected by decisions a chance to have their say, by avoiding blanket policies, by acting proportionately and by giving clear reasons); that it has treated everyone with respect (including by avoiding unnecessary embarrassment or humiliation, by enabling individuals to make their own choices so far as practicable, and by having due regard to the individual's enjoyment of physical and mental wellbeing); that it has made genuine efforts to achieve equality (including by avoiding unjustifiable discrimination, by taking reasonable steps to enable a person to enjoy participation in the processes that affect them, by enabling a person to express their own personal identity and by actively recognising and responding appropriately to difference); that it has preserved human dignity (including by taking reasonable steps to protect a person's life and wellbeing, by avoiding treatment that causes unnecessary mental or physical harm, and by avoiding treatment that is humiliating or undignified); and that it has promoted individual autonomy (including by taking reasonable steps to ensure that a person can live independently).
- 93 It is not for the Ombudsmen to make findings of law. It is, however, the role of the Ombudsmen to uphold the published *Principles of Good Administration*. These

include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsmen will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving health and social care, such considerations are so integral to the assessment of good administration and good service delivery that it is impossible to ignore them.

Health and social care

Legal framework

National Health Service Act 1977

- 94 The *National Health Service Act 1977* made it a duty for the NHS to promote services to improve health. Section 1 of the Act confers a duty on the Secretary of State to secure improvements in the physical and mental health of the population. Section 22 creates a duty of co-operation between NHS bodies and local authorities in exercising their respective functions.

National Health Service and Community Care Act 1990

- 95 The *National Health Service and Community Care Act 1990* clarified that local authorities have a duty to assess the individual community care needs of any person who, in their view, requires services and then have to decide what services should be provided. The Act also required health authorities to assist in the assessment of need in cases where the person appeared to require the services of the NHS.

National Assistance Act 1948

- 96 Section 21(1) of the *National Assistance Act 1948*, as originally enacted, placed a duty on a local authority to provide residential accommodation for persons aged 18 and over who are ordinarily resident in the council's area and who are, by reason of age, infirmity or other circumstances, in need of care and attention not otherwise available to them. Subsequent amendments replaced that duty with a power save to the extent that the Secretary of State directs that the arrangements must be made. In paragraph 2(1)(b) of Appendix 1 of Department of Health Circular *LAC (93)10* the Secretary of State has directed local authorities to make arrangements under section 21(1) of the 1948 Act. Paragraph 4 of Appendix 1 to the Circular directs local authorities to make arrangements under section 21(1) of the 1948 Act for a number of purposes, including:

'(c) to enable persons for whom accommodation is provided to obtain –

- 1. medical attention*
- 2. nursing attention ... and*

(e) to review regularly the provision made under the arrangements and to make such improvements as the authority considers necessary.'

- 97 By section 26(1) of the 1948 Act, arrangements made by a local authority under section 21 of that Act may include arrangements made with a voluntary organisation where that organisation manages premises which provide for reward residential accommodation and the arrangements are for the provision of such accommodation within those premises.

Care Standards Act 2000

- 98 The main purpose of the *Care Standards Act 2000* was to reform the regulatory system for care services in England and Wales. For the first time, local authorities were to be required to meet the same standards as independent sector providers. In England the Act provided for an independent National Care Standards Commission, replaced by the Commission for Social Care Inspection in April 2004, to undertake a regulatory function to ensure that standards were met.

Care Homes Regulations, amended 2003, incorporating National Minimum Standards for Social Care

- 99 These Regulations and standards form the basis of the regulatory framework established under the *Care Standards Act 2000* for the conduct of care homes and were drafted following consultation with service users, providers and regulators. The Regulations contain a statement of national minimum standards published by the Secretary of State under section 23(1) of the *Care Standards Act 2000* applicable to care homes (as defined by section 3 of that Act) which provide accommodation, together with nursing or personal care, for adults (aged 18 to 65). The standards for care homes for adults state:

'2.1 New service users are admitted only on the basis of a full assessment undertaken by people competent to do so, involving the prospective service user, using an appropriate communication method and with an independent advocate as appropriate.

'2.2 For individuals referred through Care Management, the registered manager obtains a summary of the single Care Management (health and social services)

assessment – integrated with the Care Programme Approach (CPA) for people with mental health problems – and a copy of the single Care Plan.

‘2.4 The home develops with each prospective service user an individual Service User Plan based on the Care Management Assessment and Care Plan or the home’s own needs assessment.

‘3.2 All specialised services offered (e.g. services for people with mental health problems, sensory impairment, physical disabilities, learning disabilities, substance misuse problems, transition services, intermediate or respite care) are demonstrably based on current good practice, and reflect relevant specialist and clinical guidance.

‘3.3 Staff individually and collectively have the skills and experience to deliver the services and care which the home offers to provide.

‘3.10 In homes providing planned respite, the statement of purpose, assessment process and individual Service User Plan are designed to meet the specific needs of the people for whom the service is intended.

‘6.2 The Plan is generated from the single Care Management Assessment/Care Plan or the home’s own assessment, and covers all aspects of personal and social support and healthcare needs as set out in Standard 2.

‘6.3 The Plan sets out how current and anticipated specialist requirements will be met (for example through positive planned interventions; rehabilitation

and therapeutic programmes; structured environments; development of language and communication; adaptations and equipment; one-to-one communication support).

‘6.5 The Plan is drawn up with the involvement of the service user together with family, friends and/or advocate as appropriate, and relevant agencies/specialists.

‘9.2 Risk is assessed prior to admission according to health and social services protocols and in discussion with the service user and relevant specialists; and risk management strategies are agreed, recorded in the individual Plan, and reviewed.

‘9.3 Action is taken to minimize identified risks and hazards, and service users are given training about their personal safety, to avoid limiting the service user’s preferred activity or choice.’

Community Care (Delayed Discharges etc) Act 2003

¹⁰⁰ The Community Care (Delayed Discharges etc) Act 2003 placed a duty upon local authorities to enable timely, well planned discharges from hospital for people who had a need for social care. It required the NHS to alert social services departments to patients who may need social care support to enable discharge from hospital.

Policy aims

¹⁰¹ During the 1990s the Government recognised that the arrangements made by the NHS and local authorities for assessment, care planning, care co-ordination and review for people with complex needs were often inadequate. Failures

to anticipate care needs or to act on care plans meant that people with complex health and social care needs experienced disjointed care and did not know what to do in a crisis or when their situation was changing. Sometimes this led to inappropriate admission to hospital, premature placement in long-term residential or nursing care, or inadequate arrangement for discharge from hospital.

¹⁰² To address these difficulties, the roles of the NHS and local authorities with respect to assessment, care planning and care co-ordination were clarified in the *National Health Services and Community Care Act 1999*. *Valuing People* described how assessment, care planning and care co-ordination should apply to people with learning disabilities. Together these documents say that for people with multidisciplinary and/or multi-agency care needs, including people with learning disabilities:

- There was to be a ‘needs-led’ system of care management, based on an assessment of the service user’s needs and circumstances. Assessment was a service in its own right and led by social services. The NHS was to co-ordinate with social services if a health needs assessment was also required.
- Once an individual’s needs had been assessed, the service to be provided or arranged and the objectives for any intervention were to be agreed in the form of a care plan, including healthcare interventions. For people with learning disabilities, care plans were to address communications needs.
- Service users’ views were to be taken into account and carers were to be appropriately involved.

- Carers were to be offered an assessment of needs in their own right to which local authorities should respond. The NHS was also to consider ways of supporting carers.
- Where people had complex needs, there was to be someone with responsibility for co-ordinating care and for people with learning disabilities who made long-term use of public services, care co-ordination was to be available by 2002.
- Care needs were to be reviewed regularly, and by someone not involved in direct service provision.
- NHS trusts, primary care providers and local authorities were to have arrangements in place to identify people who had additional health, social or other needs that needed to be met before they left hospital and were to provide them with a named person to co-ordinate all stages of their journey through hospital and back to the community.

Policy and administrative guidance

HSC 2001/016 and LAC (2001) 23: Valuing People: A New Strategy for Learning Disability for the 21st Century: implementation

¹⁰³ *Valuing People* drew on the legislation and guidance described above and clarified how it was to be applied to people with learning disabilities. *HSC 2001/016* and *LAC (2001) 23* circulars laid out specifically what was expected of the NHS and local authorities. Local authorities would, by October 2001, have established Learning Disability Partnership Boards that would develop integrated plans and services for people with learning disabilities, taking account of the health needs of the population, resources and service users and

carers' views. Councils were expected to take the lead role with the Learning Disability Partnership Boards for ensuring appropriate plans were drawn up and provision was made for people with learning disabilities to whom councils had a duty of care.

104 By winter 2002 people with learning disabilities who made substantial and long-term use of publicly funded services were to have a named person to act as their service co-ordinator. This person was to pay particular attention to achieving effective organisation and monitoring of services provided by all agencies. A health facilitator was to be available to help people to access the healthcare they needed and to help healthcare providers develop appropriate skills – especially in primary and secondary care.

105 In *Making a Difference: strengthening the nursing, midwifery and health visiting contribution to health and healthcare* (Making a Difference), issued in 1999 by the Department of Health, the Chief Nursing Officer identified a need to focus on the fundamentals of nursing care. This led to the development of a set of benchmarking tools known as *The Essence of Care: Patient-focused benchmarking for health care practitioners* (the Essence of Care), (Department of Health, 2001). At the time of this complaint benchmarking tools were available for eight areas including:

- Food and nutrition
- Personal hygiene and mouth care
- Continence and bladder and bowel care
- Record keeping
- Safety of patients with mental health needs

- Privacy and dignity, and
- Communication.

106 NHS trusts were expected to develop and implement local policies that ensured compliance with the benchmark standards.

107 In 2001 the Department of Health also issued a series of documents about consent to treatment. They are listed in circular *HSC 2001/023*, called *Good practice in consent – Achieving the NHS Plan commitment to patient-centred consent practice*, which provides an overview of the Government's commitment to patient-centred consent practice. *Seeking consent: working with people with learning disabilities* (Seeking Consent) provides comprehensive guidance about what is expected of clinical staff and covers issues such as how consent should be obtained and, where a person is unable to consent for themselves, how healthcare staff should act in the patient's 'best interests'. The guidance is clear that where there are difficulties in obtaining consent, discussions about consent and the rationale for any actions taken under 'best interest' principles should be recorded.

108 In January 2003 the Department of Health published comprehensive guidelines about discharging patients from hospital called *Discharge from hospital: pathway, process and practice* (Discharge from Hospital). The lengthy guidelines are in the form of a workbook and include principles for good practice as well as introducing a range of tools to assist professionals involved in the discharge process. Amongst other things, it expects organisations to have arrangements to ensure that people can be safely transported home or to another setting and that relevant information, such as

discharge summaries and care plans, transfer on a timely basis. Amongst the document's 'key messages' are:

'Ensure individuals and their carers are actively engaged in the planning and delivery of their care.'

‘...’

'Agree, operate and performance manage a joint discharge policy that facilitates effective multidisciplinary working at ward level and between organisations.'

'On admission, identify those individuals who may have additional health, social and/or housing needs to be met before they can leave hospital and target them for extra support.'

‘...’

'Consider how an integrated discharge planning team can be developed to provide specialist discharge planning support to the patient and multidisciplinary team.'

109 Appendices 5.6 and 5.7 of the guidelines specifically address the needs of people with learning disability, mental health problems or dementia. The importance of meeting the special needs of these groups of patients by effective multidisciplinary and multi-agency working is threaded through the guidance.

110 In March 2000 the Clinical Standards Advisory Group³ issued a report called *Services for Patients with Pain*. They recommended the following:

'NHS Trusts

- *Ensure that patients undergoing painful procedures have access to an acute pain team led by a doctor and at least one specialist nurse, working closely with pharmacists and physiotherapists.*
- *Ensure reasonable access to a pain management programme for patients with high levels of distress or disability as a result of chronic pain.*
- *Give a higher priority to effective pain management in A&E departments.*
- *Ensure that staff who manage patients with pain are adequately trained.'*

Professional standards

The General Medical Council

- 111 The General Medical Council (the body responsible for professional regulation of doctors) publishes *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet is clear that it represents standards which the General Medical Council expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of their work. Key sections of the booklet current at the time of this complaint are set out at Annex A.

³ The Clinical Standards Advisory Group was established in April 1991 as an independent source of expert advice to UK Health Ministers and to the NHS

112 Paragraph 5 of Good Medical Practice, 2001, says:

'The investigation or treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age, or social or economic status, to prejudice the treatment you arrange.'

The Nursing and Midwifery Council

113 The Nursing and Midwifery Council (the body responsible for professional regulation of nurses) publishes a booklet, *The Nursing and Midwifery Council code of professional conduct: standards for conduct, performance and ethics* (the Code of Conduct), which contains general and specific guidance on how nurses should approach their work. The booklet represents the standards which the Nursing and Midwifery Council expects nurses to meet.

114 Paragraph 1 of the Code of Conduct current in early 2004 said:

'You are personally accountable for your practice. This means that you are answerable for your actions and omissions, regardless of advice or directions from another professional.'

'You have a duty of care to your patients and clients, who are entitled to receive safe and competent care.'

115 Paragraph 2 of the Code of Conduct said:

'As a registered nurse, midwife or health visitor, you must respect the patient or client as an individual.'

‘...

'You are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'

116 Paragraph 4 of the Code of Conduct emphasised the importance of teamwork and communication. It said:

'As a registered nurse, midwife or health visitor, you must co-operate with others in the team.'

'The team include the patient or client, the patient's or client's family, informal carers and health and social care professionals in the National Health Service, independent and voluntary sectors.'

'You are expected to work co-operatively within teams and to respect the skills, expertise and contributions of your colleagues. You must treat them fairly and without discrimination.'

'You must communicate effectively and share your knowledge, skill and expertise with other members of the team as required for the benefit of patients and clients.'

'Health records are a tool of communication within the team. You must ensure that the health care record for the patient or client is an accurate account of treatment, care planning and delivery.'

Complaint handling

Council complaint handling

- 117 The *NHS and Community Care Act 1990* imposes on social services authorities a statutory duty to provide a complaints procedure. Statutory guidance has been issued by the Department of Health and authorities must have regard to it when managing complaints about their service. The statutory complaints process applicable to this complaint was that contained within the *Complaints Procedure Directions 1990* (these have now been superseded by the *Council Social Services Complaints (England) Regulations 2006* and associated guidance, for complaints made after August 2006).
- 118 The 1990 Directions established a three-part process consisting of a first, informal, stage aimed at resolving the complaint at a local level, but which progressed to the formal second stage if the complainant remained dissatisfied. The matter was considered at the second stage by the designated complaints officer and an investigator might be appointed. If the complainant remained dissatisfied at the end of this stage of the process, he or she had the right to request an independent review by a panel set up by the council to review the stage 2 investigation. The panel did not carry out a fresh investigation, nor could it consider any aspect of the complaint that had not already been considered at an earlier stage. The panel had no power to make binding findings, but could make recommendations to the council to resolve the complaint. If the council rejected the findings it had to provide reasons for doing so.

NHS complaint handling

- 119 Prior to 30 July 2004 complaint handling in the NHS was subject to various Directions produced by the Secretary of State for Health. The 1996 Directions and subsequent amendments required NHS trusts to have written procedures for dealing with complaints within their organisation (known as local resolution) and to operate the second element of the complaints procedure (independent review).
- 120 The objective of the Directions was to ensure that complainants were treated courteously and sympathetically and that their complaints were properly addressed, and each trust and authority was required to appoint a complaints manager to deal with the first, local, level of the process and a convener to manage the second, independent, level. Any complainant who was dissatisfied with the outcome of the first stage local investigation was entitled to request the holding of an independent review panel; although the convener was not obliged to comply with this request he or she was obliged to consider it, taking clinical advice where appropriate.

Complaint handling by the Healthcare Commission

- 121 For complaints commenced under the former complaints process but not completed before 30 July 2004 (the date the *NHS (Complaints) Regulations 2004* – the Regulations – came into force), transitional arrangements applied. Where by that date an investigation of a complaint had been conducted and completed by the complaints manager of the body complained about, the second element of the complaints procedure was conducted by the Healthcare Commission in accordance with the Regulations

unless the complainant had requested an independent review panel under the former procedure.

- 122 *Part III* of the Regulations (Regulations 14 to 19) sets out the statutory requirements on the Healthcare Commission when considering complaints at this second level.
- 123 Regulation 16 states that the Healthcare Commission must assess the nature and substance of the complaint and decide as soon as it is reasonably practicable how it should be dealt with '*having regard to*' a number of matters including the views of the complainant and the body or person complained against and any other relevant circumstances. There is a wide range of options available to the Healthcare Commission for dealing with the complaint, apart from investigating it, including taking no further action, referring the matter back to the body or person complained about with recommendations as to action to resolve the complaint, and referring the matter to a health regulatory body.
- 124 If the Healthcare Commission does decide to investigate, it must send the proposed terms of reference to the complainant and the body or person complained about (and any other body with an interest in the complaint) for comment. Once the investigation begins, the Healthcare Commission has a wide discretion in deciding how it will conduct the investigation (Regulation 17) and this may include taking such advice as seems to it to be required, and requesting (not demanding) the production of such information and documents as it considers necessary to enable it properly to consider the complaint. The Healthcare Commission has established its own internal standards for the handling of complaints and although, for

example, the Regulations do not specify the type of advice to be taken, the Healthcare Commission has acknowledged the need to seek appropriate guidance from a clinical adviser with relevant experience and expertise. Likewise, although the Regulations set no specific timescales for it to complete the investigatory process (Regulation 19 merely requires it to prepare a written report of its investigation '*as soon as is reasonably practicable*'), the Healthcare Commission has said that it aims in the majority of cases to take no longer than six months to complete the process.

- 125 The report produced by the Healthcare Commission at the end of its investigation must summarise the nature and substance of the complaint, describe its investigations and summarise its conclusions, including any findings of fact, its opinion of the findings and the reasons for its opinion and recommend what action should be taken and by whom to resolve the complaint or otherwise.

Section 3: the investigation

Background

¹²⁶ We have outlined the background to this complaint in Section 1 of this report. We say more about the key events associated with each aspect of the complaint in the relevant sections which follow.

The Local Government Ombudsman's investigation of the complaint against the Council

Complaint (a): provision of care and complaint handling

¹²⁷ Mr Cannon's parents complain that their son was provided with inadequate care by the Council, which led to his injury and, ultimately, his death. They believe the Council failed in its duty to keep their son safe while he was in its care as a result of poor care planning, poor supervision, weak management and inadequate staffing, including training and induction. They also say the Council repeatedly failed to properly investigate the circumstances of their son's injury or to take any responsibility for the part the failings played in his injury and subsequent death.

Key events

¹²⁸ Mr Cannon had received respite care at the Grange on many occasions in the past and his most recent stay had been in December 2002. He went to the Grange again on 17 June 2003 for two weeks while his mother and stepfather went on holiday. On this occasion he sustained the fracture which led to his admission to the Trust during the night of 26/27 June 2003.

¹²⁹ On the night that Mr Cannon sustained his injury there were three care workers on duty looking after all the permanent and respite residents; one care worker providing one-to-one care for a resident and a sleeping-in officer. Of the three care workers on duty, one was a permanent member of staff employed by the Council (the Second Care Worker). The other two carers were agency staff engaged by the Council. The senior officer on sleeping-in duties was also employed by the Council. One of the agency care workers had worked at the Grange for about two years (the Third Care Worker) and the other agency care worker had worked at the Grange for approximately one year (the First Care Worker). On the night in question, the Second Care Worker was assigned to the Chelsea Unit, the First Care Worker was assigned to the Wedgewood Unit and the Third Care Worker was assigned to the Darby Unit, which was the Unit accommodating those receiving respite care and, thus, where Mr Cannon was accommodated. No further reference is made to the care worker (also employed by the Council) providing one-to-one care to a resident and who was not involved in events referred to in this report.

¹³⁰ When starting her shift at about 10.00pm on the night of 26 June 2003, the First Care Worker went to put her belongings away and came across Mr Cannon sitting on the floor by the door of his room *'sort of rocking'*. According to the First Care Worker *'No other worker was present as they were all outside having a tea and cigarette break'*. The First Care Worker says she spoke to Mr Cannon but he did not respond so she touched the top of his arm and asked him to stand up which he did unaided. The First Care Worker then noticed that Mr Cannon had wet his pyjamas. Holding the First Care Worker's hand, Mr Cannon walked slowly to his bed, a distance of 5 to 6 feet. Then, according to the

First Care Worker, Mr Cannon *'lay on the bed and I changed him, then left to continue to put my things away. On the way back I checked on [Mr Cannon] and he was still in bed, lying down awake'*.

131 Notwithstanding that the Council contends otherwise, it appears that at no stage between that chance encounter at about 10.00pm and, at the earliest, 2.00am was any care and/or attention provided to Mr Cannon. I do not consider that that chance encounter equated to the provision of regular support and supervision or represented a planned approach to monitor the safety of Mr Cannon.

132 At the start of their shifts at 10.00pm on 26 June 2003 the Second and Third Care Workers were engaged in general duties away from the Units to which they were assigned that night. They continued to be so engaged until, at the earliest, 2.00am. In evidence given to the Registered Manager of the Grange the day after the incident, the First Care Worker indicated that she too was engaged on general duties after handover away from the Unit to which she had been assigned. The evidence is that the First Care Worker was *'still downstairs'* at 12 midnight. At about 12.15am the First Care Worker told the Second and Third Care Workers about finding Mr Cannon on the floor with wet pyjamas. In statements provided by the Second and Third Care Workers within two days of the incident, neither said that she had checked on Mr Cannon at that stage, although the Second Care Worker subsequently said that she had checked on Mr Cannon after she had *'finished her task'*. The Second Care Worker has also stated in recent evidence provided to the Council (December 2008) that she checked on Mr Cannon *'after handover and then half hourly'*. I do not accept that evidence.

133 When the general duties were finished at about 2.00am, each of the three care workers went to the respective Units to which they were assigned. The Third Care Worker thus went to the Darby Unit. In a statement made by the Third Care Worker within two days of the incident she did not say, as the Council now asserts, that she checked on Mr Cannon at 2.00am but stated that she stationed herself in the doorway of the Darby Unit at that time and remained there until she heard Mr Cannon *'calling/moaning'* at about 3.15am. Evidence to the Coroner suggests that the Third Care Worker was seated approximately 12 feet away from Mr Cannon's room, the door to which was open. The Third Care Worker was crocheting and reading with the TV on *'for background noise'*.

134 Thus, the evidence suggests that between being helped to bed by staff at about 9.30pm and when he started to *'call/moan'* at about 3.15am, Mr Cannon was seen once, quite by chance, by the First Care Worker at about 10.00pm. The Council asserts, however, that Mr Cannon had been *'regularly monitored between 10 pm and 2 am'*. In my view, that assertion does not accord with the most contemporaneous evidence. The Council also asserts that between 10.00pm and 2.00am the First Care Worker was *'walking around all 3 units comprised in the Grange generally checking that all residents were well'*. Again, that assertion does not accord with the most contemporaneous evidence. In my view, no monitoring of Mr Cannon took place between 9.30pm and, at the earliest, 2.00am.

135 Further, the Council's present position that staff at the Grange had acted in accordance with the care assessment documents in that Mr Cannon had been regularly monitored is inconsistent with:

- the recommendation made by the registered Care Manager as the result of an investigation he carried out immediately following the incident that:

'All through [although?] a staff member is always assigned to the special needs unit (Darby) it appears that they sometimes leave the Unit to complete other duties. This does not appear to be appropriate given the level of support required by some service users'

- the conclusions in the first independent investigation report (dated 18 September 2003) that:

'... interviews with staff indicate that Risk Management guidelines to ensure [Mr Cannon's] safety were not followed. This led to [Mr Cannon] being unsupervised for periods of his stay while staff carried out duties/tasks in other areas of the building'

and

'In summary, the care offered to [Mr] Cannon during his respite stay at the Grange from 17.6.03 to 27.6.03 was of a standard that does not meet the minimum requirements of the NCSC [National Care Standards Commission]'

and

'While individual staff acted with best intent to meet [Mr Cannon's] individual needs, corporate failure ultimately led to a failure to meet [Mr Cannon's] care needs during his stay'

- the Hearing Panel's decision at Stage 3 of the Council's complaints procedure (complaint relating to Mr Cannon's injury while at the Grange) that:

*'the Panel had no hesitation in upholding the complaint **which was admitted to by the service**' (emphasis added)*

and

*'the Panel strongly sympathised with [the complainants] in respect of the whole issue and listened most carefully to their representations on the standard of care that [Mr Cannon] received at his last stay at the Grange. The Panel agreed with the appellants **and the service's view** that the standard of care [Mr Cannon] received fell below what he should have been given' (emphasis added).*

- 136 When the Third Care Worker heard Mr Cannon 'calling/moaning' at about 3.15am on the night/morning of 26/27 June 2003, she thought he wanted to go to the toilet. [The Second Care Worker] turned back the bedclothes which were not in disarray and swung Mr Cannon's legs round and helped him out of his bed. In a statement provided by the Third Care Worker within two days of the incident, she said 'I tried to take him to the toilet but he could not weight bear so I helped him to the floor and went for assistance. [The Second Care Worker] could not get [Mr Cannon] to the toilet so we put [Mr Cannon] back to bed and called [the sleeping-in senior officer on duty] at approximately 4.05am'.

137 In her statement made within three days of the incident the Second Care Worker said ‘At about 3.45 [the Third Care Worker] came and asked me to look at [Mr Cannon]. [The Third Care Worker] had tried to help [Mr Cannon] to the toilet and when he could not walk she helped him to slide down to the floor. We helped [Mr Cannon] back to bed but when we left he still wanted the toilet. So we lifted him to the toilet then back to his bed. [Mr Cannon] appeared comfortable when still but movement caused him pain’.

138 In her statement made the day following the incident, the First Care Worker said:

‘At about 3pm [this must mean am] I heard [Mr Cannon] shouting out loud. I did not go down as I know someone was on the floor and would call if they wanted help. [Mr Cannon] screamed out again louder while I was checking the residents. I went back into the lounge when [the Third Care Worker] came upstairs and asked me if I had a minute to spare to come down to see [Mr Cannon] with her. We collected the lady from Chelsea unit on the way down. [The Third Care Worker] said she thought the reason why he screamed was because he wanted the toilet but he couldn’t walk, so she asked me to help her take him. One carer said we should look for the commode and the other one said no take him to the toilet as it isn’t far. All three of us helped him to the toilet and we waited 5 or 6 minutes while he went. He was rubbing his legs and making a face. When he finished we tried to help him stand but he couldn’t put any pressure on his left leg so all three of us helped him back to his room – he didn’t moan he just grimaced. We put him to bed and [the Second Care Worker] went to find [the sleeping-in officer]. She came down and tried to talk to [Mr Cannon], but he didn’t

respond to her. Then [the Second and Third Care Workers] lifted him and [the sleeping-in officer] stood opposite to see what the problem was. She asked him to walk but he couldn’t put his left leg down.’

139 A contemporaneous memorandum on 27 June 2003 states that:

‘[the sleeping-in officer] was called up at 4.05 as there was concerns regarding Mark Cannon (special needs respite).

‘Mark was very distressed & unable to weight bear on his (L) leg. The night staff stated that Mark had gone to the toilet approx 1/half hours prior to this & at that time showed no signs of pain or distress or problems weight bearing.

‘[The Third Care Worker] stated that she was outside Marks room discreetly monitering [sic] him & that he seemed fine until he cried out, she assumed he wanted to go to the toilet again & it was on this occasion that he showed the signs of pain distress & inability to weight bear on his (L) leg.’

140 No other evidence supports the contention that Mr Cannon had gone to the toilet before 3.15am. The contemporaneous evidence of the care workers is moreover inconsistent. According to the contemporaneous evidence of the Third Care Worker, the care workers tried to take Mr Cannon to the toilet but he could not weight bear on his left leg so the care workers put Mr Cannon back to bed and went to the sleeping-in officer for assistance. The contemporaneous evidence of the First and Second Care Workers, however, is that the care workers did lift Mr Cannon to the toilet and back to his room before involving the sleeping-in officer.

¹⁴¹ There is thus some discrepancy in the timing but it appears that approximately one hour passed before care workers called the senior (sleeping-in) officer. It is not clear what happened during the whole of this period but it is likely that Mr Cannon continued to be in severe pain. Once the senior officer became involved appropriate actions appear to have been taken; an ambulance was called and Mr Cannon was taken to hospital at 5.00am, accompanied by the care worker assigned to the Darby Unit.

¹⁴² The Grange closed in 2007 and its services were transferred to new facilities.

¹⁴³ On 7 July 2003 Mr Cannon's father wrote to the Council to complain about the injury that his son had sustained, which he believed was due to the '*seriously deficient care*' provided at the Grange. On 16 July 2003 Mr Cannon's mother submitted a formal complaint regarding her son's care, expressing her anger about what had happened and her anxiety about the conflicting accounts given about the circumstances of her son's injury. The complaint was accepted for investigation under the terms of the relevant legislation and it was acknowledged as a '*serious complaint*'.

¹⁴⁴ During the following two years a confusing series of contradictory communications from the Council left Mr Cannon's mother feeling frustrated and uncertain about the progress of her complaint. The Council appears to have taken the view that the police investigation and the Coroner's inquest had resolved the family's complaint. The family did not take this view. Mr Cannon's mother resubmitted her complaint in July 2004 and asked for an investigation to take place but in March 2005, following the outcome of the inquest, the Council terminated the complaint on the basis that all

the outstanding matters had been dealt with. The complaints process was only resumed when Mr Cannon's mother complained to the Local Government Ombudsman.

¹⁴⁵ The Council's complaints process was finally concluded in August 2006 when a Panel consisting of councillors and a lay chairman considered Mr Cannon's mother's complaint and concluded that there had been shortcomings in the care provided. His mother was paid £250 to reflect the inconvenience of having to make her complaint. She was not satisfied with the outcome.

Mr Cannon's mother's recollections and views

¹⁴⁶ Mr Cannon's mother told my investigator that she and her husband had been on holiday at the time of the injury and this was the reason her son had been placed in respite care. She said he received respite care at least once a year and at the time he went into the Grange on 17 June 2003 he had been well, other than the usual problems caused by his learning disability. She said her son was rarely ill and she and her husband felt content to go on holiday and leave him in the care of the home.

¹⁴⁷ Mr Cannon's mother said that on 27 June 2003 she and her husband received a message informing them of her son's injury. She said she telephoned the Grange to try to find out what had happened and could find no one to answer her questions. Because she had eventually been reassured about her son's condition she did not return from holiday immediately. She returned on 2 July 2003 and went immediately to see him and it was only at this stage that she realised how serious his injury had been.

148 Mr Cannon's mother said it was not until three weeks after her return from holiday that she was able to speak to the temporary manager of the Grange. She said she was extremely unhappy about the account given to her regarding the circumstances surrounding her son's injury. It was clear to her that her son had not been properly cared for. He should never have been left alone in such a large facility where staff were clearly overstretched. Mr Cannon's mother said staff admitted her son was left unattended for two hours and staff who should have been supervising him were elsewhere in the facility. She said staff had told her that they had checked on him but this could not have been the case. Mr Cannon's parents felt staff at the home did not want to talk to them and they never received a full explanation for their son's fall. One carer had told her that her son had been crying out from his bed but others gave a different version of events, suggesting that he had been walking about when he was found. Mr Cannon's mother said that there had been no handover from one shift to the next and the carers on duty on the night of his injury did not even know that her son was epileptic. She felt, based on her knowledge of her son, that he had got up during the night, had had a seizure and fallen, breaking his leg during the fall. She added that Social Services had contacted her as soon as she returned from holiday and they were very helpful over the coming weeks.

149 Mr Cannon's mother said when her son was found, crying in pain, staff had assumed he wanted to go to the toilet and had picked him up and tried to walk him to the toilet which must have been extremely painful for him. Because he was in such terrible pain care staff had woken up the senior staff member on duty but it was still two hours before an ambulance was called. Mr Cannon's mother said she could not understand why her son was left in such a

bad condition, crying in pain, for so long before an ambulance was called. She and her husband both felt the explanations they had been given were incomplete, contradictory and totally unsatisfactory. She also told my investigator that her son's epilepsy mat had definitely been removed by staff at the Grange after she and her husband had taken it with them and had put it in place. They had shown staff how to use it and given them details of who to contact if it did not work. It was very sensitive and had a portable walkie-talkie type alarm. She said it was probably going off regularly and staff had removed it but no one had admitted to this. Mr Cannon's mother confirmed that the epilepsy mat was always in use when her son was at home. The alarm would sound every time he moved and she and her husband would usually check on her son to make sure he was okay. She said the alarm would stop sounding by itself after a few moments when he had settled down. She confirmed that, following the injury, she collected the mat from the Grange and tested it and found it to be in full working order.

150 Commenting on the investigation carried out by the Council into events at the Grange, Mr Cannon's mother said she was not happy with its attitude as it had not identified the cause of her son's fall. She said that she was extremely unhappy that staff at the Grange who had found Mr Cannon after his fall had exacerbated his injury because they were not properly trained. The care home was just not running as it should have been and she wanted the events which took place that night fully investigated.

151 Mr Cannon's mother said her son was eligible for full-time care but she had decided to keep him living at home for as long as possible as she knew he would not last as long in full-time care and he loved being with his family. She knew

one day he would have to go into full-time care but dreaded this. She also said at no time during Mr Cannon's life had any of his doctors commented on his life expectancy. It just never came up. She had expected him to live for some considerable time.

Mr Cannon's father's recollections and views

152 Mr Cannon's father told my investigator that the circumstances of his son's fall had never been properly explained. There were several conflicting accounts and even the time of the injury could not be established with any precision. Some time in the early hours of 27 June 2003 Mr Cannon was found either in bed, crying out in pain, or lying on the floor, crying out in pain. It had been suggested that, having had his accident, he had climbed back into bed by himself. At the inquest it had been established that, having broken his leg, it would have been extremely difficult for him to get back into bed without assistance. Mr Cannon's father said, in his opinion, it was likely that carers found his son difficult to manage and he was left unsupervised. It is possible that he may have wanted to go to the toilet during the night and a carer had tried to restrain him and put him back to bed. He said he may have fallen while being restrained and as a result had broken his leg. Mr Cannon's father said he felt sure the full facts of his son's injury had not been uncovered. He found the account given by the staff at the Grange very difficult to accept.

The Council's actions

153 The following information has been taken from the Council's complaints files and other information provided to me by the Council.

Management arrangements at the Grange

- 154 The Grange was a registered care home for people with learning disabilities owned by the Council. The home had 37 places, 5 of which were set aside for respite care. The home's staff – other than the Manager – were directly employed by the Council or were agency staff engaged by the Council. The Manager was employed by the Avenues Trust.
- 155 The Council entered into a contract with the Avenues Trust effective from 1 April 2002. Under the heading 'The Contract Agreement' it stated '*That the Avenues Trust has a Management Agreement with Havering Social Services for the management of the Grange. The term of the contract will be 1 year and reviewed thereafter on a 6 monthly basis*'. The Contract Agreement also stated that it could be '*terminated by mutual agreement, giving one month's notice*'.
- 156 Under the contract, the Avenues Trust was to provide a registered Care Manager. The Registered Manager of the Grange was only in attendance at the Grange for up to two-and-a-half days each week. The Deputy Manager was a Council employee who had responsibility for the operational running of the Grange and had overall responsibility when the Registered Manager was not in attendance.
- 157 Under the heading 'Staffing', the contract provided that:

'All staff currently employed at the Grange will remain on their current terms and conditions and will remain employed and therefore pay-rolled by Havering Social Services. They will report through the operating line management structure ie through the Registered Manager and will be subject to Havering Social Service employment policies and procedures.'

158 The minutes of a contract monitoring meeting held on 11 July 2002 record that *'Havering Council are to take responsibility for the overall operation (control) of the homes'*.

159 When providing information about the staffing and management arrangements at the Grange at the relevant time, the Council's Learning Disabilities Service Manager informed my investigator that she had been involved in the management of the Grange for some time. In May 2003, a month before the incident in question, she had taken over line-management responsibility for the Grange.

Mr Cannon's injury at the Grange and his parents' complaint to the Council

160 The circumstances of Mr Cannon's injury have been described above. The Learning Disability Service Manager with responsibility for the Grange (the Learning Disability Service Manager) asked the Manager of the Grange to investigate what had happened and report back to her. The Registered Manager interviewed the Second and Third Care Workers and the sleeping-in officer over the weekend of 28/29 June 2003. He obtained a statement from the First Care Worker the day following the incident and then spoke to her on the telephone to clarify some of her statement. The Manager concluded that:

'I am unable to give a clear conclusion of how Mark Cannon broke his hip [sic] while on Respite Care at the Grange.'

'The most likely explanation is that Mark had a seizure earlier in the night and was found by [the First Care Worker] soon after. The fact that [Mr Cannon] was incontinent when she found him would suggest this. [Mr Cannon] is thin and frail and could easily damage himself during a seizure. However the [First Care Worker] states that he walked

back to bed 5 feet away with very little support which with a broken hip [sic] would be difficult. She does state that he walked slowly. The lack of reaction to the broken hip [sic] could be due to [Mr Cannon] being in recovery from seizure.'

161 Among the recommendations made by the Manager were:

'All through [although?] a staff member is always assigned to the special needs unit (Darby) it appears that they sometimes leave the unit to complete other duties. This does not appear to be appropriate given the level of support required by some service users.'

'The use of alarm mats need to be considered for some respite care users such as a mat fitted next to a bed would be set off when a service user places their foot on it and so alerting the night staff. The use of similar devices attached to beds, sensory lights may also need to be considered.'

162 It was considered that the report by the Manager was incomplete so the Learning Disability Service Manager commissioned a report from an independent person in early August 2003.

163 On 7 July 2003 Mr Cannon's father wrote to the Director of Social Services in the strongest terms to *'complain about the seriously deficient care'* that his son had received at the Grange. He said his son was recovering from surgery due *'directly to injuries mysteriously sustained while in respite care'*. He continued:

'Appropriate care while in your safekeeping and guardianship would have precluded these catastrophic injuries and ongoing consequential problems, pain and anguish to Mark and all his family.'

¹⁶⁴ Mr Cannon's father cast doubt on the account given by the Grange that his son was found in bed with his injury. He expressed deep distress about the pain that he must have suffered when he was returned to his bed and left there. He said the orthopaedic surgeon at the Trust had confirmed the injuries could not have been sustained in the way that the Grange had claimed. He went on to ask for a full investigation of the circumstances surrounding the injury and put a list of specific incidents to the Director of Social Services.

¹⁶⁵ On 16 July 2003 Mr Cannon's mother also made a formal written complaint to the Council regarding her son's care. She said the family had been told conflicting stories about what had happened to him:

'According to the Orthopaedic Surgeon there was no way he could have an injury so severe in bed. It could only have been sustained by a fall and if he had been picked up and put back to bed it could have caused further injury As there are conflicting stories, I feel that there should be an in-depth inquiry as the circumstances are very suspicious.'

The Council's investigation

¹⁶⁶ On 8 July 2003 the Personal Assistant to the Director of Social Services wrote to Mr Cannon's father saying the Director wanted to 'acknowledge that this is a serious complaint and therefore a copy of your letter has been passed to [the] Customer Relations Officer who will take this complaint through our complaints procedure'. On 30 July 2003 a customer relations assistant wrote to Mr Cannon's parents separately informing them that the First Independent Investigator, whom she described as the Community Learning Disabilities Team Manager, would be investigating their

complaint, and of their right to a Stage 2 investigation if they remained dissatisfied. The letter was headed 'CHILDREN ACT 1989 & NHS & COMMUNITY CARE ACT 1990 Stage 1 complaint'.

The report of the First Independent Investigator

¹⁶⁷ The First Independent Investigator's report was sent to Social Services on 18 September 2003. She said her investigation had been carried out by means of interviews with six staff members at the Grange including the Manager of the home and the three staff members who had been on duty on the night of Mr Cannon's injury. She had also examined evidence provided by the Learning Disability Service. Several Learning Disability Service staff members were also asked to provide evidence, as was the Manager of St Bernard's Day Care Centre. In her report the First Independent Investigator set out a detailed sequence of events based on the statements provided by staff at the Grange. Her account provides a description of events at the time of the injury. Key sections of the report are set out here together with her findings:

'Mark was admitted for respite care on 17.6.03. During the period from 17-26.6.03, 6 seizures were recorded on the record of seizures and in daily records. At home Mark [used] a piece of equipment to detect him moving from his bed. Staff at the Grange were shown by Mark's family how to use the mat. Staff at the Grange stated the equipment was not functioning during Mark's stay ... They took no action to notify management or community nurses of the failure of the equipment. ...

'Interviews with staff at the Grange established that on the evening of the 26 June 03, Mark had been assisted to go to bed at approximately 9.30pm. The epilepsy

mat that would detect movement was not in place. Mark was found on the floor, incontinent of urine, at approximately 10.00pm by an agency worker [the First Care Worker] arriving for her shift. There were no care staff in the vicinity. At this point Mark was not distressed, and was able to stand and walk to his bed unaided where he was changed into dry clothing by [the First Care Worker] and helped back to bed. [She] did not mention the incident during the handover. She did advise regular staff of the incident approximately 2 hours later. [The First Care Worker] had worked at the Grange for approximately the past year ... She had met Mark once ... during his current stay and was not fully aware of his care needs. No incident form was completed. No seizure was observed and at no time did staff connect the incident of finding Mark incontinent with the possibility that he had a seizure. [The Second Care Worker] employed by [the Council], regular staff at the Grange, checked on Mark once alerted to the earlier incident and found him to be "as usual". Mark showed no signs of distress. He was in bed at this time. [The Third Care Worker], agency staff, previously employed by [the Council] and regular staff at the Grange was allocated to Darby Unit [where Mark stayed] on 26.6.03. She was aware that Mark had seizures and therefore once all residents were settled, at approximately 2.00am, located herself outside Mark's room. Around 3.15am [the Third Care Worker] heard Mark moaning as if awakening. After a few minutes she went to assist him to the toilet. [She] helped Mark to the side of the bed. He was in discomfort; [the Third Care Worker] thought he had cramp and rubbed his legs. [She] tried a second time to help Mark off the bed, but realising there was something wrong, lowered him to the floor and went for help.

[The Second Care Worker] and [the First Care Worker] came to Mark's room. [They] tried to help Mark walk to the toilet but were unable to. [They] then carried Mark to the toilet, waited while he used the toilet then carried him back to his room. At 4.05am [the Second Care Worker] went to call [the] senior officer, sleeping in. An ambulance was called at 4.20am, arriving at 4.40am. Mark was taken to hospital at approximately 5.00am accompanied by [the Third Care Worker]. Mark's sister was informed by telephone message at 6.30am and [the Senior Officer] gave basic information at 7.14am when the call was returned [by Mr Cannon's sister]. Staff at the Grange checked on Mark's progress by telephoning the hospital but did not make contact with members of Mark's family.'

168 The First Independent Investigator then provided a description of the assessment and care management documentation produced by the Learning Disability Service which indicated the levels of care Mr Cannon required, particularly when in respite care.

'Mark had a Community Care Assessment carried out in January 2002 [by the Learning Disability Service]. The assessment identified that Mark must be monitored at all times. A Care Plan was drawn up identifying Mark's support needs and his carer's respite needs. Mark was assessed as needing 1:2 staffing ... Initially Mrs Handley requested 1:1 staffing during respite admissions. Following discussion with his family, Mark's mother agreed to the Care Plan. The Care Plan identifies that Mark is fully continent except when he has ... seizures. It also identifies a risk that Mark may be vulnerable during the night as he may wander, and has had seizures that have led to him falling

and injuring himself. It further records a risk if there is no one around to support and supervise Mark.'

- 169 The First Independent Investigator then described the documentation from the Grange relating to the planning of Mr Cannon's care during his respite stay:

'Staff at the Grange had copies of Mark's Community Care Assessment and his Care Plan ... There is no provider Care Plan available from the Grange to direct staff carrying out Mark's care during his stays.'

- 170 The First Independent Investigator described the protocol which had been implemented by the Council for use in residential and day care units for the management of epilepsy:

'A record of seizures [had] been maintained, although the information recorded [was] of a basic level and not in line with the ... protocol. A number of other forms [were] available within the protocol to enable staff to be fully equipped to deal with an individual's epilepsy [such as] Check list for Service User; Personal Characteristics relating to Seizures; Medication agreement forms. None of these forms were found in Mark's records at the Grange.'

- 171 The First Independent Investigator commented on the Grange's most recent National Care Standards Commission inspection report which was dated 31 March 2003:

'care plans must identify all areas of need and be in enough detail for anyone entering the home to have knowledge of how to care for that person.

'...

'The inspection found that care plans lacked the depth of information to make them workable documents. The lack of a plan for Mark is consistent with the [National Care Standards Commission] findings.'

- 172 Noting the absence of a Provider Care Plan for Mr Cannon, the First Independent Investigator found that a proactive risk assessment had been completed at the Grange for him in May 2001. She said:

'This document [identified] a high risk of an incident if Mark [was] left on his own. The "management controls necessary" [indicated] that "Mark must not be left alone" and that staff should "... summon additional staff to sit with Mark" whilst undertaking other duties. And continues "Mark must never be left on his own, other than when he is in bed"...

- 173 In commenting on the draft of this report the Council has provided further detail about the information contained in the May 2001 risk assessment:

'Mark has epilepsy and suffers quite severe seizures; staff to observe.

'Mark is capable of getting out of bed to use the bathroom; staff to be extra vigilant during the early morning hours and to regularly check on Mark.

'Mark is at high risk when staff need to support other residents in the unit. At such times Mark must not be left alone; staff are to activate the call alarm to summon additional staff to sit with Mark.

'When Mark has a seizure staff are to indicate type and length of seizure on chart. Staff to ensure area clear of objects which may cause injury during the seizure. Staff to place Mark in recovery position if necessary.'

'Mark must never be left on his own other than when he is in bed, he must be regularly supervised in this activity.'

The Council has also referred to an Assessment and Care Management Form (Form CM6) which concluded that Mr Cannon required a 1:2 staffing ratio during the day and evening with regular monitoring during the night to ensure that he was well and had not had a nocturnal seizure. But the CM6 also says that *'the respite environment needs to be able to provide adequate staffing ratios within the unit to ensure that it is staffed at all times during the night. Mark appears to be more vulnerable during the night as he will get up and wander and does have seizures which have led to him falling and injuring himself'*.

- 174 The Council accepts the risk assessment had not been updated but considers there was no evidence that Mr Cannon's needs had changed in that time. Prior to his respite stay in June 2003, Mr Cannon's mother completed on his behalf a form setting out 'Respite Care Medication Details'. On that form it recorded that Stesolid should be given rectally *'if a seizure is severe or giving stress'* and *'if [a] seizure lasts more than 20 minutes ...'*. Under the heading 'Additional Information' the form recorded that Mr Cannon *'often gets out of bed at night so needs constant monitoring in case of seizure which will cause injury. Epilepsy alarm supplied'*. In commenting on a draft of this report the Council has said that this document was not a formal assessment but a document prepared by Mrs Handley containing her personal opinions.

- 175 I also note that Mr Cannon apparently fell out of bed on the morning of 18 June 2003, just over one week before the incident which is the subject of this complaint. In response to the question *'Did any other factors or persons contribute to the incident'* on the Accident/Incident Report Form, the answer 'Yes' is given and *'person has epilepsy'* is inserted. In completing the section of the form requesting details of further measures or other action intended to be taken to prevent any recurrence, the response *'closer supervision'* is given.

- 176 The Council has said that a seizure chart was completed by the Grange after every seizure and on every day even if none was recorded. This is inconsistent with the fact that when Mr Cannon was found at about 10.00pm on 26 June 2003 sitting on the floor by the door of his room incontinent, no entry was made by any of the care workers on duty when it was highly likely, and the Coroner so found, that Mr Cannon had had a seizure.

- 177 Continuing her description of the events at the Grange on the night of Mr Cannon's injury, the First Independent Investigator said:

'When staff arrived for night duty, there were no staff in Darby Unit. During the handover from the afternoon shift ... to night staff ... Mark was alone in Darby Unit. There was no alarm system in place to call staff in an emergency. From 10.00pm to 2.00am night staff were involved in handover, completing tasks, helping residents with personal care and to get ready for bed. There were no specific arrangements to ensure Mark was observed during this period. The Risk Assessment [prepared in May 2001] stated that "Mark must never be left on his own, other than when he is in bed ..."'

178 The First Independent Investigator commented on the staffing arrangements at the Grange:

'The registered home manager post is currently being covered by a senior manager of Avenues Trust, who are contracted to manage the service provided at the Grange. Due to other commitments, he is only available approximately 2.5 days per week. The registered home manager had never met Mark and was unaware of the lack of a detailed care plan for staff to work to. On the whole, the Management of the home is left to the deputy manager. On 26 June there were 27 permanent residents and 2 residents for respite care ... On the night of 26.6.03 there were 4 staff on duty, including a 1:1 worker for another resident in Wedgewood unit. ... Between 12.00 midnight and 2.00am staff were carrying out general duties and no staff were located on Darby Unit. A high level of agency staff [was] in use at the Grange, due to recruitment and absence issues.

'According to senior staff ... New staff and agency staff are given basic induction when coming to the unit for the first time in respect of fire procedures, tour of building and whereabouts of records/care plans. Written information was available listing the tasks for am and pm shifts. Information is also available on action to take in a variety of emergency situations. New staff are expected to take advice from permanent staff members. It [was] recognised that in reality, it is unlikely that agency staff will have time to read through all the documentation due to the work pressure. Agency Worker [the First Care Worker] received minimal induction to the building. She was aware of being given information during handovers on residents' needs. She

[was] not aware of any induction regarding procedures following incidents, or being made aware of procedures relating to emergencies.'

179 The First Independent Investigator concluded her review of the evidence she had obtained by describing the arrangements in place at the Grange for the management of clients with epilepsy:

'Following the introduction of the [Council] protocol for administration of rectal diazepam [the Learning Disability Service] worked with the Grange staff to introduce guidance on management of Epilepsy. Staff at the Grange received training in Epilepsy, recording seizures and giving rectal Diazepam. Follow-up training is scheduled regularly, but poorly attended by staff at the Grange. [The Learning Disability Service] identified that the Avenues Trust also has its own policies regarding management of Epilepsy. Staff interviewed referred only to the guidance implemented through [the Learning Disability Service]'s training programme. Records kept at St Bernard's show that information required to assist staff in the management of Mark's epilepsy was available.'

180 The First Independent Investigator then presented the conclusions of her investigation:

'The fact that the homes manager of a large residential home is not available for half of the week leaves the service with weak management, and a lack of monitoring/management supervision.

'On the basis of all the information obtained, it is not possible to identify a definite cause, or time, at which Mark fractured his hip [sic]. However, it seems likely that the fracture occurred after 9.30pm and before 3.00am on 27.6.03. Mark was found on the floor, incontinent, by an agency worker coming on duty, who was unaware of Mark's care needs. The information was not passed to staff who knew Mark for approximately 2 hours. The lack of communication regarding Mark's needs, and the delay in communication regarding the incident, may have compromised Mark's safety. The fact that Mark was incontinent may indicate that he had a seizure that was not observed by staff. The night staff did not take immediate action to call for assistance when it was noted that Mark was in pain and unable to weight bear. With best intent, 3 night staff at the Grange carried Mark to the toilet. This action may have aggravated the injury and appears to have caused further pain to Mark.

'Whilst the staffing levels were appropriate to the registration requirements, interviews with staff indicate that Risk Management guidelines to ensure Mark's safety were not followed. This led to Mark being unsupervised for periods of his stay whilst staff carried out duties/tasks in other areas of the building. In turn this left opportunity for Mark to sustain an injury without this being witnessed and therefore immediate action could not be taken.

'Despite the training undertaken by the [Community Learning Disability Team] in respect of Epilepsy, the information recorded in the Record of

Seizures Charts indicates that staff do not understand/appreciate the importance of accurate recording. The Grange staff did not have records relating to the presentation of Mark's epilepsy, or detailed guidance on the specific management required. It is clear that the protocol is not being followed at the Grange.

'The documentation available at the Grange relating to Mark's needs was formulated by the Care Manager. However, the Grange lacks a detailed Care Plan for staff to use to care for Mark. From interviews with staff it was clear that they were not aware of Mark's specific needs, and had not received specific instruction on meeting his needs. In addition, whilst Care Management documentation was available, it is unclear how the home's management made use of the information so that staff could care for Mark.

'Induction procedures for new staff working at the Grange are poor, and result in critical procedures not being understood and followed. This occurred at the Grange in respect of: completion of incident forms; implementation of Risk Management guidelines to ensuring Mark's safety.

'Staff at the Grange believed the epilepsy mat used by Mark to be faulty. No action was taken between 17.6.03 and 26.6.03 to establish the reason for this, or to replace the equipment. No contact was made with specialist staff for advice.

'In summary, the care offered to Mark Cannon during his respite stay at the Grange from 17.6.03 to 27.6.03 was of a standard that does not meet the minimum requirements of the National Care Standards Commission

(NCSC). *Whilst individual staff acted with best intent to meet Mark's individual needs, corporate failure ultimately lead to a failure to meet Mark's care needs during his stay. This failure may not have prevented Mark injuring himself during an accident, but may have contributed to his further distress and further aggravated his injury.'*

- 181 The First Independent Investigator made a number of recommendations in her report to rectify the shortcomings she had identified. These recommendations included steps to improve the production of care plans for respite clients, ensuring effective management, staff training, induction, incident recording and risk assessment.

The Council's response and Mr Cannon's mother's further complaint

- 182 The documentary evidence does not clearly establish what happened once the report was received by the Learning Disability Service. The status of the report is also not clear as the letter sent to Mr Cannon's mother on 30 July 2003 by a customer services assistant seems to suggest that the report was an investigation into her complaint. However, that letter incorrectly describes the First Independent Investigator as the '*Learning Disabilities Team Manager*'. Moreover, in her interview (later in this report) the Learning Disability Service Manager stated that the First Independent Investigator's report was not an investigation into the complaint but, rather, an internal investigation for the benefit of the Learning Disability Service. A memorandum dated 5 February 2004 between the Council's Legal Services department and the Learning Disability Service Manager suggests that the status of the report was under discussion and that there were concerns about whether it was

appropriate to disclose the report to the family given that Mr Cannon had died after the report was finished and that the first stage of the Council's complaints procedure did not appear to have been completed.

- 183 In early 2004 Mr Cannon's mother contacted the Learning Disability Service again and repeated her concerns about what had happened to her son. On 2 June 2004 she met the Learning Disability Service Manager and the Complaints Manager and again made a formal complaint regarding her son's care. On 11 June 2004 the Council's Complaints Manager wrote to Mr Cannon's mother informing her that:

'Further to the meeting of 2 June at the Hermitage with you and your husband, I have considered your complaint and will be taking this through the statutory complaints procedure. [The Second Independent Investigator] has been appointed as the independent investigating officer and I am meeting him on 17 June for a briefing. He will be contacting you week commencing the 21 June to clarify and confirm the details of your complaint.'

The report of the Second Independent Investigator

- 184 Although it is not entirely clear from the available evidence, it would appear that a Second Independent Investigator was asked to carry out an investigation under Stage 2 of the complaints procedure. The Second Independent Investigator reviewed the case file and concluded that, before any further investigation took place, the outcome of the First Independent Investigator's report should be shared with Mr Cannon's family. This concluded the Second Independent Investigator's involvement and he did not carry out an investigation of his own and did not produce

a report. At this stage it would appear that Mr Cannon's father had again become involved in the complaint to the Council and records show that he contacted the Learning Disability Service by telephone. As a result, the Learning Disability Service Manager forwarded a copy of the First Independent Investigator's report to him on 17 August 2004. On 31 August 2004 the Council's Complaints Manager wrote to him separately, also enclosing a copy of the report and saying:

'I have been informed by the independent investigator [the Second Independent Investigator] that the [First Independent Investigator's] report forms the basis of an investigation. This report was completed by [the First Independent Investigator] on 18 September 2003 and therefore is timelier to the incident at the Grange during Mark's respite period. Would you please consider this report (I attach a copy) and advise me of what you would want an additional complaint investigation to establish.'

Mr Cannon's father's response on behalf of the family

185 Mr Cannon's father responded by providing a lengthy document on behalf of the whole family, including Mr Cannon's mother. This set out their dissatisfaction with the report which they said did not go far enough to establish what had happened to Mark and who was to blame. They also expressed their concern about the serious shortcomings which the investigation, however inadequate, had clearly identified. In particular, the family expressed concern about:

- the failure of the investigation to identify the cause of Mr Cannon's injury;

- the failure to resolve the inconsistencies in the evidence given by staff at the Grange;
- the failure of staff to take action regarding the epilepsy mat;
- the failure to adequately monitor Mr Cannon despite his assessed care needs;
- the failure to adequately record Mr Cannon's earlier fall from bed and to take necessary precautions to prevent a recurrence;
- the failure to deal with Mr Cannon's injury safely, causing him further pain and injury; and
- the failure to ensure that adequately qualified and trained staff were on duty on the night of Mr Cannon's injury.

186 Mr Cannon's family expressed their unhappiness at the fact that the Council had put vulnerable people at risk because of the 'weak management' in place at the Grange. They held the Council to blame for all the problems identified. The family concluded that the report raised more questions than it answered. They demanded that a further investigation take place so that the 'actual events and cause of Mark's severe injury' could be established.

187 Meanwhile, it had been announced that a Coroner's inquest would be held on 28 October 2004 and Mr Cannon's father (with the support of Mencap) appointed solicitors to represent the family. They contacted the Council on 25 August 2004 requesting access to all records relating to Mr Cannon. As a result of these developments, the statutory complaints process, such as it had been, was once again suspended to await the outcome of the inquest.

188 The inquest opened on 28 October 2004 and adjourned on that day after hearing most of the evidence. It resumed and concluded on 17 January 2005. The Coroner concluded that she could not establish a direct causal link between Mr Cannon's care at the Grange and his subsequent death. But she found that Mr Cannon's death 'flowed from the consequences of the injury he sustained at the Grange'. She issued a verdict which stated that he 'died as a result of an accident'. She declined to add a finding that 'neglect' had contributed to his death.

The Council's refusal to continue the complaints process

189 Following the conclusion of the inquest the Council's Complaints Manager wrote to Mr Cannon's mother on 29 March 2005 saying:

'I have reviewed your complaint file in the light of the outcome of the Coroner's inquest. It is the Council's view that all of the issues that you raised have been dealt with in a judicial context. The above report was reviewed by the Coroner during the inquest. Therefore it is no longer appropriate for the issues you raised to be addressed by the statutory complaints process within Havering.'

190 In a letter dated 6 April 2005 Mr Cannon's mother responded to the Complaints Manager's letter and explained her unhappiness at the Council's decision not to investigate her complaint further. She also restated her unresolved concerns at length and insisted that her complaint be considered. She said:

'We feel we have the right to proceed to Stage 3 as we DO NOT accept your cold letter that it is no longer appropriate for

our issues to be addressed by the statutory complaints process within Havering. What happened to Mark is extremely serious and we feel the Council is trying to hide behind a coroner's verdict. We WILL NOT allow our beloved son's accident to be swept under the carpet, his memory deserves more than that. You have a duty of care, we require this to be put into practice and insist you proceed with our complaint as we DO NOT accept your letter as closure.'

191 In her response dated 12 April 2005 the Council's Complaints Manager said:

'I remain of the view that the Complaints Procedure is no longer appropriate. All of the issues that you raise were dealt with in the coroner's inquest and a judgement has been produced as a result of this inquest. The significant question that needed to be determined was the cause of Mark's death. The coroner found that Mark would not have died had he not sustained the fracture and because of that, a verdict of natural causes would not be appropriate. However, "accidental death" is a verdict used when an event occurs over which there is no human control or when there is no intended human act. There must be a clear causal link between the event and the subsequent death. The coroner found that Mark's death flowed from the consequences of the injury he sustained whilst in the Grange. This was therefore an appropriate verdict. The coroner was asked to consider whether it would be appropriate to add the words "to which neglect contributed". The coroner concluded that there was no evidence to support gross failures at any stage of Mark's care, and therefore there was no basis to add that clause.'

'I appreciate that these may be findings that do not provide a satisfactory conclusion as far as you are concerned. However, I cannot see what useful purpose is to be served by progressing the complaint to a Stage 3 Panel Hearing.'

Mr Cannon's mother's complaint to the Local Government Ombudsman and the Local Government Ombudsman's intervention

¹⁹² Mr Cannon's mother was not satisfied by the Council's response and on 10 May 2005 she made a complaint to the Local Government Ombudsman about the Council's refusal to continue the complaints process and asked him to intervene. The Local Government Ombudsman found that the Council's decision was unreasonable and questioned its interpretation of the outcome of the inquest. He said:

'The focus of the coroner's inquest was on establishing the cause of Mark Cannon's death. The inquiry would only have looked at the care he received while at the home in considering what part this played in his death. It was not its role to consider wider issues such as whether he had been provided with a reasonable standard of care, whether there had been fault by the Council in delivering this, what changes might be required to Council procedures as a result of identified faults and if any remedy for [Mr Cannon's mother] might be appropriate.'

¹⁹³ He asked the Council to reconsider its decision and to allow the complaint to proceed through the normal complaints procedure. On 14 December 2005 the Council agreed to do this. On 23 January 2006 the Head of Adult Social Services wrote to Mr Cannon's mother to inform her that the Council had identified

an investigator with suitable experience to carry out an investigation. The Third Independent Investigator delivered his report on 9 March 2006.

The report of the Third Independent Investigator

¹⁹⁴ The Third Independent Investigator conducted his enquiries by means of a review of the relevant information and a number of telephone interviews. His report contained a number of inaccuracies which caused Mr Cannon's family to question the quality of the investigation. The date on which the injury occurred was incorrectly recorded on a number of occasions. The Third Independent Investigator's account also suggested that only Mr Cannon's father complained to the Council in July 2003 and that no further complaint was made until his mother wrote in July 2006. In fact, she also made a formal written complaint in July 2003 and numerous subsequent restatements of the complaint were made by the family in the intervening period. This is an important issue and is not acknowledged by the Third Independent Investigator who was also unclear about the status of the First Independent Investigator and describes her as the 'Community Disabilities Learning Team Manager'. According to the Learning Disability Service Manager's statement quoted later in this report, the First Independent Investigator did not work for the Council. Indeed, had she been a manager in the Council's Learning Disability Service she could not be said to be independent. And if this reference is meant to indicate that she held her position in a neighbouring council, this was not made clear.

¹⁹⁵ The Third Independent Investigator indicated that it was his role to investigate the complaint which had been made by Mr Cannon's mother to the Local Government Ombudsman, namely that:

a) the Council did not provide an appropriate level of care to her son Mark during his stay at The Grange care home;

b) the Council had refused to allow her to progress to stage 3 of the statutory social services complaints procedure and

c) the Council has not acted in a compassionate manner towards her.'

196 He also noted that his investigation was being carried out under Stage 2 of the complaints procedure. There is nothing in the available evidence to indicate why the Third Independent Investigator was limited to investigating only the complaint put to the Local Government Ombudsman rather than the broader complaint which had already been put to the Council by both Mr Cannon's parents.

197 Having reviewed the documentary evidence, the Third Independent Investigator concluded that the First Independent Investigator's report dated 18 September 2003 was *'a significant document'* and he commented on his evaluation of this report. He said:

'There is every reason to conclude from the report that an impartial and thorough investigation was carried out.'

But he agreed that:

'... it does, however, leave a number of unanswered questions. These are catalogued in correspondence from both [Mr Cannon's parents] in formulating their complaints following Mark's death. ... They are questions to which answers can no longer be found.'

He went on to say:

'The report does, however, clearly identify the areas of practice that fell below acceptable standards. It made recommendations for ways in which practice could be improved in order to minimise the likelihood of such events reoccurring.'

198 The Third Independent Investigator also reviewed the way in which the Council had handled the family's complaints and identified the confusion regarding the status of different stages of the investigation including the obvious ambiguity about the role of the First Independent Investigator. He also addressed the Council's decision to terminate the complaints process following the Coroner's inquest and concluded that this had been unreasonable.

199 The Third Independent Investigator's conclusions and recommendations are set out at Annex B. In summary, he upheld the complaint about the level of care provided to Mr Cannon and partly upheld the complaints about the Council's management of the complaint and their manner towards Mr Cannon's mother. He recommended that: Mr Cannon's mother should be informed about changes in practice resulting from her complaint; actions should be taken to address shortcomings identified; a Stage 2 investigation should be carried out; and a meeting should be offered with a senior manager in Social Services.

The Council's response to the Third Independent Investigator's report

200 Having received the Third Independent Investigator's report, the Council followed a recognisable complaints process and, on 12 May 2006, the Head of Adult Social Services issued the first formal response to Mr Cannon's family in a letter to his mother. The Head of

Adult Social Services identified his response as being the outcome of Stage 2 of the complaints process. He began by providing the Council's response to the complaint that the Council had failed to provide an appropriate level of care to Mr Cannon during his stay at the Grange:

'As with the [Third] independent investigator, I uphold an element of this complaint as the report highlighted a number of issues in relation to shortcomings in practices and training. I would like to reassure you that procedures are in place ... following the recommendations of [the First Independent Investigator]'s report. This includes ongoing induction and training for staff to ensure that they understand care needs, understanding their responsibility in relation to epilepsy and that they receive the appropriate first aid training. Support plans are in place for each resident and there is continued partnership working with health professionals. I therefore uphold an element of this complaint as there were shortcomings in practices identified at this time, however there is no indication that Mark's fall was attributed to these shortcomings.'

201 The Head of Adult Social Services also accepted in his response that there had been confusion over the progress of the complaint and attributed this to 'external investigation' involving the police and the Coroner. He said Stage 2 had now been completed and Stage 3 was open to Mr Cannon's mother. He did not, however, accept that the Council had not acted in a compassionate manner and maintained that Social Services staff had provided significant support to the family. He did, however, accept that the problems the family had experienced in pursuing their complaint (which he described as a 'procedural element') may have caused them distress and 'could have

been handled differently'. Overall, the response was brief and did not fully accept any element of the complaint.

Mr Cannon's mother's response to the Third Independent Investigator's report and the Council's subsequent actions

202 Mr Cannon's mother responded on 13 June 2006, saying she had considered the Third Independent Investigator's report and the Head of Adult Social Services' letter but was not satisfied by the Council's response. She said that she wanted to proceed to Stage 3 of the complaints process. She set out the reasons for her unhappiness with the Head of Adult Social Services' response. She said:

'I don't agree with the view of [the Head of Adult Social Services] that Mark's fall was not attributed to the shortcomings of practices by the staff on duty the night of the accident.'

She then restated her specific complaints which she said had not been addressed. These included the failure to use the epilepsy mat and the failure to supervise Mr Cannon for long periods during the night.

203 Mr Cannon's mother asked for her complaint to proceed to Stage 3 and completed the relevant form which was dated 16 July 2006. The Council acknowledged her request and informed her that Stage 3 would involve a Hearings Panel which would be chaired by an independent person who would 'hear and review the case'. The letter indicated that only one aspect of the complaint (at Mr Cannon's mother's request) would be the subject of the Stage 3 complaint. This was:

'That the council did not provide an appropriate level of care to your son Mark during his stay at the Grange care home. You do not agree with the adjudication of this point of the complaint and feel that Mark's fall was attributable to the shortcomings of practices by the staff on duty the night of Mark's accident, for the reasons outlined within your letter dated 13 June 2006.'

Stage 3 of the Council's complaints procedure: the Review Panel hearing

204 The Review Panel hearing took place on 23 August 2006. The Review Panel consisted of an independent lay chairman and two councillors. The Head of Adult Social Services, a complaints officer, a legal adviser and a committee officer were also in attendance. The minutes of the Review Panel meeting record that Mr Cannon's mother addressed the panel and set out her concerns again in detail.

205 The minutes also show that the 'head of service' (presumably the Head of Adult Social Services) had responded to the questions Mr Cannon's mother had put to the panel by saying he accepted that the staff at the Grange were 'not familiar' with the process they had to undertake. He also apologised for the wording of the letter (discontinuing the complaint process) that the family had received. He emphasised again that Social Services staff, on an individual basis, had continued to maintain contact with the family to support them following Mr Cannon's injury and subsequent death. In defence of the Council's actions following the injury, he said that it was the service itself that had triggered the investigation (presumably the First Independent Investigator's report). He said that service delivery at the Grange had been 'revamped' and that the Council had 'acted on the [First] independent investigator's report'.

206 The minutes also record that the 'head of service' had provided the Review Panel with the Council's formal response to the complaint. He said that Social Services had 'taken on board and implemented' a number of recommendations arising from Mr Cannon's mother's complaint:

- *The Council had appointed a full time manager at the Grange.*
- *Following an unannounced inspection, the Avenues Trust had been removed from delivery of services at the centre.*
- *There was now in place ongoing induction and training for all staff in order that the importance of implementing agreed policies, procedures and protocols, could be made clear.*
- *The service had now put in place a process to ensure that all staff were aware of their responsibilities to understand the care needs and risk management guidelines of all residents.*
- *A process was now in place and training was ongoing to ensure that proper recording of all incidents did take place. The incident process report goes directly to the head of Adult Social Services.*
- *Training was in place and staff were made aware of their responsibilities for recording and understanding residents' needs. The head of service added that responsibility for this procedure was now under the remit of Adult Social Services.*
- *Support plans for all residents were now in place and available on the premises.*

- *A detailed training programme for all staff as part of their personal development plan was now operational.'*

207 The minutes continued:

'The head of service added that the service had appointed someone to ensure procedures were in place and implemented. The care Mark received should have been better and the wording of an earlier letter sent to the family was not helpful to the situation. The head of service clarified that not every serious incident reached the trigger point to get the police involved. The current policy was still in draft at that time but even now Mark's accident would not have reached the level to trigger involving the police.'

208 In response to Mr Cannon's mother's view that her son had been neglected the head of service responded that he:

'... would not use the word neglect but did accept that there was poor care practice. He also accepted that there must have been a shortfall of staff for a two hour monitoring absence to occur.'

209 The Review Panel's decision was recorded in the minutes as follows:

'Following careful consideration of the representation the Panel had no hesitation in upholding the complaint which was admitted to, by the service. The Panel strongly sympathised with [Mr Cannon's parents and Mr Handley] in respect of the whole issue and listened most carefully to their representations on the standard of care that Mark received at his last stay at the Grange. The Panel agreed with the

appellants and the service's view that the standard of care Mark received fell below what he should have been given.

'The Panel was pleased to note that the service had accepted and implemented the recommendations made in the report of the independent investigators – [the First Independent Investigator] and [the Second Independent Investigator] – and that substantial changes had been made to the running of the Grange and the training of staff. The Panel was also pleased to note that the family had received support from staff at St Bernard's.'

210 The Review Panel's decision concluded with a single recommendation to the Council which was to 'arrange for [Mr Cannon's mother] to receive an appropriate amount for the inconvenience of having to go through this complaint process'. Documentary evidence shows that the minutes of the Review Panel hearing were not sent to Mr Cannon's mother until 31 January 2007. No explanation for this delay has been established. The Council's Committee Officer did, however, write to her on the day of the hearing (23 August 2006) informing her, briefly, of the outcome and telling her what would happen next:

'Following careful consideration of the representation made by you and [Mr Cannon's father] the Panel decided to uphold your complaint. The Panel sympathises with you and [Mr Cannon's father] in respect of the whole issue. The Panel was pleased to note that the service has accepted and has implemented the recommendations made in [the First Independent Investigator] and [the Second Independent Investigator]'s report.

'The legislation under which the Panel met requires that they make recommendations ... as to the steps to be taken to deal with the issues raised. Accordingly the Panel have recommended that the Group Director for Sustainable Communities arrange for you to [be] compensated with a sum of £250 for having the inconvenience of having to go through this complaint process. You will hear in due course from the Director in that respect.'

'More detailed notes of the decision, outlining the facts and reasons taken into account, will be sent to you within 28 days, as will information relating to the Local Government Ombudsman.'

211 It is not clear how the amount of £250 was determined as this was not referred to in the minutes of the Review Panel hearing, and is not referred to elsewhere in the documentary evidence. There is also no evidence to show that the more detailed explanation of the decision was sent within 28 days. Indeed, the only record Mr Cannon's mother received regarding the Review Panel hearing and its outcome was a letter from the Committee Officer dated 31 January 2007 enclosing a copy of the minutes which, it was suggested, *'set out in full the Panel's decision, outlining the facts and reasons taken into account'*. The letter also made clear that *'This completes the Council's consideration of the appeal'*. A leaflet setting out how to complain to the Local Government Ombudsman was enclosed.

212 Meanwhile, on 18 September 2006, in response to the Review Panel hearing findings and recommendations, the Council's Group Director, Sustainable Communities, wrote a short letter to Mr Cannon's mother to set out his *'decision'*. He said:

'In considering the Panel's recommendations for compensation, I agree that an ex-gratia payment of £250 would reflect the delays and effort that you have had to expend. I hope that you now feel that the service has taken on board the issues raised by this complaint. I understand this has been difficult for you, but hope you and your family are confident of the positive changes made by the service. I trust that this now resolves the points in your complaint to your satisfaction. If you still remain dissatisfied, you may contact the Local Government Ombudsman ...'

Mr Cannon's mother's response to the outcome of the Review Panel hearing

213 Mr Cannon's mother responded to the Group Director's letter on 21 January 2007 expressing her unhappiness at the Council's response to the Review Panel's findings and complaining that she had not received the further explanation promised by the Committee Officer on 23 August 2006. The Group Director wrote to her on 26 January 2007 saying:

'I have reviewed the case and the offer we have made to you and believe that it is a fair reflection of recompense for the issues that the hearing found in your favour. I realise how emotional the whole subject of Mark's death will always be for you and how you may not feel that you and your family have been treated fairly, but I believe that the offer we have made is comparable to other cases. You may wish to continue your complaint to the Ombudsman but this may not result in any changes to the proposal we have made. All our staff feel for your loss acutely but we are not able to change our offer of compensation.'

214 Mr Cannon's mother wrote a final letter to the Group Director on 5 June 2007 saying that she would accept the sum of £250 for 'inconvenience and delay' but that in all other respects she remained dissatisfied and that she would, with the help of Mencap, be taking her complaint further. On 14 June 2007 the complaints process came to an end with a letter from the Group Director which said:

'I recognise that this has been a difficult process for you, but I need to clarify that although [the First Independent Investigator]'s report indicated corporate failure in relation to meeting your late son's care needs, it does not state that your son's accident was caused by "corporate negligence" and this was also reaffirmed in [the Second Independent Investigator]'s report. I have requested that a cheque be raised for £250 and sent to you within 14 days. Please be advised that your complaint will now be closed as the statutory complaints process has now been exhausted.'

215 Mr Cannon's mother subsequently complained to the Health Service Ombudsman and me asking us to carry out a joint investigation into the care provided by the Council and, subsequently, by the NHS.

216 The Council has accepted that the complaints could have been handled in a better way. But it argues that it was not responsible for all the delays and has referred to a number of the complexities involved. They include:

- The complaint starting before Mr Cannon's death and then the incident being subject to police investigation as part of the overall inquiry into his death.

- Two separate complaints being made by two estranged parents.
- A complex Coroner's inquest and its impact on the complaints process.
- An implied threat of legal action and possible compensation.
- Different personnel within the Council handling the complaints.
- The Second Independent Investigator failing to investigate properly.
- The legal ramifications of Mr Cannon's death on the complaints process.

The relationship between the Council and the Avenues Trust

217 I have set out the relationship between the Council and the Avenues Trust in paragraphs 154-159 above. The Avenues Trust's stated aims included:

- Support service users to undergo an individual transition plan to minimise any distress that time away from their normal home may cause. This is done through liaising with the multidisciplinary team.
- To keep carers fully informed of the service through regular meetings and to incorporate their views in service provision.
- Provide support to the service user as identified by the care management assessment.
- To continue to adhere to any intervention plans relating to behaviour or self help skills during their stay.

- Ensure staff support is adequate in numbers and appropriately skilled to meet the needs of the respite users.

218 Various contract monitoring meetings between the Council and representatives of the Trust were held through 2002 and one in May 2003. Provision of respite care was specifically considered at the meeting in July 2002 and following this a pre-admission assessment form was drawn up. The Council considers that this effectively acted as a Provider Care Plan. At the meeting in May 2003 it was recorded that the manager was to carry out risk assessments for respite customers on their next visits. Despite this, the form was not completed for Mr Cannon's stay in June 2003. The Council considers that it had done all it reasonably could to ensure that the Avenues Trust had in place the appropriate procedures.

Statements and interviews: the Learning Disability Service Manager and the Complaints Manager at the time

- 219 Further information was provided to my investigator through a written statement made on behalf of the Learning Disability Service and during an interview with the Learning Disability Service Manager and the Complaints Manager at the time of the events. The Learning Disability Service Manager said that she had been involved in the management of the Grange for some time and, in May 2003, she had taken over line management responsibility for the Grange. The Council states that the Learning Disability Service Manager had a 'contract monitoring role' rather than 'line management responsibility'.
- 220 The Learning Disability Service Manager clarified staffing arrangements at the Grange at the time of the interview. She said a number of agency staff were employed at the Grange but that these

were not temporary or short-term staff employed on a shift-by-shift basis. These were long-serving, highly experienced staff, many of whom had been at the Grange for many years. The high number of agency staff reflected the fact that the facility was due for closure and permanent posts could not be filled as it was known that some posts would not be required when the new facility opened. The use of agency staff did not reflect staffing problems at the Grange. The Learning Disability Service was also asked to clarify the status of the staff on duty on the night of Mr Cannon's injury. It said that the First Care Worker was an agency employee and had worked at the Grange for about a year. The Second Care Worker was a Council employee (residential night care officer) and had joined on 9 May 1993. The Third Care Worker was a permanent employee of the Council until 29 June 2002 when she retired but was then employed at the Grange on a part-time basis through a specialist care agency. She was a night care officer. The Officer sleeping-in was also a Council employee.

- 221 The Learning Disability Service Manager was asked whether it was possible for staff undertaking duties in the Day Centre or the kitchen to carry out monitoring or supervision of clients in the Darby Unit. She responded that this was not possible as the Day Centre and the kitchen at the Grange were not within earshot or sight of the Darby Unit.
- 222 The Learning Disability Service Manager also said that she was satisfied that the Learning Disability Service had done as much as it could to support Mr Cannon's family immediately after the accident. A member of staff from the Grange had travelled with Mr Cannon to the hospital and stayed with him until family members arrived. The Manager of the Day Centre, St Bernard's, spent most of the following day at the hospital and visited every day during the first admission.

223 With regard to action taken subsequent to Mr Cannon's injury, the written statement said:

'The Head of Service, and [the Learning Disability Service Manager] decided it would be advisable to bring the management of the Grange back in-house, consequently the Avenues Trust contract was withdrawn effective from December 2003. During the immediate nine months after the incident, [the Learning Disability Service Manager] was extensively involved in overseeing management practice at the Grange. This included close contact with all residents.

'The new Manager was supported by the CLDS [the Community Learning Disability Service] Resource Manager and [the Learning Disability Service Manager]. All training, standards, and procedures which had been in place were reviewed and their enforcement was assured by the Resource Manager. The procedures included:

- *Personal Development and Performance Appraisals (PDPAs)*
- *Incident reporting*
- *Risk assessments*
- *Staff meetings*
- *Staff NVQ training*
- *Various mandatory LBH training e.g. Health and Safety, Appraisal Care Planning*
- *Epilepsy and medication administration*
- *First Aid*
- *Regular supervision for the manager.*

'Incident recording has been strictly adhered to, the incident recording process has been mandatory training for managers and others working within [the Council]. According to the nature of an incident a Protection of Vulnerable Adults (POVA) investigation could be instigated. Such investigations include the attendance of a wide variety of professionals including external agencies and the police. There is a dedicated team in Adult Social Services to the POVA process and training is mandatory for staff working with vulnerable adults. Such training courses are run regularly and are always fully booked. [The Council] also extend this training to the voluntary and private and independent sectors.

'Epilepsy training is regularly conducted by the CLDS's nurses. This training was documented in the supervision notes of the manager and seniors at the Grange.

'The Resource Manager ensured that the new manager was well supported and the multidisciplinary team were regularly involved in training and care standards at the Grange. Care plans were in place and recorded on client files and were live working documents at the Grange.'

224 The Complaints Manager said she now accepted that her decision to write to Mr Cannon's mother on 12 April 2005 saying the complaint would now be closed had been wrong. She could also see that the wording of her letter may well have caused considerable upset. The Complaints Manager said that she felt that in writing the letter she had made a mistake and, with the benefit of hindsight, she would not have written the letter in the way she did. She could now see the letter was insensitive and she took responsibility for the hurt this had caused.

225 Finally, the Learning Disability Service Manager and the Complaints Manager both said they felt extremely sad about what had happened to Mr Cannon and the obvious distress which the family were still clearly suffering. They said they hoped that this investigation would help to lay their concerns to rest and allow them to move on from this very difficult period. The Complaints Manager said she wanted to express again her regret at the distress caused by her actions and she could well imagine how Mr Cannon's mother must have felt when she received her letter.

Changes in respite care provision

226 The Council has stated that lessons have been learnt and steps taken to prevent a reoccurrence of shortcomings identified at the Grange. In order to establish the extent to which these assurances were supported by evidence, further enquiries were conducted and relevant documentary evidence obtained.

227 There was an unannounced inspection of the Grange by the Commission for Social Care Inspection in September 2006. This said:

'Respite stays are usually planned. However in an emergency the home will take people for respite stays. The file of one of the respite residents was seen at the time of the inspection and this contained information to enable staff to meet this person's needs ...

'Residents' plans contain updated information about their needs and therefore residents' current needs can be met.

'Risk assessments are comprehensive and reviewed regularly and therefore residents are supported to take risks according to their needs.

Evidence

'All of the residents have a care plan. Care plans seemed comprehensive and contained appropriate detailed information. There was clear information on individuals' likes, dislikes, routines and needs. Details on individuals' religious and cultural needs were also in their plans. The information in the plans seen reflected individual needs and showed the permanent staff know the residents well. All of the care plans have been updated as required by the previous inspection. More than half of the residents have had reviews and others are booked in the near future.'

228 There was a further unannounced inspection by the Commission for Social Care Inspection in January 2007 which reported:

'A new resident has recently moved to the Grange in preparation for his move to the new supported living scheme. The paperwork with regard to this individual was examined. This contained an assessment profile and a care plan ...

'The file of one of the respite residents was seen at the time of the inspection and this contained information to enable the staff to meet the person's needs.

'Residents' plans contain updated information about their needs therefore residents' current needs can be met.

'Risk assessments are comprehensive and reviewed regularly and therefore residents are supported to take risks according to their needs.

Evidence

'All of the residents have a care plan. Care plans seen were comprehensive and contained appropriate detailed information. There was clear information on individuals' likes, dislikes, routines and needs. Details of individuals' religious and cultural needs were also in their plans ... there was also evidence that care plans are reviewed internally every four to six weeks to ensure that they are up to date. All of the care plans seen were up to date.'

'The requirement from the previous inspection that care plans must be reviewed with the resident and significant others at least every six months and updated to reflect changing needs has not yet been fully met, but as significant progress has been made the timetable for completion has been extended to allow for the remainder of the reviews to take place.'

'There are risk assessments in place. These identify risks for the residents and indicate ways in which the risk can be reduced to enable the residents' needs to be met as safely as possible. For example, the support a resident needs to bathe or when in the kitchen. The risk assessments have been reviewed and were up to date and are relevant to individuals.'

- 229 The Grange was closed in May 2007 and replaced by several new respite care facilities. The Council's Learning Disability Service Manager confirmed that a client such as Mr Cannon would now be placed at 'Neave Crescent 74' for respite care, although there were other facilities which could also be used. A copy of the Commission for Social Care Inspection (replaced

the National Care Standards Commission in April 2004) report for this facility dated 13 November 2007 was obtained to determine whether effective action had been taken in the light of the findings set out in the investigation reports. One of the key criticisms had been the failure to produce a regularly updated provider care plan to ensure that staff were aware of individual needs.

- 230 For the most part, the Commission for Social Care Inspection report is positive and commends the 'competent and qualified staff who were well supported and supervised'. The quality of the home's management in particular was praised. However, there were a number of areas where the report suggested improvements could be made in respect of respite care and, in particular, care planning:

'What they could do better: All care plans and risk assessments need to be up to date so that the staff team know about service users' needs and likes and how to safely meet these.'

'More work is needed in the respite unit on service users' needs and likes so that it is as well run, and that information is as good as, in the residential unit.'

'For permanent service users, care plans and risk assessments contain sufficient information to enable staff to safely meet their needs. They are consulted about what happens in the home as far as they are able and their opinions are welcomed and respected. However information about respite service users is not always up to date and this can potentially place service users at risk.'

'Respite Service users. ... The care plans for two people who have recently used the service were examined. Both individuals [had] complex needs but in both cases information had not been reviewed or made up to date. Therefore staff [did] not necessarily have information about individual needs.

'It is particularly important for people who are receiving respite care that information is kept up to date, as their needs and risks may change between visits. Several of the staff team worked at the service that closed [the Grange] and do know the service users and feedback about the quality of care was positive. However there have been three incidents that have been investigated under the Council Safeguarding Adults procedure and all of these were in relation to respite service users. It is possible that if assessments, care plans and risks had been updated some of these problems may not have arisen.'

231 The report made a number of recommendations to establish 'good practice' in line with national minimum standards. However, the report indicated two 'statutory requirements' which 'must be taken so that the registered person/s meet the Care Standards Act 2000, Care Homes Regulations 2001 and the National Minimum Standards. The Registered provider(s) must comply with the given timescales [31 January 2008]'. The two requirements were:

1. Care plans must be reviewed regularly and updated as necessary, including people receiving respite care.

2. All risk assessments must be reviewed regularly and updated as necessary, including people receiving respite care.'

The police investigation and the Coroner's inquest

232 Two post mortems were carried out following Mr Cannon's death. One was ordered by the Coroner and the other was arranged at the request of the police. An overview report was later produced by a forensic pathologist. Information relating to these examinations and subsequent proceedings is recorded here only so far as it provides information about the cause of Mr Cannon's death and the nature of the injury he sustained. This information relates to both the complaint against the Council and the complaint regarding Mr Cannon's subsequent care.

233 The Coroner ordered a post mortem which was carried out on 1 September 2003. The pathologist who carried out the examination (the First Pathologist) concluded:

'In my opinion, death was due to natural causes and was a result of bronchopneumonia. There was considerable oedema of the body which affected the soft tissues and skin with pleural and pericardial effusions and ascities (fluid in the cavities around the abdomen) present. This oedema was consistent with either renal failure or multiple organ failure. Fracture of the left femur had recently occurred.

'CONCLUSIONS AND CAUSE OF DEATH

I. disease & condition directly leading to death (a) Bronchopneumonia.

II. Unrelated (contributory) Fracture left femur.'

234 On 2 September 2003 a Home Office Pathologist (the Second Pathologist) conducted a second post mortem. He concluded Mr Cannon probably had weakened bones due to his immobility and his injury was possibly the result of a fall. He recorded the cause of death as:

'1a Bronchopneumonia, 1b Perinatal hypoxic brain injury.'

235 The police conducted an investigation into the circumstances of Mr Cannon's injury and subsequent death. They asked a forensic pathologist (the Third Pathologist) to produce a medical report about Mr Cannon's death. In his report, dated 25 January 2004, the Third Pathologist provided the following opinion:

'Mark Cannon sustained a fracture of the upper part of the left femur. This is consistent with him having fallen. It is not a type of fracture that is commonly associated with being caused by an assault.'

236 Following receipt of the report, the police discontinued their enquiries. The inquest was opened on 28 October 2004 but adjourned after hearing evidence from Mr Cannon's parents, the police, medical and nursing staff from the Trust, care home staff from the Grange and the First Pathologist. The hearing continued on 17 January 2005 and evidence was taken from further witnesses, including medical staff.

237 At the inquest a consultant employed by the Trust gave evidence that *'in his opinion [Mr Cannon] would not have been able to weight bear and walk back to bed as described by [the First Care Worker] if he had sustained his fracture [between 9.30pm and 10.00pm]'*. But, he *'speculated that [Mr Cannon] could have scrambled back into bed after a fall that*

caused a fracture because the pain threshold can be altered for some time after a fit, [the] so called post-dicteric phase which could last in his opinion he thought up to thirty minutes after a fit'.

238 In her summing up the Coroner emphasised that her remit was to establish the cause of Mr Cannon's death taking into account only *'direct, causal factors'*. On this basis she concluded Mr Cannon had *'died as a result of an accident'*.

239 Having examined events on the night of Mr Cannon's accident, the Coroner concluded that:

'Having considered the matter very carefully, I consider that appropriate care was taken of Mark during his stay at The Grange.'

She considered there had been no *'gross failure to supervise Mark in The Grange in view of his known tendency to fit'*. She also found as a fact that:

'... on the balance of probabilities Mark would not have died when he did and from the cause given had he not sustained the fracture ... It is clear to me that Mark's death has flowed from the consequences of the injury he sustained in The Grange.'

My approach to my findings

240 The incident in which Mr Cannon sustained his injury occurred on 26 June 2003. Since the incident there have been a number of investigations carried out and an inquest held in which those most closely involved in the incident have given evidence. In carrying out my investigation and in reaching my conclusions,

having regard to the passage of time since the incident, and to the likelihood of those giving evidence inadvertently confusing actual events with information disclosed in the course of the subsequent investigations and inquest, I have given greater weight to the contemporaneous evidence of relevant personnel so far as that is available.

241 The Council is critical of this approach and states that it *'does not accept the facts set out [in the draft of this report] as either accurate or reasonable'*. The Council has provided to me a copy of a recent exchange of emails with the Third Care Worker in which the Council put questions to the Third Care Worker and invited her response. In responding, the Third Care Worker prefaced her reply by stating *'I will answer your questions as best I can but it was over [five] years ago and my memory is not as good as it was'*. This strengthens my view that, in considering and reaching conclusions on this complaint, I should give greater weight to the available contemporaneous evidence.

242 The Council has also questioned the standard of proof applied by me. In reaching decisions on the complaint I have adopted the standard of the balance of probabilities while bearing in mind that the more serious the allegation made, the more cogent the evidence that is required to overcome the inherent unlikelihood of what is alleged.

The actions of the Council: the Local Government Ombudsman's findings

243 Mr Cannon's family have found it difficult to comprehend the conclusions reached by the First Independent Investigator. She made numerous criticisms of the management and staff at the home who she said did not deliver

the standard of care that Mr Cannon required. Close supervision was the most important need that he had and this had been clearly identified in the past. Supervision was almost entirely lacking on the night of the injury. Despite these findings, the First Independent Investigator did not make any connection at all between these failings and the injury which Mr Cannon sustained. Having considered the evidence I have concluded that there were indeed significant failings in the care provided to Mr Cannon at the Grange which were the result of poor management, poor staffing arrangements, and poor care planning for respite clients. I describe my findings below.

Council's responsibility to ensure Mr Cannon received appropriate care

244 The Council argues that it was the responsibility of its contractors (the Avenues Trust) to ensure that its contract requirements were effectively met and, in commenting on a draft of this report, it has said that I have no jurisdiction to investigate the alleged maladministration of a party who is discharging an administrative function of the Council as the result of a contractual obligation. I note, however, that on three occasions the Council referred Mr Cannon's mother to the Local Government Ombudsman if she remained dissatisfied with the outcome of her complaints to the Council. It is not to the Council's credit that, having advised Mr Cannon's mother to take her complaint to the Local Government Ombudsman, it now says I have no jurisdiction in respect of her complaint. I am satisfied that I do have jurisdiction.

- 245 I consider that I am entitled to take into account the management arrangements at the Grange as set out earlier in this report, including that the Grange was owned and provided by the Council and that with the exception of the Registered Manager (in attendance only up to two-and-a-half days each week) it was staffed entirely by staff employed by the Council or by agency staff engaged by the Council. The reality was that, subject to the limited involvement of the Registered Manager, the home was run, and care was provided, by Council employees and Council engaged agency staff. The Deputy Manager was a Council employee who had responsibility for the operational running of the Grange and overall responsibility when the Registered Manager was not in attendance. On the night in question the only staff on duty were staff employed or engaged by the Council. In those circumstances, I have concluded that the acts and omissions to which the complaint relates were carried out by or on behalf of the Council, which must, in my view, accept responsibility for the failures I have found.
- 246 It is, moreover, the case that the Council was under a duty to take all reasonable steps to secure that there was at all times an adequate system for monitoring its contractor's performance. As Moses J, as he then was, put in *R v Servite Houses ex p Goldsmith* [2001] LGR55: '[the Council's] duties to meet the assessed needs of the applicants do not cease once it has discharged its duty under section 21 by making arrangements with Servite. It remains under a duty to see that the applicants' needs are met and if necessary to re-assess them. It remains under an obligation to ensure that the arrangements which it has made continue to be sufficient to meet the needs of those qualified for such community care provision'.
- 247 The Council was therefore under an obligation to put in place adequate arrangements for the discharge of its section 21 (*National Assistance Act 1948*) duties and under a continuing obligation to ensure that the arrangements which it had made were sufficient to meet the needs of Mr Cannon (and others) while resident at the Grange. I have considered whether the Council discharged its obligations towards Mr Cannon in a satisfactory manner.
- 248 In my view, the Council failed to take adequate steps to discharge those obligations. That is apparent from the conclusions of the First Independent Investigator whose recommendations were accepted by the Council. Having carried out my own independent consideration, I agree with those conclusions. That failure by the Council contributed to the serious failings in the standard of care provided for Mr Cannon at the Grange.
- Lack of a provider care plan*
- 249 When Mr Cannon's mother and her husband placed her son at the Grange on 17 June 2003, they did so on the understanding that his complex needs were recorded and understood and that they would be properly catered for by staff at the Grange. To ensure this happened certain administrative requirements had to be in place so staff had all the information necessary to care for his needs.
- 250 Some information was available to staff at the Grange. The Care Assessment of 2002 and the Care Plan based on it were on the Grange's files and so was a risk assessment carried out at the Grange in May 2001. By the time of Mr Cannon's stay at the Grange in June 2003, that risk assessment was over two years out of date. It still contained some relevant information. But, crucially, there was no Provider Care Plan for

June 2003 – or, alternatively, any statement that previous documentation available in respect of Mr Cannon’s care needs had been reviewed and considered still to be appropriate – and no up-to-date risk assessment produced to detail how staff at the Grange would accommodate Mr Cannon’s assessed needs, and just what steps they would take to prevent him from coming to harm during his stay. As is recorded above (paragraph 230) *‘It is particularly important for people who are receiving respite care that information is kept up to date, as their needs and risks may change between visits’*. It seems to me both these documents were required to comply with national minimum standards. The failure by the Council to ensure that they were in place in respect of Mr Cannon, who was receiving respite care commissioned by the Council, was **maladministration**. I moreover, agree with the findings of the First Independent Investigator, who concluded from interviews with staff at the Grange *‘that they were not aware of Mark’s specific needs, and had not received instruction on meeting his needs’*.

- 251 These failures also represented a failure by the Council to make reasonable adjustments to meet Mr Cannon’s needs and resulted in him being treated less favourably for reasons related to his learning disability.

Failings in the provision of care

- 252 I refer above (paragraph 180) to the finding by the First Independent Investigator, with which I agree, that:

‘The fact that the homes manager is not available for half of the week [in fact, the Manager was only available at the Grange for up to two-and-a-half days per week] leaves the service with weak management, and a lack of monitoring/management supervision.’

- 253 The First Independent Investigator was also critical, among other things, of the arrangements in place for staff training, record keeping, documentation in respect of care needs and completion of incident forms. She found, for example *‘that staff at the Grange did not have records relating to the presentation of Mark’s epilepsy or detailed guidance on the specific management required’*. Further, the protocol relating to risk management was *‘not being followed at the Grange’*. Induction procedures for new staff were said to be *‘poor and [to] result in critical procedures [including implementation of risk management guidelines] not being understood and followed’*. I agree with these criticisms.

- 254 I consider that the Council failed to secure that adequate arrangements were in place for the care of Mr Cannon at the Grange. That failure contributed to the serious failings in the standard of care provided for him at the Grange which the First Independent Investigator rightly found *‘was of a standard that does not meet the minimum requirements of the National Care Standards Commission (NCSC)’*. The Council has accepted that the standard of care Mr Cannon received fell below that which he should have been given.

- 255 The First Independent Investigator went on to find that it was a *‘corporate failure [which] ultimately [led] to a failure to meet Mark’s care needs during his stay’*. In my view the Council was under a duty to see that Mr Cannon’s needs were met but failed to do so. The Council failed to put in place adequate arrangements for the care of Mr Cannon and failed in its continuing obligation to ensure that the arrangements which it had made were sufficient to meet his needs. That was **maladministration** on the part of the Council.

256 I note, too, that the Council has previously acknowledged its failures here. The Council's Stage 3 complaints procedure upheld Mr Cannon's mother's complaint that *'the Council did not provide an appropriate level of care to (her) son'* and the Review Panel's decision records that the complaint was *'admitted by the service'*. And the Council introduced changes to its procedure and practices concerning care home placements, both in respect of the Grange and more generally in order to prevent recurrence of the failings which had been identified.

257 The Council has argued in commenting on a draft of this report that Mr Cannon can only have fractured his femur when the care worker was stationed outside his room. So, regardless of any possible shortcomings in the level of care and supervision provided earlier in the night, at the crucial point appropriate care and supervision was in place.

258 The Council suggests that Mr Cannon could have fallen and fractured his femur without the care worker (who the Council says was sitting outside his door) hearing the fall, and then managed to put himself back to bed. This seems to me to run counter to the argument the Council has advanced that Mr Cannon could not have broken his leg when the First Care Worker found him at around 10.00pm because he could not have walked back to his bed, while holding the hand of the First Care Worker, if he had a broken femur. But there is evidence that on the earlier occasion Mr Cannon had probably had a seizure as he was incontinent. In this post-seizure state he may well not have registered pain normally and so it is possible that he was able to be assisted back to bed, as reported by the First Care Worker. A consultant employed by the Trust gave evidence at the inquest that *'the pain threshold can be*

altered for some time after a fit, [the] so called post-dicteric phase, which could last in his opinion he thought up to thirty minutes after a fit'. The Registered Manager, who carried out an investigation immediately after Mr Cannon suffered his broken femur concluded that *'The most likely explanation is that [Mr Cannon] had a seizure earlier in the night and was found by the [First Care Worker] soon after. The fact that [Mr Cannon] was incontinent when she found him would suggest this. Mr Cannon is thin and frail and could easily damage himself during a seizure. However [the First Care Worker] states that he walked back to bed 5 feet away with very little support which with a broken hip [sic] would be difficult. She does state that he walked slowly. The lack of reaction to the broken hip [sic] could be due to [Mr Cannon] being in recovery from seizure'*.

259 The suggestion by the Council that Mr Cannon may have fallen out of bed or have got out of bed and fallen over and broken his femur at around shortly before 3.15am and (despite not being in a post-seizure state) climbed back into bed unassisted appears to me to be the least likely explanation, especially as, when seen by the Third Care Worker at approximately 3.15am, Mr Cannon's bedding was undisturbed.

260 I do not consider it is possible to say with any reasonable certainty when the incident happened. The Coroner did *'not think [Mr Cannon] sustained [his injury] when he had his fit and was found by [the First Care Worker]'*. The First Independent Investigator concluded that it was likely to have happened at any point between 9.30pm and before 3.00am. The Council has previously accepted the finding of that Investigator's report. In my view the injury to Mr Cannon could have been sustained at any time from 9.30pm up to 3.30am.

261 But, regardless of when the incident happened, I consider that there was not on that night an appropriate level of care and supervision provided to Mr Cannon by the staff of Council employees and Council engaged agency workers. There was a chance encounter with the First Care Worker shortly after Mr Cannon had gone to bed and according to the Council a check on him probably some time after midnight. A care worker did not take up a position near to his room until 2.00am. Accordingly, I find that there was inadequate supervision of Mr Cannon between 9.30pm and 2.00am and that the Council did not meet its obligations to ensure that the care received by Mr Cannon sufficed to meet his needs. This was **maladministration** by the Council.

Failure to maintain Mr Cannon's safety by using the epilepsy alarm

262 Mr Cannon's mother and stepfather brought his epilepsy alarm with him. They fitted it themselves to his bed and ensured that it was working. They explained to staff how the alarm worked and left information about who should be contacted in the event that the alarm failed to work. The alarm was very sensitive and would have alerted staff to movements while Mr Cannon was in bed, such as those relating to an epileptic seizure, or movements prior to falling out of bed. The alarm was not in use on the night of the injury and it has been suggested by care home staff that the alarm was not working properly.

263 In commenting on the draft of this report the Council has also suggested that there may have been particular problems on Darby Unit which meant that the mat did not work. Mr Cannon's mother felt that the mat may have been removed by staff at the Grange because it would sound frequently as it monitored movement

in bed by Mr Cannon. The Coroner said '*It appears that the mattress alarm was taken to the Grange, but it either didn't function or else it sounded so frequently that it was not in use at the home*'. But, regardless of the cause, there is no doubt that the alarm was not in use and that no attempt had been made to contact anyone who could have restored it to its proper use if it had been malfunctioning. Subsequent examination of the alarm suggests that it was in full working order.

264 Care home staff failed to ensure that an important piece of safety equipment was in use and this added to Mr Cannon's risk of serious harm. I note that the Council accepts that this was a '*shortcoming*' but appears to have misunderstood the use of the mat asserting that its function was to '*sound an alarm in the event that a person fell down onto it*'. That is incorrect. The mat was for use as a fixture to the mattress of the bed to detect movements by the person when in bed. I further note the view of the Registered Manager of the Grange, expressed shortly after the incident and before there was any question raised about the epilepsy mat provided by Mr Cannon's mother, that '*The use of alarm mats needs to be considered for respite care users such as a mat fitted next to a bed would be set off when a service user places their foot on it and also alerting night staff. The use of similar devices attached to beds, sensory lights may also need to be considered*'.

265 The Grange was provided by and was in the ownership of the Council. All the staff, save for the Registered Manager, who attended the Grange for only up to two-and-a-half days each week, were either employed by the Council or were agency staff engaged by the Council. The Deputy Manager was a Council employee who had responsibility for the operational running

of the Grange and overall responsibility when the Registered Manager was not in attendance. The Council was responsible for the acts and omissions of its staff. I therefore find the failure to ensure that this important piece of safety equipment (the epilepsy mat) was in use was **maladministration** by the Council.

266 The failures by the Council relating to the provision of care to Mr Cannon and the failure by the Council to ensure that the epilepsy mat was in use also represent a failure by the Council to make reasonable adjustments to meet Mr Cannon's needs and resulted in him being treated less favourably for reasons related to his learning disability.

Action taken by the Council after Mr Cannon's injury

267 I have carefully considered the evidence submitted by the Council to demonstrate the actions it has taken following Mr Cannon's injury to improve the arrangements for respite care. I accept that some actions were taken immediately such as the termination of the contract with the Avenues Trust. I also note that the Grange has now closed and has been replaced by a modern facility which provides respite care for clients such as Mr Cannon. I have considered a recent Commission for Social Care Inspection report relating to this facility and note that within what is, in overall terms, a very positive report, concerns are still expressed about the quality of care plans and risk assessments for respite care clients. This was precisely the issue which was raised in earlier inspection reports regarding the Grange and which lies at the heart of the failure to provide Mr Cannon with adequate care. The Commission for Social Care Inspection report suggests that a lack of up-to-date care plans and risk assessments could potentially place clients at risk. In view of this evidence I believe that the

Council has more to do in this vital area of care and I hope it will take the opportunity of this report to ensure that further improvements are put in place.

The Council's investigation of Mr Cannon's parents' complaints

268 I have considered the efforts made by the family to have the circumstances of their son's injury investigated by the Council. Both Mr Cannon's parents made formal written complaints to the Council within weeks of his injury and some time before his death. These complaints raised specific concerns about the care that he had received and asked for a full investigation to establish the facts. The Council's response to these formal complaints was extremely confused. The investigation report ordered by the Learning Disability Service Manager and produced by the First Independent Investigator was clearly produced for the purposes of an internal investigation within the Council. However, another part of the Council presented this investigation as being in direct response to the complaints made.

269 The initial complaints received no formal response and appear to have been discontinued with no more than a few acknowledgement letters. The report of the First Independent Investigator was not passed to Mr Cannon's father until the Second Independent Investigator suggested that this be done before any further investigation took place. He received the report in August 2004 and submitted detailed criticisms on behalf of the whole family which, once again, received no response. The Second Independent Investigator did not carry out an investigation nor did he produce a report and once the Coroner's inquest was announced the Council abandoned the complaints process. It was not unreasonable to suspend an investigation while the Coroner and police

were pursuing their enquiries, but these did not absolve the Council from its responsibility under the *National Health Service and Community Care Act 1990* to investigate properly made complaints, and there was no reason not to explain the reasons for the delay and to ensure that the complaints process was concluded promptly, without further intervention by Mr Cannon's family, as soon as this was possible.

270 In the event, Mr Cannon's parents were forced to restate their complaint time and time again and were given contradictory and unhelpful information about progress. Indeed, following the Coroner's inquest the Council declined to take the complaint forward and it did this in a manner which was bound to cause Mr Cannon's family deep distress. Mr Cannon's mother in particular was forced to seek my intervention before the Council initiated a Stage 2 investigation. The Council has accepted that errors were made at this time and that the way in which the decision to terminate the complaint was taken was insensitive and incorrect.

271 There was also a great deal of confusion about how the complaint progressed through the various stages of the complaints process. It was suggested that Mr Cannon's mother had found it difficult to know which stage the investigation had reached, the implication being that as she had resubmitted a fresh complaint the process had returned to Stage 1. This confusion was entirely the responsibility of the Council. Mr Cannon's mother thought she was at Stage 3 because this is what the Council had told her. This confusion added greatly to the distress the family were experiencing and raised fears that the Council was trying to obstruct the examination of the events at the Grange.

272 Having secured a Stage 2 investigation, Mr Cannon's family were entitled to expect that a full investigation would take place and that the Council would issue a formal response to them which addressed the failings identified. The report produced by the Third Independent Investigator supported the findings made by the First Independent Investigator and fully upheld the family's complaint that Mr Cannon had been provided with poor care by the Council. The subsequent letter to the family from the Head of Adult Social Services was the first time that the family had received a formal response to their complaint and this came nearly three years after Mr Cannon's injury. The response fell far short of an adequate consideration of the complaint made. The Head of Adult Social Services said he only partly upheld the complaint regarding the care that Mr Cannon had received but gave no explanation for this and did not acknowledge that this outcome differed significantly from the fully upheld verdict in the Third Independent Investigator's report. More importantly, the letter provided no apology for the shortcomings identified or the distress the family had suffered. The letter described the actions which had been taken to act on the findings of the investigation but these lacked substance and were so generalised that they did not provide evidence of specific action. In general, the response lacked sympathy and did not provide Mr Cannon's family with a satisfactory conclusion to their complaint.

273 The Review Panel hearing which constituted Stage 3 of the complaints process did no more than endorse and expand on the findings of the earlier investigations. Mr Cannon's mother received a very brief letter shortly after the hearing which told her that her complaint had been upheld and that the Review Panel expressed sympathy '*in respect of the whole issue*'. No apology was made and there was

no acknowledgement of the implications that the poor care, which was now accepted by the Council, had on Mr Cannon. His mother was told the Review Panel's only recommendation was that she should receive £250 for her trouble and the inconvenience of having to go through the complaints process. Once again, this letter lacked sympathy and was an inadequate outcome given the nature of the issues involved. The letter contained no details of the Review Panel's findings and Mr Cannon's mother had to wait another five months before the minutes of the meeting were made available to her. The failure to convey the outcome of the Review Panel hearing promptly to Mr Cannon's mother demonstrates a lack of sympathy or consideration for the ongoing distress that she and other members of the family continued to experience, several years after Mr Cannon's death.

274 I conclude that the manner in which the Council handled the complaints by Mr Cannon's parents fell far below an acceptable standard and was **maladministration** (as the Council now accepts).

Injustice

275 I have considered whether injustice was caused by the maladministration I have identified.

276 The Provider Care Plan and risk assessment were key documents to alert staff at the Grange to Mr Cannon's needs and to stipulate with precision how staff were to respond to them. Their preparation, on admission, would have ensured that care staff had drawn together the information available about Mr Cannon's care needs and made sure the requirements were fresh in people's minds. Their absence was not made good by the Care Assessment and Care Plan, previously produced by other

professionals, or by an out-of-date risk assessment unlikely to have been drawn up by the staff who would actually care for him during the stay in question. There was, then, **some** relevant information on file but not the most relevant information: how the Grange and its current staff would meet Mr Cannon's needs and take all reasonable steps to keep him from harm. I have little doubt, had this documentation been in place, it would (among other things) have required the epilepsy alarm to have been in place and in working order on the night of Mr Cannon's accident; or, in the event that it could not for unforeseen reasons have been used that night, that alternative arrangements were made for his supervision.

277 The Coroner concluded that Mr Cannon's death derived directly from his accident at the Grange. Not all accidents can be avoided. But many can be foreseen and guarded against, and it was the purpose of the Provider Care Plan and risk assessment to do just that. In fact, the arrangements to define how staff would respond to Mr Cannon's needs, how they would keep him safe and seek to **prevent** accidents happening to him, and how they would be alerted to movements while he was in bed, were not in place. In all the circumstances the question arises whether Mr Cannon's accident and injury could have been avoided had proper arrangements been in place for his care (including an up-to-date Provider Care Plan and risk assessment properly communicated to staff, the epilepsy mat in place and working, and much closer supervision while he was in bed than actually occurred). It seems to me that had they been in place this accident and injury might well have been avoided, and probably should have been.

278 The failure to put in place all proper arrangements to guard against this accident, and as a consequence the beginning of the chain of circumstances that led to Mr Cannon's death, in my view represents a very substantial injustice to Mr Cannon's parents. No expressions of sorrow now, and no financial compensation, can ever assuage the hurt they feel. Even so, I believe that they are owed some significant recognition from the Council of its failures here and of their consequences.

279 The Council's complaint handling will have compounded the hurt of the main injustice. I accept that the circumstances here were very difficult for the Council. The police and Coroner's investigations will inevitably have complicated matters. It cannot have been an easy time for the Council or its staff. But the Council's failures of communication, and its lack of openness, can only have burdened and extended the grief felt by Mr Cannon's parents.

The actions of the Council: the Local Government Ombudsman's conclusion

280 In conclusion, I have considered all the available evidence and have found that the Council failed to provide and/or secure an acceptable standard of care for Mr Cannon and that, as a result, his safety was put at risk. That failure constitutes **maladministration** by the Council. I consider that the injury might well have been avoided and probably should have been if the failures I have identified had not occurred. I say this because the very procedures that should have been in place, and the availability of the epilepsy alarm, were explicitly designed to prevent such an accident happening to him. I also find that the Council did not respond to the complaint made by Mr Cannon's parents in an appropriate way and that this caused

further distress to his family. That too was **maladministration**. The maladministration that I have found caused **injustice** to Mr Cannon's parents.

281 Therefore, I **uphold** Mr Cannon's parents' complaint against the Council.

Recommendations

282 I **recommend** that the Council formally apologise to Mr Cannon's parents for the failings I have identified, and make each of them an ex gratia payment of £10,000. I would also urge it to take all necessary steps to ensure that Provider Care Plans and risk assessments are properly in place for all persons in receipt of respite care commissioned by the Council.

The Health Service Ombudsman's investigation of the complaint against the Trust

Complaint (b): care and treatment at the Trust

283 Mr Cannon's parents complain that during each of his admissions the Trust failed to provide their son with adequate care and treatment or to properly plan his discharge and aftercare. They believe these failures led to the decline in his health and his death.

Key events

284 Mr Cannon was admitted to the Trust on three occasions. His first admission was on 27 June 2003 via A&E, following his injury at the Grange. His fractured leg was repaired and he was discharged to his mother's home on 4 July 2003.

285 Mr Cannon's second admission, on 8 July 2003, was also via A&E, following a visit by his GP earlier that day. The GP was concerned about Mr Cannon's ongoing pain and agitation. He was transferred to the Receiving Room and referred to a pain team who were unable to see him for several days. He was discharged into the care of his mother on 14 July 2003.

286 On 10 August 2003 Mr Cannon was admitted for a third time via A&E. He was found to be gravely ill, suffering from dehydration, malnutrition, renal failure and infection. He was treated initially in the Receiving Room but when his condition deteriorated he was moved to the ITU on 11 August 2003. His condition improved. He was transferred to the HDU on 13 August 2003 but his condition deteriorated once again and he suffered a cardiac arrest. After being resuscitated he was returned to the ITU on 14 August 2003 where he remained until 29 August 2003 when he died.

Mr Cannon's father's recollections and views

287 Mr Cannon's father told my investigator that his son's care during the first admission to the Trust had been generally very poor. He said his son was rarely attended and the family had to call nurses to help him. Mr Cannon's father said the family felt they were being ignored and that, instead of benefiting from the family's knowledge, staff were very defensive and regarded any communication from the family as criticism. He said nursing staff would not accept the family's attempts to inform them about Mr Cannon's disability, epilepsy, unusual distress and the pain he was suffering.

288 Mr Cannon's father said his son was clearly anxious and in pain following the operation and family members had to play an active part in his care at this time. He said nothing was done about the seizures his son was experiencing. The family recorded the seizures, but staff did nothing to control them. He said staff did not check the levels of epilepsy medication for over 80 hours after his operation. He also said no efforts were made to check blood loss until 60 hours after the operation, but when a doctor came he found that 40% of Mr Cannon's blood had been lost so an immediate blood transfusion was required.

289 Mr Cannon's father said appropriate observations were not carried out until he insisted they be done and other concerns expressed by the family were ignored. For example, Mr Cannon was not urinating normally and staff did not respond to the family's requests for a urinary catheter to be inserted.

290 Mr Cannon's father said that although the surgery to repair his son's broken bone had been successful, in all other respects he believed the hospital had failed to care for him. He said the only reason his son had survived his first admission was because of the family's efforts to convince staff to take notice of him.

291 Mr Cannon's father said his son's discharge on 4 July 2003 had been premature. He believes his son was not well enough to go home and no adequate arrangements had been made to care for him properly once he left the hospital. There was no care plan and no care package. Mr Cannon was in pain and extremely distressed but his father felt the hospital regarded him as a nuisance and could not cope with him. He said they wanted to get rid of him as quickly as possible.

- 292 Mr Cannon's father said he did not see his son following his discharge on 4 July 2003 as he went back to his mother's home. He said he did not visit his son during the second admission to hospital because he had no reason to think his condition was serious.
- 293 When Mr Cannon was admitted on the third occasion his father stayed at the Trust during the first night because of the seriousness of his son's condition. He said his son's bed was not visible from the nurses' station and he should not have been laid on his back, given the risk of vomiting and aspiration (inhaling stomach contents into the respiratory passages). Mr Cannon's father said nurses did little for his son during this time and most of the care was provided by his family. Mr Cannon's father said there was only one nurse on duty on the ward and conditions were extremely poor. He said another nurse was in the kitchen for two hours, asleep. He felt one nurse on duty for 12 or more patients was completely inadequate.
- 294 Mr Cannon's father said that while he was caring for his son, and out of sight of the nurse on duty, his son began coughing and a large amount of green bile flooded into the oxygen mask. He said he and his wife helped to clean up the vomit. Although the nurse did eventually attend to Mr Cannon she did not at any time attempt to summon her colleague who was sleeping in the kitchen. Mr Cannon's father also said that at the inquest the nurse reported she was present when Mr Cannon vomited into his mask. However, he was adamant that the nurse had not been present and his son had aspirated which he said led to the subsequent chest infection.
- 295 Mr Cannon's father said when his son was transferred from the ITU to the HDU on 13 August 2003 his condition was relatively stable, his renal function had recovered and he appeared to be on the mend. However, during his short stay in the HDU he went from being 'okay' to being gravely ill. Mr Cannon's father described events during the morning of 14 August 2003. He said he was very concerned because his son was '*very pallid and his breathing very laboured*', he was unresponsive and '*seemed unconscious*'. He described how Mr Cannon was seen by a doctor and a chest X-ray was taken. Around 1.30pm a consultant reviewed the X-ray and told Mr Cannon's family that his lung had collapsed; he was extremely ill and would be returned to the ITU. However, at around 3.00pm his son had a cardiac arrest. Mr Cannon's father believes his son was allowed to deteriorate unnoticed in the HDU and that staff ignored the concerns expressed by his family. However, he said following the cardiac arrest, Mr Cannon received good care in the ITU.
- 296 Mr Cannon's father explained his feelings about whether the care and treatment his son received was related to his learning disability. He said that in his view poor care and treatment were compounded by the failure of hospital staff to understand his son's individual needs and their refusal to involve family members. Overall, he said nurses failed to fulfil even the most basic duties such as monitoring his son's condition, administering medicines and alerting doctors to his son's changing condition. He felt that, whether hospital policy allowed it or not, it was completely inappropriate for nurses to be sleeping on the ward while patients needed attention. In his view, no nurse should ever be asleep while they are in charge of patients, especially critically ill patients. Mr Cannon's father said the failure of the nurses to provide

care led to catastrophic mistakes being made, such as the failure to maintain therapeutic levels of epilepsy medication and the failure to notice that Mr Cannon had lost a lot of blood. He said that if the hospital had provided Mr Cannon with the care and treatment he was entitled to he would still be alive.

Mr Cannon's mother's recollections and views

297 Mr Cannon's mother said that when she saw her son on 2 July 2003 in hospital he was extremely agitated and moaning a lot. She had initially assumed he was just unhappy about being in hospital. She said she had reassured him as much as she could and felt she should take him home as soon as possible as she knew he would settle down there. However, she was clear that when her son was discharged several days later, he was not well enough to go home. She felt more assessments and investigations should have been carried out. She asked for appropriate arrangements to be made for him to go home including inputs from the physiotherapy team. She said there were delays in obtaining medication from the hospital.

Mr Cannon's mother also said there were problems arranging visits from the district nurses after her son returned home and, despite assurances that the arrangements had been made, the district nurses were unaware they were expected to visit him. She said she had to make the arrangements for district nursing visits herself.

298 Regarding the general standards of care during Mr Cannon's admission to the Trust, his mother said she felt the hospital would not communicate with her and there was a general lack of care. She said she had to give her son his medication as nurses did not appear to want to do it. She also said staff did not know how to handle her son with regard to his

learning disability and, consequently, left him unattended. Family members were left to care for him and to use their knowledge of what worked and what did not work with him to try and keep him comfortable.

299 Referring to Mr Cannon's admission to the Trust on 8 July 2003 his mother said there were numerous delays at the hospital. She said Mr Cannon was not seen by a doctor for some time in A&E and his wound dressing was not changed until family members asked for this. When he was eventually readmitted to a ward, there was a delay of several days before he was seen by a pain team and his medication modified. Mr Cannon's mother said that at the time of his admission her son was in '*hysterical pain*' and may have been in shock but no assessments were done to find out why he was in this state. Mr Cannon's mother said by the time her son was discharged on 14 July 2003 he had calmed down somewhat and was sleeping a little better.

300 Mr Cannon's mother said when her son was admitted for the third time she and her husband had stayed until midnight and were told by medical staff that Mr Cannon was very dehydrated, had kidney failure and was generally very poorly. They were told his condition was so serious that he '*might not make it*'. Mr Cannon regained consciousness and seemed to be improving but she said hospital staff asked whether he should be resuscitated should his condition worsen. She felt staff were trying to encourage her to '*let him go*' without making any effort to help him.

301 Mr Cannon's mother questioned why on his third admission her son was admitted to the Receiving Room and not the HDU or the ITU despite the seriousness of his condition. Before he moved to the ITU on 11 August 2003 his

condition had worsened. He was ‘*completely out of it*’, lethargic and hardly conscious. She said that in the ITU he received very good care and she was encouraged by the attitude of staff. She said she was told medical staff were ‘*looking through his disability*’ and that they would ‘*try to save him*’. She said staff in the ITU were very caring and spoke to the family ‘*like human beings*’. However, she said she did not like the HDU which did not provide anything like the care he was receiving in the ITU. She said that the Sister was ‘*arrogant*’ and unhelpful, the care was poor and her son’s condition deteriorated. She said Mr Cannon developed a chest infection while he was in the HDU and his condition deteriorated seriously.

The Trust’s position

302 The Trust’s Director of Nursing and Clinical Governance produced a report, dated 18 May 2004, into the circumstances of Mr Cannon’s care and treatment at the Trust. The report provided an overview of Mr Cannon’s admissions and concluded there were no shortcomings in his care and treatment.

303 On 5 April 2007 the Trust’s Chief Executive wrote a letter in response to recommendations from the Commission. He explained that the hospital in which Mr Cannon had been treated had now closed and services had been reprovided at another hospital. He acknowledged that the Trust had not responded fully to concerns raised by Mr Cannon’s parents. He accepted that there had been some shortcomings in Mr Cannon’s care and treatment, including lack of involvement of his family in some decisions, and offered some apologies. His focus was on improvements which had been made at the Trust since Mr Cannon’s death, such as better record keeping, a review of discharge planning and changes to staffing.

The advice of the Health Service Ombudsman’s Professional Advisers

304 My Professional Advisers have provided advice on key aspects of care and treatment during each of Mr Cannon’s three admissions to hospital.

My A&E Medical Adviser

305 My A&E Medical Adviser studied the medical assessment carried out at around 6.00am on 27 June 2003 (the first admission) and noted that the medical team diagnosed a fracture of the shaft of femur. She said aspects of the medical assessment were ‘*very poor*’ and pointed to lack of instructions on further management or observations. She also said:

‘A drug chart shows that analgesia [pain relieving drugs] was not given until 10.15am, nearly five hours after triage. This is dreadful considering the history recounts that he was found screaming in pain and he is known to have a nasty fracture.’

She also noted that Mr Cannon was not seen by orthopaedic doctors until 10.05am and said:

‘I would expect a confirmed femur fracture to be seen and treated with far more urgency.’

306 My A&E Medical Adviser went on to say an observation chart was not commenced until 10.00am and a fluid chart commenced at 4.00pm. She commented that these records:

'... appear to demonstrate no care at all between admission at 5.22am and 10.15am when [Mr Cannon was] seen by the orthopaedic surgeons. There is no nursing note, no observation chart, no pain assessment and no analgesia. No one has made any investigation into this appalling omission.'

307 With regard to Mr Cannon's second admission on 8 July 2003, my A&E Medical Adviser noted that he was triaged at 10.55am but it was not until shortly after 9.00pm that he was given a sedative and at 10.15pm he was given analgesia. She said a doctor recorded that Mr Cannon *'... seems in agony'* and an entry by the pain team on 11 July 2003 states that regular analgesic doses must not be missed and that Oramorph (an oral preparation of morphine) must be given when Mr Cannon was in pain. She said a pain monitoring chart was suggested, but notes of a return visit by the pain team later that afternoon indicate the suggested changes to analgesia had not been implemented.

308 My A&E Medical Adviser commented on the overall evidence of the hospital records for this period. She said:

'From these it does not look as if his pain was reliably controlled and he remained very agitated at times.'

She went on to make particular comment regarding Mr Cannon's second admission. She said:

'The delay and lack of care and pain relief on this occasion was totally unacceptable. Monitoring and assessment during this time was exceptionally poor and it seems that he was left in pain for unacceptable lengths

of time. The other admissions show similar deficiencies. Mr Cannon was not, it seems, appropriately assessed for pain at any stage during the three admissions via A&E. Once the pain service became involved on 11 July [three days after admission] there is evidence of improving monitoring but there is also evidence that pain control was not good and there continued to be difficulties.'

309 My A&E Medical Adviser provided her opinion about the overall medical care Mr Cannon received during his three A&E admissions and his admissions to the Receiving Room. She said:

'I would say that the [lack of] urgency with which his fracture was managed through A&E, the lack of attention to pain relief, and lack of monitoring whilst awaiting admission (apparently about eight hours) was not what I would expect as routine care in A&E.'

'...'

'On his second admission, again there is a lack of documentation, unnecessary delay (11 hours) and lack of assessment of pain and analgesia. On the third admission when he was clearly very sick, although initial assessment was thorough and prompt, the delay (nearly eight hours) before transfer to a ward was worrying and I am not happy that we have sufficient evidence that he was transferred to an appropriate ward.'

310 She went on to compare the care Mr Cannon received to the care she would normally expect a patient in his condition to receive. She said:

'In short, I do not believe he received the standard of care that another patient should receive in similar circumstances.'

My A&E Nursing Adviser

- 311 My A&E Nursing Adviser said nursing staff in A&E often face situations where people cannot communicate and she would expect them to have the skills necessary to assess needs and make decisions about interventions based on clinical urgency in these circumstances. She said the information that carers can provide can be particularly important in such situations.
- 312 With regard to Mr Cannon's first admission to the Trust on 27 June 2003 my A&E Nursing Adviser is critical of both the nursing records and the nursing care provided in A&E. She said:

'The Triage priority status (the category allocated to each patient to denote the urgency of clinical treatment) appears to have been appropriate, however, there is little in the way of an objective assessment – the triage record consists mainly of Mr Cannon's presenting medical history. Although it is indicated that Mr Cannon had a "communication problem", there is no detail to inform colleagues how this affected him or how communication would be best achieved. No further detail was given in relation to his leg injury, nor any form of pain assessment carried out. This is poor practice.

'Overall, the A&E nursing records for this first attendance were inadequate. Physiological observations were not repeated for five hours and the communication page included just one entry, indicating the baseline observations, and that a name-band had been placed on Mr Cannon. This represents an unacceptable level of nursing documentation in a seven-hour A&E episode and falls below the standards outlined by the [Nursing and Midwifery Council].

'The level of nursing assessment, care planning and evaluation for this first A&E attendance fell below a reasonable standard of care. Little can be gleaned in terms of Mr Cannon's needs in relation to his communication difficulties and any strategies to address these through documentation of discussion with his carers. Formal pain assessment was absent, which is essential for any patient in distress, but even more so for someone like Mr Cannon, whose ability to articulate what he was feeling was compromised. The management and timeliness of his pain relief was also poor.'

- 313 My A&E Nursing Adviser said that as Mr Cannon's second admission on 8 July 2003 was organised by his GP this should have meant further medical assessment on arrival at hospital was not needed, resulting in speedier progress through A&E. She said that on arrival at around 11.00am, Mr Cannon was appropriately triaged and the triage assessment form said he had been sent to A&E as a result of an increase in his epileptic seizures and agitation since his recent surgery. His severe learning disability was also noted. My A&E Nursing Adviser said:

'Aside from this and one recording of baseline physiological observations, there is no other informative or objective triage. Neither is there a secondary assessment, which one could expect ...

'No formal pain assessment is recorded and a single further set of observations exists on a chart at 5.00pm. Given that Mr Cannon's pulse rate was substantially raised on arrival, this is unacceptable practice.

'...

'It is clear that Mr Cannon's agitation continued throughout his stay in A&E and yet no one considered that this might have been in response to pain. There was no documented communication with Mark's family as to his normal behaviour at home or what strategies were routinely used for communication with him. Mr Cannon did not receive any pain relief until he had been in A&E for eleven hours, which is astonishing.'

- 314 My A&E Nursing Adviser considered the standard of care and treatment provided to Mr Cannon in the Receiving Room and found significant shortcomings in record keeping. She said:

'The formal Nursing Assessment document is blank except for the front page, which details the reasons for admission and demographic data. This is unacceptable in any situation and particularly for a patient with special needs. I was unable to locate any risk assessments, such as nutrition, falls, pressure ulcer prevention, or patient handling, which is also unacceptable.'

'...

'Progress records are difficult to follow as they were ordered out of date sequence and one of the dates was entered incorrectly. In general they are detailed; however, they do not always reflect what I suspect to be Mr Cannon's true clinical status, for example, there are many occasions where the observation chart indicates a significant pulse increase, with no reference in the nursing records. One entry at 7.00pm on 9 July states "obs (observations) stable", yet his pulse rate at that time was 126, which is very high and by no means stable.'

On 10 July at 2.00pm, the record indicates that observations have been maintained – in fact, there was a gap in the recording of physiological observations of 11 hours between 7.00am and 6.00pm, at which time Mr Cannon's pulse rate was again 126 and his condition was described as "stable". The measurement was not repeated until 10.00pm that night. Mr Cannon was incontinent of urine at one stage and yet it is unclear whether this was a new event or whether he was prone to incontinence at home.'

- 315 My A&E Nursing Adviser noted that when he arrived in the Receiving Room, Mr Cannon was displaying signs of considerable pain. He was referred to a pain team on 9 July 2003. She noted that the Nurse Specialist from the pain team was unable to review him until 11 July 2003, apparently due to poor staffing resources. The Nurse Specialist from the pain team advised on alterations to Mr Cannon's analgesia and instructed that pain assessment charts be commenced. However, a numeric pain scale was used, implying that Mr Cannon was able to articulate how much pain he was experiencing on a scale of 1 to 10. My A&E Nursing Adviser is not convinced that this was the case and she considered an alternative tool, focusing on behaviour, would have been more appropriate. She considered the pain monitoring charts are not informative, as timings of pain assessments are unclear.

- 316 Regarding Mr Cannon's discharge home from the Receiving Room, my A&E Nursing Adviser said:

'The pre-discharge records in general are somewhat brief and do not reflect a considered and anticipatory discharge pathway. The nursing discharge record is completely blank.'

317 With regard to the whole of Mr Cannon's second admission to the Trust my A&E Nursing Adviser said:

'I was particularly concerned with the standard of the physiological observation records, such that action did not appear to have been taken at times when Mr Cannon's clinical status should have roused suspicion regardless of the cause and further the progress notes did not reflect what was written on the observations chart. Nursing records were incomplete – essential assessment documentation was blank and clearly-needed pain assessment tools were not instigated quickly enough and when they were, they were inappropriate. No risk assessments were carried out for Mr Cannon and discharge plans were blank. I am critical of the level of nursing care for this admission. Again, one could not get a sense of Mr Cannon's communication needs from any of the nursing records for this admission and that was very poor practice.'

318 My A&E Nursing Adviser said on Mr Cannon's third admission on 10 August 2003 record keeping was better. However, she was critical of the fact that there is no record of the insertion of a urinary catheter in the nursing notes and that *'a fluid balance record was not commenced until five hours after Mark's arrival ...'*

319 She noted that Mr Cannon was transferred to the Receiving Room at around midnight on 10/11 August 2003 and that all clinical records from this point onwards refer to his previous surgery as THR (Total Hip Replacement), which was incorrect.

320 My A&E Nursing Adviser said that on admission to the Receiving Room, Mr Cannon's blood pressure was very low and his decreased conscious level placed him at serious risk of airway compromise (meaning that there was a risk that his windpipe could become blocked, for example, by vomit or his tongue, such that he would not be able to breathe). Despite this, my A&E Nursing Adviser could not find any information from the records about the position in which Mr Cannon was nursed. She could not locate any nursing care plans, although she would have expected one to be drawn up as soon as possible after admission. She said she would have expected a patient with this level of deterioration to have been placed near to the nurses' station so his condition could be regularly and visually assessed. She also said the idea that:

'Mr Cannon could be observed by staff as they passed on their way to the sluice was astonishing. There could be no good rationale for locating him so far from the nurses' station. His learning disability was not the priority at that stage if this were to be used as a reason for more privacy – it was his physical state that was at great risk.'

321 Referring to the fact that nurses were sleeping in the kitchen during their breaks, my A&E Nursing Adviser said:

'The issue is not whether nursing staff contravened hospital policy in sleeping on their breaks, but whether the remaining staff on the ward were able to give safe care to their patients.'

322 With regard to record keeping she said:

'Staff chose to use a neurological observations chart to record Mr Cannon's vital signs. This was not appropriate in isolation, as patterns of fundamental observations, such as pulse rate, blood pressure and respiratory rates cannot be detected on this type of chart. Respiratory rates were not recorded at all, which is poor practice – the respiratory rate is recognised as one of the earliest and most sensitive signs of conditions such as sepsis (infection) and blood or fluid loss. I also note a significant drop in Mr Cannon's conscious level at 3.00am at a time when his blood pressure was not recorded at all. The readings were not repeated for another half an hour when they were the same, and then not for another hour. I would have expected a medical review when the Glasgow Coma Score (GCS – a mini neurological assessment which quantifies the level of consciousness) dropped by more than one point. The medical records show that the duty senior house officer was present at some time during the night but the entries are un-timed and I am not convinced that he was contacted at this time. There is a three-hour gap in recordings between 8.00am and 11.00am (at which time Mr Cannon's blood pressure was unrecordable). Mr Cannon was transferred to the ITU at 3.00pm.'

323 In summary my A&E Nursing Adviser said:

'I have grave concerns about this admission. There is little information as to the cause of the extensive A&E delay, during which time the standard of patient monitoring was below an acceptable standard, as was the record keeping.'

'I have difficulty understanding why Mark Cannon was admitted onto a ward in an unconscious state with a low blood pressure and marked dehydration where there were only two nurses to provide care for 12 acute medical patients. The situation was not appropriate ...

'...

'The use of inappropriate observations charts for patients with deranged physiological readings worries me in an acute care environment, as does the apparent lack of action following a marked decrease in Mr Cannon's conscious level. A three-hour gap in recordings is not excusable.'

My Orthopaedic Surgical Adviser

324 My Orthopaedic Surgical Adviser said when Mr Cannon was transferred from A&E to an orthopaedic ward he was rather agitated and it was decided that traction should not be applied. He considered this decision was appropriate. He noted that X-rays confirmed a spiral subtrochanteric fracture (fracture of neck of femur/hip) and that such fractures are invariably treated operatively. My Orthopaedic Surgical Adviser said:

'The fracture sustained by Mark Cannon is most commonly seen in younger patients in a high energy transfer situation such as a road accident or fall from a height. In patients with reduced mobility and relative osteoporosis such as the elderly or patients with low levels of activity, such fractures are more commonly seen after simple falls. It would be extremely unusual for such a fracture to occur spontaneously or in bed. It is possible therefore that Mr Cannon fell out of bed in his respite home, thus sustaining his injury.'

325 Mr Cannon was scheduled for operative reduction and fixation of his fracture at the first available opportunity. Surgery was performed on 28 June 2003 and my Orthopaedic Surgical Adviser said the records indicate the operation was appropriate and performed satisfactorily.

326 My Orthopaedic Surgical Adviser commented on Mr Cannon's post-operative care. He said pain relief was given in the recovery room and:

'It was noted that there was no drainage from the peri-operative drain and his dressing remained dry indicating that bleeding had been controlled at the end of the operation and there was no continued bleeding in the post-operative period. I could find no clinical records made by the medical staff of the patient's post-operative state on 29 June 2003. I note that the operation was carried out on a Saturday and therefore the first post-operative day was a Sunday.'

327 My Orthopaedic Surgical Adviser went on to explain that there should have been a formal handover at the weekend and it would have been appropriate for the operating surgeon to visit the patient on the first post-operative day. My Orthopaedic Surgical Adviser noted that on 30 June 2003 Mr Cannon started to have multiple seizures, his blood pressure was low, his urine output had decreased and he was in pain. He said a blood test taken at 10.15pm showed low haemoglobin which suggested bleeding had occurred. He noted that a blood transfusion was arranged and a urinary catheter was inserted.

328 My Orthopaedic Surgical Adviser said:

'Bleeding following the type of fracture sustained by Mr Cannon usually occurs in the immediate post injury period. The blood loss that generally occurs during the

operative procedure is most often due to the evacuation of retained haematoma [blood clot] sustained after the injury. It is not uncommon for patients to lose up to three units of blood in the type of injury sustained by Mr Cannon.'

329 My Orthopaedic Surgical Adviser considered that Mr Cannon should have been monitored more closely, particularly with regard to blood loss and urine output on the day after his operation. However, he also said:

'His remaining orthopaedic care during this admission seems to me to have been perfectly satisfactory.'

330 My Orthopaedic Surgical Adviser concluded:

'I believe that Mr Mark Cannon's orthopaedic care was at a standard that would be accepted by most Orthopaedic Surgeons in the United Kingdom. The major deficiencies relate to delay in carrying out pain management, both on his initial and subsequent admission and delay in recognising the state of hypovolaemia [decreased volume of fluid in the body] and acute anaemia [where the capacity of the blood to carry oxygen is low] following his surgery. I believe this was largely due to unfamiliar staff being responsible for his care over the weekend of 29 to 30 June 2003. This matter should certainly be rectified by having formal handovers at weekends and by ensuring that a daily trauma ward round takes place seven days a week when all patients who have been operated on or admitted as emergencies are reviewed, preferably by Consultant staff.'

My Orthopaedic Nursing Adviser

- 331 My Orthopaedic Nursing Adviser said he did not think *‘the post-operative monitoring of Mr Cannon on the orthopaedic ward was of a satisfactory standard’*. He pointed to the fact that clinical observations were not carried out frequently enough during the first 24 hours and the fluid monitoring chart was incomplete for the day of the operation. He said:

‘This falls below the standard of acceptable record keeping and means that staff could not estimate whether Mr Cannon’s fluid input and output were balanced.’

- 332 My Orthopaedic Nursing Adviser also noted that nursing records were incomplete on 30 June 2003. He said:

‘Overall, I would say that the monitoring of Mr Cannon after his operation and the recording of that monitoring do not appear satisfactory. Clinical observations were sometimes not performed as frequently as good practice would dictate and monitoring of fluid balance was poor, with incomplete documentation.’

- 333 With regard to Mr Cannon’s epilepsy medication, my Orthopaedic Nursing Adviser said:

‘... the medication chart indicates that 2 doses of carbamazepine [epilepsy medication] may not have been given before surgery – on the evening of 27 June and morning of 28 June – as the medicine was not available on the ward. However, the pharmacist has indicated on the chart that it was dispensed on 27 June, so I do not understand this. If it was available but not given then this would be a medication error and not good practice.’

‘...

‘A formal seizure chart was only begun that evening [30 June 2003], when it appears to have been completed by a relative of Mark Cannon and not the nursing staff. On 2 July the epilepsy nurse saw Mr Cannon at his mother’s request. I am surprised that the nursing staff had not thought it appropriate to contact the nurse earlier as she may have provided valuable help and advice. The medical notes do not mention the need to check the levels of the epileptic medicine in Mr Cannon’s blood until 1 July and the sample dated 2 July showed that he had a sodium valproate [epilepsy medication] level of 148 when the therapeutic range is 350-700 µmol/l.’

‘From a nursing perspective it appears that the management of his epilepsy and epilepsy medication was not of a reasonable standard. Doses of epileptic medication may not have been given, the seizures were not recorded comprehensively and the nursing staff could have made better use of available information resources such as the epilepsy nurse.’

My Anaesthetic Adviser

- 334 My Anaesthetic Adviser commented on Mr Cannon’s third admission, specifically on care and treatment in the ITU and the HDU. He noted Mr Cannon was suffering convulsions, hypotension (low blood pressure), dehydration and agitation with a low consciousness level and said:

‘The level of nursing supervision must be commented on – Mr Cannon had an impaired consciousness level. Maybe this was mistaken for his normal non-communicative self or possibly viewed

as post-ictal [somnolence following a seizure]. The nursing staff, if not sufficiently experienced to assess this, should certainly have been warned by the attending clinicians as to Mr Cannon's obtunded [mentally dulled] state. Aspiration of vomit was witnessed by members of his family and they have commented on the lack of immediate attention from the nursing staff. This is denied by the Trust particularly in the report by the Trust's Director of Nursing dated 18 May 2004. Whilst the nursing reports are confident that Mr Cannon was attended to and his airway was protected during the episodes of vomiting witnessed by the family, it is apparent from [Mr Cannon's father's] complaint letter that this was not a constant vigil. There is the possibility of a more insidious and silent aspiration in any patient with altered central protective reflexes and this risk would be increased if Mr Cannon was on his back. The picture gleaned from the respiratory findings that develop is of an "unprotected" airway admitting secretions and leading to the slow deterioration eventually necessitating ITU care.'

335 My Anaesthetic Adviser also said:

'From the first notes in ITU, aspiration and its consequences are referred to as a working diagnosis complicating Mr Cannon's condition.'

However, he also commented that it is likely that had Mr Cannon aspirated he would have required an early diagnostic and therapeutic bronchoscopy and lavage (using a telescopic instrument to examine the respiratory passages and wash out any material which had been inhaled). He also noted that a test to analyse the levels of different chemicals in the blood

did not suggest massive airway obstruction and this was in keeping with the Trust's position that Mr Cannon was nursed appropriately to prevent a significant aspiration.

336 My Anaesthetic Adviser commented on the decision not to resuscitate which was taken whilst Mr Cannon was in the Receiving Room. He said:

'There is one outstanding example where I feel the decisions made were radically different from someone of normal capacity. This is in the failure to aggressively consider treating Mr Cannon's acute renal failure with invasive monitoring and possible renal support (in the event dialysis was not actually required).'

'...

'This attitude does suggest a value judgment by the medical team in a not very considered way.'

'...

'It is inconceivable in my opinion that any 30 year old should ever fail to receive unquestioning, unqualified aggressive and immediate resuscitative care until it was apparent that all was hopeless. Fortunately, after pressure from Mr Cannon's father and discussion with [the Consultant Anaesthetist] treatment was escalated with admission to ITU.'

337 With regard to the care and treatment in the HDU on 13 and 14 August 2003, my Anaesthetic Adviser said the health records show that on the afternoon of 13 August 2003 Mr Cannon was breathing well without the support of a mechanical ventilator. He explained that

patients who do not need their breathing supported by a ventilator and do not need the full facilities of an ITU may be transferred to an HDU. In the circumstances, he thought it appropriate that Mr Cannon was moved to the HDU because, although he was very ill, his condition was stable.

338 My Anaesthetic Adviser said when Mr Cannon was transferred to the HDU he was a *'very sick young man'* who was receiving drugs to support his blood pressure. He said Mr Cannon needed close monitoring and there was evidence of regular review by clinical staff, including physiotherapists and doctors. My Anaesthetic Adviser said the records show staff were aware of the risk that Mr Cannon could deteriorate. They appropriately assessed and monitored his breathing during the morning and treated his chest infection with physiotherapy and antibiotics, and ordered blood tests and an X-ray to check whether his breathing was adequate. He said there is evidence that Mr Cannon's lungs were functioning adequately when the doctors saw him during the consultant ward round because the level of oxygen in his blood was adequate. He also said the doctors had hoped Mr Cannon's chest infection would resolve without further major intervention and there was no reason to intervene to support his breathing at this time.

339 My Anaesthetic Adviser said that at some point during the morning of 14 August 2003 a plug of sticky chest secretions blocked one of Mr Cannon's respiratory passages and this caused his lung to collapse. He said this *'could have occurred as a single acute event or as an undetectable gradual blockage during the preceding hours'* and that this development would not have been detectable. This blockage showed up on the chest X-ray and around 1.30pm doctors decided that Mr Cannon needed

the support of a ventilator and should return to the ITU. However, around 3.00pm when Mr Cannon was having a tube passed into his windpipe to enable him to be connected to the ventilator, he suffered a cardiac arrest.

340 My Anaesthetic Adviser said although Mr Cannon's father felt staff on the HDU were not paying sufficient attention to his son there is evidence that they: were aware of the risk that he would deteriorate; did monitor his condition appropriately; and did take appropriate action when they detected the problem with his lung. He also said *'the events would have been exactly the same if Mr Cannon had remained on the ITU but the time intervals would have been shorter'*. He added that if Mr Cannon had been in the ITU:

'It is ... possible that the deterioration would not have been allowed to continue to the point where a cardiac arrest was a possibility.'

341 My Anaesthetic Adviser was not critical of the actions taken by staff at the Acute Trust when Mr Cannon was in the HDU. However, he said that from Mr Cannon's father's account of events it appears staff had not communicated clearly with the family. He suggested that had they done so, the family would have realised that Mr Cannon was *'far from stable, that sputum retention and reintervention were a very real possibility but conservative measures were being tried first'*.

342 With regard to the care and treatment in the ITU my Anaesthetic Adviser said:

'I have reviewed the ITU entries up to 29 August. The picture is one of full and active treatment and the discussion of limiting treatment is only entered into when

Mr Cannon has failed to respond to all treatment for multi organ failure. There is no suggestion in the notes that this ultimate end of life management was influenced by Mr Cannon's learning difficulty. It was certainly influenced by his "premorbid" [prior to death] condition ...'

My Community Nursing Adviser

343 My Community Nursing Adviser was asked to consider arrangements which were made for Mr Cannon's discharge.

344 My Community Nursing Adviser noted that properly recorded regular assessment of a patient's needs is essential to good care and to discharge planning. She said:

'Good discharge planning should, where possible, commence within 24 hours of admission and should include a full assessment of a patient's health and social care needs. I would expect to see evidence of discussion with the patient, relative, carer or friend as appropriate and evidence that this discussion included information regarding access and availability of community resources relevant to the individual's care needs. A named nurse and/or discharge facilitator/adviser should also be identified as a point of contact to provide support and advice to the patient/family as required.

'For more complex discharges which, for example, require multiple agency involvement, large or complicated care packages or in circumstances where there are concerns regarding the "safety" of the discharge, I would expect at the very least evidence of multidisciplinary team collaboration and discharge planning. In some cases it may also be necessary to arrange a formal multidisciplinary meeting

or case conference to plan for discharge. In any circumstance the involvement of the patient and/or their representative would be essential to the process.'

345 With regard to Mr Cannon's first discharge my Community Nursing Adviser said:

'An initial nursing assessment was completed by [a staff nurse] on 27 June 2003 at 1.20pm. It is on a computer generated printed sheet and contains limited information regarding social situation and usual functional ability, Mark Cannon's height is recorded as 5 feet 6 inches and weight as 5 stone. There is no discussion regarding future rehabilitation or discharge planning needs at initial assessment or information regarding pre-admission levels of community support, for example, from the learning disabilities team, social services or district nurses or the frequency of respite care. This information, in my opinion, would have been essential in planning Mr Cannon's discharge.

'There is evidence in the medical notes that occupational and physiotherapy staff were liaising with the family regarding safe transfers between bed and chair, the need for equipment and the necessity to bring Mr Cannon's bed downstairs. However, there is no evidence of a multidisciplinary and co-ordinated approach to his discharge or communication with Mr Cannon's family regarding discharge. I am surprised that there appears to have been no discussion with [Mr Cannon's mother] regarding the possibility of a care package and that a social services referral does not appear to have been made.

'A district nurse referral was made requesting a visit for 7 June (three days after discharge) for wound care. There is limited information on the referral letter beyond this. There is no summary of the medical/nursing care Mr Cannon received during his period of in-patient care. His psychological state and understanding of condition/diagnosis are described as "not good" and in the communication section it is documented that Mr Cannon had learning difficulties. It would have been good practice and, I consider, a reasonable expectation for nursing staff to have contacted the district nursing service and discussed Mr Cannon's condition with a member of the district nursing team prior to his discharge in order to augment the information on the referral form particularly in light of the fact that a district nurse visit was not requested until three days post discharge. This would have given the district nursing sister the option of deciding if it would be more appropriate to organise an assessment visit prior to the date identified on the referral form. It would have also been reasonable to have contacted the community learning disabilities team to have informed them of Mr Cannon's discharge date.

'... it is quite clear to me that there were serious shortcomings in assessment and discharge planning (acute care) which led to serious gaps in communication and care necessitating readmission to hospital following a short and traumatic time at home for Mr Cannon and his family.'

³⁴⁶ With regard to the discharge arrangements following Mr Cannon's second discharge on 14 July 2003 my Community Nursing Adviser said:

'As with the previous admission, multidisciplinary and co-ordinated discharge planning is not apparent from Mr Cannon's clinical records. There is an entry in the nursing records indicating that Mr Cannon's mother would contact the district nursing team with regard to Mr Cannon's wound dressing. It would have been good practice for the ward nursing staff to have contacted the district nurses, particularly in view of the fact that he had been readmitted to hospital after only a few days following his previous discharge.'

³⁴⁷ My Community Nursing Adviser summarised her views on the arrangements made for discharging Mr Cannon from hospital on both occasions. She said:

'I have identified serious shortcomings in the assessment and discharge planning process in relation to the care of Mark Cannon. These were significant in both his first and second hospital admissions and it is my opinion that they had a considerable impact on the care delivery and level of support received by Mr Cannon and his family following discharge.

'The family and/or carers must at all times be central to all team and therapeutic activity if person-centred rehabilitation and discharge planning is to be achieved. It is apparent from the clinical records that there was a lack of engagement with the family or expert practitioners (e.g. learning disabilities team) which was clearly unacceptable and certainly contributed to a lack of understanding of Mr Cannon and the provision of person-centred care.'

My Learning Disability Nursing Adviser

348 I also sought advice from a specialist practitioner in learning disability nursing as to whether Mr Cannon's needs, as a patient with learning disabilities, were properly recognised and whether, all things considered, the care provided to him was adequate. She began by considering whether, during Mr Cannon's first admission to Oldchurch Hospital, the care pathways took reasonable account of his specific needs regarding his learning disabilities. She said:

'In my opinion the care pathways [during Mr Cannon's first admission] did not take reasonable account of Mr Cannon's specific needs resulting from his learning disability.

'There was little evidence within the assessment undertaken by medical or nursing staff as to how Mr Cannon normally presents, his strengths and/or needs, his level of understanding or how he normally manages pain etc. This information would have helped the nursing and medical staff to gain an understanding of Mr Cannon as a person, understand when Mr Cannon was not himself and when help should be sought. Whilst I recognise that an admission of a person with a learning disability into the acute hospital setting can be difficult for all, this is exacerbated when medical and nursing staff fail to communicate effectively with the family, refer to others for specialist advice and/or refuse the help offered by family members. I would argue that this admission would have been made easier and certainly more comfortable for Mark if the hospital staff had listened and communicated more effectively with the family and had been accepting of the help offered by family members.

'Management of analgesia has been identified as a key part of the care pathway for a fractured femur, but there is no evidence that this was a key part of the care pathway for Mr Cannon. This would have been better managed if there had been improved communication between Mr Cannon, the family and the hospital staff. His sister or any family member staying would have helped Mr Cannon and the hospital staff to understand his individual needs as a person with learning disability who had a fractured femur and how this affected the generic care pathway for a fractured femur.

'Although learning difficulties was noted within Mr Cannon's pre-operative care plan, this information is not evidenced with the development of his 12 nursing care plans, other than he may have difficulty communicating due to "slurred speech and being epileptic". The care plans do not acknowledge or relate to Mr Cannon as a person with additional needs – i.e. eating and drinking, continence, bowel management, epilepsy, communication, understanding of Mr Cannon's pain etc.'

349 My Learning Disability Nursing Adviser summarised her view of Mr Cannon's care during his first admission:

'In my opinion Mr Cannon was being nursed without an understanding and concern for his learning disability and how this may impact upon the care given. This understanding could have been achieved with improved communication between the hospital and the family carers who knew Mr Cannon really well.'

350 Regarding Mr Cannon's second admission on 8 July 2003, my Learning Disability Nursing Adviser set out her view that his pain management may have been particularly poor because of the failure to take proper account of his needs. She said:

'I am concerned that Mr Cannon needed to become aggressive, make noises or hit himself before a stronger pain relief was administered. A person with a learning disability is not aggressive without a reason; it is often that people involved with their care do not understand the reason. There is no evidence within the record of any communication with the family of trying to understand Mr Cannon and his response to pain. The maximum dosage for the PRN [as required] medication was not administered with the staff waiting for Mr Cannon to voice his distress by making noises or via his behaviours. It is of concern that staff waited for this to occur and did not request further advice from the pain team to seek to effectively manage his pain.'

351 My Learning Disability Nursing Adviser then commented briefly on Mr Cannon's third and final admission to the Trust. She said:

'There are numerous entries from the doctors with comprehensive assessments and requests for recordings and monitoring but there are once again no entries from the nursing staff; a concern when the doctors will be working with the observations and recordings from the nursing staff. There are other documents within the record i.e. the admission sheet from the HDU and the HDU daily record sheet, but not all are fully completed.'

352 My Learning Disability Nursing Adviser also considered the extent to which hospital staff had sought the involvement of learning disability services or practitioners with learning disability experience during the planning and delivery of Mr Cannon's care. She said:

'There appears to be no evidence within the record of any involvement with specialist learning disability practitioners other than the Consultant in special needs with regard to his epilepsy after his second discharge from Oldchurch Hospital. In my opinion, involvement with learning disability services would have been both appropriate and of benefit to Mr Cannon and his family with regard to the understanding of Mr Cannon's individual needs; a person who was vulnerable within the acute hospital setting because of his learning disability.'

Care and treatment at the Trust: the Health Service Ombudsman's findings

353 When Mr Cannon was well he had a lively sense of humour and enjoyed social events with his family and carers. Sometimes he just liked lazing around and sometimes he liked to join in activities and outings. However, after he broke his leg in the summer of 2003 his family encountered many difficulties in their attempts to meet his increasingly complex needs. His parents believe that staff at the Trust did not make enough effort to meet those needs.

354 Mr Cannon's parents believe that in respect of care and treatment, especially assessment, observation and monitoring, pain relief, management of epilepsy, decisions about resuscitation and discharge arrangements their son received less favourable treatment for reasons related to his learning disability.

- Mr Cannon's parents believe that had different care and treatment been provided their son would not have died.
- 355 In Section 2 of this report I have set out the legislation and national and professional standards which should have guided Trust staff involved in Mr Cannon's care. Of particular relevance are the *Disability Discrimination Act 1995*, Good Medical Practice, the nurses' Code of Conduct, the Essence of Care benchmarks and Discharge from Hospital.
- 356 I have studied all the evidence available to me and carefully considered the advice of my Professional Advisers. I find that overall the care and treatment provided by the Trust for Mr Cannon fell below a reasonable standard. This was serious **service failure**.
- 357 I now consider the key areas where I have identified significant failings in Mr Cannon's care and treatment.
- Pain management*
- 358 I begin by considering the way in which Trust staff assessed and managed Mr Cannon's pain because, to my mind, this is the most striking and significant area of service failure.
- 359 As I have explained, Mr Cannon had only limited verbal communication, so he was not able to express his feelings of pain in a way which would have been familiar to staff. However, his family knew him well and were able to understand him and communicate with him. Certainly they knew when he was unhappy, uncomfortable or in pain. Trust staff should have carried out prompt and full assessments and used their own observations in combination with information and guidance from Mr Cannon's family to enable them to assess and manage his pain. There is clear evidence that they did not do this.
- 360 When Mr Cannon was first admitted to the Trust on 27 June 2003 he had a broken leg. I cannot begin to imagine the level of pain which he was experiencing, but it must surely have been severe. Therefore, I am seriously concerned about the lack of attention which staff in A&E gave to this aspect of his care. As my Professional Advisers have said, there is no evidence of any assessment of the level of Mr Cannon's pain and neither doctors nor nurses gave him any pain relief for over five hours. One of my Professional Advisers described this as a '*dreadful*' omission and another described it as an '*appalling omission*'. My Professional Advisers are usually measured in their assessment of clinical matters and do not often use such strong language to describe their findings. In this instance, I consider they are entirely justified in expressing themselves in this way.
- 361 Mr Cannon was admitted for a second time on 8 July 2003 and again there is disturbing evidence of the lack of immediate attention to controlling his pain. Mr Cannon's mother's description of events and the Trust records provide an upsetting picture of his condition. He was in severe uncontrollable pain, in distress, shouting, screaming, biting his hand, hitting his head against the wall and slapping his own face. His mother struggled to comfort him, but no one other than his family seems to have considered that Mr Cannon's behaviour might be the result of untreated pain.
- 362 My Professional Advisers were extremely concerned by this lack of attention to relieving Mr Cannon's pain on this day. Again they described their opinion about this in the strongest terms. My A&E Nursing Adviser said:

'Mr Cannon did not receive any pain relief until he had been in A&E for eleven hours, which is astonishing.'

My A&E Medical Adviser said:

'The delay and lack of care and pain relief on this occasion was totally unacceptable.'

363 My Professional Advisers have analysed Trust records for the remainder of Mr Cannon's second admission and they have advised me that the evidence shows pain management over the rest of this period was inadequate.

364 On 9 July 2003, the day after Mr Cannon was admitted for the second time, ward staff asked the pain team to visit as he remained in pain and was very agitated and distressed. His pulse rate was raised and he was biting his hands and banging his head. However, there is no evidence that ward staff, either doctors or nurses, made a considered plan for managing this pain. During this time records show pain relief was provided intermittently and at levels which would not have relieved Mr Cannon's pain.

365 When the Nurse Specialist from the pain team saw Mr Cannon, three days after his second admission, she produced a chart for recording pain assessment and immediately suggested a stronger analgesic should be given whenever he appeared to be in pain. However, ward staff did not obtain or administer this drug and records show it was not until the Nurse Specialist from the pain team returned later in the day that stronger pain relief was given.

366 Although better pain relief was given as a result of the actions of the pain team, I have concerns about their assessment of Mr Cannon's pain because records indicate numerical pain scoring documents were used which were based on

verbal communication. Mr Cannon was not able to communicate in this way and, therefore, effective assessment could not have been carried out, even by the pain team because the scoring tool was inappropriate. My Professional Advisers have indicated that alternative methods of measuring pain using physical observations rather than verbal responses were available and should have been used to assess Mr Cannon's pain.

367 It is clear that in terms of urgent pain relief and assessment and planning for ongoing pain management, the standard of care and treatment Mr Cannon received from doctors, nurses and pain specialists at the Trust fell far below a reasonable standard. In this, the actions of neither doctors nor nurses met the requirements of their professional codes of practice and conduct. In addition, Mr Cannon had particular needs and because he could not communicate with staff in a way which was familiar to them it was all the more important that they should have sought the help of his family or carers who knew him well and were able to understand him. It appears that staff not only failed to proactively make use of such vital resources, but also ignored sustained efforts by the family to help and advise them. They should have adapted their usual practice to allow them to understand and meet his needs, but they did not do this. Consequently Mr Cannon was left in severe pain and great distress for prolonged periods of time. This was serious **service failure** which occurred for disability related reasons.

Assessment, observation, monitoring and record keeping

368 I have already described how doctors and nurses failed to assess and monitor Mr Cannon's pain. I now turn to assessment, observation, monitoring and record keeping as they relate to other aspects of his care and treatment.

- 369 My Professional Advisers have highlighted many instances when Mr Cannon was not properly assessed, observed or monitored by staff at the Trust.
- 370 During the first admission to A&E Mr Cannon's fractured leg was quickly diagnosed and baseline observations were made. However, after this, little more was recorded by nurses or doctors. In A&E there was no nursing assessment, care plan or adequate monitoring of his basic condition. There was no attempt to assess his communication needs or develop plans to meet those needs. After initial review, it seems Mr Cannon received no medical attention until he was seen by a trauma team around five hours later. My A&E Medical Adviser confirmed that Mr Cannon was left too long without medical attention.
- 371 My Orthopaedic Surgical Adviser confirmed that Mr Cannon's operation was performed without significant delay and that there were no problems with the surgical procedure. However, his post-operative care on the ward appears far from satisfactory.
- 372 Mr Cannon's surgery was performed on a Saturday and it appears that staffing arrangements over the weekend were such that he received minimal medical supervision until Monday, when the usual orthopaedic team returned. There are no medical records at all for 29 June 2003 and it appears Mr Cannon's medical care was left in the hands of the duty team who would also have been covering A&E. My Orthopaedic Surgical Adviser said a trauma team should have been available seven days a week, the consultant should have visited on the day after the operation and a more formal handover should have been organised. Good Medical Practice requires that care is properly co-ordinated and communicated to the staff to whom care is delegated. This did not happen.
- 373 My Professional Advisers agree that, following his surgery, Mr Cannon's fluid levels, blood pressure and other observations needed to be monitored regularly to pick up signs of blood or fluid loss after the operation. On the second day after his surgery, Mr Cannon was having multiple seizures and his condition deteriorated such that he needed an urgent blood transfusion. However, observations remained intermittent throughout the post-operative period. The failure to assess, observe and monitor Mr Cannon during this critical period and the failure to keep adequate records falls short of what is required in Good Medical Practice and the nurses' Code of Conduct.
- 374 When Mr Cannon was admitted for a second time he was seen in A&E but then had to wait five hours before he was seen by the duty medical team and shortly afterwards by the orthopaedic team. There was then another wait of around five hours before he was admitted to the Receiving Room. My Professional Advisers have confirmed that the process of assessment and observation in A&E at this time was poor and few records were made about Mr Cannon's condition.
- 375 On his third admission Mr Cannon was taken directly to the resuscitation room which was appropriate given his very serious condition. My Professional Advisers confirmed that at this time staff made a reasonable assessment and diagnosis of his condition. However, after that assessment record keeping was poor, for example, no fluid balance chart was started despite the probable diagnosis of dehydration and renal failure. My Professional Advisers said assessment, monitoring and record keeping remained poor after Mr Cannon was transferred to the Receiving Room, for example, neurological charts were used and these did not allow adequate monitoring of Mr Cannon's condition.

376 Furthermore, it is clear that observation and monitoring of Mr Cannon in the Receiving Room was not adequate. Mr Cannon's father described how he and his wife were left alone to manage Mr Cannon's care, even though he was very ill and not fully conscious. Mr Cannon's father believes this lack of professional supervision and attention to his son's needs meant that when Mr Cannon vomited during the night of 10/11 August 2003 he inhaled vomit and this led to his subsequent chest infection. I do not doubt Mr Cannon's father's version of events; however, my Anaesthetic Adviser has said it is not possible to say for certain whether or not Mr Cannon inhaled vomit that night, although he did think it likely that someone in Mr Cannon's condition would be at risk of aspiration in this way. Whatever actually happened regarding this episode may be disputed, but what cannot be disputed is the fact that Mr Cannon, a very ill, partly conscious patient with particular needs related to his learning disability, was left for too long without adequate professional attention.

377 Having studied available evidence and taken account of the advice of my Professional Advisers, I find that during all three admissions to the Trust there were shortcomings in assessment, observation, monitoring and record keeping. There is evidence that these shortcomings occurred in A&E, the orthopaedic ward and the Receiving Room. Professional staff did not act in line with their professional codes of conduct and the care Mr Cannon received fell below a reasonable standard. There is no evidence that staff adjusted their practice to meet Mr Cannon's particular needs. This was **service failure** which occurred at least in part for disability related reasons.

Management of Mr Cannon's epilepsy

378 Mr Cannon's family have concerns about the way in which Mr Cannon's epilepsy was managed. Mr Cannon's father believes the failures to monitor his son post-operatively left him with insufficient levels of anti-epilepsy medication in his blood. My Professional Advisers agreed and have also drawn attention to other episodes when clinical staff at the Trust paid insufficient attention to managing Mr Cannon's epilepsy. They said the failure to manage Mr Cannon's epilepsy may have begun in the period before he had his operation. They noted two doses of his epilepsy medication were prescribed for Mr Cannon in the period before his operation. Pharmacy records indicate that medication was dispensed. There is no record that Mr Cannon received it.

379 Mr Cannon suffered many seizures post-operatively, but he was not seen by an epilepsy nurse until his mother intervened. On 2 July 2003 a seizure chart and alterations to his medication were instituted. In fact, the seizure chart was completed by his family, not by nurses. My Professional Advisers said these were significant failures and may have increased the frequency of Mr Cannon's seizures and increased his agitation. I have seen no evidence that staff made adjustments to their actions to ensure they met Mr Cannon's particular needs.

380 I have considered the advice of my Professional Advisers and I find the failures to properly monitor Mr Cannon's seizures, to provide him with his medication as prescribed, and the failure to seek input from a specialist nurse without prompting are not in line with the standards set out in Good Medical Practice and the nurses' Code of Conduct and I consider the care afforded to Mr Cannon fell well below a reasonable standard. I regard this as **service failure** which to some extent was for disability related reasons.

Discharge arrangements

- 381 Twice during July 2003 (4 and 14 July) Mr Cannon was discharged to his mother's home following admission to the Trust. On each occasion he had been in hospital for just over a week following emergency admission, related initially to a fractured leg and subsequently to problems including infection and dehydration.
- 382 It is understandable that Mr Cannon's mother was keen to have her son home. She naturally felt it would be best to get him home as soon as possible because she hoped he would settle down in familiar surroundings where his family, who understood his needs and responses, could care for him appropriately. What I cannot understand is how a range of healthcare professionals at the Trust did not properly assess the risk of discharging Mr Cannon to his mother's care without arranging proper community support. In these circumstances, it is not at all surprising that Mr Cannon's mother struggled to manage her son at home.
- 383 After the first admission the evidence shows that Mr Cannon was discharged without even the most basic post-discharge arrangements. The ward staff failed even to arrange for community nurses to visit to change Mr Cannon's dressings. His mother had to make a telephone call to request a visit. The letter from ward staff to the community nurses was sent after Mr Cannon was discharged and lacks any detail which would allow proper planning for his care at home. His mother was expected to take responsibility for managing her son's care and to call on health and social services herself. She already had enough to do and worry about. It was not acceptable to place her in this position – without proper professional help and unsupported by services which should have been arranged to help her care for her son.
- 384 Mr Cannon's discharge after his second admission again appears to have been completely unplanned. My Professional Advisers found little evidence that appropriate thought had been given to his readiness to return home and that no appropriate plans had been prepared to support his mother. My Professional Advisers have told me that comprehensive plans should have been put in place on the basis of multidisciplinary liaison. In fact, the discharge documents were left blank. There was no preparation and no plan. Mr Cannon was simply returned home without additional support of any kind for his mother.
- 385 In Section 2 of this report I have set out key aspects of the Department of Health document Discharge from Hospital, which clearly sets out the way in which discharge from hospital can be arranged in a safe and effective way. The guidance emphasises the importance of discussions with relatives and carers, identification of community resources (such as learning disability teams, social services and community nurses) relevant to the patient's needs and, in complex cases such as Mr Cannon's, more intensive multidisciplinary input into the discharge process. My Community Nursing Adviser has told me what should have happened when Mr Cannon was discharged and has confirmed that what should have happened did not happen. There was no multidisciplinary liaison, no discharge plan and no arrangement for home support.
- 386 On two occasions in July 2003 the Trust failed to ensure that Mr Cannon was discharged safely. Staff did not act in accordance with relevant government guidance or their codes of professional conduct. This meant Mr Cannon was discharged without due concern for his safety and community healthcare resources

were not fully aware of his condition or the level of support he would need. Staff at the Trust did not properly consider his particular needs and his mother was left to care for him and to arrange help as best she could. This was serious **service failure** which occurred at least in part for disability related reasons.

The decision in the Receiving Room not to resuscitate Mr Cannon

387 On 11 August 2003 Mr Cannon's condition deteriorated, and my Anaesthetic Adviser said it appears a decision was made 'not to treat' by relatively junior medical staff on the basis of Mr Cannon's persistently impaired consciousness and blood pressure which was not responding to simple treatment. My Anaesthetic Adviser suggested that at this time Mr Cannon was not treated in the way someone of 'normal capacity' would have been treated. He suggested a value judgment had been made by the medical team who came to a premature decision not to resuscitate Mr Cannon when, it was possible that his condition could be reversed.

388 The General Medical Council provides guidance about doctors' duties when treating people who lack capacity. *Seeking Patients' consent, the ethical considerations*, makes it clear that wherever possible treatment options must be kept open and decisions about care and treatment should be explained to family and carers. The guidance says the reasons not to resuscitate should be clearly documented and should take account of the views of family and carers. In *Good Medical Practice*, the General Medical Council says those with responsibility for junior medical staff should ensure that they understand their roles and that they are properly supervised.

389 It is clear that in this instance junior doctors should not have been left in a situation where they could make a decision about whether or not to resuscitate Mr Cannon. There is no evidence that they knew how to make a decision of this nature according to the law and professional guidance taking into account Mr Cannon's best interests. They should have been supervised by a consultant. In the event it is clear that they made an inappropriate, value-based judgment. This was serious **service failure** which occurred for disability related reasons.

Care in the ITU and the HDU

390 Once Mr Cannon arrived in the ITU on 11 August 2003 his condition stabilised and he received appropriate supervision and active treatment which reflected the seriousness of his condition. For the first time, his family were satisfied that their son was in good hands. However, Mr Cannon was transferred from the ITU to the HDU on 13 August 2003 and he was there for only a short time before his condition deteriorated, he suffered a cardiac arrest and was transferred back to the ITU.

391 It is clear from the account provided by Mr Cannon's father that family members were greatly concerned about Mr Cannon's condition when they saw him in the HDU on the morning of 14 August 2003. They thought staff were not paying adequate attention to Mr Cannon and had not recognised how ill he was. When his lung collapsed and he subsequently suffered a cardiac arrest they understandably took this as evidence that he had not received appropriate care and treatment. However, my Anaesthetic Adviser told me that although Mr Cannon was very ill his condition was stable and, therefore, the 'wait and see' plan of care and the care and treatment provided in the

HDU were appropriate. He also told me staff acted reasonably in the way they observed, assessed and treated Mr Cannon's condition. In particular, I note my Anaesthetic Adviser's advice that Mr Cannon was very ill and at risk of developing a collapsed lung caused by a plug of secretions and that he would have suffered this complication even if he had stayed in the ITU.

³⁹² That said, it is clear to me that staff did not communicate effectively with Mr Cannon's family who, consequently, did not fully appreciate how his care and treatment were being managed. Specifically, they did not know staff were aware of the risk of sudden decline and were monitoring Mr Cannon appropriately for just such an event.

³⁹³ I have identified a shortcoming in the service provided for Mr Cannon while he was in the HDU, namely ineffective communication with his family. However, I find that other key aspects of his care and treatment were of a reasonable standard in the circumstances. Therefore, on balance, I find that any shortcomings in the care and treatment provided at this time **do not amount to service failure**.

³⁹⁴ My Professional Advisers have said that the care Mr Cannon received on his return to the ITU was of a very high standard.

Care and treatment at the Trust: the Health Service Ombudsman's conclusions

³⁹⁵ In relation to Mr Cannon's parents' complaints about their son's care and treatment at the Trust I conclude that there was significant **service failure**, at least some of which was for disability related reasons. The key service failings were:

- i. management of Mr Cannon's pain was inadequate because his urgent need for pain relief was not met and assessment and planning for ongoing pain management was not of a reasonable standard;
- ii. assessment, observation, monitoring and recording of Mr Cannon's condition was inadequate, particularly during his three admissions to A&E, during the first days following his operation and when he was in the Receiving Room on his third admission;
- iii. management of Mr Cannon's epilepsy was inadequate because his seizures and medication levels were not properly monitored and his medication was not always given as prescribed;
- iv. on two occasions discharge arrangements did not meet the standard set out in government guidelines; and
- v. the first decision not to resuscitate Mr Cannon was not appropriate and did not conform with legal and professional guidance.

Complaint (c): complaint handling by the Trust

³⁹⁶ Mr Cannon's parents believe the Trust has failed to investigate the family's complaint about their son's care properly or to apologise for the many shortcomings which they believe occurred. Mr Cannon's father told my investigator he was completely dissatisfied with the Trust's response to his complaint.

The complaint to the Trust

397 In his complaint letter to the Trust dated 9 September 2003 Mr Cannon's father provided a detailed account of the care and treatment his son had received. This included a day-by-day narrative account of his son's care, clearly identifying what he believed were the major shortcomings. In his letter, Mr Cannon's father said that his son had:

'become the victim of an astonishing lack of care and blunders of the most extraordinary kind by people who neither paid heed to, listened to, understood or noticed symptoms and indications of how critically ill Mark was becoming. It was this disregard, omissions, errors of judgment, blunders that ... were to progressively be the cause of our beloved son Mark's demise.'

398 He said that each day in the Trust's care had lessened his son's chances of survival. He set out his concerns about a general lack of care which he attributed to his son's learning disability which made it necessary for his family to try to communicate on his son's behalf to hospital staff.

399 Mr Cannon's father said his family's attempts to communicate his son's needs were ignored. He also attributed his son's decline, which he said went unnoticed, to the inability of hospital staff, both nurses and doctors, to see beyond his learning disabilities. He also raised a number of specific issues which he said had been instrumental in his son's decline and subsequent death. These included his recollection that nurses were sleeping regularly on duty which led to a lack of supervision which in turn led to his son vomiting and aspirating bile which caused his pneumonia. Mr Cannon's father said this was *'the prime cause of Mark's chest infection leading to a profound overnight deterioration,*

cardiac arrest and the fatal infection that finally overwhelmed Mark'. Mr Cannon's father said inattention by Trust staff, related to his son's learning disability, resulted in medical and nursing care not being given and his declining health not being noticed. He also asked for answers to a number of questions relating to issues such as blood loss, the efficacy of epilepsy medication, discharge arrangements and general nursing and medical care.

The Trust's response to the complaint

400 The Trust began internal enquiries into the complaint but did not proceed because of the police investigation and Coroner's enquiries. On 29 September 2003 the Trust's Chief Executive wrote to Mr Cannon's father explaining the situation and indicating that there might be a considerable delay before he received a response.

401 On 24 August 2004 the Trust sent Mr Cannon's father a copy of a report, dated 18 May 2004, about the care of his son. Extracts from the report, including the detail of the conclusion, are set out at Annex C. In the report, the Trust's Director of Nursing and Clinical Governance provided an overview of Mr Cannon's care and concluded that his care had been reasonable and that he was actively managed during the time he was in the hospital's care. She did not identify any significant shortcomings in his care.

402 Some time in March or April 2005 the Trust sent an undated letter to Mr Cannon's father's MP indicating that the Trust's report represented the formal outcome of its consideration of his complaint. The Trust also pointed out that the inquest had not attributed Mr Cannon's death to a lack of care in hospital.

403 Mr Cannon's father wrote to the Trust's Chief Executive asking for further information. The

Chief Executive replied on 29 June 2005, saying he regarded the report of 18 May 2004 as the Trust's full response to the complaint.

The Trust's response to the outcome of the Healthcare Commission's review

- 404 Mr Cannon's father was dissatisfied with the Trust's response and complained to the Healthcare Commission. The Healthcare Commission's decision letter was issued on 20 December 2006 and contained a number of specific recommendations.
- 405 On 5 April 2007 the Trust's Chief Executive responded to the Healthcare Commission's recommendations. He explained that the hospital where Mr Cannon had been treated had closed and services had been reprovided at another hospital with better ward facilities. His response focused on improvements at the Trust since Mr Cannon's death and included information about changes in arrangements in areas which were the focus of the complaint, for example, record keeping, discharge planning and pain assessment documentation.
- 406 The Trust's Chief Executive accepted that there had been some shortcomings in Mr Cannon's care and treatment, such as liaison with the family, administration of medicines and the time Mr Cannon waited in A&E before being admitted to a ward. However, there was no overt acceptance that in other key areas, such as pain relief, the Trust had failed to provide a reasonable standard of care and treatment, and there were no clear apologies for those failings. The Trust's Chief Executive acknowledged that the Trust's response to the complaint *'did not address [the family's concerns] in a satisfactory and comprehensive way'* and for this failing he offered his *'sincere apologies'*. He also said:

'I would wish to extend my sincere apologies to [Mr Cannon's family] for the length of time it has taken to resolve [their] concerns regarding Mark's care and treatment.'

Complaint handling by the Trust: the Health Service Ombudsman's findings

- 407 Mr Cannon's father complained to the Trust in September 2003 when, as I have described in Section 2 of this report, the procedures for handling complaints against the NHS were set out in various Directions produced by the Secretary of State. Therefore, I have compared the Trust's actions at the local resolution stage with the requirements of these Directions. However, the complaint was reviewed by the Healthcare Commission under the *NHS (Complaints) Regulations 2004*, which I have summarised in Section 2, and these Regulations apply to the Trust's response to the Healthcare Commission's review.
- 408 Mr Cannon's father complained on 9 September 2003, expressing detailed criticisms and concerns about his son's care and treatment. The Trust should have investigated his complaint in accordance with policy and provided him with explanations about Mr Cannon's care and treatment. This did not happen. Instead, the Trust told Mr Cannon's father that it could not respond to his complaint because the police and the Coroner were investigating his son's death. On 29 September 2003 the Trust's Chief Executive informed Mr Cannon's father that there might be a considerable delay before he received a response. There was no reason for this unacceptable delay because there was no reason why action by the police or the Coroner should have delayed the Trust's investigation or response. This was **maladministration**.

409 In fact, at some point the Trust did conduct an investigation and a report was produced by the Director of Nursing and Clinical Governance. As I have said, this report was produced in May 2004, but it was not shared with Mr Cannon's family until August 2004. The Trust told Mr Cannon's father, and subsequently his MP, that this report represented the Trust's final response to the complaint. However, the report was limited in scope as it focused mainly on the nursing care which Mr Cannon received and it did not address many of Mr Cannon's family's concerns. Moreover, given the significant service failings which my investigation has revealed, it is clear that the Trust's investigation, which identified no shortcomings whatsoever in Mr Cannon's care and treatment, was inadequate. This was **maladministration**.

410 The report was sent to Mr Cannon's father on 24 August 2004 and, therefore, it would have arrived around the first anniversary of his son's death. In addition, in one instance, the report incorrectly records Mr Cannon's date of death as 1 September 2003. The impact of this significant error of fact is compounded by other insensitivities in the report. For example, the report refers to a '*difference of opinion*' between Mr Cannon's parents and makes reference to Mr Cannon's '*inability to understand the care process*' as a reason for his distress. The Trust should have demonstrated a caring and conciliatory approach. Instead its response was defensive and insensitive. This was **maladministration**.

411 It was not until the Trust was asked to respond to the shortcomings in care and treatment identified in the Healthcare Commission's review that Mr Cannon's family received any acknowledgement of failings or apologies from the Trust. I recognise that the Healthcare

Commission's recommendations focused on asking the Trust to inform Mr Cannon's family about progress which had been made since Mr Cannon's death and that the Trust's Chief Executive framed his response in this way. That said, this would have been an opportunity for the Trust to offer further explanations as well as acknowledge and apologise for the failings in Mr Cannon's care and treatment. Although the Trust's Chief Executive acknowledged some failings and offered some apologies these did not by any means cover all the shortcomings in Mr Cannon's care and treatment. The Trust's Chief Executive apologised that it had taken so long to resolve the family's concerns when the family were, rightly, far from satisfied with the Trust's response. This was **maladministration**.

Complaint handling by the Trust: the Health Service Ombudsman's conclusions

412 I conclude that there were major failings in the way in which the Trust handled Mr Cannon's father's complaint. Specifically the Trust failed:

- i. to properly investigate the complaint;
- ii. to provide an appropriate response which covered all the issues complained about;
- iii. to handle the complaint with appropriate sensitivity; and
- iv. to take opportunities to offer full explanations and appropriate apologies.

413 In these respects the Trust failed to comply fully with the applicable standards for complaint handling. Its actions did not accord with principles of good administration and it did not provide an appropriate or adequate remedy. These failings amount to **maladministration**.

414 However, I have found no evidence which indicates that these failings in complaint handling were for disability related reasons.

The complaint against the Trust: the Health Service Ombudsman's conclusions

415 I am in no doubt that the Trust failed to provide a reasonable standard of care and treatment for Mr Cannon. In particular, Trust staff did not meet his needs in terms of pain relief, management of his epilepsy, or assessment, observation and monitoring of his condition. In addition the Trust failed to maintain proper records, a decision about resuscitation status was not in line with legal and professional guidelines and on two occasions staff made inadequate plans to ensure Mr Cannon's safe discharge. I consider this **service failure** was at least in part for disability related reasons.

416 **Maladministration** in the Trust's complaints process meant Mr Cannon's family's questions about the care and treatment he received were not properly addressed by the Trust in an appropriate, efficient and timely way.

Injustice

417 The Trust has informed me of actions it has taken to address the failures in the service it provided for Mr Cannon. These actions include:

- introducing a Safeguarding Adults Policy and setting up a Safeguarding Adults Board;
- developing guidance for enabling patients with learning disabilities to access the Trust's services;

- introducing communication tools to aid communication with people with learning disabilities;
- providing training for professional staff on the implications of the *Mental Capacity Act*; and
- introducing specific advocacy services for people with learning disabilities.

418 I recognise that these measures represent improvements at the Trust based on learning from failings in Mr Cannon's care and treatment. Nonetheless, I conclude that had the Trust provided appropriate and reasonable care and treatment according to existing standards and guidance, it is likely Mr Cannon's suffering would have been less and it is possible that he would have survived. Furthermore, his family would have suffered less anxiety and distress. These findings represent **unremedied injustice**.

419 I conclude that service failure and maladministration at the Trust have led to unremedied injustice to Mr Cannon's parents.

420 Therefore, I **uphold** Mr Cannon's parents' complaint against the Trust.

421 We say more about injustice in Section 4 of this report.

The Health Service Ombudsman's recommendations

422 I **recommend** that the Chief Executive of the Trust apologise to Mr Cannon's parents for the failings I have set out in this report.

423 I also **recommend** that the Trust offer compensation of £10,000 to each of Mr Cannon's parents in recognition of the injustice they have suffered in consequence of the service failure and maladministration I have identified.

The Trust's response

424 The Chief Executive of the Trust wholly accepted my recommendations. He assured me he will send a full apology to Mr Cannon's parents. He also assured me that changes had been made and lessons learnt as a result of this case. The Chief Executive accepted my recommendation regarding a compensation payment.

The Health Service Ombudsman's investigation of the complaint against the Practice

Complaint (d): care and treatment by the Practice

425 Mr Cannon's parents complain that the Practice failed to provide their son with adequate care and that more could have been done to diagnose the factors underlying the deterioration in his condition following his discharge from the Trust in July 2003.

Key events

426 At Annex D I have summarised key events relating to Mr Cannon's care and treatment by the Practice from 4 July to 10 August 2003. This summary is based on my GP Adviser's review of Mr Cannon's health records.

Mr Cannon's mother's recollections and views

427 Mr Cannon's mother said that after he was discharged on 4 July 2003 her son's condition was '*terrible*'. He was not sleeping and was in constant pain. He repeatedly slapped his own face and would not use his commode. She said she called the GP who came to see Mr Cannon and said he was not sure what was wrong but he thought there may be some underlying problem causing her son to be agitated. She said the GP recommended that Mr Cannon returned to hospital so that his condition could be further investigated and he arranged his readmission later that day.

428 Mr Cannon's mother said that by the time her son was discharged on 14 July 2003 his family had managed to calm him down a little and he was sleeping a little better. However, she said her son remained very agitated and was obviously in pain. She said she and her husband were finding it quite hard to cope with Mr Cannon at home. They were up all night and found it exhausting to care for him in his agitated state. They felt they were at the end of their tether and, via the Day Care Centre, they asked for further respite care at a home other than the Grange. This was arranged for four or five days at the end of July 2003.

429 Mr Cannon's mother said that on his return from respite care her son appeared to be sleeping a bit better but his condition started to deteriorate quickly. He was not eating and had a high temperature. He was also having frequent seizures and was dehydrated. She said Mr Cannon did not seem to be '*right*' at this time and she was very concerned about his condition. On 6 August 2003 she contacted the GP following a home visit from the Learning Disability Consultant. She said the GP came,

examined Mr Cannon and prescribed antibiotics. At this time she said her son was dehydrated, had a high temperature, was having seizures and losing weight. Mr Cannon's mother said she could see he was deteriorating rapidly and was surprised the GP had not noticed the seriousness of his condition and immediately readmitted him to hospital. She said the district nursing staff had only seen her son once during all the time he was home from hospital.

The GP's response to my enquiries

430 In response to my enquiries, the GP who had visited Mr Cannon at home during the events complained about provided a statement in which he said he had very little contact with the patient and could not recall the details of the visits he made. However, he provided the following summary based on Mr Cannon's health records:

'On the 8th July 2003, a home visit was requested and I saw him at home with a history of increased agitation and difficulty sleeping at night despite diazepam. The patient indicated that he had discomfort with his bowels and examination was unremarkable. As there was no clear diagnosis he was referred to the medical team on call and admitted to Oldchurch Hospital in Romford. I then saw him again and for the last time on 6 August 2003 because he had been refusing to eat and drink and was complaining of a sore throat. Examination confirmed that he possibly had a viral upper respiratory tract infection but his chest was clear but in view of his complex past history he was placed on antibiotics to cover secondary infection and he was encouraged to drink.'

The advice of my GP Adviser

431 My GP Adviser began by reviewing the evidence regarding the GP's actions contained in the health records:

'The GP records demonstrate that the GP's interventions were appropriate as far as they went. Very minimal information was passed to primary care on the discharge summary about the clinical condition and issues surrounding the ongoing and future care of Mark Cannon. As a consequence there was no one document where a GP could look for an accurate summary of Mark Cannon's needs post-discharge.'

She also said:

'There was, however, inadequate information on the discharge summary about the blood loss and consequent anaemia that occurred as a result of surgery and no guidance for the GP or multidisciplinary team about management of the patient post-discharge.'

432 My GP Adviser noted:

'The GP records accurately reflect the medication prescribed in primary care, contacts by telephone between healthcare professionals and contacts with Mark Cannon's family where the GP responded appropriately to family requests for additional medication. The recording of AED (Anti-epileptic drugs) was in accordance with secondary care prescription. No one professional was designated as the co-ordinator of care for Mark Cannon. Apart from communication between the Consultant Neuro-physiologist and

LD [Learning Disability] psychiatrist the GP (who probably has the least training and expertise in dealing with complex cases such as Mark Cannon's) was apparently the only healthcare professional to receive letters from other healthcare professionals care specialists about Mark Cannon's ongoing condition.'

- 433 My GP Adviser described the picture of Mr Cannon's condition presented in his GP records. She said:

'The GP records reflect an accurate picture of the difficulties experienced in managing Mark Cannon's epilepsy prior to June 2003. There was no problem with the fixation of the fracture or the healing of the wound and there is adequate documentation of secondary care reviews (LD Consultant, Epilepsy Consultant, Orthopaedic Consultant) to the GP during Mark Cannon's first hospitalisation and whilst in the community.'

- 434 Referring to the GP's visit to Mr Cannon on 6 August 2003, my GP Adviser said:

'[The Learning Disability Consultant] reviewed Mark Cannon at home [6 August 2003] because he was too ill to attend outpatients. He noted that Mark Cannon was very drowsy and dehydrated and advised the parents to call the GP because in his opinion Mr Cannon required IV fluids. The GP visited the same day (time unknown) and examined the patient. A note was made that the patient was refusing to eat or drink, urine was concentrated, pulse was 78, blood pressure 90/60, it was very hot day, and patient was at risk of dehydration. The GP's opinion was that an infection (urinary or chest) was the cause of the problems and antibiotics were prescribed.'

'...

'Although a risk of dehydration was mentioned by the GP no actual mention was made of an assessment of Mr Cannon's hydration or of advising his parents about keeping the patient cool, fluid intake and calling the GP if the patient continued to refuse fluids or stopped passing urine.'

'In view of [the Learning Disability Consultant]'s obvious concern about Mr Cannon's level of hydration the GP could also have taken a blood sample for urea and electrolytes to get a more accurate assessment of the problem. In view of the comment about the environmental temperature it would have been prudent for the GP to arrange to visit or telephone Mr Cannon's parents next day to reassess the patient's condition. There was no mention of such actions in the notes.'

- 435 My GP Adviser said that in view of the environmental temperature:

'... the patient's recent medical history should have indicated closer surveillance of the patient and a lower threshold for referral to secondary care.'

Care and treatment by the Practice: the Health Service Ombudsman's findings and conclusion

- 436 Mr Cannon was discharged from hospital on two occasions with no discharge plan in place. However, on each occasion notice of discharge and brief details were sent to the Practice and a referral was made to the district nursing service.

- 437 Four days after his first discharge from hospital on 4 July 2003, Mr Cannon's GP organised readmission so that his pain and epilepsy could be controlled and I am advised by my GP Adviser that this was appropriate. Therefore, my findings focus on the care provided to Mr Cannon by the Practice in the period following his second discharge from hospital on 14 July 2003 and, particularly, the days before his readmission to hospital on 10 August 2003.
- 438 Mr Cannon's mother believes the GP did not act appropriately during this time and should have arranged for her son to be readmitted to hospital. In particular, she believes the GP should have taken this action when he visited Mr Cannon on 6 August 2003.
- 439 I note that on 6 August 2003 the GP made a home visit at the suggestion of the Learning Disability Consultant who had seen Mr Cannon earlier that day. After he visited Mr Cannon the Learning Disability Consultant had written to the GP setting out his findings and opinion. My GP Adviser said the GP could have taken more account of the information provided by this consultant. However, it is clear to me that the consultant's letter would not have been available to the GP on 6 August 2003 because it was sent to him in the post. Therefore, when the GP visited he would have been unaware of the detail of the Learning Disability Consultant's reasons for suggesting a GP house call.
- 440 I have seen evidence of the examination performed by the GP to assess Mr Cannon's condition. It is clear that the GP was aware that Mr Cannon might be becoming dehydrated as he recorded his observations that he was not drinking and his urine was concentrated. He also noted that it was a hot day. However, on the basis of his examination and assessment of Mr Cannon, the GP did not consider he was so dehydrated at that point that he required hospital admission. Rather, he diagnosed an infection and prescribed antibiotics.
- 441 There is no contemporaneous record of any other action which the GP took or any advice which he gave to Mr Cannon's mother at this time, although in his comments to my investigator the GP said he had suggested Mr Cannon should be encouraged to drink.
- 442 My GP Adviser said the GP's interventions were appropriate, although she thought he could have gone further, perhaps advising Mr Cannon's mother about measures to cool her son. She also suggested that, given the environmental conditions and Mr Cannon's recent medical problems, the GP should have had a 'lower threshold' for monitoring and taking action on his condition. I share the concerns expressed by my GP Adviser. If the GP had acted in line with the principles set out in Once a Day he might have taken a different view or acted differently. It seems to me that, at the least, he should have put in place arrangements to review the situation, perhaps by arranging for a GP to call again, or conducting a telephone consultation the following day.
- 443 I can understand why Mr Cannon's mother believes the GP should have taken more radical action when he saw her son on 6 August 2003. After all, only a few days later he became extremely ill and was readmitted to the Trust. The judgment I have to make, however, is whether the shortcomings in the service provided by the GP were so serious as to constitute service failure. I have reached the view that they were not. I conclude that shortcomings in the care and treatment provided by the GP **do not amount to service failure.**

444 Therefore, I **do not uphold** Mr Cannon's parents' complaint against the Practice.

The Health Service Ombudsman's investigation of the complaint against the Healthcare Commission

Complaint (e): the Healthcare Commission's review of Mr Cannon's parents' complaint

445 Mr Cannon's parents are dissatisfied with the way the Healthcare Commission (the Commission) handled their complaint. They say the Commission failed to properly investigate their complaints against the Trust or take appropriate action where they identified serious shortcomings. They also say the Commission's review took too long.

The basis for the Health Service Ombudsman's determination of the complaints

446 The regulations and standards which apply to the Commission's handling of complaints are set out in Section 2 of this report. When assessing the way in which the Commission handled Mr Cannon's parents' complaint I have regard to those regulations and standards and to my own *Principles of Good Administration* and *Principles for Remedy*.

The Health Service Ombudsman's jurisdiction and role

447 Section 1 of this report sets out the basis of my jurisdiction in relation to complaints made to me that a person (or body) has sustained injustice or hardship in consequence of maladministration by the Commission in the exercise of its complaint handling function.

448 When complaints have already been reviewed by the Commission, I do not normally carry out an investigation of the original complaint, but investigate the way in which the Commission conducted its review. Specifically, I consider whether:

- i. there were any flaws in the Commission's review process which makes the decision unsafe;
- ii. the Commission's decision at the end of the review process was reasonable; and
- iii. whether the service the Commission provided was reasonable and in line with its own service standards.

449 When I uphold a complaint about the Commission's complaint handling, because I find that the review process was flawed, or the decision unreasonable, I normally refer the complaint back to the Commission for it to remedy the failure by conducting a further review.

The Health Service Ombudsman's decision

450 For the reasons given below, I **uphold** Mr Cannon's parents' complaint about the Commission's complaint handling. However, I did not consider it appropriate to recommend a further review by the Commission. Therefore, I decided to investigate the complaint myself.

The Commission's review

Key events

451 On 29 July 2005 Mr Cannon's parents complained to the Commission. Their complaint centred on the clinical care their son received during each of his three admissions to hospital.

They said he had suffered an atrocious lack of care and that if even minimal care had been provided they believed he would still be alive. They singled out the lack of nursing supervision in particular as being the fundamental cause of their son's death.

452 In August 2005 the Commission accepted Mr Cannon's parents' complaint for review. The Commission next contacted them in November 2005 when it asked them to complete a consent form. In January 2006 the case was allocated to a Case Manager who contacted Mr Cannon's parents at that point to introduce himself. From that point onwards, they were updated at approximately monthly intervals to inform them of progress with their complaint.

453 The Commission divided Mr Cannon's parents' complaint into 14 issues and sought clinical advice from a registered nurse (the Commission's Nurse Adviser) and a consultant anaesthetist (the Commission's Medical Adviser).

454 The advice provided by the Commission's Medical Adviser consists, for the most part, of a summary of Mr Cannon's medical records with his opinion about the standard of the medical care Mr Cannon received limited to a small number of paragraphs. The Commission's Medical Adviser said:

- his overall opinion on Mr Cannon's first admission was that *'The management of the patient was difficult due to cerebral palsy and pre-existing epilepsy that was not well controlled. All reasonable care was given'*;
- the delay in A&E prior to Mr Cannon's second admission was unacceptable. There was no record of pain or sedation in the admission records. Had the admitting medical staff

assessed Mr Cannon's pain in A&E, it could have been assessed and monitored as appropriate; and

- the care Mr Cannon received in the HDU during his third admission was well documented. Despite many attempts to resuscitate him during this admission he died.

455 The Commission's Medical Adviser's overall view of the care and treatment Mr Cannon received was that there were areas for improvement, but he could *'find no evidence that the care was bad'*.

456 The Commission's Nursing Adviser produced a more detailed report. His conclusions included that:

- nursing staff did not provide appropriate care in relation to Mr Cannon's incontinence during his first admission;
- the standard of record keeping during Mr Cannon's first admission was barely adequate;
- the discharge arrangements in respect of Mr Cannon's first admission were inadequate;
- the pain relief given to Mr Cannon during his second admission was inadequate;
- the nursing care during Mr Cannon's third admission was adequate. Nursing staff dealt with a difficult period without adequate information and time fully to appraise themselves of Mr Cannon's condition;
- it was not uncommon for nurses to sleep in a ward kitchen during breaks and it was up to nurses to decide how best to use their break time; and

- staff appeared to lack knowledge and skills in dealing with the special needs of patients with learning disabilities.

The Commission's decision

457 On 20 December 2006 the Commission issued its decision. The Commission referred nine issues back to the Trust for further local resolution because it did not consider the Trust had provided an adequate response and some of the issues raised had not previously been put to the Trust. The Commission upheld Mr Cannon's parents' complaints about:

- the discharge arrangements in respect of Mr Cannon's first admission;
- the delay in A&E prior to Mr Cannon's second admission; and
- inadequate pain relief during his second admission.

458 The Commission made various recommendations including that the Trust:

- audit current record keeping with a view to ensuring patient documentation is completed in line with Nursing and Midwifery Council guidelines;
- review procedures for assessing and recording pain;
- apologise to Mr Cannon's parents for the delay in A&E prior to Mr Cannon's second admission and inform them of the steps being taken to reduce waiting times in A&E; and
- update Mr Cannon's parents on how the Trust ensures practice is accorded with the

Valuing People guidance and provide them with information about the steps being taken to ensure the Trust complies with the requirements of the *Disability Discrimination Act 2005*.

459 On 8 January 2007 Mr Cannon's parents wrote to the Commission to express their concerns about the decision. They said they were dismayed at the inattentiveness of the Commission's reading of their account of events. Further, they considered the Commission's decision was unsafe because fundamental times and dates had been inaccurately interpreted and erroneous evidence had been relied upon. They also said they were disturbed that the most crucial aspects of their complaints had not been upheld.

460 On 22 April 2007 the Commission responded to Mr Cannon's parents' concerns. The Commission accepted there had been a number of factual errors, but said this did not affect the overall decision. The Commission said appropriate clinical advice had been taken, all the relevant evidence had been considered, and no further action on its part was necessary.

461 On 13 April 2007 the Trust responded to the Commission's recommendations.

The advice of the Health Service Ombudsman's Professional Advisers

462 I asked my Professional Advisers for their views about the clinical advice which the Commission obtained. My Anaesthetic Adviser said that:

- the advice from the Commission's Medical Adviser was brief, given it had to cover three complicated admissions and it consisted largely of a distillation of events;

- the statement that ‘*all reasonable care was given*’ was not substantiated;
- the delay in Mr Cannon receiving adequate analgesia by the orthopaedic and pain teams was not adequately addressed; and
- the events and possible explanations for Mr Cannon’s death during his third admission were summarised but not analysed.

463 My A&E Medical Adviser said that because the Commission did not obtain advice from a consultant with experience of emergency medicine, the care and treatment Mr Cannon received in A&E was not addressed properly.

464 My A&E Nursing Adviser said the Commission’s Nursing Adviser presented a detailed report, much of which was appropriate in its criticisms of some areas of the nursing care. She also said the recommendations which the Commission made were relevant and reflected many of the problems encountered by Mr Cannon and his family.

465 However, she said the Commission should have obtained advice from a senior A&E nurse in order to address the episodes of care relating to A&E properly. My A&E Nursing Adviser also said that:

- the Commission’s nursing advice did not refer to the delay in A&E prior to Mr Cannon’s second admission;
- Mr Cannon’s admission to the poorly staffed Receiving Room on his third admission and the care and treatment he received subsequently were not properly addressed;

- she disagreed, fundamentally, with the conclusion reached by the Commission’s Nursing Adviser that the care Mr Cannon received during his third admission was reasonable; and
- the Commission’s response to Mr Cannon’s parents’ concern that nurses slept in the ward kitchen during breaks was inadequate because the true issue was overlooked. She said the issue was not whether nursing staff contravened hospital policy in sleeping on their breaks, but whether nursing staff on duty could give safe care to their patients.

The Health Service Ombudsman’s findings

466 I have explained that I assess the way in which the Commission has conducted its review by considering the review process, the decision and whether the service provided was reasonable.

467 The Commission decided to refer the majority of Mr Cannon’s parents’ complaints back to the Trust for further action. The Regulations give the Commission the discretion to recommend that an NHS body take further action to resolve a complaint. I agree that, in this case, there was scope for the Trust to investigate matters further and it was not inappropriate that it was given the opportunity to do so. I also note that my Advisers consider the recommendations the Commission made, at this stage, were appropriate and the Trust provided evidence that it had addressed the recommendations. Therefore, I see no basis on which to criticise the Commission’s decision to refer the majority of the complaint back to the Trust to resolve and, furthermore, I welcome the fact that the Trust complied with the Commission’s recommendations.

468 I am, however, critical of the clinical advice which the Commission took. The Commission may take any advice which is needed to make a decision. I would expect that, when the Commission reviews complaints which involve clinical care, it would obtain appropriate advice from professional advisers with relevant experience and expertise. In reaching its decision, the Commission obtained professional advice from a consultant anaesthetist and registered nurse. They were competent to provide some of the advice required to address the issues raised by Mr Cannon's parents. However, the care and treatment which Mr Cannon received in A&E formed a significant part of this complaint. Therefore, it was necessary to have clinical advice from professionals with relevant experience of A&E. The Commission failed to seek such advice.

469 I find that the clinical advice which the Commission did receive was inadequate. The advice from the Commission's Medical Adviser was particularly poor. That advice was not supported by the available evidence and did no more than provide a brief comment on what were very complex issues. The Commission should not, in my view, have accepted such a superficial clinical report given the complexities of Mr Cannon's clinical care which spanned three hospital episodes. My A&E Nursing Adviser also identified flaws in the Commission's nursing advice. Some of the issues which were central to Mr Cannon's parents' complaint were not covered adequately and the conclusions reached in respect of Mr Cannon's third admission were not, in her view, reasonable in the light of the available evidence.

470 I find that the clinical advice which the Commission obtained was inappropriate and inadequate. This renders its decision unreliable and unsafe.

471 I also find that the Commission's report on its review was not comprehensive, failing as it did to consider key elements of Mr Cannon's parents' complaint, such as the pain relief afforded to their son. The report also contained significant factual inaccuracies which gave them the impression that a robust review had not taken place.

472 Finally, the Commission had the opportunity to put these failings right when Mr Cannon's parents drew attention to the shortcomings in the report. The Commission's response, however, was superficial, incomplete and not evidence-based. I can appreciate why Mr Cannon's parents lost confidence in the Commission's ability to address their legitimate complaints.

473 However, I have not found that the service which the Commission provided was poor. It took the Commission 17 months to complete the review. The Commission's service standard at that time was that, in the majority of cases, the review process should take no longer than six months. Whilst the Commission did not complete its review within this service standard, Mr Cannon's parents had asked the Commission to review a significant number of complex complaints about the care and treatment their son received. I do not consider that, in the circumstances of such a complex and sensitive case, the time the Commission took to complete the review is so unreasonable as to constitute maladministration. In reaching this decision I take account of the fact that the Commission kept Mr Cannon's parents regularly updated about progress with the complaint. One of the six *Principles of Good Administration* (referred to in Section 2 of this report) is that public bodies should be customer focused and, specifically, that they should tell people if things are going to take longer than

they said they would. In their update letters, the Commission apologised for the delay, set out progress on the review and explained when Mr Cannon's parents could expect a further update. This reflects good administrative practice.

474 I conclude that the failings I have identified in the Commission's handling of Mr Cannon's parents' complaint amount to **maladministration**.

Injustice

475 The injustice arising from the Commission's maladministration is that Mr Cannon's parents experienced a further year and a half of uncertainty and distress about the circumstance of their son's illness and death. The Commission's review was conducted without the necessary rigour, and I can understand why Mr Cannon's parents remained dissatisfied when the review was concluded. Maladministration in the Commission's review led to this **unremedied injustice**.

476 Therefore, I **uphold** Mr Cannon's parents' complaint against the Commission.

The Health Service Ombudsman's recommendation

477 I **recommend** that the Commission apologise to Mr Cannon's parents for failing to carry out a proper review of their complaint.

The Commission's response

478 The Chief Executive has accepted my recommendation and she will write to Mr Cannon's parents to express her apologies once the final report has been issued.

Section 4: the Ombudsmen's final comments

Introduction

- 479 Mr Cannon's parents' overarching complaint is that their son's death was avoidable and that he was treated less favourably for disability related reasons. They told us they have not had full answers to all their questions about their son's care and treatment and they hope our investigation will provide them with those answers. They hope other people will not go through the same experience as their son. In this final section of our report we address Mr Cannon's parents' overarching complaint.
- 480 In assessing the actions of the Council, the Trust and the Practice we have taken account of relevant legislation and related policy and administrative guidance as described in Section 2 of this report. We have taken account of available evidence and considered the advice of our Professional Advisers.
- 481 The Local Government Ombudsman has found maladministration in respect of the failure by the Council to provide and/or secure an acceptable standard of care for Mr Cannon and in respect of its complaint handling. The Health Service Ombudsman has found service failure in respect of several aspects of care and treatment provided by the Trust, as well as maladministration in the way the Trust handled Mr Cannon's parents' complaint.
- 482 We now turn to the issues of whether these failings were for reasons related to Mr Cannon's learning disabilities and whether his death was avoidable.

Was Mr Cannon treated less favourably for reasons related to his learning disabilities?

- 483 Mr Cannon's parents believe their son was treated less favourably for reasons related to his learning disabilities.
- 484 In the light of the evidence we have seen, we consider that the Council and the Trust failed to respond to relevant legislation and guidance such as Valuing People, which has been in place for some years before the events complained about. As we have explained in Section 2, this guidance required public services to make reasonable adjustments to ensure that arrangements were in place for appropriate care and treatment of people with learning disabilities.
- 485 In the light of the evidence she has seen, the Health Service Ombudsman considers that failings in the care and treatment provided by the Trust cannot be separated from the fact that in key areas of care (including pain relief, epilepsy care, assessment and monitoring, and arrangement and provision of support services) staff did not attempt to make reasonable adjustments to the way in which they organised and delivered services to meet Mr Cannon's complex needs. She concludes that in some significant respects the service failures at the Trust were for disability related reasons.
- 486 In Section 2, we set out our approach to human rights. On that basis, we also conclude that the acts and omissions of the Council and the Trust constituted a failure to live up to human rights principles, especially those of dignity, equality and autonomy. There is no evidence of any positive intention to humiliate or debase Mr Cannon. Nevertheless, by omitting to provide and/or secure proper care for

Mr Cannon public services failed to have due regard to his dignity and status as a person, and to the need to observe the principle of equality.

Was Mr Cannon's death avoidable?

487 Mr Cannon's parents believe that had their son received appropriate and reasonable service from the Council and the Trust his death would have been avoided.

488 In considering whether to make a finding about avoidable death we assess whether the injustice or hardship complained about (in this case Mr Cannon's death) arose in consequence of the service failure and/or maladministration we have identified.

489 The Local Government Ombudsman has found that the Council failed to provide and/or secure an acceptable standard of care for Mr Cannon and that, as a result, his safety was put at risk. The Local Government Ombudsman considers that the accident, from which Mr Cannon suffered a major injury – a broken leg – might well have been avoided.

490 The Health Service Ombudsman has found that after Mr Cannon broke his leg there was a series of serious service failures in his care and treatment by the Trust.

491 Mr Cannon's father is particularly concerned about the events of the night of 10/11 August 2003. He believes that poor care by the Trust on this night played a decisive role in his son's death. He believes that his son breathed vomit into his lungs whilst being nursed on his back without supervision and that this led to the pneumonia which ended his life.

492 The Health Service Ombudsman has concluded that Mr Cannon may have aspirated on that night and this may have resulted in some level of infection in his lungs but she cannot say whether, or to what extent, any infection at this time gave rise to the pneumonia which caused his death.

493 We consider Mr Cannon's death cannot be attributed to one specific incident or action. That said, we conclude that the Council and the Trust failed Mr Cannon. The injury suffered by Mr Cannon might well have been avoided. In any event he should not have died as a consequence of that injury. Our finding is that Mr Cannon's death arose in consequence of the service failure and maladministration which we have identified. We conclude his death was avoidable.

Mr Cannon's parents' response to the Ombudsmen's draft report

494 Mr Cannon's parents welcomed our report saying it was *'tough and hard hitting'*. Nevertheless, they were particularly disappointed that the Health Service Ombudsman did not uphold their complaint against the Practice. They continue to believe their son did not receive a reasonable standard of care from the Practice. In response to Mr Cannon's parents' comments the Health Service Ombudsman asked Dr Owen to review the evidence about the service provided by the Practice. Dr Owen said there were no new clinical matters which had been raised in the response to the draft report which the Health Service Ombudsman should take into account in considering this aspect of the complaint. Therefore, she sees no reason to depart from her findings and conclusions set out in this report.

495 Mr Cannon's father, although welcoming the Health Service Ombudsman's decision to uphold the complaint against the Trust, expressed reservations about some of her findings and conclusions. In particular, he did not agree with specific aspects of her assessment of events of the night of 10/11 August 2003, when he believes Mr Cannon aspirated bile into his lungs. The Health Service Ombudsman asked Mrs Lowson to review the complaint about acute nursing care at the Trust. Mrs Lowson said she had not found any evidence that would cast doubt on the Health Service Ombudsman's findings and conclusions.

496 Mr Cannon's father also expressed concerns about the Health Service Ombudsman's findings regarding the care and treatment his son received in the HDU. In response, the Health Service Ombudsman reviewed the evidence about this period of Mr Cannon's stay at the Trust and sought further professional advice from Dr Skoyles. As a result she provided a more detailed consideration of this aspect of the complaint. This is included in the section of this report which deals with care and treatment at the Trust.

The Ombudsmen's concluding remarks

497 In earlier sections of this, our joint report, we have set out our investigation, findings and conclusions with regard to the care, treatment and service Mr Cannon and his parents received from the Council, the NHS and the Healthcare Commission. We are acutely aware that our findings are likely to cause further distress to Mr Cannon's parents, but we hope we have provided them with the long-awaited responses to their complaints.

498 We also hope our report will provide Mr Cannon's parents with the explanations and answers they sought and that the remedies we have recommended will go some way towards addressing the injustice they and their son suffered. We also hope they will be reassured that as a result of their complaint and our investigation others are less likely to suffer the same experiences as their son.



Ann Abraham
Parliamentary and Health Service Ombudsman



Jerry White
Local Government Ombudsman

March 2009

ANNEX A

Good Medical Practice, 2001: Relevant sections

The duties of a doctor

'Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- *make the care of your patient your first concern;*
- *treat every patient politely and considerately;*
- *respect patients' dignity and privacy;*
- *listen to patients and respect their views;*
- *give patients information in a way they can understand;*
- *respect the rights of patients to be fully involved in decisions about their care;*
- *keep your professional knowledge and skills up to date;*
- *recognise the limits of your professional competence;*
- *be honest and trustworthy;*
- *respect and protect confidential information;*
- *make sure that your personal beliefs do not prejudice your patients' care;*

- *act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;*
- *avoid abusing your position as a doctor; and*
- *work with colleagues in the ways that best serve patients' interests.*

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.'

Providing a good standard of practice and care (sections 2 and 3)

'Good clinical care must include:

- *an adequate assessment of the patient's conditions, based on the history and symptoms and, if necessary, an appropriate examination;*
- *providing or arranging investigations or treatment where necessary;*
- *taking suitable and prompt action when necessary;*
- *referring the patient to another practitioner, when indicated.*

In providing care you must:

- *recognise and work within the limits of your professional competence;*
- *be willing to consult colleagues;*

- *be competent when making diagnoses and when giving or arranging treatment;*
- *keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions made, the information given to patients and any drugs or other treatment prescribed;*
- *keep colleagues well informed when sharing the care of patients;*
- *provide the necessary care to alleviate pain and distress whether or not curative treatment is possible;*
- *prescribe drugs or treatment, including repeat prescriptions, only where you have adequate knowledge of the patient's health and medical needs. You must not give or recommend to patients any investigation or treatment which you know is not in their best interests, nor withhold appropriate treatments or referral;*
- *report adverse drug reactions as required under the relevant reporting scheme, and co-operate with requests for information from organisations monitoring the public health;*
- *make efficient use of the resources available to you.'*

Working with colleagues (section 36)

'Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide. When working in a team, you must:

- *respect the skills and contributions of your colleagues;*
- *...*
- *communicate effectively with colleagues within and outside the team.'*

ANNEX B

The Third Independent Investigator's conclusions and recommendations

Conclusions

'The first element of Mrs Handley's complaint is that the Council did not provide an appropriate level of care to her son Mark during his stay at the Grange care home.

'8.1.2 This element of the complaint is upheld in the light of the findings of [the First Independent Investigator]'s report.

'8.1.3 That report was written following an investigation that took place shortly after the accident occurred to Mark. The investigation appeared to have been thorough and was, for the most part, carried out while Mark was alive. The shortcomings in practice identified are explicit and evidenced. It is reasonable to assume that the Social Services department accepted the findings of the report because it made it available, on the prompting of the [second] independent complaints investigator, to Mrs Handley and to Mr Cannon.

'8.1.4 This should not be taken to imply or suggest that Mark's fall occurred as a result of the below standard practices identified. The practices were identified during the course of the investigation of the accident Mark suffered, but the report does not attribute his fall, at some time during the night, to poor practice.

'8.1.5 The Council has refused to allow Mrs Handley to progress her complaint to Stage 3 of the statutory complaints procedure.

'8.1.6 This element is partly upheld.

'8.1.7 The reason for this decision is that it was difficult for Mrs Handley to know at what stage of the complaints process she was in. The acknowledgement of her initial complaint in July 2003 indicated that [the First Independent Investigator] was investigating her complaint, presumably at Stage 1. This acknowledgement rightly advised Mrs Handley that if she were not satisfied with the response she could have the complaint re-investigated by a different officer under Stage 2. It might therefore have been reasonable to assume that [the Second Independent Investigator] was engaged to carry out a Stage 2 investigation. However, as Mrs Handley had newly registered her complaint in June 2004, it is possible that [the Second Independent Investigator] was acting at Stage 1 in relation to a new complaint. The point is that the stages appear not to have been made explicit.

'8.1.8 Clearly the investigation which is the subject of this report has explicitly moved the complaint on to Stage 2. The question of moving to Stage 3 would therefore only arise following this current investigation.

'8.2 The department has not acted in a compassionate manner.

'8.2.1 This element is also partly upheld.

'8.2.2 It is upheld in relation to the way that Mrs Handley has been responded to since the inquest into her son's death. The notification that her complaint would not be pursued further is legalistic and abrupt. While the letter to her acknowledges that this is a sensitive issue that "produces significant emotions", the tone of the letter from that point onwards lacks sensitivity. The words "as Mark is deceased, he is not a qualifying individual" are a particular example of this.'

The Third Independent Investigator explained that this aspect of the complaint could not be upheld in full as Mr Cannon's mother had acknowledged that some individuals within the Learning Disability Service had treated her sympathetically and supported her, such as staff at St Bernard's Day Centre.

Recommendations

'9.1 The department should accept or reject, in its response to Mrs Handley's complaint, the findings in [the First Independent Investigator]'s report concerning the standard of care offered to Mark at the Grange.

'9.2 If it accepts the findings it should give Mrs Handley an assurance that [the First Independent Investigator]'s recommendations have been acted upon; that procedures and practices have been changed and that monitoring arrangements have been put in place to ensure that the changes continue to be implemented and maintained.

'9.3 It should address the measures taken to improve on the shortcomings specifically referred to in [the First Independent Investigator]'s report.

- *Poor communication between staff*
- *Risk management guidelines not followed*
- *Inadequate procedures and practices around the management of epilepsy*
- *Lack of detailed care plans and poor awareness of individual needs*
- *Poor induction procedures for new staff.*

'9.4 The department should respond to Mrs Handley's complaint under Stage 2 in the manner prescribed in the department's complaints manual.

'9.5 The department should acknowledge to Mrs Handley that its legalistic written response to her, following the outcome of the inquest into her son's death, did appear to be lacking in compassion. While it was no doubt necessary for the Council to make clear its legal position, that could have been tempered by a show of concern for her well-being either through personal contact or in writing.

'9.6 In addition to the formal written response to Mrs Handley, in accordance with the complaints procedure, Mrs Handley and Mr Handley should be offered a meeting with a senior manager in the social services department to re-enforce, clarify or explain the substance and import of the written response.'

ANNEX C

Extracts from the Trust's Director of Nursing and Clinical Governance's investigation and report

Mr Cannon's first admission and the repair of his fractured femur

'Mark Cannon was admitted via Oldchurch A&E on 27 June 2003 with fracture of femur and was admitted to Ward E5 (Orthopaedic). ... Mark's father was concerned about the degree of nursing observation as he was not placed in front of the Nurses' Station; however, Mark's petit mal fits were recorded and following the family's concern, Staff Nurse moved Mark closer to the Nurses' Station.

'Mark had a surgical repair on 28 June. Post-operatively Mark was alert and responsive but distressed. ... Mark's inability to understand the care process led to continued distress over the next few days. Mark's family became distressed and the nursing staff asked the Orthopaedic SHO to reassure the family that care was appropriate.

'Mark's father continued to be dissatisfied with the care; however the record shows adequate recording and care plan. Mark was treated by both physiotherapists and occupational therapists. Sister notes that the Physiotherapist had worked with Mark's mother on movement and transfer. The Occupational Therapist assessed the home environment and the Ward Nursing Staff arranged for District Nurses to care for Mark's wound at home. The Ward Clerk arranged a follow up out patient appointment and posted this. Sending follow up appointments by post is usual practice. Mark was discharged from E5 on 4 July 2003.'

Mr Cannon's second admission

'Mark presented at Oldchurch A&E on 8 July 2003. Mark waited 11 hours for a bed in the Receiving Room (Admissions Ward). Mark was distressed and appeared to be in pain. The Ward Sister in the Receiving Room contacted the Clinical Nurse Specialist for Pain Services on 9 July for advice and support. The medical staff formally referred Mark to the Pain Service on 10 July. Due to vacancies within the Pain Service, the Clinical Nurse Specialist was unable to visit until 11 July. The Clinical Nurse Specialist for Pain Services was concerned about the level of analgesia. She visited Mark three times that day. Pain assessment charts were commenced. The Pain Clinical Nurse Specialist noted that with the exception of the level of analgesia administration, the nurses were giving good care.

'Mark's learning difficulty and difficulty with communication would have led to a degree of disorientation. Allowing Mark the privacy and quiet of a bed away from the main traffic of the ward was a good nursing decision. The Pain Nurse recommended changes to the analgesia prescription verbally and in the medical records. She also spoke to Mark's family. Mark was discharged from the Receiving Room on 14 July.'

Mr Cannon's third admission

The Director of Nursing and Clinical Governance said there were two nurses on duty on 10 August 2003 and described the nursing interventions which took place. She then turned to the specific criticisms made about the overnight staffing arrangements.

'One Staff Nurse then took her break. Due to space constraints, there are no staff rest room facilities on this ward and staff take their breaks in the ward kitchen. Staff are permitted to spend their break however they wish and sleeping during the night break is not a breach of hospital policy. The second Staff Nurse discovered that Mark had passed a large amount of loose faeces. She cleaned Mark with the assistance of his relatives. Whilst she was still at the bedside, Mark vomited a large amount of fluid. The Staff Nurse states that the vomit was projectile and that there was no gurgling or ensuing rattling. She did not observe any change in his condition or vital signs following this episode. She cleaned and settled Mark on his side to prevent aspiration from further vomiting.'

'Mark was seen [the following] morning by the Consultant Physician who decided to transfer him to the Intensive Care Unit. The Consultant Physician discussed Mark's condition with his mother and it was decided not to give cardiopulmonary resuscitation in the event of a cardiac arrest. After the Consultant left the ward, Mark's mother told Sister that Mark's father was not happy with this and wanted CPR to be given. Sister informed the Specialist Registrar of this. Sister noted that there was a difference of opinion between Mark's mother and father about the appropriate course of treatment.'

'At 11.30 Mark's condition deteriorated; his blood pressure became unrecordable and his respirations became laboured. The Specialist Registrar was called and returned to the Ward and a dobutamine (a drug to stimulate the heart muscle) infusion was recommenced to support his cardiac function. Mark was transferred to Intensive Care at 15.00. Mark received active treatment in Intensive Care. Mark's condition stabilised and a decision was taken to transfer him to the High Dependency Unit (B2) on 13 August.'

The events of 14 August 2003

'The Consultant Anaesthetist arrived around 9.00 am but had to attend to another patient first. The consultant examined Mark but was not unduly concerned. He asked for a chest X-ray. Mark was then seen by a Physiotherapist who auscultated (listened for sounds) his chest and agreed with the Sister's findings. It was agreed that Mark should be turned 1 to 2-hourly to improve chest expansion and to give frequent saline nebulisers. At this time Mark remained responsive only to physical stimuli. There was some confusion over the time of Mark's chest X-ray as the radiographer needed to return to the Radiology department to collect extra film to X-ray all the patients. When the exposed X-ray film arrived on HD, the Sister viewed it and immediately called the Consultant Anaesthetist. He viewed the X-ray and decided to intubate Mark and transfer him to Intensive Care for ventilation, however before this was done, Mark suffered a cardiac arrest. Mark was successfully resuscitated and transferred to Intensive Care.'

'Mark's condition remained poor and on 28 August, medical staff met the family to outline the seriousness of his condition and poor prognosis and there was agreement to withdraw treatment. Mark Cannon died on 1 September [sic].'

The Trust's overall position on the care provided to Mr Cannon

'CONCLUSION. The admission of any patient to hospital is always distressing but the anxiety and disorientation experienced by a patient with learning difficulties is profound. Mark Cannon was admitted to Oldchurch with a fractured femur. Whilst there could have been improvements in his care, the care documented together with the Nurses statements demonstrate an adequate level of care and planning for discharge. Review by the Orthopaedic Surgeon shows satisfactory care of the wound and review by the Consultant Neurophysiologist shows therapeutic blood drug levels demonstrating that anti-epileptic medication had been administered. There was a brief readmission between 8 and 14 July to stabilise his pain management and there is evidence from the Clinical Nurse Specialist for Pain Services that nursing care was good.'

'When Mark was readmitted on 10 August, he was clearly in a very ill state. He was pyrexial, responsive only to physical stimuli, hypotensive and hypoxic. His condition did not deteriorate whilst on the Receiving Room and his nursing there was appropriate. The staff were in regular contact with medical staff and monitoring his vital signs and urine output hourly. The Night Co-ordinator was also involved in assessing his care. The family note some deficits in the care of other patients but the records and the nurses' statements demonstrate satisfactory care.'

'Sister from the Receiving Room actively managed Mark the following day and he was appropriately transferred to ITU on 11 August. Mark's illness was clearly a very difficult time for all his family, however Mark's father appeared to have a different view of the treatment that Mark should be receiving and Sister has noted that there was a clear difference of opinion between the parents over his resuscitation status. The Sister on duty in ITU notes that when she transferred him to the High Dependency (B2) on 13 August, she observed that it was a pity to keep moving him but that it was she who transferred him and that she reassured Mark's father that he was stable enough to be moved. The care in the High Dependency Unit was satisfactory and Sister conducted a thorough assessment on the morning of 14 August. This assessment was verified by a separate assessment by the physiotherapist.'

'Critically ill patients can deteriorate very rapidly and Mark's respiratory status deteriorated leading to cardiac arrest. He had been assessed that morning by a Nursing Sister, a Chest Physiotherapist and a Consultant Anaesthetist. Following the cardiac arrest, Mark was transferred to Intensive Care where he remained critically ill until the withdrawal of treatment and his death on 29 August.'

ANNEX D

Summary of events relating to the Practice from 4 July to 10 August 2003

4 July 2003

Mr Cannon was discharged from the Trust. A discharge note states that he had undergone surgical repair of a fractured femur and lists his usual medication.

7 July 2003

Note in GP records from a GP saying Mr Cannon is receiving analgesics and antibiotics but is distressed. Diazepam (a sedative) is prescribed.

8 July 2003

The GP made a home visit and recorded that Mr Cannon was more agitated and not sleeping despite the diazepam. He noted that Mr Cannon had passed a loose stool. He examined Mr Cannon and found he did not have a temperature, his fluid level was decreasing and his abdomen was soft. He found no abnormalities in the abdomen or the rectum. He queried the cause of Mr Cannon's symptoms and arranged for admission to the Trust.

14 July 2003

Mr Cannon was discharged from the Trust.

16 July 2003

Note in the GP records of a discussion between a GP and Mr Cannon's mother about pain killers and that later she visited the Practice to ask for sleeping medication for her son. This was prescribed and side-effects explained.

21 July 2003

Letter from an orthopaedic surgeon to the Practice describing his findings and follow-up care arranged (physiotherapy and further clinic appointment) during Mr Cannon's visit to out-patients on 17 July 2003.

24 July 2003

Mr Cannon was seen by a neurophysiologist who advised diazepam should be reduced.

25 July 2003

A community psychiatric nurse from the Learning Disability Service called the Practice to say Mr Cannon needed stronger sleeping tablets. These were prescribed.

28 July 2003

Mr Cannon was seen by his Learning Disability Consultant who wrote a letter to the Practice saying: *'Since the operation he has become agitated, anxious, very moody and can become aggressive towards himself and others. His appetite is poor and he sleeps poorly. He drinks a lot of water and milk'*. He also gave instructions about Mr Cannon's epilepsy medication.

6 August 2003

The Learning Disability Consultant and a learning disability nurse visited Mr Cannon at home because he was too unwell to attend for an appointment. The Consultant wrote to the Practice saying: *'[Mr Cannon] had been refusing food and drinks and appeared very drowsy and dehydrated. I advised that they need to call the GP as he may probably need intravenous fluids'*. This note was sent in the post and would not have been available when the GP visited.

Subsequently, the GP visited. He recorded that Mr Cannon was not eating or drinking and that he was at risk of dehydration. He recorded Mr Cannon's pulse and blood pressure and noted his urine was concentrated. The GP noted that he thought the likely diagnosis was urinary or respiratory tract infection and prescribed antibiotics.

10 August 2003

Mr Cannon was admitted to the Trust.

PHSO-0006

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office

ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.

Six lives: the provision of public services to people with learning disabilities

Part three: the complaint made by Mr and Mrs Cox

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Second report

Session 2008-2009

Presented to Parliament pursuant to
Section 14(4) of the Health Service Commissioners Act 1993

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-III
London: The Stationery Office
£64.15

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ISBN: 9 78 010295 8577

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Section 1: introduction and summary

- 1 This is the final report of my investigation into Mr Cox's parents' complaint against the Harold Road Surgery (the Surgery), a GP employed by South East Health Ltd (the Out of Hours GP), East Sussex Hospitals NHS Trust (the Trust) and the Healthcare Commission. The report contains my findings, conclusions and recommendations with regard to Mr Cox's parents' areas of concern.
- 5 On Friday 24 September 2004 Mr Cox's father rang the Surgery for more medication for his son's seizures. During that day Mr Cox got no better. In the early hours of 25 September 2004 his parents noticed that his stomach had swollen up and called the Out of Hours service.

The complaint

- 2 Mr Cox was a 30 year old man with severe learning disabilities. His parents describe him as a very happy and contented young person with a great sense of humour and a love for everyone. They explained that he was usually very fit. He lived at home with his parents who were his carers. Mr Cox had very little speech, but he could make himself understood to his family.
- 3 Mr Cox's parents say they were first aware their son was in discomfort on 3 August 2004. They were worried because he was making a repeated noise, although normally he was quiet. They telephoned the Surgery on 4 August 2004, and three doctors from there visited over the next five days. Mr Cox seemed to recover, but his parents feel that this episode was in fact caused by a 'grumbling appendix' (a term sometimes applied to people who have episodic abdominal pain and who eventually undergo an appendectomy – surgical removal of the appendix).
- 4 On 21 September 2004 Mr Cox again had difficulty sleeping. The following morning he had a bad epileptic seizure and his parents telephoned the Surgery and spoke to the First GP. The First GP visited and examined Mr Cox. She told his parents he had a viral infection. On 23 September 2004 Mr Cox's father rang the First GP to say how worried he was.
- 6 The Out of Hours GP attended and said Mr Cox would need an X-ray to determine whether or not he had a bowel obstruction. His parents decided it would be better to wait until the X-ray department was open in normal working hours. However, Mr Cox deteriorated so they rang the Out of Hours service again and an ambulance was called.
- 7 Mr Cox was admitted to the Medical Admissions Unit of the Trust early on the morning of 25 September 2004. He had an X-ray and had just returned to the Medical Admissions Unit when he suffered a cardiac arrest. Sadly, the resuscitation attempt was unsuccessful and he died. A post mortem was carried out which concluded that he had died of aspiration pneumonia (caused by inhaling vomit into the lungs) and paralytic ileus (cessation of normal bowel activity), following peritonitis (inflammation of the lining of the abdomen).
- 8 Mr Cox's parents were profoundly shocked and saddened by the sudden death of their son. They strongly believe doctors failed to listen to their concerns about the extent of their son's distress or to their view that he might have been suffering from either a bowel obstruction or appendicitis. They believe that if they had been listened to their son might not have died. Mr and Mrs Cox's recollections and views about the care and treatment provided for their son are set out in detail in later sections of this report.

- 9 Mr Cox's parents have given permission for Mencap to act as their representative.

The overarching complaint

- 10 Mr Cox's parents believe their son's death was avoidable and that he received less favourable treatment for reasons related to his learning disabilities. I have called these aspects of their complaint 'the overarching complaint'.

Complaint against the Surgery

- 11 Mr Cox's parents complain that:

Complaint (a): during August and September 2004, doctors at the Surgery failed to diagnose that their son had appendicitis and failed to carry out further investigations when it was clear he was in pain and they were expressing concern about his condition.

Complaint (b): the Surgery did not act on a letter from a learning disability nurse about their son's epilepsy medication.

Complaint (c): the Surgery did not provide a reasonable response to their complaint.

Complaint against the Out of Hours GP

- 12 Mr Cox's parents complain that:

Complaint (d): the Out of Hours GP did not tell them how serious their son's condition was and the delay in calling an ambulance and getting him to hospital may have affected the outcome of his illness.

Complaint against the Trust

- 13 Mr Cox's parents complain that:

Complaint (e): their son should have been treated with greater urgency. They say his pain was not managed; communication was poor; they did not receive an explanation about what was happening; their questions were not answered; their concerns were not listened to; and staff were insensitive. They also complain that they were excluded from the room when attempts were being made to resuscitate their son and, as a result, they were unable to comfort him and lost the opportunity to say goodbye.

Complaint (f): the Trust did not provide a reasonable response to their complaint.

Complaint against the Healthcare Commission

- 14 Mr Cox's parents complain about:

Complaint (g): the way the Healthcare Commission handled their complaint. In particular, they do not consider the Healthcare Commission's report bore any relation to their complaints and they are concerned that the Healthcare Commission did not take account of the specialist clinical advice they submitted with their complaint.

- 15 Mr Cox's parents believe they have not had answers to all their questions and they hope my investigation will provide them with those answers. They do not want others to go through the same experiences as their son.

The Ombudsman's remit, jurisdiction and powers

General remit of the Health Service Ombudsman

- 16 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In the exercise of my wide discretion I may investigate complaints about NHS bodies such as trusts, family health service providers such as GPs, and independent persons (individuals or bodies) providing a service on behalf of the NHS.
- 17 When considering complaints against an NHS body, I may look at whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the body, a failure by the body to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.
- 18 Failure or maladministration may arise from action of the body itself, a person employed by or acting on behalf of the body, or a person to whom the body has delegated any functions.
- 19 When considering complaints against GPs, I may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Again, such action may have been taken by the GP himself or herself, by someone employed by or acting on behalf of the GP or by a person to whom the GP has delegated any functions.
- 20 I may carry out an investigation in any manner which, to me, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as I think fit.
- 21 If I find that service failure or maladministration has resulted in an injustice, I will uphold the complaint. If the resulting injustice is unremedied, in line with my *Principles for Remedy*, I may recommend redress to remedy any injustice I have found.

Remit over the Healthcare Commission

- 22 By operation of section 3(1E) of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints about injustice or hardship in consequence of maladministration by any person exercising an NHS complaints function. As the Healthcare Commission is the second stage of the NHS complaints procedure set out in the *National Health Service (Complaints) Regulations 2004*, it is within my remit.

Premature complaints

- 23 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Health Service Ombudsman generally may not investigate any complaint until the NHS complaints procedure has been invoked and exhausted, and this is the approach I have taken in the majority of NHS complaints made to me.

- 24 However, section 4(5) makes it clear that if, in the particular circumstances of any case, I consider it is not reasonable to expect the complainant to have followed the NHS route, I may accept the case for investigation notwithstanding that the complaint has not been dealt with under the NHS complaints procedure. This is a matter for my discretion after proper consideration of the facts of each case.
- 25 In this instance, Mr Cox's parents had not complained directly to the Out of Hours GP, although they had asked the Healthcare Commission to investigate the care and treatment provided by the Out of Hours GP. In order to obtain a complete picture of the events leading up to Mr Cox's death and to provide the complainants with a full response to their complaint, I exercised my discretion to investigate the complaint against the Out of Hours GP under the provisions of the Act which govern my work.
- 27 I obtained specialist advice from a number of professional advisers (my Professional Advisers): Dr T Owen and Dr E Ward, both GPs (my First and Second GP Advisers); Dr E M Phillips, a consultant gastroenterologist (my Gastroenterology Adviser); Mr D Richens, a consultant surgeon (my Surgical Adviser); Dr T Malpass, an Accident and Emergency consultant (my A&E Adviser); Ms L Etherington, a senior hospital nurse (my Nursing Adviser); and Ms M Setterfield, a learning disability nurse (my Learning Disability Adviser).
- 28 My Professional Advisers are specialists in their field and in their role as my advisers they are completely independent of any NHS body and the Healthcare Commission. Their role is to help me and my investigative staff understand the clinical aspects of complaints.
- 29 In this report I have not referred to all the information examined in the course of my investigation, but I am satisfied that nothing significant to the complaint or my findings has been overlooked.

The investigation

- 26 During the investigation my investigator met Mr Cox's parents and their representatives to ensure I had a full understanding of their complaint. I examined complaint correspondence between Mr Cox's parents and the Surgery, the Trust and the Healthcare Commission, and documents relating to the attempted resolution of the complaint as well as health records from the Surgery, the Out of Hours GP and the Trust. The Surgery, the Trust and the Out of Hours GP all provided additional information in response to my enquiries.

My decision

- 30 Having considered all the available evidence related to Mr Cox's parents' complaint, including their recollections and views and their response to my draft report, and taken account of the clinical advice I have received, I have reached the following decisions.

Complaint against the Surgery

- 31 Although doctors from the Surgery did not diagnose Mr Cox's appendicitis, I find **no service failure** in the care and treatment they provided for him. The GP visits and telephone consultation were of a reasonable standard in the circumstances and doctors at the Surgery were aware of the need, highlighted by his parents, to consider a bowel obstruction and appendicitis. Nor do I criticise the Surgery regarding his epilepsy medication. I find **no maladministration** in the way the Surgery handled Mr Cox's parents' complaint. I **do not uphold** the complaint against the Surgery.

Complaint against the Out of Hours GP

- 32 I find **no service failure** in the care and treatment provided by the Out of Hours GP. I find he carried out a comprehensive examination, acted appropriately in asking the Surgery to review Mr Cox later that day, provided suitable medication, put measures in place to monitor him and acted promptly when his parents telephoned again. I find the Out of Hours GP could not have predicted that Mr Cox would deteriorate rapidly. I **do not uphold** the complaint against the Out of Hours GP.

Complaint against the Trust

- 33 I find **no service failure** in the care and treatment provided by the Trust. I find the observations and investigations carried out when Mr Cox was admitted to the Trust were reasonable. I acknowledge it would have been better had Mr Cox received pain relief earlier but, in the light of the extensive tests which were being undertaken, I do not regard this as a

service failure. I do not criticise the decision not to allow Mr Cox's parents to stay in the room while their son was being resuscitated. I find **no maladministration** in the way the Trust handled Mr Cox's parents' complaint. I **do not uphold** the complaint against the Trust.

Complaint against the Healthcare Commission

- 34 I find **maladministration** in the way the Healthcare Commission reviewed the complaints against the Surgery and the Trust. This maladministration meant Mr Cox's parents did not get a proper review of their complaint. This is an unremedied injustice. I **uphold** the complaint against the Healthcare Commission.

The overarching complaint

- 35 I have found no evidence that Mr Cox received less favourable treatment for reasons related to his learning disabilities and I do not conclude his death was avoidable.
- 36 In this report I explain the detailed reasons for my decision and comment on the areas where Mr Cox's parents have expressed particular concern.

Section 2: the basis for my determination of the complaints

Introduction

- 37 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, I generally begin by comparing what actually happened with what should have happened.
- 38 So, in addition to establishing the facts that are relevant to the complaint, I also need to establish a clear understanding of the standards, both of general application and which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. I call this establishing the overall standard.
- 39 The overall standard has two components: the general standard which is derived from general principles of good administration and, where applicable, of public law; and the specific standards which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.
- 40 Having established the overall standard I then assess the facts in accordance with the standard. Specifically, I assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard.
- 41 If so, I then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

- 42 The overall standard which I have applied to this investigation is set out below.

The general standard

Principles of Good Administration

- 43 Since it was established my Office has developed and applied certain principles of good administration in determining complaints of service failure and maladministration. In March 2007 I published these established principles in codified form in a document entitled *Principles of Good Administration*.
- 44 The document organises the established principles of good administration into six Principles. These Principles are:
- Getting it right
 - Being customer focused
 - Being open and accountable
 - Acting fairly and proportionately
 - Putting things right, and
 - Seeking continuous improvement.
- 45 I have taken all of these Principles into account in my consideration of Mr Cox's parents' complaint and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:¹

¹ *Principles of Good Administration* is available at www.ombudsman.org.uk

'Getting it right' means:

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

'Being customer focused' means:

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

'Being open and accountable' means:

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.

- Stating criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for actions.

'Acting fairly and proportionately' means:

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

'Putting things right' means:

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

‘Seeking continuous improvement’ means:

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Principles for Remedy

- ⁴⁶ In October 2007 I published a document entitled *Principles for Remedy*.²
- ⁴⁷ This document sets out the Principles that I consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how I think public bodies should put things right when they have gone wrong. It also confirms my own approach to recommending remedies. The *Principles for Remedy* flows from, and should be read with, the *Principles of Good Administration*. Providing fair and proportionate remedies is an integral part of good administration and good service, so the same principles apply.
- ⁴⁸ I have taken the *Principles for Remedy* into account in my consideration of Mr Cox’s parents’ complaint.

The specific standards

Disability discrimination

Legal framework

Disability Discrimination Act 1995

- ⁴⁹ The sections of the *Disability Discrimination Act 1995* most relevant to the provision of services in this complaint were brought into force in 1996 and 1999 respectively. Although other parts of the *Disability Discrimination Act 1995* were brought into force in 2004 and further provisions added by the *Disability Discrimination Act 2005*, these changes either post-date or are not directly relevant to the subject matter of this complaint.
- ⁵⁰ Since December 1996 it has been unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified.
- ⁵¹ Since October 1999 it has in addition been unlawful for service providers to fail to comply with the duty to make reasonable adjustments for disabled people where the existence of a practice, policy or procedure makes it impossible or unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.
- ⁵² It has also been unlawful since October 1999 for service providers to fail to comply with the duty to make reasonable adjustments so as to provide a reasonable alternative method of making the service in question available to disabled people where the existence of a physical feature makes it impossible or

² *Principles for Remedy* is available at www.ombudsman.org.uk

unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

- 53 Since October 1999 it has been unlawful for service providers to fail to comply with the duty to take reasonable steps to provide auxiliary aids or services to enable or facilitate the use by disabled people of services that the service provider provides, unless that would necessitate a permanent alteration to the physical fabric of a building or unless such failure is justified.

Policy aims

- 54 The *Disability Discrimination Act 1995* recognises that the disabling effect of physical and mental impairment will depend upon how far the physical and social environment creates obstacles to disabled people's enjoyment of the same goods, services and facilities as the rest of the public.
- 55 The key policy aim behind the legislation is to ensure that as far as reasonably possible disabled people enjoy access not just to the same services, but to the same standard of service, as other members of the public. In other words, those who provide services to the public, whether in a private or public capacity, are to do whatever they reasonably can to eradicate any disadvantage that exists for a reason related to a person's physical or mental impairment.
- 56 The critical component of disability rights policy is therefore the obligation to make 'reasonable adjustments', which shapes the 'positive accent' of the *Disability Discrimination Act 1995*. This obligation recognises that very often equality for disabled people requires not the same treatment as everyone else but different treatment. The House of Lords made

explicit what this means in a case (*Archibald v Fife Council*, [2004] UKHL 32, judgment of Baroness Hale) which, although arising from the *Part 2* employment provisions of the *Disability Discrimination Act 1995*, has bearing on the *Part 3* service provisions also:

'The 1995 Act, however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment.'

- 57 As the Court of Appeal has also explained, specifically in respect of the *Part 3* service provisions of the *Disability Discrimination Act 1995* (*Roads v Central Trains* [2004] EWCA Civ 1451, judgment of Sedley LJ), the aim is to ensure 'access to a service as close as it is possible to get to the standard offered to the public at large'.

Policy and administrative guidance

Disability Rights Commission Codes of Practice

- 58 Between April 2000 and October 2007 the Disability Rights Commission had responsibility for the enforcement and promotion of disability rights in Britain. In that capacity, and by virtue of the provisions of the *Disability Rights Commission Act 1999*, it had a duty to prepare statutory codes of practice on the law. These statutory codes of practice, although not legally binding, are to be taken into account by courts and tribunals in determining any issue to which their provisions are relevant.

- 59 Before the establishment of the Disability Rights Commission in April 2000, the relevant Secretary of State, on the advice of the National Disability Council, published a statutory code of practice on the duties of service providers under Part 3 of the *Disability Discrimination Act 1995* entitled *Code of Practice: Goods, Facilities, Services and Premises* (1999), itself a revision of an earlier code of practice published in 1996.
- 60 On its establishment in 2000, the Disability Rights Commission consulted on a further revised code of practice, which came into force on 27 May 2002 as the *Disability Discrimination Code of Practice (Goods, Facilities, Services and Premises)*. The revised code of practice not only updated the previous codes but anticipated the changes to the law that were due to come into effect in 2004, in particular with respect to the duty to remove obstructive physical features.
- 61 The 2002 code made it clear that a service provider's duty to make reasonable adjustments is a duty owed to disabled people at large and that the duty is 'anticipatory':
- 'Service providers should not wait until a disabled person wants to use a service which they provide before they give consideration to their duty to make reasonable adjustments. They should be thinking now about the accessibility of their services to disabled people. Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.'*
- 62 It also drew attention to the pragmatic strain of the *Disability Discrimination Act 1995*. For example, in respect of the forthcoming 'physical features' duty, the code says:
- 'The Act does not require a service provider to adopt one way of meeting its obligations rather than another. The focus of the Act is on results. Where there is a physical barrier, the service provider's aim should be to make its services accessible to disabled people. What is important is that this aim is achieved, rather than how it is achieved.'*
- Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)**
- 63 In 2001 the Department of Health published a White Paper, explicitly shaped by the relevant legislation (including the *Disability Discrimination Act 1995* and the *Human Rights Act 1998*), with a foreword written by the then Prime Minister, outlining the Government's future strategy and objectives for achieving improvements in the lives of people with learning disabilities.
- 64 The White Paper identified four key principles that it wanted to promote: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion (in the sense of being part of mainstream society and being integrated into the local community).
- 65 As the White Paper explained, the intention was that 'All public services will treat people with learning disabilities as individuals, with respect for their dignity'.

66 The fifth stated objective of the Government was to *'enable people with learning disabilities to access health services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary'*.

67 The Department of Health also published in 2001 two circulars aimed jointly at the health service and local authorities, focusing on the implementation of Valuing People and including detailed arrangements for the establishment of Learning Disability Partnership Boards: *HSC 2001/016* and *LAC (2001) 23*.

68 The Department of Health has published a series of reports to help the NHS meet its duties under the *Disability Discrimination Act 1995*.

Signposts for success in commissioning and providing health services for people with learning disabilities (1998)

69 This was published by the Department of Health and was the result of extensive consultation undertaken with people with learning disabilities, carers and professionals with the aim of informing good practice. It was targeted at the whole NHS and emphasises the need for shared values and responsibilities, respecting individual rights, good quality information and effective training and development. It also encourages the use of personal health records. The accompanying executive letter *EL (98)3* informs chief executives of the availability of the guidance.

Doubly Disabled: Equality for disabled people in the new NHS – access to services (1999)

70 This Department of Health report, also aimed at the whole NHS, contains a specific section on learning disability. It provides guidance for managers with specific responsibility for advising on access for disabled patients to services

and employment. It also provides information for all staff on general disability issues. The accompanying circular *HSC 1999/093* emphasises the purpose of the document saying:

'... it will be essential for service providers to ensure that they have taken reasonable steps to ensure that services are not impossible or unreasonably difficult for disabled people to use.'

Once a Day: A Primary Care Handbook for people with learning disabilities (1999)

71 This was issued jointly by the Department of Health and the Royal College of General Practitioners, and was specifically aimed at primary care services. It draws attention to the interface between primary care and general hospital services and sets out actions which healthcare providers should take to facilitate equal access to health services for people with learning disabilities. The overall purpose of the handbook was described in the accompanying circular *HSC 1999/103* which says:

'The purpose of this guidance, for GPs and primary care teams, is to enhance their understanding, improve their practice and promote their partnerships with other agencies and NHS services.'

In practice

72 The practical effect of the legal, policy and administrative framework on disability discrimination is to require public authorities to make their services accessible to disabled people. To achieve this objective they must take all reasonable steps to ensure that the design and delivery of services do not place disabled people at a disadvantage in their enjoyment of the benefits provided by those services.

73 Failure to meet this standard will mean not only that there is maladministration or service failure, but that there is maladministration or service failure for a disability related reason. This does not require a deliberate intention to treat disabled people less favourably. It will be enough that the public authority has not taken the steps needed, without good reason.

74 To be confident that it has met the standard, a public authority will need to show that it has planned its services effectively, for example, by taking account of the views of disabled people themselves and by conducting the risk assessments needed to avoid false assumptions; that it has the ability to be flexible, for example, by making reasonable adjustments to its policies, practices and procedures, whenever necessary; and by reviewing arrangements regularly, not just when an individual disabled person presents a new challenge to service delivery.

75 It should also be noted that a failure to meet the standard might occur even when the service in question has been specially designed to meet the needs of disabled people. This might be because, for example, the service design meets the needs of some disabled people but not others, or because good design has not been translated into good practice.

76 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsman will be mindful of that in determining the overall quality of administration and service provided in the

particular case. In cases involving disabled people, such considerations are so integral to good administration and service delivery that it is impossible to ignore them.

Human rights

Legal framework

Human Rights Act 1998

77 The *Human Rights Act 1998* came into force in England in October 2000. The *Human Rights Act 1998* was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. To that extent, the *Human Rights Act 1998* did not so much create new substantive rights for UK citizens but rather established new arrangements for the domestic enforcement of those existing substantive rights.

78 It requires public authorities (that is, bodies which exercise public functions) to act in a way that is compatible with the *European Convention on Human Rights*; it requires the courts to interpret statute and common law in accordance with the *European Convention on Human Rights* and to interpret legislation compatibly with the *European Convention on Human Rights* wherever possible; and it requires the sponsors of new legislation to make declarations when introducing a Bill in Parliament as to the compatibility of that legislation with the *European Convention on Human Rights*.

79 Of particular relevance to the delivery of healthcare to disabled people by a public authority are the following rights contained in the *European Convention on Human Rights*:

- Article 2 Right to life
- Article 3 Prohibition of torture, or inhuman or degrading treatment
- Article 14 Prohibition of discrimination.

Policy aims

80 When the UK Government introduced the *Human Rights Act 1998*, it said its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new ‘*human rights culture*’ among public authorities and among the public at large.

81 A key component of that human rights culture is observance of the core human rights principles of Fairness, Respect, Equality, Dignity and Autonomy for all. These are the principles that lie behind the *Human Rights Act 1998*, the *European Convention on Human Rights* and human rights case law, both in the UK and in Strasbourg.

82 These principles are not new. As the Minister of State for Health Services remarked in her foreword to *Human Rights in Healthcare – A Framework for Local Action* (2007):

‘The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.’

83 The policy implications for the healthcare services are also apparent, as one aspect of that aim of using human rights is to improve service delivery. As the Minister of State also observed:

‘Quite simply we cannot hope to improve people’s health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people’s lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.’

84 At the time of the introduction of the *Human Rights Act 1998* in October 2000, the importance of human rights for disabled people was recognised. Writing in the Disability Rights Commission’s publication of September 2000 entitled *The Impact of the Human Rights Act on Disabled People*, the then Chair of the Disability Rights Commission noted that:

‘The Human Rights Act has particular significance for disabled people ... The withdrawal or restriction of medical services, the abuse and degrading treatment of disabled people in institutional care, and prejudiced judgements about the parenting ability of disabled people are just some of the areas where the Human Rights Act may help disabled people live fully and freely, on equal terms with non-disabled people.’

In practice

85 The practical effect of the legal, policy and administrative framework on human rights is to create an obligation on public authorities not only to promote and protect the positive legal rights contained in the *Human Rights Act 1998* and other applicable human rights instruments but to have regard to the practical application of the human rights principles of Fairness, Respect, Equality, Dignity and Autonomy in everything they do.

- 86 Failure to meet this standard will not only mean that the individual has been denied the full enjoyment of his or her rights: it will also mean that there has been maladministration or service failure.
- 87 To be confident that it has met the requisite standard, a public authority will need to show that it has taken account of relevant human rights principles not only in its design of services but in their implementation. It will, for example, need to show that it has made decisions that are fair (including by giving those affected by decisions a chance to have their say, by avoiding blanket policies, by acting proportionately and by giving clear reasons); that it has treated everyone with respect (including by avoiding unnecessary embarrassment or humiliation, by enabling individuals to make their own choices so far as practicable, and by having due regard to the individual's enjoyment of physical and mental wellbeing); that it has made genuine efforts to achieve equality (including by avoiding unjustifiable discrimination, by taking reasonable steps to enable a person to enjoy participation in the processes that affect them, by enabling a person to express their own personal identity and by actively recognising and responding appropriately to difference); that it has preserved human dignity (including by taking reasonable steps to protect a person's life and wellbeing, by avoiding treatment that causes unnecessary mental or physical harm, and by avoiding treatment that is humiliating or undignified); and that it has promoted individual autonomy (including by taking reasonable steps to ensure that a person can live independently).
- 88 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsman will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving health and social care, such considerations are so integral to the assessment of good administration and good service delivery that it is impossible to ignore them.

Healthcare

National guidance

- 89 In 1996 the Resuscitation Council (UK), a charity whose aim is to improve patient outcome after cardiac arrest, issued good practice advice, *Should Relatives Witness Resuscitation?*. The advice is not statutory but was guidance current at the time of the events complained about. The report recognises that the presence of relatives during attempted resuscitation is a controversial issue. The advice also recognises that when someone collapses elsewhere than in A&E there may be fewer staff, space and privacy available to enable family members to be properly supported through the traumatic event. It states that this should not preclude the adoption of a flexible policy, balancing local difficulties against the relatives' needs.

Professional standards

The General Medical Council

90 The General Medical Council (the body responsible for professional regulation of doctors) publishes a booklet, *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet is clear that it represents standards which the General Medical Council expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of work, including record keeping. Key sections of the booklet current at the time of this complaint are set out at Annex A.

91 Paragraph 5 of Good Medical Practice, 2001, says:

'The investigation or treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age, or social or economic status, to prejudice the treatment you arrange.'

The Nursing and Midwifery Council

92 In 2002 the Nursing and Midwifery Council (the body responsible for professional regulation of nurses) published a booklet, *The Nursing and Midwifery Council code of professional conduct* (the Code of Conduct), which contains general and specific guidance on how nurses should approach their work. The booklet represents the standards which the Nursing and Midwifery Council expects nurses to meet.

93 Paragraph 1 of the Code of Conduct current in 2004 said:

'You are personally accountable for your practice. This means that you are answerable for your actions and omissions, regardless of advice or directions from another professional.'

'You have a duty of care to your patients and clients, who are entitled to receive safe and competent care.'

94 Paragraph 2 of the Code of Conduct said:

'As a registered nurse, midwife or health visitor, you must respect the patient or client as an individual.'

‘...’

'You are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'

95 Paragraph 4 of the Code of Conduct emphasised the importance of teamwork and communication. It said:

'As a registered nurse, midwife or health visitor, you must co-operate with others in a team.'

'The team includes the patient or client, the patient's or client's family, informal carers and health and social care professionals in the National Health Service, independent and voluntary sectors.'

'You are expected to work co-operatively within teams and to respect the skills, expertise and contributions of your colleagues. You must treat them fairly and without discrimination.'

'You must communicate effectively and share your knowledge, skill and expertise with other members of the team as required for the benefit of patients and clients.'

'Health care records are a tool of communication within the team. You must ensure that the health care record for the patient or client is an accurate account of treatment, care planning and delivery.'

Complaint handling

NHS complaint handling

- 96 Prior to 2004 complaint handling in the NHS was subject to various Directions which required NHS trusts to have written procedures for dealing with complaints within their organisation (known as local resolution) and to operate the second element of the complaints procedure (independent review). Complaints against primary care providers were dealt with at the local level under practice-based complaints procedures required under the providers' terms of service.
- 97 However, on 30 July 2004 the *NHS (Complaints) Regulations 2004* (the Regulations) came into force, and created the procedure applicable to this complaint. These Regulations made detailed provision for the handling of complaints at local level by NHS bodies and, if the complainant was dissatisfied with this local resolution, for the complaint to be given further consideration by the Healthcare Commission. Complaints
- 98 *Complaints against NHS bodies* The Regulations (Regulation 3(2)) emphasise that complaint handling arrangements by NHS bodies at the local level must ensure that complaints are dealt with speedily and efficiently and that complainants are treated courteously and sympathetically and, as far as possible, involved in decisions about how their complaints are handled. The guidance issued by the Department of Health to support the Regulations emphasises that the procedures should be open, fair, flexible and conciliatory, and encourage communication on all sides, with the primary objective being to resolve the complaint satisfactorily while being fair to all parties.
- 99 *Part II* of the Regulations (Regulations 3 to 13) sets out the statutory requirements for NHS bodies managing complaints at the local level and deals with such matters as who may make complaints, when they may be made and the matters which may be complained about. A dedicated complaints manager must be identified along with a senior person in the organisation to take responsibility for the local complaints process and for complying with the Regulations. Regulation 13 states that the response to the complaint, which must be signed by the Chief Executive where possible, must be sent to the complainant within 20 working days from when the complaint was made, unless the complainant agrees to a longer period. That response must also inform complainants of their right to refer the complaint to the Healthcare Commission.

against primary care providers continue to be dealt with at the local level by practice-based complaints procedures, but likewise move to the Healthcare Commission for the second stage of the process.

Complaints against GPs

- ¹⁰⁰ Guidance to GPs is found in the 1996 *Practice-based Complaints Procedures. Guidance for General Practices*. This is intended to be a good practice guide and sets out a model for a practice-based complaints procedure with sample resource leaflets and suggested forms. It is not intended to be prescriptive, so the only mandatory part of the guidance is that relating to the national criteria. These criteria, found in paragraph 3.1, are:
- Practice-based procedures should be managed by the practice.
 - One person should be nominated to manage the procedure.
 - The procedure must be in writing and must be publicised (and should include details of how to complain further).
 - Complaints should normally be acknowledged within two working days and an explanation normally provided within ten working days.
- ¹⁰¹ The aim of the practice-based complaints procedure is to make the process more accessible, speedier and fairer to everyone and to try to resolve most complaints at practice level. Detailed procedures are expected to be workable, flexible and ‘user-friendly’ for patients and practices alike.

Complaint handling by the Healthcare Commission

- ¹⁰² Complainants who are dissatisfied with the outcome of their complaint may ask the Healthcare Commission to consider the complaint, and *Part III* of the Regulations (Regulations 14 to 19) sets out the statutory requirements on the Healthcare Commission when considering complaints at this second level.

- ¹⁰³ Regulation 16 states that the Healthcare Commission must assess the nature and substance of the complaint and decide as soon as it is reasonably practicable how it should be dealt with ‘*having regard to*’ a number of matters including the views of the complainant and the body or person complained against and any other relevant circumstances. There is a wide range of options available to the Healthcare Commission for dealing with the complaint, apart from investigating it, including taking no further action, referring the matter back to the body or person complained about with recommendations as to action to resolve the complaint, and referring the matter to a health regulatory body.
- ¹⁰⁴ If the Healthcare Commission does decide to investigate, it must send the proposed terms of reference to the complainant and the body or person complained about (and any other body with an interest in the complaint) for comment. Once the investigation begins, the Healthcare Commission has a wide discretion in deciding how it will conduct the investigation (Regulation 17) and this may include taking such advice as seems to it to be required, and requesting (not demanding) the production of such information and documents as it considers necessary to enable it properly to consider the complaint. The Healthcare Commission has established its own internal standards for the handling of complaints and although, for example, the Regulations do not specify the type of advice to be taken the Healthcare Commission has acknowledged the need to seek appropriate guidance from a clinical adviser with relevant experience and expertise. Likewise, although the Regulations set no specific timescales for it to complete the investigatory process (Regulation 19 merely requires it to prepare a written report of its investigation ‘*as soon as is reasonably practicable*’), the

Healthcare Commission has said that it aims in the majority of cases to take no longer than six months to complete the process.

- 105 The report produced by the Healthcare Commission at the end of its investigation must summarise the nature and substance of the complaint, describe its investigations, summarise its conclusions, including any findings of fact, its opinion on the findings and the reasons for its opinion, and recommend what action should be taken and by whom to resolve the complaint or otherwise.

Section 3: the investigation

Background

106 I have outlined the background to the complaint in Section 1 of this report. I say more about the key events associated with each aspect of the complaint in the relevant sections which follow.

Information about appendicitis

107 Information about the nature of appendicitis is central to an understanding of Mr Cox's illness and the actions of healthcare professionals involved in his care. It is, therefore, relevant to my consideration of Mr Cox's parents' complaint. My Gastroenterology Adviser provided the following information about diagnosis of acute appendicitis:

Diagnosis of acute appendicitis is extremely difficult. Only 1 to 3% of patients presenting with abdominal pain will have acute appendicitis and many patients with appendicitis will have atypical symptoms. The symptoms may be very mild, or they may be symptoms not normally associated with appendicitis. There is little or no evidence in the medical literature to support the existence of a diagnosis of 'grumbling appendicitis'. The majority of people who experience episodic abdominal pain and eventually undergo an appendectomy have a normal appendix removed and the abdominal pain is attributed to other causes.

Symptoms are variable in all patients so the precise nature of the symptoms is very important in pointing towards a diagnosis of appendicitis. The classical symptoms are loss of appetite, abdominal discomfort in the upper area which moves between 36 to 48 hours later to the central abdomen and then to

the lower right side of the abdomen. Fever is often not present early on. If the patient is admitted for investigation even the tests in hospital may not confirm a diagnosis. For example, the white blood cell count is not raised in every patient and abdominal CT scan is not diagnostic in around 4 to 20% of cases.

Research has shown that appropriate clinical diagnosis is often not made until after at least two visits from a doctor. Delay in diagnosis is directly related to complication rates. Increased complications, such as intra-abdominal sepsis (serious infection), peritonitis, wound sepsis, chest infections, septicaemia (infection in the blood stream) and death are all associated with perforation of the appendix.

The complaint against the Surgery

Complaint (a): diagnosis and investigations

108 Mr Cox's parents complain that GPs at the Surgery failed to diagnose their son's condition and failed to carry out further investigations when it was clear that he was in some pain and they were expressing concern about his condition.

Key events

109 Mr Cox was usually fit. However, he suffered from epilepsy, for which he received medication. He was also prone to constipation and needed enemas on a regular basis. When they first moved to the area his parents had found it difficult to obtain bowel care for him. Therefore, Mr Cox's parents had taken care of his bowel problems for five years prior to his illness in August 2004.

110 Mr Cox's parents first noticed their son was unwell on the evening of 3 August 2004. When his distress, which was indicated by a repeated noise in his throat, continued the next day they thought his pain might have been caused by an incident when the seatbelt in the car had tightened round him. They telephoned the Surgery and the First GP conducted a home visit later that day. The First GP concluded that Mr Cox may have had some bruising from the seatbelt incident. In response to Mr Cox's parents' concerns, the First GP said that she did not think the cause of the pain was an intestinal blockage, either because of constipation or a problem with his appendix.

111 On 6 August 2004 Mr Cox was still making the same repeated noises, which his parents felt indicated that something was wrong with him and he was in pain. Mr Cox's father rang the Surgery and requested a home visit. The Second GP visited and examined Mr Cox. She concluded that he did not have an intestinal blockage or appendicitis.

112 When Mr Cox was still making the repeated noises on 9 August 2004, his father rang the Surgery and asked the Third GP to visit. The Third GP examined Mr Cox. Mr Cox's father has said that the Third GP assured them there was nothing wrong with his son.

113 The Surgery's records also indicate a telephone conversation with the Second GP on 9 August 2004. This says Mr Cox's father had called to say his son was feeling better.

114 On 21 September 2004 Mr Cox had difficulty sleeping again. He had a bad epileptic seizure the following morning and his parents rang the Surgery and spoke to the First GP. The First GP advised them to administer the epilepsy medication rectally and she visited later that day.

Mr Cox's parents said that their son was making a slight coughing noise, was having difficulty in swallowing and his abdomen was tender. The First GP diagnosed a viral infection. Later that day there was a telephone consultation between the family and the First GP which was not documented.

115 On 23 September 2004 Mr Cox's father called the Surgery and spoke to the Third GP. This telephone conversation was not documented by the Surgery.

116 The following day, 24 September 2004, Mr Cox's father telephoned the Third GP to request a prescription for more rectal epilepsy medication, as Mr Cox was still having seizures and was not able to take his oral medication. His father picked up the prescription later the same day. There was no further contact with the Surgery before Mr Cox was admitted to hospital.

Mr Cox's parents' recollections and views

117 Mr Cox's parents said the possibility of a bowel obstruction was always a matter of concern for them because sometimes an enema did not relieve their son's constipation. Mr Cox's mother explained that she had also been worried about the possibility of him developing appendicitis. She had read an article about a girl who had died as a consequence of a failure to diagnose appendicitis and she was concerned that her son would not be able to let them know if he developed this condition.

118 Mr Cox's parents said that after 30 years of caring for their son they knew when he was trying to communicate that something was wrong. His mother said he was always quiet, so if he made a noise or appeared agitated it meant something was wrong.

- 119 Mr Cox's parents said they knew their son was in pain when he was ill in August 2004 because he had been up a great deal in the night. He was also making strange noises in his throat, had difficulty swallowing and he was off his food. They recalled that when the Second GP visited she assured them that their son did not have appendicitis and that he was *'just being Warren'*. The Third GP, who usually saw Mr Cox, also visited. He could find nothing wrong and Mr Cox's parents were reassured. They said their son was unwell for about a week to ten days and then improved. They said they felt relieved by his improvement. However, with hindsight, they were convinced that he had experienced a 'grumbling appendix'.
- 120 Mr Cox's parents said that when their son became ill in September 2004 his symptoms were more severe. His mother said she had difficulty in giving him his epilepsy medication because he was not eating, and consequently he was having quite severe seizures.
- 121 On 22 September 2004 Mr Cox's parents called the Surgery. They recalled their son was having a bad seizure at the time of the call. They said the First GP told them to give rectal epilepsy medication and that she would visit. When the First GP attended they told her that the last enema, a couple of days previously, had not been successful and so they asked whether their son might have an obstruction or appendicitis. They said the First GP felt Mr Cox's stomach and said his colon was tender. She told them he had a high temperature. They said the First GP suggested that they try another enema and she told them their son had a viral infection which would cause him pain.
- 122 Mr Cox's parents said that the next day, 23 September 2004, their son was not eating and could not therefore take his medication or paracetamol for the pain. Mr Cox's father said he had never seen his son look so ill. He said he telephoned the Surgery and spoke to the First GP. He told her how ill and distressed his son was, that he was having difficulty with his throat, could only drink a small amount and could not swallow anything whole. The First GP told him his son would look ill as he had a virus and that he would be aching all over. She suggested they remove some of Mr Cox's clothes and open a window to cool him down. Although his parents were still worried, they said they understood he had a virus and hoped to see some improvement in the next day or two.
- 123 Mr Cox's father said he rang the Third GP on 24 September 2004 to ask for a prescription for rectal epilepsy medication as his son was still having bad seizures and was not taking the medication he would normally take with his food. He recalled that when he collected the prescription from the Surgery later that day the Third GP said to *'keep up the good work'*.
- 124 Mr Cox's parents said they had no further contact with the Surgery until two days after their son's death.

The Surgery's position

- 125 The Surgery's position is set out in the First GP's letter of 3 December 2004, in which she responded to Mr Cox's parents' complaint. In that letter the First GP described the actions taken by GPs at the Surgery and the rationale for those actions. Overall, she said that the GPs had *'examined [Mr Cox] fully and carefully and options were considered, both when we saw him with abdominal discomfort in August and again when we saw him in late September'*.

The Surgery's response to my enquiries

126 My investigator made further enquiries of the Surgery. The First GP responded on 10 December 2007. She said she had taken Mr Cox's previous bowel problems into account when forming her diagnosis and she believed she would have considered guidelines on caring for people with learning disabilities during her consultations with him. She also confirmed that she did visit Mr Cox on 22 September 2004 and received a telephone call from his father later that day. She said on the basis of that telephone consultation she decided a further home visit was *'not indicated at that time'*. She said she had not taken a call from Mr Cox's father on 23 September 2004, but that this call was taken by the Third GP.

The advice of my Professional Advisers

My GP Advisers

127 My GP Advisers both agreed that the events of August 2004 were unlikely to have been directly related to Mr Cox's final illness in September that year.

128 My First GP Adviser said the First GP's notes for 22 September 2004 were typical of what might be recorded at a consultation involving abdominal pain. Both my GP Advisers said the GP records show that Mr Cox had refused food and that he had a slightly raised temperature. The notes say his ears, nose, throat and chest were clear and the abdominal signs and symptoms seemed to be low down on the left side. My First GP Adviser explained that with appendicitis he would expect pain in the lower right quadrant of the abdomen and would have expected some reaction if Mr Cox had been tender there. Both GP Advisers considered that the First GP's initial examination and diagnosis were reasonable, although my First

GP Adviser said he would have expected to see a record about whether guarding (tensing of the abdominal muscles identified during examination of the abdomen) was present and a record of bowel sounds (noises made by the gut which can be heard through a stethoscope). He also noted that as constipation had been a frequent problem, a rectal examination would have been appropriate.

129 Both my GP Advisers drew attention to the special circumstances of Mr Cox's case. My First GP Adviser said Mr Cox would not be able to convey information such as any change in the site of pain, which would have helped diagnosis. He said clinicians should respond in three ways to a potential lack of information: (i) listen carefully to what carers have to say; (ii) pay more attention to objective findings arising from examination and tests; and (iii) allow a sufficient safety margin by putting arrangements in place to enable a review of the diagnosis. He said these arrangements could include further visits or advising carers to contact the GP after a specified period of time, or if the patient's condition did not improve or deteriorated. He said the doctor could also initiate a telephone follow-up to check on improvement.

130 My First GP Adviser said that in cases such as this where assessment was difficult and pain appeared to be a continuing feature, he would have expected a GP to have a low threshold for going to visit. However, he found no suggestion in the medical notes that a review was arranged. He said (particularly given that there appeared to have been further telephone consultations about Mr Cox's parents' concerns) it would have been reasonable for the family to have expected a GP to have visited again to review the diagnosis.

- 131 My First GP Adviser could not say with certainty at what point appendicitis had developed in September 2004. He also could not say for certain whether or not the outcome would have been different for Mr Cox had appendicitis been identified sooner and an earlier admission arranged.
- 132 My First GP Adviser was critical of the lack of documentation about the telephone conversations.
- My Gastroenterology Adviser*
- 133 My Gastroenterology Adviser said none of the symptoms or signs of appendicitis were present when Mr Cox was ill in August 2004. She explained that loss of appetite is usually the most common and earliest symptom to develop with appendicitis and she noted that in August 2004 Mr Cox was recorded as eating well and his bowels were open with enema assistance. He had no temperature and there were no abnormal abdominal signs. There was, for example, no deep tenderness recorded in the medical notes. She concluded therefore that his illness in August 2004 was unrelated to the later development of acute appendicitis.
- 134 My Gastroenterology Adviser said she found no evidence to indicate that the doctors had dismissed Mr Cox's parents' view that their son was ill in September 2004. She said they could not have conveyed to the doctors the precise nature of their son's pain – where it started, whether it had moved to another part of the abdomen or whether the pain was constant or intermittent. She said it is the lack of such detail which makes the diagnosis of appendicitis difficult when people have communication difficulties.
- 135 My Gastroenterology Adviser considered that the GP's diagnosis of a viral respiratory infection had resulted from misleading symptoms including difficulty in swallowing and a cough. She noted that on 22 September 2004 Mr Cox was refusing food and had a slight fever for which no cause could be found when he was examined. She also noted his abdomen was not distended, but was tender on the left-hand side and it was not unusual for Mr Cox to be constipated. He had no history of vomiting or diarrhoea. My Gastroenterology Adviser said the finding of abdominal tenderness on the left side is very unusual in appendicitis and could be misleading. She said this might be interpreted as a sign of a more generalised abdominal tenderness associated with other conditions.
- 136 My Gastroenterology Adviser said the clinical signs of acute appendicitis had not fully developed at the time of the First GP's visit on 22 September 2004. However, she said that it would have been prudent to examine him again within 12 to 24 hours to assess any development in his symptoms.

My findings

- 137 Mr Cox's parents are dissatisfied with the care provided by the Surgery. They say the GPs should have carried out more investigations and paid more attention to their concerns about their son. They believe that, as a consequence, the GPs failed to diagnose appendicitis.
- 138 Mr Cox's parents are correct in that the GPs did not diagnose their son's appendicitis. We know this because he was admitted to the Trust for investigations of his distended abdomen for which no specific cause had been established. However, the fact that the GPs did not reach a definitive diagnosis does not necessarily mean their actions were unreasonable. This is because

it is not always possible for GPs to make a diagnosis on the basis of the limited information which may be available to them.

139 In order to make an assessment of the GPs' actions I have looked at the treatment the Surgery offered Mr Cox in comparison with the standards set out in Good Medical Practice and considered the guidance in Valuing People and Once a Day.

140 My Professional Advisers have explained why acute appendicitis is difficult to diagnose. Mr Cox's communication difficulties made diagnosis of appendicitis even more difficult. It is against this background that I consider the actions of GPs at the Surgery in August and September 2004.

141 My GP Advisers and my Gastroenterology Adviser have advised me that Mr Cox's illness in August 2004 was not a 'grumbling appendix' and was unrelated to his subsequent illness in September 2004.

142 Having taken account of my Professional Advisers' advice, I am also satisfied that the First GP's examination of Mr Cox on 22 September 2004 was adequate, that the diagnosis was reasonable and that the likelihood of a bowel obstruction and appendicitis was properly considered.

143 The critical question is what did happen, and should have happened, when Mr Cox's parents telephoned the Surgery on 23 September 2004. The absence of a record of that telephone conversation makes my assessment more difficult. The failure to record this consultation is contrary to the Good Medical Practice principle of keeping clear, accurate, legible and contemporaneous patient records. However, there seems to be broad agreement about what

was said. Mr Cox's parents said how ill their son seemed, that he was still not eating and was not able to take his medication. They were assured by the Third GP that these symptoms were consistent with a viral infection. He did not visit Mr Cox.

144 I have received mixed advice on whether the decision not to visit on 23 September 2004 was reasonable. Mr Cox had been examined only 24 hours previously and there were no new symptoms, so in normal circumstances it would seem reasonable that the GP did not visit. However, both my GP Advisers drew attention to Mr Cox's learning disabilities and suggested that, following the examination on 22 September 2004, a further visit, or telephone call, or advice to his parents to contact the Surgery after a specific time could have been considered. My Gastroenterology Adviser similarly said that when assessing a person with communication difficulties and Mr Cox's symptoms, more than one assessment over a period of time would have been prudent.

145 I am conscious that all three of my Professional Advisers have said GPs at the Surgery could or should have considered more proactive management. They did not say definitively that the GPs should have visited Mr Cox on 23 September 2004. Also, I have seen no policy or guidance which says a GP must visit in such circumstances. Furthermore, given the difficulty of diagnosing acute appendicitis, there can be no certainty that a further visit would have resulted in a firm diagnosis at that time or, indeed, a different outcome for Mr Cox. I conclude that, whilst it would have been good, proactive management for a GP to visit Mr Cox on 23 September 2004, the fact that a GP did not visit **does not amount to service failure**.

Complaint (b): epilepsy medication

¹⁴⁶ Mr Cox's parents complain that the Surgery did not act on a letter from a learning disability nurse about their son's epilepsy medication.

Mr Cox's parents' recollections and views

¹⁴⁷ Mr Cox's parents said their son had seen a psychiatrist in 1996. Since then he had not had a neurological examination for his epilepsy and they had simply obtained repeat prescriptions. They recalled that there had been a telephone call from the Surgery to check that his medication was alright.

¹⁴⁸ Mr Cox's mother recalled that a nurse from the Community Learning Disability Team had called about 18 months prior to her son's last illness and said she would write a letter requesting a review of his epilepsy medication, but nothing had subsequently happened and no review had taken place.

The Surgery's position

¹⁴⁹ In her response of 3 December 2004 to Mr Cox's parents' complaint about their son's care and treatment at the Surgery, the First GP explained about his epilepsy medication. She said he was followed up regularly until around 1996 when the hospital consultant said he did not need regular review. She said once someone is balanced on their epilepsy medication there is usually no need to review them unless they suffer more seizures or their weight changes significantly. She noted that Mr Cox's parents had been asked by the Surgery about their son's epilepsy in May 2004 at which point he was having two to four seizures a month. She said the Surgery had no record of a letter from the learning disabilities service, or any other contact, about Mr Cox's epilepsy.

The advice of my Professional Advisers

¹⁵⁰ My First GP Adviser noted that Mr Cox was having two to four seizures a month despite being on three types of epilepsy medication. He said he did not consider Mr Cox's epilepsy was well controlled because a patient with well controlled epilepsy would have no seizures or only very occasional seizures.

¹⁵¹ Both my GP Advisers noted that there had been a telephone assessment of Mr Cox's epilepsy medication in the past year. They said that, although this would not conform to today's standards, it reflected the approach taken at the time. They said records contained no evidence of correspondence from a learning disability nurse.

My findings

¹⁵² Mr Cox's parents are dissatisfied with the way the Surgery managed their son's epilepsy medication and they say the Surgery did not respond to a letter from a learning disability nurse regarding epilepsy medication.

¹⁵³ First, my Professional Advisers could find no evidence of a letter about epilepsy medication and the First GP said there was no such correspondence in the Surgery's documents. Although I do not doubt Mr Cox's parents' version of events, I cannot comment further on this matter without seeing the letter and this piece of evidence has not come to light.

¹⁵⁴ Secondly, I consider the way in which Mr Cox's epilepsy was managed. The Surgery has confirmed that it was usual practice not to carry out regular reviews for a person with epilepsy and I note the First GP told Mr Cox's parents in her response to their complaint that the consultant managing Mr Cox's epilepsy

had said this was not necessary. However, in the same letter the First GP said that Mr Cox's epilepsy had been discussed during a telephone conversation with the Surgery in May 2004.

155 Having considered the advice of my Professional Advisers, I am concerned that there appears to have been no regular review of Mr Cox's epilepsy between 1996 and 2004 and a telephone consultation, such as that which apparently took place in May 2004, would not now be considered adequate. That said, my Professional Advisers have told me that, although this standard of monitoring would not be accepted today, it was accepted practice at the time of the events complained about. Therefore, I find no reason to criticise the Surgery on this point. I find **no evidence of service failure**.

Complaint (c): complaint handling by the Surgery

156 Mr Cox's parents remain dissatisfied with the way the Surgery handled their complaint.

Key events

157 On 13 October 2004 Mr Cox's parents complained to the Surgery about the care and treatment provided to their son. There were five main areas of complaint:

- the GPs had not diagnosed Mr Cox's condition, despite the fact that his family had raised concerns about a bowel obstruction and appendicitis;
- the GPs had not carried out further investigations despite Mr Cox's pain;

- Mr Cox's medication had not been regularly reviewed;
- no action had been taken on the letter about constipation and epilepsy; and
- the GPs had not paid sufficient attention to the views of Mr Cox's parents, who were best placed to understand him when he was not well.

158 In November 2004 the Surgery offered to meet Mr Cox's parents to address the issues complained about but they declined because they preferred to receive a written response.

159 On 3 December 2004 the First GP responded in writing to the complaint. She apologised for the delay, explaining that time had been taken to discuss the case at a meeting of Surgery staff. She said she had reviewed all Mr Cox's GP records and spoken to the pathologist who had carried out the post mortem.

160 In her response the First GP explained the sequence of events in the Surgery's care and treatment of Mr Cox in August and September 2004. She explained in detail what the GPs had done during consultations, what they had found and the reasons for their decisions. She said the Surgery had no record of a letter from a nurse about Mr Cox's constipation and epilepsy and explained why Mr Cox's medication had not been reviewed routinely. She said the hospital consultant had decided Mr Cox's epilepsy medication did not need to be reviewed regularly and it was usual that once a person was established on drugs there was no need for regular review if their condition was stable.

161 The First GP said:

'I fully understand your concerns about your son but I feel that I did treat his condition seriously, did assess him and was fully aware of the difficulties in assessing a man who was unable to communicate fully with me. I think he was examined fully and carefully and options were considered, both when we saw him with abdominal discomfort in August and again when we saw him in late September.'

162 She expressed her sympathy to Mr Cox's parents and offered to meet with them if they would like further explanations as she realised that it was difficult to explain things fully in a letter.

My findings

163 In Section 2 of this report I have summarised the Regulations relating to the way in which NHS bodies should handle complaints. I have compared the Surgery's actions with those Regulations.

164 I find the Surgery acted appropriately in offering to try and resolve the complaint at a local resolution meeting and in offering a further meeting once it had provided a written response.

165 I find the Surgery took appropriate action to investigate Mr Cox's parents' concerns by looking at recorded evidence, seeking further evidence about the cause of death and discussing the case with professional colleagues. I also find the First GP's response addressed all the key issues in the complaint and provided an appropriate level of detail and explanation. The tone of the response was sensitive and conciliatory.

166 The Surgery took around six weeks to respond to the complaint which is outside the timeframe set out in the Regulations. However, it is clear that the Surgery initially hoped to resolve Mr Cox's parents' concerns through a meeting which was offered in November 2004. Furthermore, the First GP apologised for the delay and explained why the response had been delayed.

Complaint handling by the Surgery: my conclusion

167 In terms of complaint handling, I find the Surgery acted in line with the Regulations and demonstrated good practice as set out in my *Principles of Good Administration*. I conclude that there is **no evidence of maladministration** in the way in which the Surgery responded to Mr Cox's parents' complaint.

The complaint against the Surgery: my conclusion

168 I have studied the evidence about Mr Cox's parents' complaint against the Surgery regarding his care and treatment in August and September 2004, and the management of his epilepsy medication. I have considered the complainants' recollections and views and the professional advice I have received. I am satisfied that the actions of GPs at the Surgery were reasonable and I find **no evidence of service failure** on their part. I have also considered the way in which the Surgery responded to the complaint made by Mr Cox's parents and I find **no evidence of maladministration**.

169 Therefore, I **do not uphold** Mr Cox's parents complaint against the Surgery.

The complaint against the Out of Hours GP

Complaint (d): actions of the Out of Hours GP

¹⁷⁰ Mr Cox's parents complain that the Out of Hours GP who saw their son on 25 September 2004 did not tell them how serious his condition was and they believe the doctor's delay in calling an ambulance may have affected the eventual outcome of his illness.

Key events

¹⁷¹ In the early hours of the morning of 25 September 2004, Mr Cox deteriorated and his parents put him to bed. They then noticed his stomach had swollen up. At 1.30am they called the Out of Hours service. A GP visited 45 minutes after he received the call. He examined Mr Cox and advised that an X-ray was needed. Mr Cox's parents asked whether it was necessary to take their son to hospital immediately because they were concerned that there might be a considerable wait for the X-ray department to open. They felt this would be distressing for him and would have made the management of his epilepsy more difficult. The Out of Hours GP gave Mr Cox pain relief and advised his parents to contact the Out of Hours service again if there was any change or they continued to be worried.

¹⁷² Mr Cox's parents contacted the Out of Hours service again at 3.46am and said their son seemed worse. The Out of Hours GP received the details of the second call just before 4.00am. He arranged for an ambulance to take Mr Cox to hospital urgently. The ambulance record shows that a 'GP urgent' call was received at 4.00am. The ambulance arrived to collect Mr Cox at 4.27am and reached the hospital at 4.41am.

Mr Cox's parents' recollections and views

¹⁷³ Mr Cox's parents said they called the Out of Hours service on 25 September 2004 because they were so worried about their son. They said they expressed their concerns to the service about a bowel obstruction or appendicitis. Mr Cox's father said he noticed how distended his son's stomach was and that he had never seen anything like it. He said his son could not bend his legs and was clearly in great discomfort. Mr Cox's father said when he rang the Out of Hours service, he got the impression that the Out of Hours doctors thought Mr Cox's parents had got matters out of proportion and there was a reluctance to visit.

¹⁷⁴ Mr Cox's parents understood that the reason why the Out of Hours GP had suggested an X-ray should be taken was to determine whether or not Mr Cox had a bowel obstruction. They said that at no time had the Out of Hours GP indicated to them that their son was dangerously ill. Because they had previously attended the hospital outside normal hours and had a long wait for the X-ray department to open, they had asked the Out of Hours GP if it would be better for Mr Cox if they waited until the X-ray department would definitely be open. They said they had also taken into account, when asking this question, the fact that they could not give their son his epilepsy medication while waiting in a hospital corridor for an X-ray. They were anxious to prevent him having seizures if possible. They recalled that the Out of Hours GP had said he would be off duty in half an hour and if they were still worried by their son's condition they should give him a call within that time. They said they did contact him again and they recalled he had said that he would call an ambulance straight away,

but it took an hour to arrive. Mr Cox's father said that by the time the ambulance arrived his son was in considerable distress, and the wait seemed to last for an eternity. He said the time they had waited had indicated to them that their son was not being treated as an emergency.

- 175 Mr Cox's mother said she thought her son had displayed the classic symptoms of appendicitis, which was why they had drawn their concerns about this and a possible bowel obstruction to the attention of all the doctors who had seen him.
- 176 Mr Cox's parents said that had the Out of Hours GP conveyed to them an urgency in the need to take Mr Cox to hospital they would have done so immediately.

Information from the Out of Hours GP

- 177 The Out of Hours GP recorded that Mr Cox was seen 45 minutes after the call was received on 25 September 2004. He noted that he had been informed that Mr Cox appeared to have breathing difficulties. His record of the examination says he advised admission to A&E but Mr Cox's parents '*would prefer analgesic and review, if no better will need a visit later today*'.
- 178 In correspondence with my investigator, the Out of Hours GP said the visit of 25 September 2004 was the only contact he had had with Mr Cox's parents. It was now over three years since the events occurred and he could only provide information based on his contemporaneous records and say what he would usually do. He explained that he would have been concerned by Mr Cox's condition, otherwise he would not have advised admission to hospital. He believed he had informed Mr Cox's parents of his concerns at the time. However, he had also taken into account their anxiety about

admission and their desire to minimise any distress caused to their son. As a result, he agreed to try pain relief and to review the situation if Mr Cox did not improve. He noted that Mr Cox's parents had understood that further investigations should be conducted because they called back later. He thought he had explained that he was arranging an ambulance to arrive within the hour and this would have indicated that he thought Mr Cox needed urgent attention.

The advice of my Professional Advisers

My GP Advisers

- 179 My First GP Adviser said there were clear signs that Mr Cox was seriously unwell by the time the Out of Hours GP was called. He said Mr Cox's abdomen was distended which was a potentially serious examination finding, and he had a raised pulse and raised temperature with reduced bowel sounds. My First GP Adviser said the records indicate clearly what the Out of Hours GP had said and that during the consultation he advised that Mr Cox should be admitted to hospital at that point. He had advised the family to call back if Mr Cox's condition worsened, but he also logged a request for a GP from the Surgery to visit the following day. My First GP Adviser said when Mr Cox's parents called him for a second time the Out of Hours GP promptly arranged admission to hospital.
- 180 My First GP Adviser considered that the Out of Hours GP had made an appropriate examination, kept good records and put in place a strategy for monitoring Mr Cox whilst taking account of his parents' views about not wanting to attend hospital in the early hours of the morning. Furthermore, he had acted promptly when they called a second time. He said there were no grounds for criticism of the Out of Hours GP.

My Gastroenterology Adviser

181 My Gastroenterology Adviser considered that the Out of Hours GP made a comprehensive assessment. She said the Out of Hours GP had noted that Mr Cox had not eaten for more than 48 hours, his bowels were not open and on rectal examination there was no stool present. She also said the Out of Hours GP had noted that an enema had not produced any result, that Mr Cox had a fever and a raised pulse rate, and his abdomen was grossly distended and painful. My Gastroenterology Adviser said these factors would point to a diagnosis of intestinal obstruction and the Out of Hours GP advised appropriately that Mr Cox should attend hospital for abdominal X-ray.

182 My Gastroenterology Adviser noted that in the light of Mr Cox's parents' concerns, the Out of Hours GP gave Mr Cox a rectal painkiller and advised that they should call again if they were still worried.

183 My Gastroenterology Adviser said it was clear that the signs of intestinal obstruction were well established when the Out of Hours GP saw Mr Cox, but it would not have been possible for him to give a definitive diagnosis without further investigation. She concluded that the Out of Hours GP's attendance was timely, that his assessment was thorough and his recommended action was appropriate. She said the analgesia chosen was correct for a patient where the diagnosis was not yet fully established.

The complaint against the Out of Hours GP: my findings and conclusion

184 Mr Cox's parents say the Out of Hours GP did not inform them their son was dangerously ill. They say they did not expect him to be admitted to hospital, only that he would attend for X-rays.

185 My First GP Adviser and Gastroenterology Adviser agree that the Out of Hours GP provided a good standard of care. He carried out a comprehensive examination, acted appropriately in asking the Surgery to review Mr Cox later that day, provided suitable medication, put measures in place to monitor Mr Cox and acted promptly when Mr Cox's parents telephoned again. Both Professional Advisers remarked that the Out of Hours GP took appropriate note of Mr Cox's parents' concerns about taking their son for an X-ray in the early hours of the morning.

186 I understand that Mr and Mrs Cox maintain the view that, had the Out of Hours GP conveyed to them that their son needed to be taken to hospital urgently, they would have done so immediately. I do not doubt the integrity of Mr and Mrs Cox's recollection that they were not told about the seriousness of their son's illness. At the same time I can understand why the Out of Hours GP thought he had conveyed to Mr and Mrs Cox, through his actions and advice described above, that their son was very ill.

187 I can also understand why Mr Cox's parents thought the Out of Hours GP did not call an ambulance immediately, because it did not arrive for around half an hour. However, there is clear evidence in the ambulance record that, having spoken to Mr Cox's parents for a second time, the Out of Hours GP immediately called for an urgent ambulance to take Mr Cox to hospital.

188 I consider it is reasonable for the Out of Hours GP to have thought he had conveyed the urgency of the situation to Mr Cox's parents. I can also appreciate that their son's very rapid decline after admission to hospital might have led Mr Cox's parents to think that the Out of Hours GP had not acted quickly enough to arrange the admission. However, it is clear to

me that, at the time of his visit, the Out of Hours GP could not have predicted Mr Cox's subsequent rapid deterioration and that his actions were therefore appropriate at the time. Moreover, I have not found that, had Mr Cox been admitted to hospital immediately after the Out of Hours GP's first visit, his life could have been saved.

189 Having considered all the available evidence and the advice of my Professional Advisers I am satisfied that the Out of Hours GP acted reasonably. I conclude that there is **no evidence of service failure** by the Out of Hours GP.

190 Therefore, I **do not uphold** Mr and Mrs Cox's complaint against the Out of Hours GP.

191 In reaching this conclusion I would like to make clear, for the avoidance of any doubt, that I have seen nothing in any of the evidence which suggests that Mr and Mrs Cox were in any way to blame for the death of their son. On the contrary, I have no doubt that at all times they acted in what they understood and believed to be his best interests.

The complaint against the Trust

Complaint (e): care and treatment at the Trust

192 Mr Cox's parents complain that their son should have been treated with greater urgency when he reached hospital. They also say communication was poor, their concerns were not listened to and staff were insensitive. They complain that they were excluded from the room when attempts were being made to resuscitate their son and, as a result, they were not with him when he died. They consider he

received less favourable treatment for reasons related to his disabilities and that his death was avoidable.

193 I have considered all the complaints about care and treatment together because the events complained about and the evidence available are closely linked.

Key events

194 Mr Cox arrived at the Trust and was received by nursing staff in the Medical Admissions Unit at 4.43am. He was seen within ten minutes by a junior doctor, who started tests and sent him for an X-ray. The duty specialist registrar (a more senior doctor) was called.

195 Observations made at 5.00am show Mr Cox had a rapid pulse, but normal blood pressure and his temperature was only slightly raised. A monitor showed that the level of oxygen in his blood was normal. A saline drip was started at 5.20am and blood was taken for testing at 5.46am.

196 At 6.15am, following the X-ray, Mr Cox began to vomit while a nurse was getting drugs to treat his pain. The junior doctor recorded that at about 6.00am he was called from writing up his notes to help turn Mr Cox on his side because he was vomiting. He returned to his work only to hear the arrest alarm a few minutes later.

197 The junior doctor recorded a cardiac arrest call at 6.24am. Records about the resuscitation set out the actions and drugs given from 6.23am until attempts to resuscitate Mr Cox were stopped at 6.43am when he was declared dead.

Mr Cox's parents' recollections and views

- 198 Mr Cox's parents said when they arrived at the Trust they were surprised that they were taken to the Medical Admissions Unit as they had expected just to attend for an X-ray. They recalled that staff looked anxious but no one explained how ill their son was. Mr Cox's father said the doctor who was on duty did not appear to have a good command of English. He had not explained anything to them and they could not understand what he was saying. Mr Cox's mother said she had to ask for pain relief for her son.
- 199 Mr Cox's mother said when they went to the X-ray department they were asked if their son bit or scratched, which she thought was insensitive. She said the radiographer had told them they were right about a blockage in Mr Cox's abdomen but had said nothing about anything else, although he had been X-rayed in the chest area as well as the abdomen.
- 200 Mr Cox's mother said she had placed a pillow under her son's head while he was in the X-ray department because his head had fallen back and increased his discomfort. When they left the radiographer had taken the pillow saying, *'you can't take that we will never get it back'*. Mr Cox's mother said it was clear that her son was uncomfortable and she thought the radiographer's comment showed a lack of concern for his comfort and distress.
- 201 Mr Cox's mother said she had also asked nurses in the Medical Admissions Unit about giving her son his epilepsy medication and had been told she could not do this because it might be dangerous. She noted that she did not mean medication should be given orally because she knew Mr Cox could not swallow. She felt that no attempt had been made to take her son's epilepsy into account.
- 202 On return from X-ray Mr Cox's parents noticed that staff still looked anxious. With hindsight, they were sure staff were aware that Mr Cox was very ill. His mother said she asked one nurse what was the matter but then Mr Cox started to vomit and there had been a rush for a bowl. She said there appeared to be more concern that he might be sick in the bed than concern about his wellbeing.
- 203 Mr Cox's mother recalled that she had handed the X-ray notes to a nurse. There was no doctor present at the time and she understood he had gone to write up his notes. She then saw her son's colour was changing and drew the nurse's attention to this. The nurse had said *'oh my God'* and rang a bell, and repeatedly shouted at Mr Cox's father to pass tubes to her. Mr Cox's father said there were several tubes to hand and he did not know which ones she meant. They said they were then pushed out of the room and a lot of people attended including a different doctor who had said *'it's big'* and left them. They said they could hear their son crying out as attempts were made to resuscitate him. This caused them considerable distress. They said they were informed their son had died and told that if he had lived he would have needed major surgery which he would have been unlikely to survive.
- 204 Mr Cox's parents said they had been left bewildered by the events of 25 September 2004 and still had unresolved questions about their son's care. They attended hospital thinking this admission would mirror previous ones. They had expected to be going home after Mr Cox had been X-rayed and received appropriate treatment, which they had anticipated would be an enema. Instead they had been pushed out of the room when their son had stopped breathing, they had had to listen to his distress as attempts were made to resuscitate him and had not been present when he died. They said they had,

therefore, lost the opportunity to say goodbye. They believe that had they been present during resuscitation they would have been able to comfort their son and perhaps might have been able to have given him the will to live.

The Trust's position

205 The Trust's position about the care and treatment provided for Mr Cox on 25 September 2004 is set out in its responses to his parents' complaints.

206 In summary, the Trust said Mr Cox received '*expedient and correct*' care and treatment. It said he was admitted as an emergency and had been seen by a doctor within ten minutes of arrival. Examinations, tests and investigations had been carried out urgently and a diagnosis of intestinal obstruction reached. After an X-ray was performed Mr Cox returned to the Medical Admissions Unit and a senior doctor was called. However, his condition deteriorated unexpectedly. His heart stopped and he stopped breathing. The Trust said when resuscitation attempts began Mr Cox's parents were led away to a nearby seating area.

207 The Trust also said the nursing team on the Medical Admissions Unit were experienced in dealing with patients with learning disabilities.

The advice of my Professional Advisers

My Surgical Adviser

208 My Surgical Adviser said when Mr Cox arrived at the Trust he received timely and appropriate treatment. He did not believe anything more could have been done in the limited time that was available. He considered any shortfalls in the service provided by the Trust appeared to be related primarily to communication with Mr Cox's parents. He noted the Trust had accepted this and had apologised for some of

the failings. However, he thought there were some areas where further explanation would have been helpful, for example to address their concerns about the way Mr Cox was resuscitated.

209 My Surgical Adviser commented on the timing of Mr Cox's admission and its impact on the outcome of his illness. He said the earlier Mr Cox was admitted, the greater the chances of his survival would have been. Having studied the post mortem report, he concluded that Mr Cox had developed appendicitis and a few days later the appendix had ruptured leading to generalised peritonitis. My Surgical Adviser said had Mr Cox been admitted prior to the development of peritonitis he would have had a better chance of survival. However, he also said it is impossible to establish exactly when the appendicitis began.

My A&E Adviser

210 My A&E Adviser said the observations and investigations carried out on admission were acceptable and an appropriate history was taken. She said the working diagnosis of intestinal obstruction was in keeping with the history and examination findings and Mr Cox's vital signs (measures including pulse, respirations and blood pressure) did not indicate that cardiac arrest was imminent.

211 With reference to Mr Cox's parents' complaint that no one informed them that their son was dangerously ill, my A&E Adviser said he was only in the unit for a little over 90 minutes, during which time a range of essential tests were carried out. She said that although it would have been evident on admission that Mr Cox was seriously ill, it would not have been possible to predict the subsequent sequence of events. In the light of this it was reasonable for staff to wait for a senior doctor to make his assessment

and confirm the junior doctor's diagnosis before discussing Mr Cox's care with his parents. The senior doctor would have been in a position to explain any surgery required and give them a clearer idea of prognosis. My A&E Adviser noted that a senior doctor had been called, but unfortunately by the time he arrived Mr Cox had already collapsed. She confirmed this was an event that could not have been foreseen.

212 That said, my A&E Adviser commented that the junior doctor and nurses should have updated Mr Cox's parents about their plan of care, including asking a senior doctor to review their son, the actions they were taking to address immediate problems, investigations such as hydration and blood tests, and answered any questions as far as it was possible.

213 With regard to Mr Cox's epilepsy, my A&E Adviser said staff had appropriately focused on his immediate needs. She said once a drip had been inserted this could have been used to control any seizures which may have occurred. She did not consider there had been any major failing in this respect.

214 My A&E Adviser said Mr Cox's abdomen was distended and tender and he would have been in considerable discomfort. She considered Mr Cox was known to be in pain when he was admitted and he should have been given pain relief then.

215 My A&E Adviser noted that many hospitals now have an open attitude to the presence of relatives during resuscitation. However, whether relatives can be present depends on available space and staff. She said if there are not enough staff to support relatives and if space is limited, the resuscitation effort must take precedence. She also said it is clear that the resuscitation had been very traumatic for Mr Cox's parents

and she considered an explanation of what happened at the resuscitation attempt would have been helpful for them.

216 My A&E Adviser's overall conclusion was that, with the exception of the management of pain relief and some shortcomings in communication, the medical treatment Mr Cox received on admission was appropriate and reasonable.

My Gastroenterology Adviser

217 My Gastroenterology Adviser confirmed that Mr Cox's condition could not have been assessed more quickly and initial treatment with intravenous fluids was speedily followed by further assessment with blood tests and X-rays. She said the junior doctor's clinical diagnosis was accurate but that further treatment, such as placement of a nasogastric tube, would not have been appropriate until the X-ray had confirmed the diagnosis.

218 My Gastroenterology Adviser also said had Mr Cox not collapsed he would not have gone for an operation immediately, but would have required further assessment and treatment with intravenous antibiotics before a decision was made about his fitness for surgery.

219 My Gastroenterology Adviser explained that normal practice would have been that as soon as Mr Cox returned from X-ray he would have been reviewed by a senior doctor. Clinical assessment and review of the X-rays would have followed, a further management plan would have been drawn up, and there would have been a discussion with Mr Cox's parents about the diagnosis and the severity of his illness. She said the severity of Mr Cox's condition could not be confirmed until the X-rays had been examined. Unfortunately, Mr Cox arrested and this discussion did not occur.

220 My Gastroenterology Adviser noted that when Mr Cox collapsed he had no pulse or blood pressure and no electrical activity in his heart. She said very few patients survive such an event, despite resuscitation attempts. My Gastroenterology Adviser said Mr Cox would not have been able to cry out when he was being resuscitated because he was unconscious and unable to make sounds. She noted that his parents had thought he was crying out in distress, but this was likely to have been noises associated with the attempt to revive him.

My Nursing Adviser

221 My Nursing Adviser found it was clear from entries in the health record, that the nurse who first assessed Mr Cox recognised his poor condition and contacted the doctor immediately. My Nursing Adviser noted further nursing assessments and plans were incomplete, for example nothing was recorded about management of his epilepsy medication and she said more frequent basic observations, such as pulse and respiratory rate, should have been recorded. However, my Nursing Adviser also said, given the circumstances, she did not consider the failure to fully complete the nursing assessment was unreasonable. She said it would have been appropriate and acceptable for the assessment to have been completed, and for a care plan to have been written once his condition had been stabilised.

222 My Nursing Adviser was concerned about the management of Mr Cox's pain. She noted he was not given pain relief until just before he collapsed. She could find no appropriate assessment of his pain although there was space on the assessment chart for this. Although she recognised the difficulty of the circumstances, such as the need for urgent X-ray, she considered the lack of pain assessment may have been partly the reason

why he was not given pain relief when he was admitted.

223 My Nursing Adviser noted that Mr Cox's father had been distressed at being asked to pass 'tubes' to the nurse. She said that while having to ask carers to act in this way might not be ideal, in an emergency situation such as this, she could not criticise the nurse for her actions.

224 My Nursing Adviser explained that allowing carers and family to witness resuscitation has been shown to result in a positive outcome for the majority of people when they can be supported properly. However, she also said that to allow people to witness such a potentially distressing and traumatic event unsupported by trained staff may have lasting negative effects. She also noted that in A&E staff are often warned in advance of the arrival of a collapsed patient and have time to prepare, whereas the environment in a Medical Admissions Unit is likely to be very different. This is because a cardiac arrest cannot always be anticipated and there may not be enough staff to offer sufficient support to witnesses. She agreed with my A&E Adviser that except in A&E, it is difficult to involve witnesses at cardiac arrests.

My Learning Disability Nursing Adviser

225 My Learning Disability Nursing Adviser noted that there are still a number of terms used internationally in relation to people with learning disabilities and this can be confusing. She said it was only in 2004 that the term 'mental handicap' stopped being used in the coding systems of the NHS to be replaced by the term 'learning disability'. While she found it disappointing to see that 'mental handicap' had been written in Mr Cox's health record, she felt that the use of this term had not necessarily reflected a poor attitude towards him.

My findings

226 Mr Cox's parents are dissatisfied with the care and treatment their son received when he was admitted to the Trust on 25 September 2004. Shortly after he was admitted he suffered an unexpected cardiac arrest and died, so I can fully understand why they question whether his death could have been avoided if he had received different care and treatment.

227 Understandably, Mr Cox's parents' key question is whether more urgent treatment should have been initiated. My Professional Advisers have told me that Mr Cox was very ill when he was admitted and that staff recognised this and took appropriate action to assess him quickly before arranging urgent investigations and a review by a senior doctor. Regrettably, before the senior doctor arrived Mr Cox collapsed. My Professional Advisers have told me that this collapse was a sudden event which could not have been predicted and which he was unlikely to survive. Having studied all the evidence about events in the early morning of 25 September 2004, including Mr Cox's parents' recollections, and taken account of the advice of my Professional Advisers, I find there is no reason to believe that Mr Cox would have survived if different or quicker treatment had been provided by staff at the Trust.

228 Mr Cox's parents are particularly concerned that their son may have been in pain when he was admitted and that his pain was not treated appropriately. Health records show Mr Cox had been in the Trust for around 90 minutes before he was given pain relief. My A&E Nursing Adviser commented that Mr Cox's pain should have been assessed and pain relief should have been administered earlier. However, my other Advisers were less critical, recognising that

the staff had focused on the urgent action to diagnose and treat Mr Cox. I recognise it is likely that Mr Cox was in pain and pain relief should have been given more quickly to alleviate his distress. However, in the circumstances, especially in the light of the extensive tests, diagnosis and treatment which were taking place at the time, I do not consider this shortcoming amounted to service failure.

229 Mr Cox's parents remain distressed by remarks in their son's health records, particularly the reference to him being 'mentally handicapped' and they ask whether this indicated he was treated less favourably with regard to his learning disabilities. I have considered this issue in the light of the advice of my Learning Disability Nursing Adviser and, although I consider the remarks were insensitive, I do not find they indicated that Mr Cox was treated less favourably by the doctor concerned. The Trust has acknowledged and apologised for the distress this insensitivity caused Mr Cox's parents.

230 I now turn to the way staff communicated with Mr Cox's parents about his medical condition. My Professional Advisers have told me that medical staff would not have been in a position to provide much information about their diagnosis and proposed treatment plan until X-rays and tests had been completed. However, I share my A&E Adviser's view that it would have been preferable if more information could have been provided about Mr Cox's immediate management when he arrived at the Medical Admissions Unit. That said, I recognise there was a great deal of activity at the time and staff were focusing on assessing and investigating Mr Cox's condition. Therefore, I consider that, on balance, it was reasonable for staff to wait until tests had been completed before discussing Mr Cox's

condition with his family. Staff could not have predicted he would collapse suddenly and they expected they would have time to gather more information before explaining their findings and treatment plan to his family.

- 231 Mr Cox's parents feel deeply that they should not have been asked to leave the area where their son was being resuscitated. They feel they should have been allowed to be with him when he died and that they would have been able to comfort him at this time. In considering this issue I have taken account of advice from my Professional Advisers and referred to the guidelines about whether relatives should be present to witness resuscitation.
- 232 First, I consider whether Mr Cox's parents should have been allowed to stay with him during the attempted resuscitation. As I have said in paragraph 89, the Resuscitation Council (UK) issued good practice advice in 1996. This advice recognises that outside A&E departments there may be insufficient space and staff available to enable family members to be supported properly when resuscitation is being attempted. It is clear to me that this was the case when Mr Cox was being resuscitated in the Medical Admissions Unit at the Trust. Although I sympathise with Mr Cox's parents' wish to be with him when he died, I do not feel that I can criticise the decision to ask them to leave the area where he collapsed so staff could focus their effort on attempting to save his life.
- 233 I now turn to the issue of whether Mr Cox would have been aware of his parents' presence had they been with him while he was being resuscitated. Mr Cox's parents believe they could hear their son crying out, but they were not allowed to comfort him. However, as my Gastroenterology Adviser has explained, Mr Cox

would have been unconscious because his heart had stopped and he was not breathing so it would not have been possible for him to cry out. Therefore, although I fully acknowledge the distress which Mr Cox's parents suffered at this time, I am persuaded that the noises which they heard were not the result of their son crying out in pain and, regrettably, there is little they could have done to comfort him during the resuscitation attempt.

Care and treatment at the Trust: my conclusion

- 234 I have studied all the evidence about the actions of staff at the Trust when Mr Cox was admitted on 25 September 2004 and taken account of his parents' recollections and the advice of my Professional Advisers. Although I have identified some areas where the care and treatment could have been better, for example management of Mr Cox's pain and communication with his family, I have found the overall standard of care and treatment provided was in line with prevailing standards. I found no evidence to suggest that Mr Cox was treated less favourably for reasons related to his disability. I conclude that on balance, although there were shortcomings in the service provided by the Trust, these **did not amount to service failure**.

Complaint (f): complaint handling by the Trust

- 235 Mr Cox's parents remain dissatisfied with the way the Trust handled their complaint.

Key events

236 On 13 October 2004 Mr Cox's parents complained to the Trust about the care and treatment provided to their son. There were seven main areas of complaint:

- they felt unsupported and were not told how ill their son was;
- Mr Cox was not treated urgently enough;
- the admitting doctor did not notice Mr Cox's distended abdomen;
- staff were not concerned about Mr Cox's epilepsy medication;
- Mr Cox was not given pain relief;
- staff did not have an understanding of how to care for people with learning disabilities; and
- some of the radiographer's actions and comments were inappropriate.

237 A few days later Mr Cox's father clarified specific points of the complaint. In particular he said staff did not seem to realise the seriousness of the situation or take appropriate action although his son was in a critical condition.

238 On 22 November 2004 the Trust responded in writing to the complaint. The response referred to written health records and recollections of staff who were involved in caring for Mr Cox. It also referred to a review of events which was conducted by the surgical consultant who was on-call on 25 September 2004. Based on the consultant's review the Trust explained how Mr Cox's condition had developed and what

had happened inside his abdomen. It also noted the consultant had concluded that the care and treatment offered to Mr Cox had been '*expedient and correct*'.

239 The response included an explanation of the sequence of events when Mr Cox was admitted. It gave details about the actions of individual staff and the reasons for those actions. It included an explanation of the way in which the junior doctor had assessed Mr Cox, the examinations he performed and tests he carried out. It also explained that he had diagnosed an intestinal obstruction and had asked a senior doctor to review Mr Cox.

240 In particular, the response addressed the complaint about epilepsy medication and pain control, explaining that it had not been safe to give Mr Cox oral medication, but injections had been given for pain and nausea after the X-ray.

241 With regard to the actions and attitude of the radiographer, the Trust apologised for any unintentional offence which she had caused. The response also said that the team in the Medical Admissions Unit were used to caring for people with learning disabilities. Nonetheless, following the complaint, additional action had been taken to ensure staff were aware of local guidelines for managing patients with learning disabilities.

242 The Trust also offered to meet with Mr Cox's parents if they would find this helpful.

243 In January 2005 Mr Cox's parents made a second complaint because they had found the words '*mentally handicapped*' written in their son's health record by one of the doctors treating him on 25 September 2004. They said this indicated to them that staff were not prepared to put

in extra effort to assess Mr Cox's pain and, therefore, he had received a lower standard of care with regard to his learning disabilities and communication problems.

- 244 On 3 February 2005 the Trust responded offering an apology and explanation. It said the doctor concerned was new to this country and was unaware that he had used what was considered inappropriate language. The response included additional information about initiatives the Trust had taken to improve care and management of patients with learning disabilities. Mr Cox's parents were invited to work with Trust staff on further improvements if they wished.

My findings

- 245 In Section 2 of this report I have summarised the Regulations relating to the way in which NHS bodies should handle complaints. I have compared the Trust's actions with those Regulations.
- 246 I find the Trust took appropriate action to investigate Mr Cox's parents' concerns by looking at recorded evidence and questioning staff involved in Mr Cox's care and treatment. It was also appropriate for the Trust to ask a consultant who had not been involved in the events complained about to review the care and treatment provided.
- 247 I find the Trust's response addressed all the key issues in the complaint and provided an appropriate level of detail and explanation. The tone of the response was sensitive and conciliatory. Appropriate apologies were offered relating to acknowledged shortcomings. The Trust also demonstrated commitment to providing a remedy for Mr Cox's parents and

this was in line with my *Principles for Remedy*. In addition to apologies, it gave an explanation about developments at the Trust which were relevant to the matters complained about and invited Mr Cox's parents to help with those developments. The Trust also appropriately offered a meeting to try and achieve resolution of any outstanding concerns.

- 248 Both of the Trust's responses were sent within the timeframe set out in the Regulations.

Complaint handling by the Trust: my conclusion

- 249 In terms of complaint handling, I find the Trust acted in line with the Regulations and demonstrated good practice as set out in my *Principles of Good Administration* and *Principles for Remedy*. I conclude that there is **no evidence of maladministration** in the way in which the Trust responded to Mr Cox's parents' complaints.

The complaint against the Trust: my conclusion

- 250 I have studied the evidence about Mr Cox's parents' complaint against the Trust regarding his care and treatment in the Medical Admissions Unit on 25 September 2004. I have considered the complainants' recollections and views and the professional advice I have received. I am satisfied that the actions of staff at the Trust were reasonable and I find **no evidence of service failure** on their part. I have also considered the way in which the Trust responded to the complaint made by Mr Cox's parents and I find **no evidence of maladministration**.
- 251 Therefore, I **do not uphold** Mr Cox's parents complaint against the Trust.

The complaint against the Healthcare Commission

Complaint (g): the Healthcare Commission's review

252 Mr Cox's parents are dissatisfied with the way the Healthcare Commission (the Commission) handled their complaint. In particular, they do not consider the Commission's report bore any relation to their complaints and they are concerned that the Commission did not take account of the specialist clinical advice they submitted with their complaint.

The basis for my determination of the complaints

253 The regulations and standards which apply to the Commission's handling of complaints are set out in Section 2 of this report. When assessing the way in which the Commission handled Mr Cox's parents' complaint I have regard to those regulations and standards and to my own *Principles of Good Administration* and *Principles for Remedy*.

My jurisdiction and role

254 Section 1 of this report sets out the basis of my jurisdiction in relation to complaints made to me that a person (or body) has sustained injustice or hardship in consequence of maladministration by the Commission in the exercise of its complaint handling function.

255 When complaints have already been reviewed by the Commission, I do not normally carry out an investigation of the original complaint, but investigate the way the Commission conducted its review. Specifically, I consider whether:

- there were any flaws in the Commission's review process which makes the decision unsafe;
- the Commission's decision at the end of the review process was reasonable; and
- the service the Commission provided was reasonable and in line with its own service standards.

256 When I uphold a complaint about the Commission's complaint handling, because I find that the review process was flawed, or the decision unreasonable, I normally refer the complaint back to the Commission for it to remedy the failure by conducting a further review.

My decision

257 For the reasons given below, I **uphold** Mr Cox's parents' complaint about the Commission's complaint handling. However, I did not consider it appropriate to recommend a further review by the Commission. Therefore, I decided to investigate the complaint myself.

The Commission's reviews

Key events

258 On 5 January 2005 Mr Cox's parents set out their complaints to the Commission in two separate letters. One letter centred on their complaints about the Surgery and the Out of Hours service; the other on the care and treatment Mr Cox received from the Trust. They included with their letter advice from a learning disability specialist. It is clear from those letters that Mr Cox's parents wanted to establish in particular whether:

- the Surgery had managed Mr Cox's care appropriately from August to September 2004;

- the actions of the Out of Hours GP had been appropriate;
- Mr Cox was seriously ill when he was admitted to the Trust; and
- the outcome would have been different had he been admitted to hospital earlier.

259 On 19 April 2005 the Commission decided to undertake a review of the complaint. The Commission took clinical advice from a GP Adviser and reported its draft decision to Mr Cox's parents on 27 February 2006. The Commission did not regularly update them about progress or any departure from its published timescales for the review.

The Commission's first decision

260 The Commission concluded that:

- the onset of appendicitis would have occurred over a period of a few days, and it was unlikely, therefore, that Mr Cox's episode of ill health in August 2004 related to his final illness in September 2004;
- telephone conversations had not been appropriately recorded by the Surgery;
- Mr Cox's epilepsy medication had been monitored appropriately by the Surgery; and
- the standard of care and treatment Mr Cox had received from the Trust had been appropriate.

261 The Commission made various recommendations to the Surgery including that it improve its record keeping. The Commission did not address Mr Cox's parents' complaint about the Out of Hours GP.

The Commission's final decision

262 On 28 March 2006 Mr Cox's parents wrote to the Commission saying they were dissatisfied with the Commission's findings because they felt no nearer to understanding why, or how, their son had died, which was the very purpose of making their complaint. They were also disappointed that no specialist advice about learning disabilities had been taken despite assurances to the contrary. Following those comments, the Commission decided to undertake further work on their complaint. Clinical advice was taken from a different GP Adviser and the case was discussed with a clinical practitioner with experience in the field of learning disabilities.

263 On 22 August 2006 the Commission reported its final decision. The Commission's findings about the Surgery and Trust, and its recommendations, remained broadly the same as in its draft report. The Commission did not address Mr Cox's parents' complaint about the Out of Hours GP and no mention was made in the Commission's decision of the specialist advice which Mr Cox's parents had submitted with their complaint.

My findings

264 I have explained that I assess the way in which the Commission has conducted its review by considering the review process, the decision and whether the service provided was reasonable.

265 I find the Commission's review process was flawed. Mr Cox's parents' complaint to the Commission had two distinct components: the care provided by the Surgery and the Out of Hours GP; and the care provided by the Trust. Despite two attempts, the Commission did not review the care provided by the Out of Hours GP at all. It also failed to respond to the

main thrust of the complaint about the Surgery and the Trust which was to establish whether the outcome for Mr Cox would have been different had he been admitted to hospital and treated earlier.

266 The Commission may take any advice which is needed for it to make a decision. I would expect that when the Commission reviews complaints about clinical care, it would obtain appropriate advice from a Clinical Adviser with relevant experience and expertise. In reaching its decision, the Commission only obtained professional advice from a GP. Clearly, in order to address Mr Cox's parents' complaints about the Trust appropriately, it was also necessary to obtain advice from a suitably qualified hospital clinician. Following Mr Cox's parents' intervention, the Commission did seek advice from a Learning Disability Nurse Adviser. However, the Commission's Adviser's comments were based on the Commission's Case Manager's oral précis of the case, rather than on a review of Mr Cox's clinical records. There is no evidence that the Commission took into account the professional advice which had been submitted.

267 I consider the clinical advice which the Commission obtained to make its decision about Mr Cox's parents' complaints was inappropriate and inadequate. This renders its decision, in respect of their complaint about the Trust, unreliable and unsafe.

268 I also find the service which the Commission provided was poor. It took the Commission 19 months to complete its review. The Commission's service standard at the time was that, in the majority of cases, the review process should take no longer than six months. Whilst I do not consider that failing to complete the review of Mr Cox's parents' complaints within

the Commission's general timeframe would necessarily amount to poor service, the Commission failed to keep them updated about the progress of their complaint. One of the six *Principles of Good Administration* (referred to in Section 2 of this report) is that public bodies should be customer focused, and specifically that they should tell people if things are going to take longer than they had stated they would. Failing to do this, and failing to have kept Mr Cox's parents abreast of the progress of their complaint does not reflect good administrative practice or customer service from the Commission.

269 I conclude that the failings I have identified in the Commission's handling of Mr Cox's parents' complaint amount to **maladministration**.

Injustice

270 The injustice arising from the Commission's maladministration is that Mr Cox's parents experienced a further year and a half of uncertainty about the circumstances of Mr Cox's illness and death. They did not get the proper review of their complaint to which they were entitled and I can understand why they remained frustrated and dissatisfied at the end of the process.

271 Therefore, I **uphold** Mr Cox's parents' complaint against the Commission.

My recommendation

272 I **recommend** that the Commission apologise to Mr Cox's parents for failing to carry out a proper review of their complaint. The Chief Executive of the Commission has accepted my recommendation.

Section 4: the Ombudsman's final comments

273 Mr Cox's parents' overarching complaint is that their son's death was avoidable and he was treated less favourably for reasons related to his learning disabilities.

274 In assessing the actions of the bodies complained about I have taken account of relevant legislation and related policy and administrative guidance as described in Section 2 of this report. I have taken account of available evidence and considered the advice of my Professional Advisers.

275 I have found no service failure in terms of the care and treatment provided to Mr Cox by the Surgery, the Out of Hours GP or the Trust and, although some insensitive remarks were written in the Trust records, I have found no evidence that Mr Cox was treated less favourably by any of the bodies complained about for reasons related to his disability.

276 I have found no maladministration in the way the Surgery or the Trust handled Mr Cox's parents' complaint. I have upheld Mr Cox's parents' complaint against the Healthcare Commission and I have recommended that the Healthcare Commission apologise to them for failing to carry out a proper review of their complaint.

277 In considering whether to make a finding about avoidable death I assess whether the injustice or hardship complained about (in this case Mr Cox's death) arose in consequence of any service failure or maladministration I have identified.

278 Having considered all the evidence and taken account of Mr Cox's parents' recollections and views, as well as the clinical advice I have received, I have found no service failure or maladministration relating to the care and treatment Mr Cox received from any of the bodies complained about. On that basis, my finding is that Mr Cox's death did not arise in consequence of any service failure or maladministration. Therefore, I cannot conclude that his death was avoidable.

Mr Cox's parents' response to my report

279 In their response to my draft report Mr Cox's parents expressed their great sadness at the death of their son, which they believe could have been avoided. They said they still feel very strongly that the actions of the GPs at the Surgery led to a delay in diagnosing his condition and that the Out of Hours GP failed him.

280 Mr and Mrs Cox raised a series of points and questions in response to my draft report. These principally related to the actions of the GPs at the Surgery and the Out of Hours GP, so I asked my First GP Adviser whether the response contained any new evidence which would cause me to question my findings and conclusions. My First GP Adviser told me he had carefully considered the matters raised in the response to the draft report but had found no new evidence that should cause me to reconsider my judgments in this case. My First GP Adviser also addressed a number of specific clinical questions posed by Mr Cox's parents and I have included this information at Annex B.

My concluding remarks

281 I acknowledge that Mr Cox's parents do not agree with all of my findings and decisions. However, I can assure them that their views have been taken into account, their complaints have been thoroughly and impartially investigated and that my conclusions have been drawn from careful consideration of the evidence, including the advice of independent professional advisers. I hope my report will draw what has been a long and complex complaints process to a close.



Ann Abraham
Parliamentary and Health Service Ombudsman

March 2009

ANNEX A

Good Medical Practice, 2001: relevant sections

The duties of a doctor

'Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- *make the care of your patient your first concern;*
- *treat every patient politely and considerately;*
- *respect patients' dignity and privacy;*
- *listen to patients and respect their views;*
- *give patients information in a way they can understand;*
- *respect the rights of patients to be fully involved in decisions about their care;*
- *keep your professional knowledge and skills up to date;*
- *recognise the limits of your professional competence;*
- *be honest and trustworthy;*
- *respect and protect confidential information;*
- *make sure that your personal beliefs do not prejudice your patients' care;*
- *act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;*

- *avoid abusing your position as a doctor; and*
- *work with colleagues in the ways that best serve patients' interests.*

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.'

Providing a good standard of practice and care (sections 2 and 3)

'Good clinical care must include:

- *an adequate assessment of the patient's conditions, based on the history and symptoms and, if necessary, an appropriate examination;*
- *providing or arranging investigations or treatment where necessary;*
- *taking suitable and prompt action when necessary;*
- *referring the patient to another practitioner, when indicated.*

'In providing care you must:

- *recognise and work within the limits of your professional competence;*
- *be willing to consult colleagues;*
- *be competent when making diagnoses and when giving or arranging treatment;*
- *keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions made, the information given to patients and any drugs or other treatment prescribed;*

- *keep colleagues well informed when sharing the care of patients;*
- *provide the necessary care to alleviate pain and distress whether or not curative treatment is possible;*
- *prescribe drugs or treatment, including repeat prescriptions, only where you have adequate knowledge of the patient's health and medical needs. You must not give or recommend to patients any investigation or treatment which you know is not in their best interests, nor withhold appropriate treatments or referral;*
- *report adverse drug reactions as required under the relevant reporting scheme, and co-operate with requests for information from organisations monitoring the public health;*
- *make efficient use of the resources available to you.'*

Working with colleagues (section 36)

'Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide. When working in a team, you must:

- *respect the skills and contributions of your colleagues;*
- *...*
- *communicate effectively with colleagues within and outside the team.'*

ANNEX B

Specific questions raised by Mr Cox's parents in their response to my draft report

My First GP Adviser provided the following information.

The link between constipation and appendicitis

There is no clear link here. When I say no clear link, what I mean is that there is no recognised association that is clinically useful when trying to diagnose patients. It is known that some cases of appendicitis seem to be associated with and probably caused by a small faecalith. This is a little grain of faeculent matter contained within the appendix that seems to be causing inflammation and hence the appendicitis. One might speculate that perhaps these are more likely to occur in somebody with constipation but there is no clearly recognised association of that sort and nothing that is in general use that links the two when trying to assess and diagnose patients. I am quite happy to state that there is no recognised link between the two that is used clinically at the bedside of patients. I have discussed this with a consultant surgeon who agrees with this view.

The link between a blocked bowel and appendicitis

There is not usually a link of this sort. I think the lay phrase blocked bowel could cover two separate well recognised surgical entities. The first is intestinal obstruction where the lumen of the bowel is blocked by, shall we say, faeces and constipation or a large tumour in cancer. The typical signs here are developing colicky abdominal pain, there may be constipation and vomiting, the abdomen may become distended and the bowel sounds, listened to with a stethoscope, become loud and have a characteristic nature. The other situation is a so-called ileus. This is where the bowel is not

blocked but just shuts down and stops working. The overall effect can be similar in that there can be pain, vomiting and constipation. Distension may be present. Peritonitis resulting from a burst somewhere in the stomach or intestines is a potent cause of ileus. In that case, there would also be generalised abdominal pain, typically not of a colicky nature and absent bowel sounds.

The clinical scenario of intestinal obstruction or ileus is not a feature of developing appendicitis. Once the early stages of acute appendicitis are over, it is possible that this could develop. Most people with acute appendicitis where the appendix is not surgically removed will probably develop a ruptured appendix with peritonitis. A variant of that is that the inflamed mass may be walled off into an abscess in the right lower abdomen. This variant is less serious in terms of the general health of the patient and they are more likely to survive this than perforation and peritonitis. A lot of surrounding structures get drawn into the inflammatory mass and this may cause bowel blockage and obstruction. So as a later feature in a typical case, it is possible. One can also get some of the features of ileus if the developing appendicitis is not recognised, perforation goes on to occur and ileus occurs.

In the comments from Mr Cox's parents, there is mention of the GP examining Mr Cox and identifying the fact that his colon was tender. I think in this case, the fact that he had tenderness on the left side was probably rather misleading for the GP. One of the characteristics of appendicitis is pain and tenderness in the right lower abdomen (often called the right iliac fossa). Tenderness on the other side of the abdomen would obviously lead the diagnosis away from appendicitis. Conditions of the large bowel such as diverticulitis or constipation can particularly cause left-sided tenderness.

The link between swallowing problems and appendicitis

Again, there is no recognised link that is clinically useful in assessing and diagnosing patients here. The only aspect that I can think to mention here is somewhat tangential to the case. Particularly in children, there is a recognised cause of abdominal pain called mesenteric adenitis. This is a situation where abdominal pain that can be similar to appendicitis is presented. However, the underlying cause is swollen lymph glands along the course of the intestinal blood supply. It is thought to be caused by a viral infection that may very easily cause a simultaneous sore throat and sometimes swollen lymph glands in the neck as well. So again, in this case, some of the features such as a reported cough and swallowing difficulties might be ascribed to another condition that can cause abdominal pain. In summary, there is no recognised link that is clinically useful.

The link between vocal sounds, acid reflux and bowel blockage

I have looked at and thought about the complainants' line of reasoning here. I think it is theoretically possible that obstruction and distension could be putting pressure on the stomach and causing acid reflux up into the oesophagus (gullet). If that was happening, it would cause indigestion, heartburn-type symptoms. It is conceivable that Mr Cox had such symptoms and made vocal sounds in response to that pain. However, it is my opinion that the pain from peritonitis and abdominal distension would be of a much greater magnitude than the indigestion experienced by this postulated mechanism. I cannot see, even if one accepts that there is a possibility this occurred, how that would be helpful in diagnosing or assessing the problem for the GP. I do not see how the GP could be expected to think

this was acid reflux in the oesophagus. Even if they did, that would again probably represent some false, misleading localisation of the problem away from appendicitis/peritonitis.

The absorption of rectal epilepsy medication

Again, this is an interesting and thoughtful point from Mr Cox's parents which I have considered carefully. I think it is perfectly reasonable to think from a common sense, first principle viewpoint that the presence of constipation might interfere with rectal absorption and/or that administration of enemas might wash out medication from the rectum and make a difference in that way. The question is whether it would make such a significant difference that the GP should have done something else which, in this case, I think would have to be admission for control of epilepsy by perhaps intravenous medication. Here, although the GP might well recognise the theoretical problem, I do not think they would have access to knowledge about how significant a difficulty this would present. I think that continuing to give the medication by the rectal route, despite this potential problem, would represent reasonable general practice.

The link between seizures and diagnosis

Once again here, I do not think there is any specific link that would have been helpful to the GP. It is known that intercurrent illness and the presence of fever itself can apparently lower the seizure threshold and lead to more frequent or more severe convulsions. That is a generally observed phenomenon by epileptics and their carers. There is nothing there that particularly points to a diagnosis of appendicitis. I think the GP would have accepted immediately that there was some other illness going on which in fact they characterised as a viral infection and they would not be surprised that that led to an increase in seizures of itself. That also, of course, was combined with difficulty in giving oral medication which would have had an effect as well. So there is nothing in that line of reasoning that I can see would have pushed the GP to consider appendicitis which is one particular (actually rather rare) cause for fever seen in general practice.

PHSO-0006

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office

ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.

Six lives: the provision of public services to people with learning disabilities

Part four: the complaint made by Mrs Kemp

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Second report

Session 2008-2009

Presented to Parliament pursuant to
section 14(4) of the Health Service Commissioners Act 1993
(as amended)

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-IV
London: The Stationery Office
£64.15

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ISBN: 9 78 010295 8577

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Section 1: introduction and summary

¹ This is the final report of my investigation into Mrs Jane Kemp's complaints against NEWDOC GP out of hours service (NEWDOC)¹, GPs at Falkland Surgery and Eastfield House Surgery, Royal Berkshire NHS Foundation Trust (the Trust)² and the Healthcare Commission. The report contains my findings and conclusions with regard to Mrs Kemp's areas of concern.

The complaint

- ² Miss Kemp was a 26 year old woman with severe learning disabilities. Mrs Kemp described her daughter as a '*party animal*' who was caring, friendly, sociable and loved dressing nicely to go out with her family and friends. She had many interests including dancing, bowling, television and computers. Mrs Kemp said there was not a day in the week when her daughter was not doing something. She was lively, active and always up early, eager to go out. Miss Kemp could understand what people said to her as long as they used simple direct language and she liked talking to people about her activities.
- ³ At the time of the events complained about Miss Kemp lived in supported living accommodation in Newbury (the Residential Home). She moved to the Residential Home in February 2004 after her previous home closed. She shared the house with two other residents with learning disabilities and her live-in carers who were provided by Mencap. She regularly spent time with her mother and grandparents who also lived in Newbury.
- ⁴ Miss Kemp became unwell in late April 2004. Over the following month her main problems were bowel disturbances, tiredness, an unusually

poor appetite and weight loss. Between 3 and 26 May 2004 Miss Kemp was seen on seven occasions by GPs from NEWDOC, Falkland Surgery and Eastfield House Surgery because her carers and her mother were worried about her. During this time she was also seen several times by a community nurse and there was contact with the Community Team for People with Learning Disabilities. On 26 May 2004 Miss Kemp was nauseous and pale and carers told the community nurse that she had passed blood in her stool. The community nurse arranged an emergency appointment with a GP at Eastfield House Surgery. The GP found Miss Kemp's abdomen was tender and arranged for her to be admitted to Heygrove Ward (the First Ward) at the Trust for investigations.

- ⁵ At the Trust a doctor examined Miss Kemp and found a lump in her left groin which he thought might be a hernia or an enlarged lymph node. Miss Kemp remained in hospital until 7 June 2004. She underwent various examinations, tests and investigations, including an ultrasound (where sound waves are used to identify structures in the body), a CT scan (where a picture of parts of the body is built up by a series of X-rays) and a biopsy (removal of a small sample of tissue for laboratory analysis) of the lump. Miss Kemp was discharged to her mother's home and on the following day the Community Team for People with Learning Disabilities made arrangements for day care.
- ⁶ On 18 June 2004 Mrs Kemp and her daughter saw a GP at Eastfield House Surgery and they were told the provisional diagnosis of B cell lymphoma. The options for Miss Kemp's future care were discussed. Later that day they attended the oncology out-patient clinic at the Trust where they saw two oncologists (the First and

¹ In 2004 NEWDOC was subsumed by WestCall. WestCall is currently managed by Berkshire West Primary Care Trust

² Formerly Royal Berkshire and Battle Hospitals NHS Trust

Second Oncologists) and a specialist cancer nurse (the Clinical Nurse Specialist). Following this meeting Mrs Kemp's understanding of her daughter's prognosis was that there was a 50% chance of survival with active treatment, initially intensive chemotherapy, but that there would be considerable problems treating her daughter with regard to her learning disabilities.

- 7 After the appointment Miss Kemp was admitted to Bailey Thomas House (the Respite Home) and Mrs Kemp went on holiday on 19 June 2004. However, staff at the Respite Home became concerned because Miss Kemp was not eating or drinking properly and on 23 June 2004 they took her to Eastfield House Surgery. She was seen by a GP who advised emergency admission to hospital. By chance Mrs Kemp had returned early from her holiday and took her daughter to the Trust where she was admitted to Benyon Ward (the Second Ward) under the care of the Second Oncologist.
- 8 Mrs Kemp was dissatisfied with the care and treatment her daughter was receiving at the Trust. In particular, she was concerned Miss Kemp was dehydrated, and on 24 June 2004 she instructed solicitors who wrote to the Trust threatening legal action. They informed the Trust that unless measures were taken to rehydrate Miss Kemp they would make an application to the High Court for '*a declaration regarding Miss Kemp's best interests*'. Mrs Kemp also asked for a second opinion on her daughter's diagnosis because the Second Oncologist told her there was a low chance of effective treatment. Another consultant oncologist from the Trust (the Third Oncologist) provided the second opinion and told Mrs Kemp the likelihood of successful treatment was less than 10%. Mrs Kemp agreed with the Third Oncologist's view that

active treatment was not in her daughter's best interests. On 28 June 2004 Miss Kemp was transferred to the Rainbow Room at Newbury for palliative care (care which focuses on controlling symptoms, such as pain and discomfort, rather than cure) where she died on 25 July 2004.

- 9 Mrs Kemp feels very strongly that her daughter was treated less favourably with regard to her learning disabilities. In particular, she says the oncologists' decision not to provide cancer treatment was based solely on assumptions they had made about Miss Kemp's learning disabilities. She says that surely any 26 year old woman should receive treatment for cancer and, therefore, she questions why her daughter should have been treated differently in this regard. Mrs Kemp's recollections and views about the care and treatment provided for her daughter are set out in detail in later sections of this report.
- 10 Mrs Kemp has given permission for Mencap to act as her representative. Mencap have been involved with Miss Kemp since she moved to the Residential Home and they have supported Mrs Kemp throughout the complaints process.

The overarching complaint

- 11 Mrs Kemp believes her daughter's death was avoidable and that she received less favourable treatment for reasons related to her learning disabilities. I have called these aspects of her complaint 'the overarching complaint'.

Complaint against NEWDOC, Falkland Surgery and Eastfield House Surgery

12 Mrs Kemp complains about:

Complaint (a): the actions of the GPs who saw Miss Kemp between 3 and 26 May 2004. She says the GPs did not realise the seriousness of her daughter's symptoms and, therefore, did not refer her to hospital for investigations until 26 May 2004.

Complaint against the Trust

13 Mrs Kemp complains about:

Complaint (b): the way diagnostic investigations were undertaken between 26 May and 4 June 2004 and the length of time taken to investigate and diagnose her daughter's condition.

Complaint (c): the decision not to treat Miss Kemp's cancer with chemotherapy.

Complaint (d): the care and treatment provided by the Trust, including nutrition, hydration, pain relief and nursing care as well as the arrangements made by the Trust when Miss Kemp was discharged on 7 June 2004.

Complaint (e): the standard of accommodation and facilities provided during Miss Kemp's second admission (23 to 28 June 2004). In particular, she believes her daughter should have been cared for on an adult oncology ward.

Complaint (f): the way in which the Trust responded to her complaint.

Complaint against the Healthcare Commission

14 Mrs Kemp complains about:

Complaint (g): the way the Healthcare Commission handled her complaint, including the time taken to respond.

15 Mrs Kemp believes she has not had answers to all her questions and she hopes my investigation will provide her with those answers. She hopes the outcome of her complaint will be improvements in health services and she wants to be convinced things have changed for the better.

The Ombudsman's remit, jurisdiction and powers

General remit of the Health Service Ombudsman

16 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In the exercise of my wide discretion I may investigate complaints about NHS bodies such as trusts, family health service providers such as GPs, and independent persons (individuals or bodies) providing a service on behalf of the NHS.

17 When considering complaints against an NHS body, I may look at whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the body, a failure by the body to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.

- 18 Failure or maladministration may arise from action of the body itself, a person employed by or acting on behalf of the body, or a person to whom the body has delegated any functions.
- 19 When considering complaints against GPs, I may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Again, such action may have been taken by the GP himself or herself, by someone employed by or acting on behalf of the GP or by a person to whom the GP has delegated any functions.
- 20 I may carry out an investigation in any manner which, to me, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as I think fit.
- 21 If I find that service failure or maladministration has resulted in injustice, I will uphold the complaint. If the resulting injustice is unremedied, in line with my *Principles for Remedy*, I may recommend redress to remedy any injustice I have found.

Remit over the Healthcare Commission

- 22 By operation of section 3(1E) of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints about injustice or hardship in consequence of maladministration by any person exercising an NHS complaints function. As the Healthcare Commission is the second stage of the NHS complaints procedure set out in the *National Health Service (Complaints) Regulations 2004*, it is within my remit.

Premature complaints

- 23 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Health Service Ombudsman generally may not investigate any complaint until the NHS complaints procedure has been invoked and exhausted, and this is the approach I take in the majority of the NHS complaints made to me.
- 24 However, section 4(5) makes it clear that if, in the particular circumstances of any case, I consider it is not reasonable to expect the complainant to have followed the NHS route, I may accept the case for investigation notwithstanding that the complaint has not been dealt with under the NHS complaints procedure. This is a matter for my discretion after proper consideration of the facts of each case.
- 25 In this instance, Mrs Kemp had not previously complained to the GPs from Falkland Surgery, Eastfield House Surgery or NEWDOC. However, in her complaint to the Ombudsman she made clear her concern about the actions of various GPs from 3 to 26 May 2004. These concerns are integral to Mrs Kemp's key complaint about the diagnosis and treatment of her daughter's cancer. Therefore, I have exercised my discretion to investigate the complaint against the GPs under the provisions of the Act which governs my work.

The investigation

- 26 During the investigation my investigator met Mrs Kemp and her representatives to ensure I had a full understanding of her complaint. Mrs Kemp also provided a copy of an informal diary (the Daily Diary). On most days either Mrs Kemp or Miss Kemp's carers wrote

something about Miss Kemp's day, such as what she had done, what she had eaten or how she was feeling. The Daily Diary travelled with Miss Kemp to aid communication with different people involved in her care. Mrs Kemp also provided a copy of her 'Diary from April 2004' in which she summarised events relating to her daughter's condition and her care and treatment.

27 I also examined relevant documents about the case including: Miss Kemp's health records from the Trust and the GPs' surgeries; papers provided by Newbury Community Team for People with Learning Disabilities; papers about legal action; complaint correspondence between Mrs Kemp, Mencap and the bodies complained about; papers related to attempted resolution of the complaint at local level; and the Healthcare Commission's review. The Trust provided additional information in response to my specific enquiries and my investigation staff met Trust staff. Also, the Primary Care Trust (which is now responsible for services provided by Newbury Community Hospital) responded to my enquiries about the Rainbow Room.

28 I obtained specialist advice from a number of professional advisers (my Professional Advisers): Professor J Radford, a professor specialising in cancers of the blood (my Oncology Adviser); Ms J Wood, a senior acute nurse (my Acute Nursing Adviser); Ms S Lalljee, a senior learning disabilities nurse (my Learning Disability Adviser); and Dr R Childs, an experienced GP (my GP Adviser). In addition, Dr C Chandler (an experienced consultant and the Medical Director of an acute NHS trust) and Mrs S Lowson (an experienced acute nurse and a Lead Clinician in my Office) provided further professional advice in respect of Mrs Kemp's response to my draft report.

29 My Professional Advisers are specialists in their field and in their role as my advisers they are completely independent of any NHS body and the Healthcare Commission. Their role is to help me and my investigative staff understand the clinical aspects of complaints.

30 In this report I have not referred to all the information examined in the course of my investigation, but I am satisfied that nothing significant to the complaint, or my findings, has been overlooked.

My decisions

31 Having considered all the available evidence related to Mrs Kemp's complaint, including Mrs Kemp's recollections and views and her response to the draft report, and taken account of the clinical advice I have received, I have reached the following decisions.

Complaint against NEWDOC, Falkland Surgery and Eastfield House Surgery

32 I find that the GPs at NEWDOC, Falkland Surgery and Eastfield House Surgery provided a reasonable standard of care and treatment for Miss Kemp. I found **no evidence of service failure** in this regard. Therefore, I **do not uphold** the complaint against them.

Complaint against the Trust

33 I find **no service failure** in the care and treatment provided by the Trust in terms of diagnostic investigations, nutrition, hydration, pain relief, discharge arrangements or the decision not to treat Miss Kemp's cancer.

I find **no service failure** in the standard of accommodation and facilities provided for Miss Kemp by the Trust. Therefore, I **do not uphold** these aspects of the complaint against the Trust.

- 34 I find **maladministration** by the Trust in its handling of Mrs Kemp's complaint and I find **injustice** occurred in consequence of that maladministration. Therefore, I **uphold** this aspect of the complaint against the Trust. However, I find the Trust has subsequently provided an appropriate remedy for that injustice so I make no recommendation in this regard.

Complaint against the Healthcare Commission

- 35 I find failings in the Healthcare Commission's handling of Mrs Kemp's complaint in relation to its first decision and these failings amount to **maladministration**. However, I find **no maladministration** by the Healthcare Commission in its second decision. I conclude that there is **no unremedied injustice** to Mrs Kemp in relation to the Healthcare Commission's reviews and, therefore, I **do not uphold** her complaint against the Healthcare Commission.

The overarching complaint

- 36 I have found no evidence that Miss Kemp received less favourable treatment for reasons related to her learning disabilities and, as I found no evidence of service failure by the bodies complained about, I do not conclude that her death was avoidable.
- 37 In this report I explain the detailed reasons for my decisions and comment on the areas where Mrs Kemp has expressed particular concern.

Section 2: the basis for my determination of the complaints

Introduction

38 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, I generally begin by comparing what actually happened with what should have happened.

39 So, in addition to establishing the facts that are relevant to the complaint, I also need to establish a clear understanding of the standards, both of general application and which are specific to the circumstances of the case, which applied at the time the events complained about occurred; and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. I call this establishing the overall standard.

40 The overall standard has two components: the general standard which is derived from general principles of good administration and, where applicable, of public law; and the specific standard which is derived from the legal, policy and administrative framework, and the professional standards relevant to the events in question.

41 Having established the overall standard I then assess the facts in accordance with the standard. Specifically, I assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard.

42 If so, I then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

43 The overall standard which I have applied to this investigation is set out below.

The general standard

Principles of Good Administration

44 Since it was established my Office has developed and applied certain principles of good administration in determining complaints of service failure and maladministration. In March 2007 I published these established principles in codified form in a document entitled *Principles of Good Administration*.

45 The document organises the established principles of good administration into six Principles. These Principles are:

- Getting it right
- Being customer focused
- Being open and accountable
- Acting fairly and proportionately
- Putting things right, and
- Seeking continuous improvement.

46 I have taken all of these Principles into account in my consideration of Mrs Kemp's complaint and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:³

³ *Principles of Good Administration* is available at www.ombudsman.org.uk

'Getting it right' means:

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

'Being customer focused' means:

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

'Being open and accountable' means:

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.

- Stating criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for actions.

'Acting fairly and proportionately' means:

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

'Putting things right' means:

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

‘Seeking continuous improvement’ means:

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Principles for Remedy

- 47 In October 2007 I published a document entitled *Principles for Remedy*.⁴
- 48 This document sets out the Principles that I consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how I think public bodies should put things right when they have gone wrong. It also confirms our own approach to recommending remedies. The *Principles for Remedy* flows from, and should be read with, the *Principles of Good Administration*. Providing fair and proportionate remedies is an integral part of good administration and good service, so the same principles apply.
- 49 I have taken the *Principles for Remedy* into account in my consideration of Mrs Kemp’s complaint.

The specific standard

Disability discrimination

Legal framework

Disability Discrimination Act 1995

- 50 The sections of the *Disability Discrimination Act 1995* most relevant to the provision of services in this complaint were brought into force in 1996 and 1999 respectively. Although other parts of the *Disability Discrimination Act 1995* were brought into force in 2004 and further provisions added by the *Disability Discrimination Act 2005*, these changes either post-date or are not directly relevant to the subject matter of this complaint.
- 51 Since December 1996 it has been unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified.
- 52 Since October 1999 it has in addition been unlawful for service providers to fail to comply with the duty to make reasonable adjustments for disabled people where the existence of a practice, policy or procedure makes it impossible or unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.
- 53 It has also been unlawful since October 1999 for service providers to fail to comply with the duty to make reasonable adjustments so as to provide a reasonable alternative method of making the service in question available to disabled people where the existence of a physical feature makes it impossible or

⁴ *Principles for Remedy* is available at www.ombudsman.org.uk

unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

- 54 Since October 1999 it has been unlawful for service providers to fail to comply with the duty to take reasonable steps to provide auxiliary aids or services to enable or facilitate the use by disabled people of services that the service provider provides, unless that would necessitate a permanent alteration to the physical fabric of a building or unless such failure is justified.

Policy aims

- 55 The *Disability Discrimination Act 1995* recognises that the disabling effect of physical and mental impairment will depend upon how far the physical and social environment creates obstacles to disabled people's enjoyment of the same goods, services and facilities as the rest of the public.
- 56 The key policy aim behind the legislation is to ensure that as far as reasonably possible disabled people enjoy access not just to the same services, but to the same standard of service, as other members of the public. In other words, those who provide services to the public, whether in a private or public capacity, are to do whatever they reasonably can to eradicate any disadvantage that exists for a reason related to a person's physical or mental impairment.
- 57 The critical component of disability rights policy is therefore the obligation to make 'reasonable adjustments', which shapes the 'positive accent' of the *Disability Discrimination Act 1995*. This obligation recognises that very often equality for disabled people requires not the same treatment as everyone else but different treatment. The House of Lords made

explicit what this means in a case (*Archibald v Fife Council*, [2004] UKHL 32, judgment of Baroness Hale), which although arising from the *Part 2* employment provisions of the *Disability Discrimination Act 1995*, has bearing on the *Part 3* service provisions also:

'The 1995 Act [the Disability Discrimination Act 1995], however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment.'

- 58 As the Court of Appeal has also explained, specifically in respect of the *Part 3* service provisions of the *Disability Discrimination Act 1995* (*Roads v Central Trains* [2004] EWCA Civ 1451, judgment of Sedley LJ), the aim is to ensure 'access to a service as close as it is possible to get to the standard offered to the public at large'.

Policy and administrative guidance

Disability Rights Commission Codes of Practice

- 59 Between April 2000 and October 2007 the Disability Rights Commission had responsibility for the enforcement and promotion of disability rights in Britain. In that capacity, and by virtue of the provisions of the *Disability Rights Commission Act 1999*, it had a duty to prepare statutory codes of practice on the law. These statutory codes of practice, although not legally binding, are to be taken into account by courts and tribunals in determining any issue to which their provisions are relevant.

- 60 Before the establishment of the Disability Rights Commission in April 2000, the relevant Secretary of State, on the advice of the National Disability Council, published a statutory code of practice on the duties of service providers under Part 3 of the *Disability Discrimination Act 1995* entitled *Code of Practice: Goods, Facilities, Services and Premises*, 1999, itself a revision of an earlier code of practice published in 1996.
- 61 On its establishment in 2000 the Disability Rights Commission consulted on a further revised code of practice, which came into force on 27 May 2002 as the *Disability Discrimination Code of Practice (Goods, Facilities, Services and Premises)*. The revised code of practice not only updated the previous codes but anticipated the changes to the law that were due to come into effect in 2004, in particular with respect to the duty to remove obstructive physical features.
- 62 The 2002 Code made it clear that a service provider's duty to make reasonable adjustments is a duty owed to disabled people at large and that the duty is 'anticipatory':
- 'Service providers should not wait until a disabled person wants to use a service which they provide before they give consideration to their duty to make reasonable adjustments. They should be thinking now about the accessibility of their services to disabled people. Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.'*
- 63 It also drew attention to the pragmatic strain of the *Disability Discrimination Act 1995*. For example, in respect of the forthcoming 'physical features' duty, the Code says:
- 'The Act does not require a service provider to adopt one way of meeting its obligations rather than another. The focus of the Act is on results. Where there is a physical barrier, the service provider's aim should be to make its services accessible to disabled people. What is important is that this aim is achieved, rather than how it is achieved.'*
- Valuing People – A New Strategy for Learning Disability for the 21st Century (2001)**
- 64 In 2001 the Department of Health published a White Paper, explicitly shaped by the relevant legislation (including the *Disability Discrimination Act 1995* and the *Human Rights Act 1998*), with a foreword written by the then Prime Minister, outlining the Government's future strategy and objectives for achieving improvements in the lives of people with learning disabilities.
- 65 The White Paper identified four key principles that it wanted to promote: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion (in the sense of being part of mainstream society and being integrated into the local community).
- 66 As the White Paper explained, the intention was that 'All public services will treat people with learning disabilities as individuals, with respect for their dignity'.

67 The fifth stated objective of the Government was to *'enable people with learning disabilities to access health services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary'*.

68 The Department of Health also published in 2001 two circulars aimed jointly at the health service and local authorities, focusing on the implementation of Valuing People and including detailed arrangements for the establishment of Learning Disability Partnership Boards: *HSC 2001/016* and *LAC (2001) 23*.

69 The Department of Health has published a series of reports to help the NHS meet its duties under the *Disability Discrimination Act 1995*.

Signposts for success in commissioning and providing health services for people with learning disabilities (1998)

70 This was published by the Department of Health and was the result of extensive consultation undertaken with people with learning disabilities, carers and professionals with the aim of informing good practice. It was targeted at the whole NHS and emphasises the need for shared values and responsibilities, respecting individual rights, good quality information and effective training and development. It also encourages the use of personal health records. The accompanying executive letter *EL (98)3* informs chief executives of the availability of the guidance.

Doubly Disabled: Equality for disabled people in the new NHS – access to services (1999)

71 This Department of Health report, also aimed at the whole NHS, contains a specific section on learning disability. It provides guidance for managers with specific responsibility for advising on access for disabled patients to services and employment. It also provides information for all staff on general disability issues. The accompanying circular *HSC 1999/093* emphasises the purpose of the document, saying:

'... it will be essential for service providers to ensure that they have taken reasonable steps to ensure that services are not impossible or unreasonably difficult for disabled people to use.'

Once a Day: A Primary Care Handbook for people with learning disabilities (1999)

72 This was issued jointly by the Department of Health and the Royal College of General Practitioners, and was specifically aimed at primary care services. It draws attention to the interface between primary care and general hospital services and sets out actions which healthcare providers should take to facilitate equal access to health services for people with learning disabilities. The overall purpose of the handbook was described in the accompanying circular *HSC 1999/103*, which says:

'The purpose of this guidance, for GPs and primary care teams, is to enhance their understanding, improve their practice and promote their partnerships with other agencies and NHS services.'

In practice

- 73 The practical effect of the legal, policy and administrative framework on disability discrimination is to require public authorities to make their services accessible to disabled people. To achieve this objective they must take all reasonable steps to ensure that the design and delivery of services do not place disabled people at a disadvantage in their enjoyment of the benefits provided by those services.
- 74 Failure to meet this standard will mean not only that there is maladministration or service failure, but that there is maladministration or service failure for a disability related reason. This does not require a deliberate intention to treat disabled people less favourably. It will be enough that the public authority has not taken the steps needed, without good reason.
- 75 To be confident that it has met the standard, a public authority will need to show that it has planned its services effectively, for example, by taking account of the views of disabled people themselves and by conducting the risk assessments needed to avoid false assumptions; that it has the ability to be flexible, for example, by making reasonable adjustments to its policies, practices and procedures, whenever necessary; and by reviewing arrangements regularly, not just when an individual disabled person presents a new challenge to service delivery.
- 76 It should also be noted that a failure to meet the standard might occur even when the service in question has been specially designed to meet the needs of disabled people. This might be because, for example, the service design meets the needs of some disabled people but not others, or because good design has not been translated into good practice.

- 77 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman to uphold the published *Principles of Good Administration*. These include the obligation to ‘get it right’ by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsman will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving disabled people, such considerations are so integral to good administration and service delivery that it is impossible to ignore them.

Human rights

Legal framework

Human Rights Act 1998

- 78 The *Human Rights Act 1998* came into force in England in October 2000. The *Human Rights Act 1998* was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. To that extent, the *Human Rights Act 1998* did not so much create new substantive rights for UK citizens but rather established new arrangements for the domestic enforcement of those existing substantive rights.
- 79 It requires public authorities (that is, bodies which exercise public functions) to act in a way that is compatible with the *European Convention on Human Rights*; it requires the courts to interpret statute and common law in accordance with the *European Convention on Human Rights* and to interpret legislation compatibly with the *European Convention on Human Rights* wherever possible; and it requires the sponsors of new legislation to

make declarations when introducing a Bill in Parliament as to the compatibility of that legislation with the *European Convention on Human Rights*.

- 80 Of particular relevance to the delivery of healthcare to disabled people by a public authority are the following rights contained in the *European Convention on Human Rights*:

Article 2 Right to life

Article 3 Prohibition of torture, or inhuman or degrading treatment

Article 14 Prohibition of discrimination.

Policy aims

- 81 When the UK Government introduced the *Human Rights Act 1998*, it said its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new ‘*human rights culture*’ among public authorities and among the public at large.

- 82 A key component of that human rights culture is observance of the core human rights principles of Fairness, Respect, Equality, Dignity and Autonomy for all. These are the principles that lie behind the *Human Rights Act 1998*, the *European Convention on Human Rights* and human rights case law, both in the UK and in Strasbourg.

- 83 These principles are not new. As the Minister of State for Health Services remarked in her foreword to *Human Rights in Healthcare – A Framework for Local Action* (2007):

‘The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.’

- 84 The policy implications for the healthcare services are also apparent, as one aspect of that aim of using human rights is to improve service delivery. As the Minister of State also observed:

‘Quite simply we cannot hope to improve people’s health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people’s lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.’

- 85 At the time of the introduction of the *Human Rights Act 1998* in October 2000, the importance of human rights for disabled people was recognised. Writing in the Disability Rights Commission’s publication of September 2000 entitled *The Impact of the Human Rights Act on Disabled People*, the then Chair of the Disability Rights Commission noted that:

‘The Human Rights Act has particular significance for disabled people ... The withdrawal or restriction of medical services, the abuse and degrading treatment of disabled people in institutional care, and prejudiced judgements about the parenting ability of disabled people are just some of the areas where the Human Rights Act may help disabled people live fully and freely, on equal terms with non-disabled people.’

In practice

- 86 The practical effect of the legal, policy and administrative framework on human rights is to create an obligation on public authorities not only to promote and protect the positive legal rights contained in the *Human Rights Act 1998* and other applicable human rights instruments but to have regard to the practical application of the human rights principles of Fairness, Respect, Equality, Dignity and Autonomy in everything they do.
- 87 Failure to meet this standard will not only mean that the individual has been denied the full enjoyment of his or her rights; it will also mean that there has been maladministration or service failure.
- 88 To be confident that it has met the requisite standard, a public authority will need to show that it has taken account of relevant human rights principles not only in its design of services but in their implementation. It will, for example, need to show that it has made decisions that are fair (including by giving those affected by decisions a chance to have their say, by avoiding blanket policies, by acting proportionately and by giving clear reasons); that it has treated everyone with respect (including by avoiding unnecessary embarrassment or humiliation, by enabling individuals to make their own choices so far as practicable, and by having due regard to the individual's enjoyment of physical and mental wellbeing); that it has made genuine efforts to achieve equality (including by avoiding unjustifiable discrimination, by taking reasonable steps to enable a person to enjoy participation in the processes that affect them, by enabling a person to express their own personal identity and by actively recognising and responding appropriately to difference); that it has preserved human dignity (including by taking reasonable steps to protect a person's life and wellbeing, by avoiding treatment that causes unnecessary mental or physical harm, and by avoiding treatment that is humiliating or undignified); and that it has promoted individual autonomy (including by taking reasonable steps to ensure that a person can live independently).
- 89 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsman will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving health and social care, such considerations are so integral to the assessment of good administration and good service delivery that it is impossible to ignore them.

Professional standards

The General Medical Council

- 90 The General Medical Council (the body responsible for professional regulation of doctors) publishes a booklet, *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet is clear that it represents standards which the General Medical Council expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of work. Key sections of the booklet current at the time of this complaint are set out at Annex A.

91 Paragraph 5 of Good Medical Practice, 2001, says:

'The investigation or treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age, or social or economic status, to prejudice the treatment you arrange.'

The Nursing and Midwifery Council

92 The Nursing and Midwifery Council (the body responsible for professional regulation of nurses) publishes a booklet, *The Nursing and Midwifery Council code of professional conduct: standards for conduct, performance and ethics* (the Code of Conduct), which contains general and specific guidance on how nurses should approach their work. The booklet represents the standards which the Nursing and Midwifery Council expects nurses to meet.

93 Paragraph 1 of the Code of Conduct current in early 2004 said:

'You are personally accountable for your practice. This means that you are answerable for your actions and omissions, regardless of advice or directions from another professional.'

'You have a duty of care to your patients and clients, who are entitled to receive safe and competent care.'

94 Paragraph 2 of the Code of Conduct said:

'As a registered nurse, midwife or health visitor, you must respect the patient or client as an individual.'

‘...

'You are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'

95 Paragraph 4 of the Code of Conduct emphasised the importance of teamwork and communication. It said:

'As a registered nurse, midwife or health visitor, you must co-operate with others in the team.'

'The team includes the patient or client, the patient's or client's family, informal carers and health and social care professionals in the National Health Service, independent and voluntary sectors.'

'You are expected to work co-operatively within teams and to respect the skills, expertise and contributions of your colleagues. You must treat them fairly and without discrimination.'

'You must communicate effectively and share your knowledge, skill and expertise with other members of the team as required for the benefit of patients and clients.'

'Health care records are a tool of communication within the team. You must ensure that the health care record for the patient or client is an accurate account of treatment, care planning and delivery.'

Specific professional standards and guidance

- 96 There are a number of specific professional standards and guidance which are particularly relevant to this case.

Nursing care and pain management

- 97 In *Making a Difference: strengthening the nursing, midwifery and health visiting contribution to health and healthcare* (Making a Difference), 1999, the Chief Nursing Officer identifies a need to focus on the fundamentals of nursing care. This led to the development of a set of benchmarking tools known as *The Essence of Care: Patient-focused benchmarking for healthcare practitioners* (the Essence of Care), 2001. At the time of this complaint benchmarking tools were available for eight areas including food and nutrition, and the safety of clients with mental health needs in acute mental health and general hospital settings. NHS trusts were expected to develop and implement local policies that ensured compliance with the benchmark standards.
- 98 *Services for Patients with Pain*, 2000, makes a number of recommendations about provision, organisation and management of pain services. For example, it recommends that staff who manage patients with pain should be adequately trained. The National Council of Hospice and Specialist Palliative Care Services issued *Guidance for Managing Cancer Pain in Adults*, 2003. This describes the nature of cancer pain as well as the aims and principles of cancer pain management. It also sets out practical guidance, such as alternative routes for administration of painkilling medication.

Cancer care

- 99 *The NHS Cancer Plan: A plan for investment, a plan for reform*, 2000, sets out the National Service Framework for cancer care through prevention, screening, diagnosis, treatment and palliative care. It also set targets to reduce waiting times for all stages of the care pathway. The overall goal was that by 2005 no one should wait more than one month from urgent referral for suspected cancer to treatment.
- 100 *Referral Guidelines for Suspected Cancer*, 2000, explains that most GPs would see very few patients with cancer and that, even for the commonest cancers, a GP could expect to see only one or two cases a year. The document recognises the difficulties for GPs in differentiating ‘*between patients whose symptoms may be due to cancer and the much larger number of patients with similar symptoms arising from other causes*’. It says that for certain symptoms ‘*it may be entirely appropriate for a GP to wait to see if the symptom resolves*’.

Discharge from hospital

- 101 In January 2003 the Department of Health published comprehensive guidelines about discharging patients from hospital called *Discharge from hospital: pathway, process and practice* (Discharge from Hospital). The lengthy guidelines are in the form of a workbook and include principles for good practice as well as introducing a range of tools to assist professionals involved in the discharge process. Some key details from the document are set out at Annex B. Amongst the ‘*key messages*’ are:

'Ensure individuals and their carers are actively engaged in the planning and delivery of their care.

‘...

'Agree, operate and performance manage a joint discharge policy that facilitates effective multidisciplinary working at ward level and between organisations.

'On admission, identify those individuals who may have additional health, social and/or housing needs to be met before they can leave hospital and target them for extra support.

‘...

'Consider how an integrated discharge planning team can be developed to provide specialist discharge planning support to the patient and multidisciplinary team.'

- 102 Appendices 5.6 and 5.7 of the guidelines specifically address the needs of people with learning disabilities, mental health problems or dementia. The importance of meeting the needs of these groups of patients by effective multidisciplinary and multi-agency working is threaded through the guidance.

Consent to treatment

- 103 A number of documents issued by professional bodies, including the General Medical Council's document *Seeking patients' consent: the ethical considerations*, 1998, and by the Government, including the *Reference guide to consent for examination and treatment*, 2001, set out the ethical and legal principles of managing patients who lack capacity to consent to investigations

and treatment. *Good practice in consent: Achieving the NHS Plan commitment to a patient-centred consent practice*, 2001, focuses on the action necessary to ensure the guidance was reflected in day-to-day NHS practice. The document explains that:

'A patient will lack capacity to consent to a particular intervention if he or she is:

- *unable to comprehend and retain information material to the decision especially as to the consequences of having, or not having, the intervention in question: and/or*
- *unable to use and weigh this information in the decision-making process.'*

- 104 Professional and government guidance available at the time of the events complained about is clear that:

- no one can give or withhold consent to treatment on behalf of someone who lacks the capacity to consent;
- adults are assumed to have capacity to consent, but where this is in doubt it is the responsibility of the healthcare team to assess whether a person is able to make an informed decision about the treatment;
- where the patient lacks capacity to consent, it is the responsibility of the healthcare team to decide whether to carry out investigations or treatment based on their assessment of the patient's best interests;

- best interests should be assessed taking account of the circumstances of each individual case and the assessment should not be confined to medical interests, but should include other welfare considerations. These additional considerations can include the patient's known values and preferences, their wellbeing, religious and spiritual welfare, and quality of life;
 - there should be discussion and collaboration, both with other health professionals and family and friends;
 - where there is doubt, concern or disagreement about specific decisions a second medical opinion should be sought and where agreement cannot be reached the High Court should be approached for a ruling; and
 - discussions, decisions and actions should be recorded.
- 105 The Department of Health also issued a guidance document, *Seeking consent: working with people with learning disabilities* (Seeking Consent), 2001. This reiterates the key principles outlined above with additional guidance specific to people with learning disabilities. The guidance reminds anyone who has responsibility for treating or caring for people with learning disabilities that:
- [They] must never make assumptions that particular treatments are inappropriate just because the person has a learning disability. This is discriminatory and unlawful.'*
- 106 With regard to best interest decisions, Seeking Consent makes the additional specific point that such decisions should:
- '... never include assumptions about the quality of life of someone with learning disabilities, or how that person values their life. In particular, [healthcare practitioners] should use the person's ordinary life with their disability as the baseline from which to judge whether treatment will impose excessive burdens on them.'*
- 107 But Seeking Consent also says:
- '..., people who lack capacity to consent to or refuse a particular treatment option may still express willingness or unwillingness to co-operate with what is being offered. Such preferences should always be taken into account when deciding whether the proposed care or treatment is genuinely in the person's best interests. For example, if, despite all reassurance, a patient becomes very distressed by a particular investigatory procedure, this will be an important factor to bear in mind when deciding if the procedure is really essential.'*
- 108 Seeking Consent says the same 'broad principles' apply to decisions about providing or withholding life-prolonging treatment for people who lack capacity to consent as apply to any other kind of treatment.
- 109 The British Medical Association published *Withholding and Withdrawing Life-prolonging Medical Treatment: Guidance for decision making*, 1999. This document says that where patients lack capacity and there is doubt about the benefit of treatment, that treatment should be provided on a trial basis and reviewed.

Treatment can be withdrawn if review shows ‘*the burdens of providing the treatment outweigh the benefits*’.

- 110 The General Medical Council guidance *Withholding and withdrawing life-prolonging treatments: Good practice in decision-making*, 2002, states that:

‘Where it has been decided that a treatment is not in the best interests of the patient, there is no ethical or legal obligation to provide it and therefore no need to make a distinction between not starting the treatment and withdrawing it.

‘Where patients lack capacity to make decisions about treatment, and there is a reasonable degree of uncertainty about the appropriateness of providing a particular treatment, treatment which may be of some benefit to the patient should be started until a clearer assessment can be made. [Treatment] may be withdrawn at a later stage, if it is proving to be ineffective or too burdensome for the patient.’

Local policy at the Trust

- 111 At the time of the events complained about a *Checklist for admitting patients with learning disabilities or specialist care needs* was in use at the Trust. This was aimed at nursing staff and emphasised the importance of assessing and recording needs. It also stressed the importance of co-operation and negotiation with carers in drawing up a care plan. It said nurses should not expect carers to carry out the key caring activities such as feeding, washing and toileting.

- 112 A discharge policy was also in place. Its aim was to ‘*assist staff in ensuring effective, timely and safe discharges from hospital for all patients, optimising patient and carer participation and satisfaction with all issues relating to discharge*’. The policy emphasised the importance of multi-agency working and co-operation and included a statement that where community staff had been involved in care ‘*they must be contacted and involved in the discharge process*’. The policy highlighted the importance of clear communication, including discharge care planning, comprehensive discharge documentation and multi-agency planning meetings for those patients with complex needs. The policy also pointed up the role of the Patient Co-ordination Team in providing advice and assistance with complex discharges, including liaison with community services where necessary.

- 113 The Trust also had a *Policy for Consent to Examination or Treatment* which mirrored the Government’s *Good practice in consent implementation guide* and included guidance for healthcare staff on how to act when a patient lacked capacity to consent.

Complaint handling

NHS complaint handling

- 114 Prior to 2004 complaint handling in the NHS was subject to various Directions which required NHS trusts to have written procedures for dealing with complaints within their organisation (known as local resolution) and to operate the second element of the complaints procedure (independent review). Complaints against primary care providers were dealt with at the local level under practice-based complaints procedures required under the provider’s terms of service.

115 However, on 30 July 2004 the *NHS (Complaints) Regulations 2004* (the Regulations) came into force, and created the procedure applicable to this complaint. These Regulations made detailed provision for the handling of complaints at local level by NHS bodies and, if the complainant was dissatisfied with this local resolution, for the complaint to be given further consideration by the Healthcare Commission. Complaints against primary care providers continue to be dealt with at the local level by practice-based complaints procedures, but likewise move to the Healthcare Commission for the second stage of the process.

Complaints against NHS bodies

116 The Regulations (Regulation 3(2)) emphasise that complaint handling arrangements by NHS bodies at the local level must ensure that complaints are dealt with speedily and efficiently and that complainants are treated courteously and sympathetically and, as far as possible, involved in decisions about how their complaints are handled. The guidance issued by the Department of Health to support the Regulations emphasises that the procedures should be open, fair, flexible and conciliatory, and encourage communication on all sides, with the primary objective being to resolve the complaint satisfactorily while being fair to all parties.

117 *Part II* of the Regulations (Regulations 3 to 13) sets out the statutory requirements for NHS bodies managing complaints at the local level and deals with such matters as who may make complaints, when they may be made and the matters which may be complained about. A dedicated complaints manager must be identified along with a senior person in the organisation to take responsibility for the local complaints process and for complying with the Regulations. Regulation 13 states that

the response to the complaint, which must be signed by the Chief Executive where possible, must be sent to the complainant within 20 working days from when the complaint was made, unless the complainant agrees to a longer period. That response must also inform complainants of their right to refer the complaint to the Healthcare Commission.

Complaints against GPs

118 Guidance to GPs is found in the 1996 *Practice-based Complaints Procedures. Guidance for General Practices*. This is intended to be a good practice guide and sets out a model for a practice-based complaints procedure with sample resource leaflets and suggested forms. It is not intended to be prescriptive, so the only mandatory part of the guidance is that relating to the national criteria. These criteria, found in paragraph 3.1, are:

- Practice-based procedures should be managed by the practice.
- One person should be nominated to administer the procedure.
- The procedure must be in writing and must be publicised (and should include details of how to complain further).
- Complaints should normally be acknowledged within two working days and an explanation normally provided within ten working days.

119 The aim of the practice-based complaints procedure is to make the process more accessible, speedier and fairer to everyone and to try to resolve most complaints at practice level. Detailed procedures are expected to be workable, flexible and ‘*user-friendly*’ for patients and practices alike.

Complaint handling by the Healthcare Commission

¹²⁰ Complainants who are dissatisfied with the outcome of their complaint may ask the Healthcare Commission to consider the complaint, and *Part III* of the Regulations (Regulations 14 to 19) sets out the statutory requirements on the Healthcare Commission when considering complaints at this second level.

¹²¹ Regulation 16 states that the Healthcare Commission must assess the nature and substance of the complaint and decide as soon as it is reasonably practicable how it should be dealt with '*having regard to*' a number of matters including the views of the complainant and the body or person complained against and any other relevant circumstances. There is a wide range of options available to the Healthcare Commission for dealing with the complaint, apart from investigating it, including taking no further action, referring the matter back to the body or person complained about with recommendations as to action to resolve the complaint, and referring the matter to a health regulatory body.

¹²² If the Healthcare Commission does decide to investigate, it must send the proposed terms of reference to the complainant and the body or person complained about (and any other body with an interest in the complaint) for comment. Once the investigation begins, the Healthcare Commission has a wide discretion in deciding how it will conduct the investigation (Regulation 17) and this may include taking such advice as seems to it to be required, and requesting (not demanding) the production of such information and documents as it considers necessary to enable it properly to consider the complaint. The Healthcare Commission has established its own

internal standards for the handling of complaints and although, for example, the Regulations do not specify the type of advice to be taken the Healthcare Commission has acknowledged the need to seek appropriate guidance from a clinical adviser with relevant experience and expertise. Likewise, although the Regulations set no specific timescales for it to complete the investigatory process (Regulation 19 merely requires it to prepare a written report of its investigation '*as soon as is reasonably practicable*'), the Healthcare Commission has said that it aims in the majority of cases to take no longer than six months to complete the process.

¹²³ The report produced by the Healthcare Commission at the end of its investigation must summarise the nature and substance of the complaint, describe its investigations, summarise its conclusions, including any findings of fact, its opinion of the findings and the reasons for its opinion, and recommend what action should be taken and by whom to resolve the complaint or otherwise.

Section 3: the investigation

Background

124 I have outlined the background to Mrs Kemp's complaint in Section 1 of this report. I say more about the key events associated with each aspect of the complaint in the relevant sections which follow.

Non Hodgkins lymphoma

125 Information about the nature of Miss Kemp's cancer is central to an understanding of her care and treatment and is relevant to my consideration of all aspects of Mrs Kemp's complaint. Therefore, I now set out some clinical information about non Hodgkins lymphoma including characteristics, diagnosis, treatment and prognosis.³

126 Lymphoma is a cancer of the lymphatic system – the network of lymph glands and channels which occurs throughout the body. Lymph is a fluid which bathes all body cells. The lymphatic system is part of the immune system which helps the body keep free of infection. Cells within the lymph tissue are called lymphocytes and they are classified as T or B cells depending on microscopic appearance and function. More than 90% of non Hodgkins lymphomas arise from B cells.

127 The cause of the majority of non Hodgkins lymphomas is unknown. There are about 8,450 new cases each year in the UK and the disease is more common in older adults. The average age of diagnosis is around 65 years. Classification of non Hodgkins lymphoma is complex but, when deciding about treatment, doctors usually group all cases as either indolent or low grade (slow progressing), or aggressive or high grade (rapidly progressing).

128 Many patients with non Hodgkins lymphoma have no symptoms at the time of diagnosis and the disease may be discovered because they have other investigations such as a routine chest X-ray. Patients with aggressive non Hodgkins lymphoma usually present with one or more enlarged, usually painless lymph nodes (glands) in the neck, collar bone area, armpit or groin. Later symptoms include recurrent fevers (greater than 38°C), drenching night sweats, weight loss (greater than 10% in six months) and severe and persistent fatigue.

129 *The Referral Guidelines for Suspected Cancer, 2000*, say a doctor who suspects a patient may have a lymphoma should make an urgent referral to a cancer specialist if: swollen lymph nodes have been present for more than six weeks; the liver and spleen are enlarged; or there is a constellation of three or more of the following symptoms – fatigue, night sweats, weight loss, itching, breathlessness, bruising, recurrent infection and bone pain. Usually a biopsy (removal of a small piece of tissue for laboratory analysis) is obtained from one or more of the affected nodes and a chest X-ray taken. Further scans and other investigations are usually performed if the biopsy shows a lymphoma.

130 Most non Hodgkins lymphomas are treated with various combinations of drugs (chemotherapy) or sometimes chemotherapy combined with radiation (radiotherapy). The most common combination of drug treatment for non Hodgkins lymphoma is CHOP (cyclophosphamide, hydroxydaunorubicin, vincristine and prednisolone) which may be combined with an antibody called rituximab (R-CHOP). It is usual to wait until all laboratory results are available before starting treatment because any delay is offset by planning the ideal treatment.

³ *Non Hodgkins Lymphoma (NHL)*, Leukaemia Research 2006

- 131 There is a range of possible side-effects of R-CHOP⁴, some of which are common and some of which occur occasionally. The common side-effects include fatigue, nausea and vomiting, hair loss, nerve problems and skin changes. A temporary drop in bone marrow function may occur and this increases the risk of contracting infections which can be life threatening. Reduced bone marrow function can also cause tiredness, breathlessness and bruising.
- 132 The prognosis for non Hodgkins lymphoma depends on the type and stage of the disease at the time of diagnosis. Doctors look at the combination of clinical features in each individual patient before suggesting the likely prognosis and recommending treatment.
- 133 The prognosis for cancer can be expressed using several parameters. These are:
- cure (the likelihood of removing all traces of cancer);
 - survival (the percentage of patients who are still alive at two years and five years);
 - mortality due to treatment (the percentage of patients who die as a consequence of treatment); and
 - treatment response (the percentage of patients who have any positive response to treatment).

Miss Kemp's cancer

- 134 A limited amount of information is available about the nature of Miss Kemp's particular cancer. She had undergone an ultrasound, a CT scan and a biopsy and the clinical team had seen the site of the tumour. What we know from these tests and investigations is that the tumour was a large B cell non Hodgkins lymphoma. The clinical team decided it was a high grade (aggressive) tumour. When they saw Miss Kemp's groin they noted that the tumour had caused skin changes over an area of about 5cm. Later they described this as 'fungation' – ulceration where the tumour breaks through the skin surface. They also found evidence that the tumour was diffuse (not limited to one location in the body), for example the lymph nodes in Miss Kemp's groin were enlarged.
- 135 My Oncology Adviser agreed that the available information suggested the tumour was diffuse and aggressive. However, he noted that from the information available it was not possible to reach a definite conclusion about the tumour's classification in the International Prognostic Index (a tool which predicts the probability of disease-free and overall survival based on a range of indicators).
- 136 One of the factors in deciding about treatment for non Hodgkins lymphoma is the evidence provided by the results of pathology tests. In Miss Kemp's case the biopsy of the lump in her groin provided information about the cellular characteristics of the tumour. This is an area where my investigation has uncovered some uncertainty about the features of the tumour and the impact of those features on Miss Kemp's prognosis. I have decided to set out the facts and different opinions about this

⁴ Cancer Research UK www.cancerhelp.org.uk

issue at this stage in my report in the interests of transparency and openness. However, for reasons which I go on to explain, I do not consider this information is material to my decision. Therefore, I do not make a finding related to this matter.

137 The initial results of the biopsy were available on 11 June 2004 and showed the tumour was probably a large B cell lymphoma. The specimen was sent to a Professor of Pathology for further analysis. The Professor of Pathology's report confirmed the earlier findings about the nature of the tumour and included further detailed information about its cellular characteristics. This additional information included the finding that the specimen displayed angiocentricity (this is a descriptive term which means the tumour cells were grouped around blood vessels). However, he did not say whether or not this feature was significant in terms of Miss Kemp's prognosis.

138 The Professor of Pathology's formal written report is dated 30 June 2004, although it was not typed until 2 July 2004, which is a week after the decision not to treat Miss Kemp's cancer had been made. It is not clear when the full pathology results became available to the clinical team of cancer specialists treating Miss Kemp. From additional information provided by the clinical team during my investigation it appears they had received a verbal report of the Professor of Pathology's findings by 25 June 2004 when the decision not to provide chemotherapy was made. However, there is no evidence of this in the health record. This means it is not possible to say for certain whether the full pathology results were available to the clinical team when they assessed Miss Kemp's chances of survival. Consequently, it is not possible to say precisely what influence the Professor of Pathology's findings had on that assessment.

139 That said, information provided by the clinical team in the course of my investigation suggests some prognostic significance was attached to the angiocentric features of the tumour. The Second Oncologist said angiocentricity had no impact on his assessment of Miss Kemp's chances, but the Third Oncologist, who gave a second opinion on Miss Kemp's case on 25 June 2004, said:

'... this was not a standard B cell lymphoma but instead came from a narrow subset called angiocentric lymphomas, which are rare. Sadly the likelihood of successful treatment from chemotherapy was much lower with this type of tumour, particularly in the presence of dissemination or spread and I gave the mother a figure of only 10% likelihood of successful treatment.'

140 Subsequently, the Third Oncologist said the estimate of 10% chance of successful treatment was '**not** based solely on the presence of angiocentricity'. He suggested that he lowered his estimate by 2 to 3%. He went on to assert that angiocentricity was one of a number of factors influencing his decision. These factors included the difficulties of administering chemotherapy and the potentially harmful consequences of the side-effects of the treatment in Miss Kemp's case. He said:

'The key factor in my view was that the indication of the latest histology at the time was that Emma had a much more aggressive type of lymphoma, with a lower response rate, than had previously been thought. I did want to give Mrs Kemp an idea of what this meant in broad percentage terms, and this is why I gave a figure of 10% for the likely success rate of treatment.'

141 I considered it was important to try to establish the meaning and possible significance of the finding of angiocentricity in Miss Kemp's tumour.

142 I sought advice from my Oncology Adviser and he told me that:

'Although [the Professor of Pathology] did not confer any prognostic significance to this finding [of angiocentricity], the clinical team associated angiocentricity with a particularly poor prognosis. I am not aware of any such association in B cell lymphoma.

‘...’

'There are several variants of diffuse large B cell lymphoma described in the WHO [World Health Organisation] classification but angiocentric is not one of them and angiocentricity is not a recognised adverse prognostic feature in [this type of lymphoma].'

143 My Oncology Adviser also said he thought the Professor of Pathology's additional finding of angiocentricity *'weighed heavily with the clinical team'*.

144 However, in the course of my investigation I also saw an opinion about this issue from a UK Professor of Cancer Medicine (not associated with the Trust) who acted as an independent adviser to the Trust (the Trust's Independent Medical Adviser). He referred to the Professor of Pathology's findings, quoted several research papers⁵ and concluded that:

'The presence of angiocentric features with a very poor differentiation in a pattern suggestive of a mixed neoplastic cellular population type all confer a significantly poor prognosis.'

145 In the view of the Trust's Independent Medical Adviser the Third Oncologist was correct to include the impact of the finding of angiocentricity in his estimate of Miss Kemp's chances of survival. In fact he said:

'[The Third Oncologist's] second opinion was a particularly impressive analysis of the clinical situation.'

146 It is clear to me that even eminent experts in cancer hold different views about the prognostic significance of the detailed characteristics of the cells in Miss Kemp's tumour. It is not for me as a lay Ombudsman to make a judgment about which of these views is right or wrong. I acknowledge the difference of expert opinion about the significance of the angiocentric features of Miss Kemp's tumour. However, my decision in this case does not turn upon those differences because, as I go on to explain, the key issue from my perspective as a lay Ombudsman does not lie in the detail of the nature of the tumour. Rather, with regard to my assessment of decisions taken by the clinical team about Miss Kemp's care and treatment, I apply a test of fairness and reasonableness, taking into account the circumstances of her particular case, not a test of perfection.

147 I now move on to my consideration of Mrs Kemp's detailed complaints.

⁵ Melnyk et al (1997), Takeshita et al (1996) and Armitage et al (1986)

My investigation of the complaint against NEWDOC, Falkland Surgery and Eastfield House Surgery

Complaint (a): the actions of GPs between 3 and 26 May 2004

¹⁴⁸ Mrs Kemp is dissatisfied with the actions of various GPs from NEWDOC, Falkland Surgery and Eastfield House Surgery who saw her daughter between 3 and 26 May 2004. She says they did not recognise that Miss Kemp's symptoms meant she was seriously ill and should have been admitted to hospital for investigations. She believes their actions resulted in delayed diagnosis and treatment.

Key events

¹⁴⁹ As I have described in Section 1, Miss Kemp's carers first became concerned about her in late April 2004. Her main symptoms were tiredness, unusual loss of appetite, bowel disturbances (first diarrhoea and later constipation) and weight loss. There were also signs of a possible urinary infection. From mid-May 2004 she developed intermittent abdominal pain.

¹⁵⁰ Between 3 and 26 May 2004 Miss Kemp was seen on seven occasions by various GPs from NEWDOC, Falkland Surgery and Eastfield House Surgery because her carers and/or her mother were concerned about her. She also saw a community nurse on several occasions and had contact with staff from the Community Team for People with Learning Disabilities. On 26 May 2004 staff from the Residential Home said she passed blood in her stool and was nauseous and pale. A community nurse arranged for an emergency appointment with a GP who decided Miss Kemp should be admitted to the Trust as an emergency for investigation.

¹⁵¹ A more detailed chronology of key events extracted from Miss Kemp's health records and the Daily Diary is provided at Annex C.

Mrs Kemp's recollections and views

¹⁵² In discussion with my investigator, Mrs Kemp said she was dissatisfied with the actions of the GPs who saw her daughter because she thought they were not doing enough to establish what was wrong with her or to help her. However, she said the Fifth GP seemed to take her daughter's symptoms seriously and started investigating them by ordering a barium meal and a blood test. She also said the Fifth GP had tried to address Miss Kemp's nutritional state by prescribing a fortified drink. She said the Fifth GP was very good at looking for alternative ways of treating her daughter.

¹⁵³ Mrs Kemp questioned why the GPs did not suspect her daughter had cancer and why they did not refer her more quickly for an expert opinion. However, she told my investigator that the lump in Miss Kemp's groin was not visible until the evening of 26 May 2004 (when Miss Kemp was admitted to the Trust) when her carers noticed it and drew it to the attention of hospital doctors.

The advice of my Professional Adviser

¹⁵⁴ My GP Adviser considered the consultations which took place between 3 and 26 May 2004. He found that the consultations with the First GP on 3 May 2004 and the Third GP on 6 May 2004 were appropriate and reasonable. He commented that although the Fourth GP (who saw Miss Kemp on 10 May 2004) did not suggest any action or follow-up, her actions were not unreasonable as the symptoms had been present for a little over a week and there was a suggestion that Miss Kemp was somewhat

- improved. My GP Adviser found that there was no indication during these consultations that hospital admission was necessary or that the GPs treated Miss Kemp less favourably with regard to her learning disabilities.
- 155 My GP Adviser considered that the Fifth GP's actions when he saw Miss Kemp on 13 May 2004, including his request for blood tests and a barium swallow, and his plan to review in two weeks, were reasonable. He also noted that the Fifth GP advised his colleagues in the X-ray department that they would need to make special arrangements for the barium swallow to meet Miss Kemp's particular needs and this was good practice on the Fifth GP's part. My GP Adviser also noted that the results of the blood tests requested by the Fifth GP showed only minor abnormalities, which were not diagnostic of lymphoma.
- 156 My GP Adviser said that because the Sixth GP received an urgent request to see Miss Kemp on 18 May 2004 she made adjustments to her normal working pattern and visited her in the evening in the Residential Home. My GP Adviser said the Sixth GP's actions, records, diagnosis and treatment plan were reasonable and there was no indication to admit Miss Kemp to hospital at this time.
- 157 My GP Adviser noted that the Seventh GP saw Miss Kemp on 22 May 2004, examined her and found a swelling in her abdomen, above her pubic area, which he thought was faeces. He recommended she should go to hospital for further treatment. It appears Miss Kemp refused this suggestion and, in the light of this, my GP Adviser said the Seventh GP's plan to arrange for a community nurse to administer an enema was reasonable.
- 158 With regard to the consultation with the Third GP on 26 May 2004, my GP Adviser said that although the Third GP had no definite diagnosis she acted in Miss Kemp's best interests by arranging for her to be admitted to hospital.
- 159 In summary, my GP Adviser found no evidence that Miss Kemp had received unreasonable care and treatment from GPs who saw her between 3 and 26 May 2004 or that she had received less favourable treatment for reasons related to her learning disability. He said the symptoms of lymphoma are not specific and that although Miss Kemp had loss of appetite, some abdominal pain and a disturbance in her bowel function, there is no record that she had any other relevant symptoms (such as enlarged lymph nodes, recurrent fevers, night sweats or severe fatigue) prior to 26 May 2004. Furthermore, he said the blood tests taken by the Fifth GP did not indicate any problems. He concluded that, given these circumstances, the GPs who saw Miss Kemp had no reason to refer her to hospital any sooner and no reason to suspect she had cancer.

My findings

- 160 Mrs Kemp believes the care and treatment provided by GPs who saw her daughter between 3 and 26 May 2004 was inadequate. She believes that had they acted differently, in particular taken more account of Miss Kemp's symptoms and referred her for investigations in hospital, the cancer would have been detected earlier leading to earlier diagnosis and treatment.
- 161 I can understand why Mrs Kemp finds it difficult to accept that her daughter was found to have a tumour in her groin on 26 May 2004 when none of the GPs who had seen Miss Kemp in the preceding three weeks had found any evidence

of cancer or had taken any specific steps to find out if her symptoms were being caused by cancer. In that time Miss Kemp had been seen by six different GPs on seven occasions and by a community nurse.

- 162 In reaching my decision I have considered contemporaneous evidence in Miss Kemp's health records and the Daily Diary as well as Mrs Kemp's recollections and views. I have also considered the actions and attitudes of the GPs in the light of guidance and standards applicable at the time, in particular Good Medical Practice, which sets out duties and responsibilities of doctors and essential elements of good clinical care and practice, and Once a Day, which reminds primary care providers about their responsibilities when referring people with learning disabilities to hospital. In addition, I have considered the *Referral Guidelines for Suspected Cancer*, which are intended to help GPs identify who would require urgent assessment by specialist doctors because they are most at risk of cancer.
- 163 I have taken account of the advice of my GP Adviser who, having made a detailed study of the contemporaneous evidence about Miss Kemp's condition and her consultations with GPs, concluded that their actions and attitudes were appropriate and reasonable. I note that Miss Kemp did not have any of the features of disease which the *Referral Guidelines for Suspected Cancer* list as requiring urgent referral to a specialist doctor. I also note that Mrs Kemp said the lump in her daughter's groin was not visible until she was admitted to hospital on 26 May 2004. I have also taken account of the GP Adviser's opinion that, given Miss Kemp's non-specific symptoms, none of the GPs could reasonably have been expected to suspect that Miss Kemp had cancer.

The complaint against NEWDOC, Falkland Surgery and Eastfield House Surgery: my conclusion

- 164 I have studied the evidence about Mrs Kemp's complaint against the GPs. I have considered the complainant's recollections and views, and taken account of the opinion of my GP Adviser. I am satisfied that there is no reason to criticise the service provided by the GPs who saw Miss Kemp between 3 and 26 May 2004. The evidence and my GP Adviser's opinion suggest they acted in line with professional and national guidelines. I found evidence that several of the GPs, particularly the Fifth GP and the Sixth GP, made reasonable adjustments to their practice with regard to Miss Kemp's learning disabilities. I also note that Mrs Kemp was complimentary about the Fifth GP's actions in this regard.
- 165 There is no evidence to suggest the GPs involved in Miss Kemp's care at the time of the events complained about treated her less favourably for reasons related to her disability. I find **no evidence of service failure** in the care and treatment they provided.
- 166 Therefore, I **do not uphold** Mrs Kemp's complaint against the GPs.

My investigation of the complaint against the Trust

Complaints (b), (c) and (d): Miss Kemp's care and treatment, including investigations, nutrition, hydration, pain relief and cancer treatment

- ¹⁶⁷ I have considered these aspects of the complaint together because the key issues and available evidence are fundamentally linked.
- ¹⁶⁸ Mrs Kemp believes her daughter's death was avoidable. She complains about the way in which diagnostic investigations were undertaken between 26 May and 4 June 2004 and the length of time taken to investigate and diagnose her daughter's condition. She also believes assumptions were made about Miss Kemp and she was offered a less favourable service for reasons related to her learning disability. Mrs Kemp questions the decision not to provide her daughter with cancer treatment. She is also dissatisfied with the level of general nursing care and the way in which Miss Kemp was discharged on 7 June 2004. Mrs Kemp also complains about the care and treatment provided with respect to nutrition, hydration and pain relief.

Key events

- ¹⁶⁹ The basic facts about Miss Kemp's care and treatment during her visits to the Trust are set out in Section 1 above. More detailed chronologies of key events between 26 May and 7 June 2004 and between 23 and 28 June 2004 are provided at Annex D and Annex E.

Sequence of clinical events

- ¹⁷⁰ I now summarise the sequence of key clinical events from 26 May 2004, when Miss Kemp was first admitted to the Trust, to 25 June 2004, when the decision was made not to treat her cancer.
- ¹⁷¹ On 26 May 2004 Miss Kemp was admitted to the Trust. She was found to have a lump in her groin. On 27 May 2004 she underwent an ultrasound scan. After a Bank Holiday weekend, on 2 June 2004, a CT scan was attempted, but Miss Kemp was unable to co-operate. The CT scan was successfully performed on 3 June 2004 and it confirmed the presence of a lump in her groin. The lump was biopsied on 4 June 2004 by a general surgeon (the Consultant Surgeon) who requested urgent histology tests (laboratory analysis of cells in the tissue sample). He considered information available to him at the time (including blood tests) and thought the lump might be an ovarian cancer. Therefore, he referred Miss Kemp to a gynaecologist. He decided Miss Kemp was fit to go home as no further treatment decisions would be made until the biopsy result was available.
- ¹⁷² On 28 May 2004 contact had been made between Miss Kemp's carers and the Community Team for People with Learning Disabilities and the potential need for additional support for Miss Kemp and her family had been identified. After liaison on 4 June 2004 between Mrs Kemp, the Trust's nurses, the Community Team for People with Learning Disabilities and the Residential Home the decision was made that Miss Kemp would stay in hospital over the weekend and be discharged to her mother's home on 7 June 2004.

173 The written histology result on the biopsy, which indicated a probable large B cell lymphoma, was available on 11 June 2004. On 15 June 2004 a gynaecology multidisciplinary team meeting decided that, in the light of the initial histology result, a referral should be made to the First Oncologist. On 17 June 2004 a fax was sent to Mrs Kemp's GP, the Fifth GP, informing him of the likely diagnosis and asking him to tell Mrs Kemp that her daughter probably had malignant disease before she attended an out-patient appointment with the First and Second Oncologists the following day. The Fifth GP discussed the provisional diagnosis with Mrs Kemp on the morning of 18 June 2004.

174 At the out-patient appointment on 18 June 2004 Mrs Kemp and her daughter met the First and Second Oncologists and the Clinical Nurse Specialist.

175 The Second Oncologist wrote a summary immediately after the appointment. He included Miss Kemp's social and medical history and summaries of the available histology and radiology results. In particular, he noted the extensive lymphadenopathy (swollen lymph nodes) and the presence of scar tissue at the base of her right lung. He considered the evidence of the scan was consistent with high grade non Hodgkins lymphoma. He concluded:

'There will be MAJOR problems in treating this patient. She will need a [general anaesthetic] for CT scan of chest, bone marrow and probably a Hickman line [an intravenous cannula for drug and fluid infusions], but before organising this we need to have widespread discussions.

'I [spoke] with [colleagues in paediatric oncology]. And we are following up their suggestions. In summary we will need to have a case conference about her involving legal department as well as medical, nursing, social services, GP, and family contributions. Further approaches will be made to other Centres nearby (Oxford, Bristol) and further discussion with her mother will be undertaken.'

176 On 23 June 2004 the Second Oncologist wrote to the Fifth GP explaining how a patient with non Hodgkins lymphoma would normally be offered further investigations, including a CT scan of the chest and a bone marrow examination, to stage the disease (determine the current state and likely progress of the condition) before starting chemotherapy. He wrote:

'With her severe learning disability, her unwillingness to be examined and needle aversion, and her inclination to be very vocal when things are not going well for her we have a major problem in offering her treatment be it radical or palliative.'

177 He said he intended to organise a case conference to decide on the best way forward and concluded by writing that attempts had been made to contact other centres including Bristol and Oxford to see if anywhere could 'meet her needs' but without success. He mentioned that Mrs Kemp would like her daughter treated at the Royal Marsden Hospital and that he would contact them to see if they could help.

178 On the evening of 23 June 2004 Miss Kemp returned to the Trust as an emergency because her carers were concerned she was not drinking and she was or could become dehydrated. The Second Oncologist saw Miss Kemp that evening and arranged for her to be admitted to the Second Ward. He saw her again before 8.30am the following morning and again in the afternoon and made further attempts to contact the Royal Marsden Hospital and Social Services. He also spoke to Miss Kemp's father on the telephone.

179 On 25 June 2004 the nurses recorded that Miss Kemp was refusing food. They completed a nutritional risk assessment tool which showed she was at medium risk. Three care plans were written relating to personal hygiene, hydration and nutrition.

180 On the same day the Second Oncologist discussed the position with the Trust's Solicitors and asked for advice from the Trust's Consultant in Palliative Care. He spoke to Mrs Kemp and explained that he thought chemotherapy would not be appropriate for Miss Kemp and suggested palliative care should be instigated. He wrote in the health record that *'radical treatment is virtually doomed to failure and would actually add to Emma's distress'*. He contacted the Rainbow Room regarding palliative care and established that a place would be available for her there on 28 June 2004. Subsequently he asked a colleague, the Third Oncologist, to provide a second opinion on his decision.

181 At around 6.00pm on 25 June 2004 the Third Oncologist saw Miss Kemp and wrote his opinion in the health record. He noted that he had discussed the situation with the Second Oncologist and the Clinical Nurse Specialist. He wrote:

'I believe there are 3 major issues in deciding whether active anti-lymphoma treatment is indicated. 1) the chances of benefit to the pt [patient]. 2) the chances of harming the pt [patient]. 3) the chances of causing distress by the giving of active treatment.'

'I understand that the chances of cure for this condition are less than 10% if full active support and care can be offered. Due to Emma's learning difficulties it would cause the pt [patient] considerable and unwarranted distress to manage the consequences of intensive chemotherapy. The chances of causing harm, or indeed death, as a result of treatment are therefore high.'

'In my opinion, the correct management of this difficult situation is to offer palliative treatment to alleviate distress, [and] relieve suffering.'

'An intensive approach to treatment is not warranted, [and] would be detrimental to the pts [patient's] well-being.'

182 Mrs Kemp was persuaded by the Third Oncologist's second opinion and agreed with the Second Oncologist's proposal that her daughter should not be treated with chemotherapy, but should receive palliative care only.

183 On 28 June 2004 the Third Oncologist wrote to the Fifth GP saying:

'The prognosis from [Miss Kemp's] condition is extremely poor with only an approximately 10% chance of cure with intensive chemotherapy and full supportive care.'

'In view of Emma's learning difficulties it has been felt by both doctors and nurses that the likely side effects of treatment would outweigh possible benefits, and that in essence her malignancy should be regarded as untreatable ...

'I have explained the rationale for our decisions in detail to Emma's mother and grandparents who are in agreement with our treatment plan.'

Legal action

- 184 I now summarise the key points of actions taken by Miss Kemp's legal representative (the Legal Representative) and the Trust's Legal Department on 24 and 25 June 2004. This evidence is taken from papers provided by the Trust's Legal Department and by an external solicitor who was engaged to deal with the case on behalf of the Trust (the Trust's Solicitor).
- 185 During the morning of 24 June 2004 the Legal Representative contacted the Trust's Legal Department. A file note made in the Trust's Legal Department says the Legal Representative said: Miss Kemp was dehydrated and needed treatment for this; the Second Oncologist was not providing this treatment because he was not prepared to override her wishes; the Second Oncologist planned to discharge her; and he was refusing to speak to the social worker responsible for Miss Kemp's care. The Trust's Legal Department tried to contact the Second Oncologist but he was not available.
- 186 At around 3.45pm on 24 June 2004 the Legal Representative faxed the Trust's Legal Department saying that *'unless re-hydration begins tomorrow morning we are instructed to make an application to the High Court for a declaration regarding [Miss Kemp's] best interests'*.
- 187 During the morning of 25 June 2004 the Legal Representative contacted the Trust's Legal Department and asked if Miss Kemp had been rehydrated. The Trust's Solicitor was contacted and she telephoned the Legal Representative asking to be told about all the issues which were of concern to Mrs Kemp with a view to discussion and resolution. The key matters raised were: dehydration; lack of pain relief; the standard of accommodation; and that Mrs Kemp wanted her daughter treated at the Royal Marsden Hospital or their opinion sought on her cancer treatment.
- 188 The Trust's Solicitor spoke with the Second Oncologist and found that he was waiting to speak with doctors at the Royal Marsden Hospital. The Trust's Solicitor recorded that the Second Oncologist said the clinical team had decided not to instigate chemotherapy because this would not be in Miss Kemp's best interests and, in these circumstances, he did not think hydrating her intravenously would be in her best interests.
- 189 During the afternoon of 25 June 2004 the Trust's Solicitor received advice from a barrister that a meeting should take place between the clinical team and Mrs Kemp and that it would be best to obtain a second clinical opinion. The Trust's Solicitor contacted the Official Solicitor. The Official Solicitor acts for people who lack mental capacity, cannot properly manage their own affairs and are unable to represent themselves. The Trust's Solicitor recorded that the Official Solicitor said a court declaration should be sought regarding Miss Kemp's best interests with regard to treatment. However, shortly after this conversation, the Trust's Solicitor received a message from the Second Oncologist which said he had spoken to Mrs Kemp and they had agreed that palliative

care was appropriate for her daughter. The Trust's Solicitor recorded her subsequent telephone contact with the Official Solicitor who said that, in the circumstances, the Trust would not now be expected to obtain a court declaration regarding Miss Kemp's best interests.

¹⁹⁰ The Trust's Solicitor contacted the Second Oncologist who confirmed that he had discussed the situation with Mrs Kemp and she had agreed that palliative care was the best course of action. He also said he would be asking a colleague to provide a second opinion.

¹⁹¹ At around 3.00pm on 25 June 2004 the Legal Representative contacted the Trust's Solicitor. The Trust's Solicitor's note of the conversation records that the Legal Representative said the Second Oncologist had altered his assessment of Miss Kemp's survival with chemotherapy from 50% (the figure which Mrs Kemp says she was given at the out-patient appointment of 18 June 2004) to 10% and, therefore, Mrs Kemp wanted a second opinion, preferably from the Royal Marsden Hospital. Following further discussion between the legal teams, and including the Second Oncologist, an agreement was reached and a summary faxed to the Legal Representative. The fax summarised the agreement as follows:

1. The Trust facilitates, as far as possible, your client's transfer to the Rainbow Room at Newbury.

2. Palliative care be implemented and maintained for your client, by the Trust.

3. A second opinion be obtained on your client's behalf and disclosed to/discussed with your client's mother.

4. Your client's treatment be reviewed in light of the said second opinion and, so far as possible, agreement reached between the Trust and your client's mother as to the further management of your client, if necessary.

It is agreed that this course is in your client's best interests.'

¹⁹² On 30 June 2004 the Legal Representative wrote to the Trust's Solicitor confirming the terms of the agreement and, in particular, noting that Mrs Kemp had agreed her daughter should be given palliative care only.

Mrs Kemp's recollections and views, including information from the Daily Diary and the Diary of Events from April 2004

Investigations during the first admission

¹⁹³ Mrs Kemp told my investigator that during the first admission the Trust's clinical staff did not listen to Miss Kemp's family and carers. She said she warned staff that her daughter would be frightened of the scanning equipment and would not comply without a general anaesthetic, but this was not taken on board by the clinical team. Mrs Kemp also said she was given the impression that the CT scan would be carried out under general anaesthetic and she thought the doctors should have taken the opportunity to carry out the biopsy at the same time. Overall, she said the way the investigations were carried out increased the opportunity for her daughter to become anxious and frightened, there was no appreciation of her needs and investigations were not modified to take account of those needs.

Nutrition, hydration, pain relief and nursing care

194 During the first admission (26 May to 7 June 2004) entries in the Daily Diary clearly show that Miss Kemp was eating very little. However, on most days there are entries which suggest she was drinking reasonably well. There are details of the various types of fluid she drank as well as some information about the volume she drank. There are three entries which suggest Miss Kemp was in some pain, although it is not clear where she felt the pain or how severe it was. The fact that she was offered paracetamol on various occasions is recorded. Sometimes this was given to her in drinks.

195 Mrs Kemp recalled that when her daughter was in hospital she and the carers were largely left to care for Miss Kemp on their own. She told my investigator there was no discussion about the role the carers would play while she was in hospital and it was just assumed the carers would attend to her needs. With regard to helping her daughter to eat, Mrs Kemp said food was left for her, but no attempt was made to help her eat it. She was left to try and persuade her daughter to eat. Mrs Kemp said there was no understanding of Miss Kemp's needs in this respect. She said she contacted a solicitor because she was concerned about the lack of care and treatment her daughter was receiving.

Discharge arrangements

196 Mrs Kemp told my investigator that she was not informed about the plan to discharge her daughter on 7 June 2004 until the last minute. She said she had to arrange the transport herself and when she arrived at the Trust to collect her daughter, nurses offered her no help. She said the nurses offered no advice about managing her daughter's eating and drinking or her pain relief.

The out-patient appointment of 18 June 2004

197 Mrs Kemp has given her account of what she was told, and her understanding of the situation following the oncology out-patient appointment on 18 June 2004. In the Diary of Events from April 2004 Mrs Kemp wrote:

'Saw [the First Oncologist] and [the Second Oncologist] with Emma and Nan. We were told Emma had lymphoma B1 and 50% chance with treatment, but they decided she would not co-operate. [The Second Oncologist] said that if she had been a normal 26 year old they would not hesitate. [The First Oncologist] said she was going on holiday and I was advised to take my week's holiday as [there was] no rush to decide on things ... There was no advice given to us [regarding] Emma's care or pain killing solutions.'

198 When my investigator met Mrs Kemp, she said she was told her daughter might have a 50% chance of survival if she underwent active cancer treatment, but that the oncologists thought such treatment would be distressing because of Miss Kemp's learning disability. Mrs Kemp said she suggested her daughter could be an in-patient and possibly be sedated for the duration of the cancer treatment. However, according to Mrs Kemp, she was told this would not be possible at the Trust, and there were no in-patient facilities for cancer patients to remain in hospital throughout their treatment. Mrs Kemp said the Second Oncologist told her he would not hesitate to treat Miss Kemp if she did not have a learning disability.

199 However, Mrs Kemp explained that the First Oncologist told her no decisions had to be made immediately, and it would be alright for her to continue with her planned holiday to Cornwall. She said the impression given to her at the end of the appointment was not that of a

hopeless situation. She left with the impression that the oncologists would make efforts to find a facility that could treat her daughter's cancer. Mrs Kemp also said Emma was *'just sent home'* after the appointment, despite that fact that she was still not eating and drinking, and was *'obviously unwell'*.

Admission on 23 June 2004

200 Mrs Kemp told my investigator she thought the GP wanted her daughter to be admitted to the Trust on 23 June 2004 because she was dehydrated and in a critical condition. She thought her daughter was 'critical' at this stage because she was not eating or drinking.

201 In the Diary of Events from 2004 Mrs Kemp recorded her concerns about the Second Oncologist's attitude and actions when Miss Kemp was in the Clinical Decision Unit during the evening of 23 June 2004 before she was transferred to the Second Ward. She said he was *'rude'* and she was annoyed that he had contacted her former husband, Miss Kemp's father. She also recorded her dissatisfaction with the lack of treatment for her daughter's pain and noted that she had contacted a solicitor about this. Mrs Kemp told my investigator that the Second Oncologist told her to take her daughter home because there was nothing more he could do. She said it was only when she would not take her daughter home that the Second Oncologist found her a bed.

The decision not to treat Miss Kemp's cancer

202 Mrs Kemp told my investigator that her main priority in instructing solicitors to act on 25 June 2004 was to obtain improved care and pain relief for her daughter. However, she said the threatened legal action resulted in an agreement between her and the Trust that Miss Kemp would be transferred to the Rainbow Room and palliative care would be started. Also

there was agreement that a second opinion would be sought and the decision about treatment would be reviewed in the light of that opinion.

203 Mrs Kemp said that on 25 June 2004 the Third Oncologist had explained that:

'Emma now only had a 10% chance of survival with treatment. This was now considered to be cruel as the cancer had advanced and the only thing was palliative care treatment. We were told expectancy would be 2 days to 2 months at the most.'

204 Mrs Kemp also said she had agreed at the time that with only a 10% chance of survival, active cancer treatment and the distress that treatment would cause was not in her daughter's best interests. However, she said that even at this stage she was reluctant to accept that cancer treatment should not at least be attempted.

205 Mrs Kemp told my investigator that at the time the decision not to treat her daughter was taken Miss Kemp's condition had deteriorated because the Trust had refused to attend to her nutrition and hydration needs. In her view it was this physical deterioration which prompted the Third Oncologist to put her daughter's chances of survival at only 10%. She said Trust staff used her daughter's inability to consent as an excuse for not treating her. They did not consider whether more flexible options existed to treat her cancer. She said the reason why the Trust did not treat the cancer was simply because of her daughter's learning disability. In her view, further steps should have been taken to stage the cancer because without this information the doctors could not be sure of her chances of survival. She said she thought it would have been worth trying treatment because if it had not worked or if her daughter could not have coped with it, the outcome would have been the same.

206 Mrs Kemp also said her daughter's condition improved significantly when she was at the Rainbow Room and doctors there asked the oncologists at the Trust to reconsider their decision not to treat her. Mrs Kemp said the Trust's doctors refused to reconsider their decision.

Statements and additional information from Trust staff

207 In response to Mrs Kemp's complaint to my Office, the Trust provided statements, from key staff involved in Miss Kemp's care and treatment. I have decided not to reproduce these lengthy detailed documents in full, but to set out information from the statements which is particularly relevant to the specific matters complained about. My investigators also met Trust staff during the investigation and information from the meetings is included below.

The Consultant Surgeon

208 The Consultant Surgeon provided a statement dated 20 September 2007, but did not meet with my investigators.

209 The Consultant Surgeon explained that he had been a consultant surgeon at the Trust since 2001 specialising in breast surgery and skin lesions.

210 The Consultant Surgeon described how he had become involved with Miss Kemp's care when she was admitted as an emergency on 26 May 2004, when he was consultant on call. He also described how doctors on his team had encountered difficulty assessing and treating Miss Kemp because she would not allow them to examine her or perform tests. He noted that, having obtained advice from the Trust's Legal Department, he had proceeded with investigations, a CT scan and a biopsy, which he considered were in Miss Kemp's best interests.

211 The Consultant Surgeon recalled that before he took the biopsy he explained the procedure to Miss Kemp's carer who explained to her what was going to happen. He said that he '*worked to preoccupy her and obscure the site so she could not see precisely what was being done*' and following administration of local anaesthetic she did not resist the biopsy.

212 With regard to discharging Miss Kemp on 7 June 2004, the Consultant Surgeon said '*as there was no immediate need for intervention or surgery it would be best for her to be in a home environment until the results were received*'.

The First Oncologist

213 The First Oncologist provided a statement dated 19 October 2007 and met my investigators on 15 May 2008.

214 The First Oncologist explained that she had been a consultant in oncology since 1991 and that since 2001, lymphoma had been one of her specialist areas and she is the Trust's principal specialist in that disease.

215 Referring to the out-patient appointment of 18 June 2004, which she recalled lasted 60 to 90 minutes, the First Oncologist described the difficulty of assessing Miss Kemp because she did not want to undress, lie down or be touched. She said she thought this was because Miss Kemp was anxious and frightened and did not know what the doctors were going to do. She said there was no evidence that Miss Kemp was physically unwell or dehydrated and she did not get the impression that she was in pain. She added that the lymphoma would not necessarily have caused pain.

216 The First Oncologist said that from the information which was available at that time she considered Miss Kemp had a *'large diffuse B cell non-Hodgkins lymphoma'* which was at *'least stage II B but probably would be more advanced than that'*.

217 The First Oncologist said it was clear that there would be problems in diagnosing and treating Miss Kemp. She described the chemotherapy which would comprise six three-weekly cycles of infusions of four drugs and high dose oral steroids and other drugs. She said each infusion could take several hours. She listed the side-effects of treatment including nausea, vomiting, bone marrow suppression (which can give rise to infections) and hair loss as well as longer term complications, such as heart problems.

218 With regard to Mrs Kemp's recollection that the doctors initially told her that Miss Kemp had a 50% chance of cure, the First Oncologist said:

'I have no specific recollection of precisely what I said but I am likely to have said something rather different regarding prognosis. I am likely to have told her that if this were a straightforward lymphoma the chances of survival at 5 years are between 40% and 50% but that we would need to carry out further investigations in order to stage the disease.'

219 With regard to treatment options, the First Oncologist said:

'There was a real question of the practicalities of the situation and I can recall that we were concerned about what treatment would be feasible in light of this. This is particularly the case if one has a patient who cannot swallow tablets, will

not accept injections, and where the options for treatment are in reality very limited.'

220 The First Oncologist also said:

'... I believe that Emma had problems that were almost unique and I think it is doubtful that anywhere in the UK would have had the facilities that would have allowed her care to have been managed in any better way. The limiting factor was her inability to tolerate injections, investigations or indeed any intervention, whilst her disease progressed.'

221 In terms of the decision about further treatment, the First Oncologist said:

'When I left on that day [18 June 2004] there was certainly no decision as to whether we were or were not going to treat. The decision that had been taken was that we need to investigate this further; this is going to be a difficult problem and therefore we need to make sure we have all the resources at our disposal and need to see how Emma is getting on.'

The Second Oncologist

222 The Second Oncologist provided a statement dated 19 October 2007 and met my investigators on 15 May 2008.

223 The Second Oncologist explained that he had been a consultant in clinical oncology since 1994 and that, at the time of the events complained about, lymphoma was one of his specialist areas.

224 He had first heard about Miss Kemp at the routine multidisciplinary meeting on 15 June 2004, where the consensus was that the groin lump was probably a large B cell lymphoma.

He said he went beyond what he would normally do by organising the joint out-patient appointment with the First Oncologist on 18 June 2004. It was not normally his job to organise out-patient appointments but he said it had appeared that the diagnostic pathway for Miss Kemp had been *'somewhat traumatic'* up to that point. He had discussed Miss Kemp with the First Oncologist because she was the lead consultant for lymphoma care, but he agreed to be involved in the case because the First Oncologist was due to go on leave.

225 The Second Oncologist explained that at the clinic appointment of 18 June 2004 it was clear that Miss Kemp:

'... could not understand why we wanted to look at her groin, or why we needed to examine and investigate her condition; in reality her capacity to participate in decision making about her treatment was non-existent or very limited. Notwithstanding this she was clearly able to express her objection to medical interventions of any sort and this was clearly something that we very much need to take into account.'

226 He said the appointment had lasted about 90 minutes (his normal clinic appointments lasted 40 minutes) and much of the time had been spent persuading Miss Kemp to allow the doctors to look at the area which had been biopsied. When he saw the area, he recognised signs of malignant disease. He said there was no indication Miss Kemp was in pain and that had there been any suggestion she was in pain, for example had Mrs Kemp said her daughter was in pain, he would have prescribed a stronger painkiller than the paracetamol she was receiving.

227 The Second Oncologist also explained that the purpose of the clinic was to assess the extent of Miss Kemp's illness and *'her physical and mental reaction to the illness'*. The aim was to make an interim management plan, pending availability of more information about the biopsy and further investigations. He said it was important to get as much information as possible before deciding on treatment.

228 The Second Oncologist described how he and the First Oncologist had discussed the investigations and treatment which would normally be required to treat a B cell lymphoma and the dangers that these would pose, in particular the risk of infection. He recalled discussing the difficulties of providing chemotherapy for Miss Kemp as the usual out-patient setting would not be appropriate for her. He also recalled discussing whether drugs could be given orally instead of the normal intravenous route, but noted that oral preparations would have provided *'inadequate treatment against the tumour'*. He also confirmed that he and his team had contacted cancer centres in Oxford, Bristol, Southampton and in the London area (including the Royal Marsden Hospital) seeking help and advice on treatment.

229 The Second Oncologist recalled that the doctors *'did explain the various treatment options to Mrs Kemp, and what treatment [they] would like to offer her daughter, and the likely problems'*. He agreed with the First Oncologist's suggestion that survival rates of up to 40% are possible in some types of high grade non Hodgkins lymphoma, but he did not recall saying that the doctors would not hesitate to treat Miss Kemp if she did not have learning disabilities. He said:

'It is wholly wrong to suggest that we had in some way given up on Emma's treatment at that appointment particularly as we awaited further details about the type of her tumour & its final pathology.'

230 He added that on 18 June 2004 the doctors did not discuss all the issues of possible risks and alternative treatments with Mrs Kemp because the Trust staff were aware that they needed to find out what resources they were going to need to sort out the challenges of Miss Kemp's needs. The Second Oncologist said after the appointment they began investigating to get information. At that time they expected that within ten days or so they would have gathered enough information for a reasonable decision to be made about Miss Kemp's treatment and to have a plan of action.

231 In relation to the evening of 23 June 2004 when Miss Kemp was readmitted to the Trust, the Second Oncologist described how he had finished work for the day, but had returned to the Trust when he heard she had been sent in as an emergency by a GP. He said he had come back to the hospital because he was concerned about her, in particular he thought she would have been seen by staff who did not know her and she may have been admitted to an unsuitable environment. He said he knew the busy atmosphere of the Clinical Decision Unit would be distressing for Miss Kemp and he hoped he would be able to facilitate her care. He also said he had had no intention to discharge Miss Kemp the following day. Rather, he would have intended to ensure that a *'satisfactory management plan would be agreed'* before considering discharging her.

232 The Second Oncologist said the decisions about pain and hydration overnight on 23 June 2004 were based on what Miss Kemp needed at the time. He added that there was no question whatever that treatment for pain was withheld, because the drugs Miss Kemp was taking already were written on her hospital drug chart and pain relieving drugs were offered. He said Miss Kemp was offered water to drink and at times she took sips and that there is no question that Miss Kemp was not offered hydration or that it was withheld. He added that there was no reason to set up an intravenous infusion overnight because Miss Kemp was not in a collapsed state from dehydration. He said he accepted Miss Kemp was not drinking enough, but this did not mean she was dehydrated. He said what he wanted to do was ensure Miss Kemp was in a quieter environment and he hoped that overnight she would settle down to some degree so staff could monitor how much fluid was going in and out and, maybe with the co-operation of the carer, she could be persuaded to have a blood test.

233 The Second Oncologist recalled seeing Miss Kemp on the morning of 24 June 2004 and spending 90 minutes with her and her carer that afternoon, during which he tried to assess her condition and talked with her about her social circumstances. As a result of that discussion he telephoned Miss Kemp's father to discuss the situation and the problems of treating her. He also attempted (unsuccessfully) to contact Social Services because he believed a case conference was due to take place specifically about social and legal matters.

234 The Second Oncologist described the difficulties he encountered in trying to liaise with the Trust's Solicitor while attending to his clinical work on 25 June 2004. He described the 'succession of telephone calls' about legal matters which he received while he was conducting an oncology out-patient clinic. He said that at one point he was involved in conversations on three separate telephone lines and he felt under pressure from the Trust's Solicitor to provide 'concrete detailed clinical information, when in fact the situation with respect to firm diagnosis and possible alternatives for her care were fluid, and we were still in the course of gathering information'.

235 At the same time as he was dealing with the Trust's Solicitor and managing his out-patient clinic, the Second Oncologist was also following up his request for advice and help from the Royal Marsden Hospital. He remembered talking to a doctor from the Royal Marsden Hospital who told him the Professor of Radiotherapy there had said they could not help with Miss Kemp's care and treatment. The Second Oncologist said:

'I had consulted widely throughout the south of England to try and find a venue where there was appropriate resource and expertise to provide a further assessment of Emma and explore any treatment options, but I had been unable to find anyone who was able to offer anything further to assist.'

236 The Second Oncologist said that on 25 June 2004 he knew Miss Kemp had high grade non Hodgkins lymphoma requiring R-CHOP treatment and that normally the chances of survival with treatment were one in three. However, he considered the side-effects and potential hazards of this treatment were significantly higher than average because of

Miss Kemp's inability to accurately report symptoms. The Second Oncologist explained that monitoring Miss Kemp during treatment would have been difficult. For example, he was unable to examine her abdomen at any time through her illness. He said:

'... we knew it was a high grade lymphoma for which the treatment was R-CHOP and therefore the constraints around us were whether we could give the treatment safely and whether it would be in her best interests. We concluded that giving it was fraught with danger and therefore ... we weren't going to get her through it.'

237 The Second Oncologist said the subtype of lymphoma did not make a difference to him in terms of consideration of treatment. He added that the finding of angiocentricity did not affect the decision to treat because this decision was based on the potential complications of treatment rather than the response rate. He added:

'If a colleague of mine says that they consider a particular subtype of lymphoma to have a slightly worse prognosis or better prognosis, it doesn't necessarily alter whether you should try to treat. The figure I have for high grade lymphoma response and successful outcome is about a third of patients, or 27 per cent of patients do well, potentially. I reckon the circumstances surrounding the difficulties of treating Emma reduce that by about two-thirds, hence the figure I reached of about ten per cent.'

238 The Second Oncologist also said:

'I believe that the decision that was reached regarding treatment offered was the correct one, and that this was in Emma's best interest. I have seen [the Third Oncologist's] opinion ... and I agree with his conclusions. Within the next week we had the definitive pathology results which confirmed that the outlook for Emma's lymphoma was in fact worse than we had originally hoped. I should emphasise that no decision had been made not to offer definitive treatment to Emma Kemp prior to 25th June 2004.'

239 In relation to communication with Miss Kemp's family, the Second Oncologist suggested it was regrettable that on 25 June 2004 Mrs Kemp's concerns about clinical matters were being 'routed via solicitors' and that he, himself, was receiving 'various pieces of advice' from the Trust's Solicitor. He recalled being told that if a decision could not be reached straight away he might need to 'go to court and appear before a judge' and that the court had the power to instruct him to treat Miss Kemp. He said:

'I felt that this would be unethical and completely ineffective and in effect an assault on Emma, given what we knew at the time and supported by my own observations.'

240 The Second Oncologist described how he was later able to speak with Mrs Kemp on the telephone to explore 'the nature of Emma's illness, the progression we might expect without treatment, the likely outcome and side effects of attempting to treat her along with the additional suffering and distress induced by the attempt to administer treatment'.

The Clinical Nurse Specialist

241 The Clinical Nurse Specialist provided a statement dated 19 October 2007 and met my investigator on 21 May 2008.

242 The Clinical Nurse Specialist explained that she had been in her current role for 6 years, had worked in haematology for 17 years and had worked with adults and children. She explained that an important part of her role was working with families. She said she saw all patients with newly-diagnosed high grade lymphomas.

243 The Clinical Nurse Specialist confirmed she had not met Miss Kemp during her first admission to the Trust. Referring to the out-patient appointment of 18 June 2004, the Clinical Nurse Specialist described how Miss Kemp did not take part in any discussion and, although she did not seem acutely unwell, she appeared 'withdrawn and frightened'. She also described how Miss Kemp resisted the doctors' attempt to examine her and how she could only be persuaded to allow doctors to look at her groin, but not to touch her body. The Clinical Nurse Specialist said:

'When I saw [Miss Kemp] there was no evidence to me that she was in pain. She appeared frightened and distressed but she wasn't wincing or crying or holding herself in any way, and her mother didn't say she was in any pain. She didn't look dehydrated. She didn't look unwell. Obviously she had a learning disability so her behaviour wasn't what you would normally expect in a 26 year old woman, but her mother implied that was normal behaviour for Emma.'

244 The Clinical Nurse Specialist recalled that during the out-patient appointment the difficulties of treating Miss Kemp were openly discussed with Mrs Kemp. She said no final treatment plan was formulated because further information was needed before gathering appropriate people together to discuss how to manage Miss Kemp's condition.

245 The Clinical Nurse Specialist explained that the plan following the out-patient appointment was that the Trust would organise a case conference with Miss Kemp's family and carers. This would be arranged once the Trust had made enquiries about hospitals which might have facilities for people with severe learning difficulties and, from her recollection, when there was more information on the biopsy result.

246 The Clinical Nurse Specialist added that when she saw Miss Kemp on 24 June 2004, she spoke to her carer about how much she had been drinking. She said the carer confirmed Miss Kemp had been drinking, but not very much, although she had passed urine. The Clinical Nurse Specialist explained that from this information and from looking at Miss Kemp she did not find any indication of clinical dehydration. She said Miss Kemp did not have sunken eyes, had not been fainting or falling over and did not appear to have a temperature which might have indicated clinical dehydration. She said:

'We did consider an IV [intravenous] drip but we couldn't take her pulse and we couldn't get close enough to examine her, and she was still drinking and she had passed urine, so the distress caused by forcing her to have a cannula [a tube inserted into a vein for the drip], when at that time she was still drinking and had passed urine, seemed to

be too strong. Also we were waiting to come up with a plan, so if the plan had been to sedate her ... I wanted to do it all at once. I didn't want to continually try and do things and make her more and more distressed, and because she wasn't acutely unwell we didn't give her IV fluids.'

247 The Clinical Nurse Specialist said she contacted the Trust's Consultant Nurse in Palliative Care to develop a plan for pain relief to see if that would help Miss Kemp as she thought her sore mouth was stopping her drinking. She explained how Miss Kemp would not let her or the carer look into her mouth to examine it and she would not open her mouth. The Clinical Nurse Specialist said there was no indication to her that Miss Kemp had pain anywhere other than possibly pain in her mouth.

248 The Consultant Nurse in Palliative Care saw Miss Kemp with the Clinical Nurse Specialist on 25 June 2004 and they devised a plan for a fentanyl (a strong painkiller) skin patch, which was prescribed as well as some pain relieving cream. They thought that if they treated any mouth pain Miss Kemp would be able to drink, which would be better than having to sedate her or set up a drip as Miss Kemp was not acutely unwell. The Clinical Nurse Specialist said that by the time Miss Kemp had been on the ward 24 hours she was really frightened and, in her opinion, distraction techniques, which she would usually have considered using to enable care to be given, would not have worked.

249 The Clinical Nurse Specialist explained she was with Miss Kemp virtually all day on 25 June 2004 supporting her and her carer. When she was not with Miss Kemp she was with the Second Oncologist or the Consultant Nurse in Palliative Care discussing possible care and treatment.

She said Miss Kemp's care was her only clinical commitment that day. She did not see or have contact with Mrs Kemp or Miss Kemp's father on that day, although she would normally have expected family to be present and involved in discussion in such a situation. Her only discussion was with the carer, whom she kept informed of what was happening.

The Third Oncologist

250 The Third Oncologist provided a statement dated 12 July 2007 and met my investigators on 15 May 2008.

251 The Third Oncologist explained that he had been a consultant in clinical oncology at the Trust since 1994, with a specialist interest in cancer of the gastrointestinal tract, head and neck, and lung. He said he had had experience of treating lymphomas, but at the time of the events complained about lymphomas were principally managed by the First Oncologist. However, he said he commonly gave second opinions within the oncology department.

252 The Third Oncologist said he had not been involved in Miss Kemp's care before the Second Oncologist asked him to give a second opinion on 25 June 2004. He had been in London and returned to see Miss Kemp around 6.00pm. He was unaware at that time that the Legal Representative had been involved in asking for a second opinion.

253 The Third Oncologist described how he first discussed the case with the Second Oncologist and the Clinical Nurse Specialist before going to see Miss Kemp to try and get an idea of her level of pain and discomfort and how she might cope with treatment. He said he spent about 20 minutes with Miss Kemp and her carer and found she would not even allow him to touch her hand. The Third Oncologist added:

'She was awake, she was walking round the room, she was not in any apparent distress, but as soon as you tried either to introduce yourself or touch her or say hello, let alone try and examine, she would shy away ...'

and

'[She] was not displaying the classical clinical signs of dehydration in terms of dry skin, sunken eyes, dry cracked lips, or indeed the more advanced signs which would mean somebody can't stand up due to their blood pressure and falling over.'

and

'She didn't appear to be in any apparent distress physically, although she was certainly distressed at the prospect of contact with a stranger.'

254 He also described how he discussed the situation and his opinion with Miss Kemp's grandparents and Mrs Kemp, and how he felt they all agreed with the decision to instigate palliative care. He also had conversations with Miss Kemp's carer.

255 With regard to weighing up the risks and benefits of treating Miss Kemp, the Third Oncologist said that, in view of Miss Kemp's age, he was *'inherently uncomfortable about the proposal that active cancer treatment could not be offered'*. He also said:

'It is important to understand that at that stage all that was known was that Emma was suffering from a high grade cell B lymphoma which, as a generic term, meant overall that there were a range of possible outcomes but that 50% [chance of survival with chemotherapy] represented a

reasonable broad view. By the time I became involved we had a verbal report on the biopsy (which was later confirmed) that this was not a standard B cell lymphoma but instead came from a narrow sub set called angiocentric lymphomas, which are rare. Sadly, the likelihood of successful treatment from chemotherapy was much lower with this type of tumour, particularly in the presence of dissemination or spread and I gave the mother a figure of only 10% likelihood of successful treatment.'

256 The Third Oncologist said the angiocentric features of the tumour had very little influence on the decision not to treat, adding that had he not known about the angiocentricity he would still have considered that a 10% chance of successful treatment was correct. He said the angiocentric features did not sway the decision not to treat as the decision was linked to his assessment of Miss Kemp, the assessment of the aggressiveness of the disease, the difficulties of providing treatment and, in his opinion very importantly, the implications for Miss Kemp if attempts were made to subject her to the sort of very intensive treatment required. The Third Oncologist explained that the 10% figure:

'... was not a scientific statement, it's an overall figure given to the carer, to the grandparents, to Emma's mother, to try and make them understand what we were putting Emma through and for what purpose, were we to have given treatment.'

257 The Third Oncologist said his 'considered view' was that 'the harm involved in intensive treatment would outweigh likely benefits'. Although Miss Kemp was young and relatively physically fit he felt the chances of cure were small and there were risks of toxicity and

infection which could lead to her death. He said he also considered the impact of other side-effects including diarrhoea, nausea, vomiting, hair loss and rarer complications as well as the problems of treating her. In his view, she would need repeated sedation or general anaesthetic for each intervention and, although this might be possible, he had never known intensive chemotherapy to be given 'under such constraints'. He said he also considered the impact of harmful side-effects, and the difficulties and the potential harm of giving treatment, on Miss Kemp's life during treatment.

258 The Third Oncologist said the team did consider giving chemotherapy as a palliative measure but decided against this because the same chemotherapy would have to be given for palliation as for cure. Miss Kemp would have needed the same tests, anaesthetics and sedation, and the same level of interference. He said exactly the same problems of toxicity would have been involved and exactly the same risks.

259 The Third Oncologist concluded:

'Overall my view was that it would be extremely difficult, if not impossible, to provide her with intensive treatment, given the above situation, and we had to bear in mind that the chances of success were low. This resulted in the balance of benefit versus harm seeming to me to very much fall in favour of supportive and palliative care rather than intensive investigation and treatment.'

'My considered view was that we should attempt to make her life more comfortable on the basis that the prospects of harm and inherent difficulties of treatment outweighed any likely benefit.'

Further comments by the Trust

- 260 The Trust has commented that there is no clinical evidence that Miss Kemp was clinically dehydrated on or after her admission on 23 June 2004.
- 261 As I have previously said, during the course of my investigation a report on Miss Kemp's care and treatment was produced by the Trust's Independent Medical Adviser. The Trust provided me with a copy of that report and I set out some of the key points made by the Trust's Independent Medical Adviser below.
- 262 The Trust's Independent Medical Adviser said Miss Kemp had a complex tumour which was an extremely rare subclass of non Hodgkins lymphoma. He said the treatment of such a tumour would be R-CHOP chemotherapy and this involved a complex mixture of five drugs given in cycles every three weeks for a minimum of six cycles. He noted that the drugs are toxic and can cause a range of serious side-effects.
- 263 The Trust's Independent Medical Adviser said:

'In my opinion the correct series of investigations were carried out within a very limited time frame by the surgical admission team. The care Emma received during this period was excellent by any standards.

‘...

'The correct diagnosis of a complex B cell lymphoma was made after the biopsy had been reviewed by local pathologists and the lymphoma expert at Oxford. There was no significant delay in obtaining the relevant complex immunohistochemical analysis. An unusual B cell lymphoma with angiocentric features was confirmed by the external expert at Oxford who specialises in these types of tumours.

‘...

'This was an aggressive lymphoma. The standard treatment is R-CHOP ... The tumour was unusual but as it was positive for CD20 [a specific test result] the use of R-CHOP would in my opinion have been the first choice of therapy.

‘...

'The average cure rate for patients with B cell lymphoma is around 40%. The presence of angiocentric features with a very poor differentiation pattern suggestive of a mixed neoplastic cellular population type all confer a significantly poorer prognosis.

'I therefore conclude from my review of the literature and the pathology reports available to the Reading consultants that Emma's chances of cure with optimal chemotherapy were at a 10% level. However, the schedule of drugs is complex and requires considerable cooperation from the patient to administer. If drugs are missed or given out of sequence the results would be significantly poorer.

‘...

'I believe [the decision not to actively treat the tumour] was a very reasonable decision given all the circumstances. It was taken with considerable thought and much discussion and with the whole patient care team. Furthermore the views of Emma's mother were, according to the notes, adequately sought. The process was in no way rushed. [The Third Oncologist's] second opinion was a particularly impressive analysis of the clinical situation. On the balance of probability Emma would have been unlikely to survive her lymphoma whether treated or not, so the outcome would have been the same whatever decision had been made.'

264 The Trust's Independent Medical Adviser concluded:

'I believe the staff at the Trust acted entirely appropriately throughout their encounter with Emma and her family. They reached a rapid diagnosis and sought outside opinions in relation to her management.'

'The decision not to treat Emma actively was not an easy one for those involved and was only made after much thought, discussion and consideration and also involvement of the family. I believe it was the correct choice considering the likely poor outcome, the difficulty in administering chemotherapy, its toxicity ... and the suffering and distress that it would inevitably cause to a very vulnerable member of our society.'

Information from the Rainbow Room

265 The Chief Executive of the Primary Care Trust responded to my enquiries concerning Miss Kemp's condition while she was in the Rainbow Room. He said:

'From the medical notes, it is evident that Miss Kemp's condition varied daily. However, overall there was no significant improvement in Miss Kemp's condition whilst on Highclere Ward [the location of the Rainbow Room].'

266 The Chief Executive of the Primary Care Trust also said:

'Miss Kemp was looked after by ... a GP with a specialist interest in Palliative Care and also ... a Palliative Care Consultant from the local Hospice. I can confirm there was an entry made in the medical notes that [the Third Oncologist], Consultant Oncologist at the RBH [the Trust], contacted the ward to discuss Miss Kemp's condition. However, there is no evidence that the ward contacted the oncologists at the RBH to request a review of their decision not to provide chemotherapy for Miss Kemp.'

The advice of my Professional Advisers

The advice of my Oncology Adviser

267 My Oncology Adviser said there was no doubt that Miss Kemp lacked capacity to understand her illness or to weigh up the advantages and disadvantages of receiving or refusing treatment.

268 With regard to the time taken to obtain a diagnosis, my Oncology Adviser said this was reasonable and within national guidelines although he thought the doctors could have expedited the investigations as Miss Kemp was a vulnerable adult. He also said that, bearing in mind the challenges of managing Miss Kemp, the investigations were carried out in a reasonable way.

269 With regard to nutrition, hydration and pain relief my Oncology Adviser said:

'My view is that timely provision of hydration, nutrition and pain relief is basic medical care and appropriate in any circumstances. Not only are these interventions appropriate in their own right (relief of suffering) but may lead to an improvement in patient behaviour/ co-operation and provide reassurance to a distressed relative who sees that their loved one is being cared for and made to feel better. I should add that the provision of these basic needs does not undermine a future decision not to intervene further once additional information about the underlying disease process has been obtained.'

270 In addition, my Oncology Adviser said he recognised the difficulties in treating Miss Kemp but said improving her hydration status and relieving her pain would not have taken more than 48 hours, although improving her nutritional status could have taken longer.

271 He also said:

'Initially Miss Kemp would have required significant sedation to allow an intravenous line ... to be inserted for re-hydration and pain relief to be commenced. These two

measures might have caused her to feel significantly better so that she felt able to take some light food.

' ...

'Although treatment of Miss Kemp was never going to be straightforward, relief of pain, hunger and thirst would have in my view gone some way to re-assuring her that she was in a safe place and possibly made her management a little easier.'

272 My Oncology Adviser considered the way in which the Trust's clinical team came to their decision about treating Miss Kemp. He said that the team were considering R-CHOP therapy and this was *'entirely appropriate'*. However, he expressed concerns about the way they reached their decision not to treat Miss Kemp. He said they decided against R-CHOP therapy:

'... on the basis of four principal arguments. First, that it would be very difficult to administer treatment (I agree that it would have certainly not been easy), second that there was a low chance of benefit, third there was a real possibility of serious complications and fourth it would cause Miss Kemp an unjustified level of distress.'

and

'... Although this was an extremely difficult clinical situation and I am reviewing with the benefit of hindsight, I think that the decision not to proceed with active treatment for the lymphoma is questionable.'

273 My Oncology Adviser said chemotherapy is the best way of relieving symptoms and improving a patient's general condition even when cure is unlikely. He also said it was likely (but not guaranteed) that Miss Kemp's overall condition may have improved with chemotherapy. He said:

'Rather than creating unreasonable distress therefore my view is that treatment had a reasonable chance of relieving symptoms of disease and reducing her level of distress.'

274 My Oncology Adviser considered the weight which the clinical team attached to the potential problems and side-effects of giving Miss Kemp chemotherapy. He did not agree with their view that side-effects would be unduly burdensome for her. He said that although R-CHOP can be expected to cause side-effects, these are *'predictable and manageable'* and *'can usually be dealt with effectively'*, for example with drugs to control nausea and minimise the risk of infection, as well as more input from community services.

275 With regard to the most appropriate location for treatment, my Oncology Adviser confirmed that R-CHOP is usually given as an out-patient treatment and that it would have been difficult to provide Miss Kemp with chemotherapy in this setting because of her particular needs. He considered a large regional cancer centre should have been able to take Miss Kemp as a patient, or at least to offer the clinical team support. He said *'there is no doubt that strenuous efforts were made by [the Second Oncologist] to enlist the help of specialists'* at regional centres and that no help was forthcoming. He added:

'... the Trust were placed in the invidious position of being forced to continue looking after Miss Kemp when a major national oncology centre felt unable to do so.'

276 Turning to the issue of the estimated chance of effective treatment for Miss Kemp, my Oncology Adviser said:

'For patients with previously untreated diffuse large B cell lymphoma the estimated 2 year survival is 37% for patients under the age of 60 years in the so-called high risk group⁶ ... and 59% for patients in the high intermediate risk group ... Miss Kemp had not been fully staged and so it is not possible to know for certain which prognostic group she fell into although it seems unlikely to me that she had low intermediate or low risk disease (where the estimated 2 year survivals are 79% and 90% respectively). It should be remembered that a small number of patients (less than 5%) will die during treatment as a result of complications.'

'So, even if we assume Miss Kemp was in the worst prognostic group she had an estimated 2 year survival of 37% (and 5 year survival of 32%).'

277 In relation to Miss Kemp's treatment my Oncology Adviser concluded:

*'I believe Miss Kemp's death was **potentially** avoidable. It is impossible for guarantees of cure to be provided in these circumstances but if appropriate treatment and supportive medical care had proved possible in the correct specialist environment (a large regional Cancer Centre for example) there was a realistic chance of remission and even cure.'*

⁶ Shipp et al, *New England Journal of Medicine*, 1993

'Clearly her behavioural problems were extremely challenging and although interventions in best interest would in my view have been possible on two occasions (one, to correct dehydration/establish pain control and two, to administer the first cycle R-CHOP chemotherapy), if Miss Kemp's level of co-operation had not improved following these I think it would have been extremely difficult and probably impossible for nursing/medical staff to subsequently continue treating her apparently against her will.'

'So, in my view, initial treatment of dehydration and pain followed by cycle 1 of chemotherapy would have been reasonable under the principle of best interest. If however these measures failed to improve her physical condition (relief of symptoms and initial shrinkage of tumour) or she remained resolutely opposed to treatment as evidenced by continuing unco-operative behaviour it would have then been appropriate to withdraw to a position of palliative care.'

278 My Oncology Adviser added:

'I believe that some doctors would have acted in the same way as the Reading team and others would have acted to intervene along the lines I have suggested – so in that sense what happened falls within a spectrum of reasonable clinical opinion.'

279 My Oncology Adviser also looked at the way in which Miss Kemp was discharged on 7 June 2004. He said that *'providing appropriate support and advice had been provided, the decision of the clinical team was reasonable'*.

The advice of my Learning Disability Adviser

280 My Learning Disability Adviser reflected on how attempts to communicate with Miss Kemp impacted on the care and treatment she received. She said there was evidence of some appropriate attempts to communicate with Miss Kemp, for example with regard to the biopsy, but there was no evidence of a consistent approach. She said there should have been an assessment of Miss Kemp's communication needs and a plan to meet those needs, but she found no evidence of this. In particular, she said more could have been done to assess whether Miss Kemp was in pain, for example by asking her carers how she expressed pain or how she might cope with different painkilling preparations.

281 My Learning Disability Adviser also said the fact that Miss Kemp was reported to have a 'needle phobia' had a negative impact on management of her hydration in hospital. She pointed to several episodes when Miss Kemp had, with appropriate measures in place such as anaesthetic cream, tolerated needles for blood taking, drug injections and the biopsy. Overall, she thought assumptions about Miss Kemp's 'needle phobia' *'deterred staff from trying more imaginative ways of working ... to give treatment which would have been given to a person without such difficulties'*.

282 My Learning Disability Adviser remarked that the measures taken by the Consultant Surgeon when he carried out the biopsy were *'sensitive, mindful of [Miss Kemp's] particular needs and excellent practice'*. She also said that had *'such principles and flexibility'* been applied to other procedures and treatments *'things could have gone much better'*.

283 Based on her reading of evidence about Miss Kemp, my Learning Disability Adviser said it was clear that Miss Kemp did not have capacity to consent in respect of the decision about whether or not she should receive chemotherapy. She said that, therefore, it was correct for the clinical team to make a decision in Miss Kemp's best interests. She said ideally a formal best interests meeting should have been convened when a full discussion could have taken place.

284 My Learning Disability Adviser said that had such a meeting taken place the option of trying one course of treatment could have been more fully considered. She said she thought it would have been 'difficult but not impossible' to deliver this treatment. She acknowledged that she had had limited experience of cancer care or chemotherapy, but from her experience of working with people with learning disability she thought Miss Kemp:

'... could probably have been supported to have at least one course of chemotherapy as an in-patient with appropriate monitoring and input from people who knew her well and preferably advice or input from a learning disability specialist; appropriate adjustments to the usual way of doing things could have been made to make administration of the treatment easier or safer for Emma.'

285 However, she also said she considered doctors had acted in what they believed to be Miss Kemp's best interests given their understanding of the situation at the time and the pressures they were under. She told me the oncologists' decision was 'within the realms' of reasonable clinical practice.

286 My Learning Disability Adviser was clear that the decision not to treat Miss Kemp's cancer did not mean she was treated less favourably for reasons related to her learning disability. She said:

'I do not believe that the decision not to offer Emma active treatment was affected by the fact that Emma had a learning disability in itself. It was, however, affected by the obvious difficulties which would have arisen from treating Emma actively, due to her communication difficulties, lack of understanding of the reasons for the treatment and hospital procedures generally and most importantly in my opinion, her inability and reluctance to report symptoms ... all of which were associated with her learning disability.'

The advice of my Acute Nursing Adviser

287 Having reviewed health records for both admissions, my Acute Nursing Adviser said she could find no evidence from contemporaneous documentation that the nursing team developed effective plans to meet Miss Kemp's hygiene, eating, drinking or pain relief needs.

288 My Acute Nursing Adviser acknowledged the practical difficulties of meeting Miss Kemp's needs and the risks involved in using more invasive treatments, such as intravenous hydration. However, she said there could have been discussion and exploration of alternative methods of ensuring Miss Kemp was adequately hydrated, nourished and pain free. She pointed towards subcutaneous (under the skin) infusion of fluid which Miss Kemp may have found less distressing than an intravenous infusion, and the use of simple pain scoring tools using colours or faces to indicate feelings of pain.

- 289 My Acute Nursing Adviser said it was reasonable to discharge Miss Kemp on 7 June 2004 because there was no evidence that she had acute problems, such as dehydration, which could not be managed in her home environment. However, she remarked on the poor discharge documentation which gave no indication of the care which Miss Kemp would need on discharge.
- 290 My Acute Nursing Adviser said the Palliative Care Nurse who reviewed Miss Kemp on 25 June 2004 gave reasonable and appropriate advice regarding pain and comfort and her recommendations were followed appropriately in the following days before Miss Kemp was transferred to the Rainbow Room.
- 293 In Section 2 above I have set out the legislation and national and professional standards which should have guided Trust staff involved in Miss Kemp's care. Of particular relevance are the *Disability Discrimination Act 1995*, the General Medical Council's Good Medical Practice, the Nursing and Midwifery Council's Code of Conduct, the Essence of Care benchmarks, Discharge from Hospital and the guidance in various documents about consent.
- 294 I have studied all the evidence available to me and carefully considered the opinions of my Professional Advisers.

Mrs Kemp's specific complaints about care and treatment

My findings

- 291 When she was well, Miss Kemp has been described as an active, fun-loving person who cared about her family and friends and enjoyed many aspects of her busy life. However, when she became ill in early summer 2004, all the people caring for her, including her family, her carers and staff at the Trust, faced great difficulty in their attempts to meet her increasingly complex needs. Mrs Kemp says staff at the Trust did not make enough effort to meet those needs.
- 292 Mrs Kemp believes that, through their actions and decisions about care and treatment for nutrition, hydration, pain relief, discharge arrangements and cancer, staff at the Trust treated her daughter less favourably for reasons related to her disability. Mrs Kemp believes that had different decisions been made, her daughter would not have died.
- 295 I now consider the different aspects of Mrs Kemp's complaint about her daughter's care and treatment.
- Investigating Miss Kemp's condition*
- 296 First, I consider Mrs Kemp's belief that doctors did not act quickly enough to diagnose her daughter's cancer. I then consider her dissatisfaction with the way in which the diagnostic tests were carried out.
- 297 As I have said in Section 2 above, a key goal of the NHS Cancer Plan was that no one should wait longer than one month from urgent referral for suspected cancer to the beginning of treatment.
- 298 We know from the Daily Diary and Miss Kemp's consultations with GPs that, for several weeks before she was first admitted to the Trust on 26 May 2004, she had been suffering from a group of non-specific symptoms, principally reduced appetite and weight loss. We have seen that these symptoms did not point doctors towards any particular disease. In fact, the Third GP sent her to the Trust as an emergency principally because she had a tender abdomen

and had apparently passed blood in her stool, not because he thought she might have cancer. Therefore, doctors at the Trust were faced with the problem of trying to find out why she was unwell. In these circumstances, it does not seem unreasonable that the doctors proceeded with a series of tests which progressively led them towards the diagnosis of cancer.

299 I can understand why Mrs Kemp found the time when she was waiting for the biopsy result frustrating and difficult. I can only imagine the anxiety she must have felt knowing her daughter had a lump in her groin, but not knowing whether it was a cancer. However, only a fortnight passed between the point when the Consultant Surgeon first suspected Miss Kemp might have cancer and the provisional diagnosis and discussion about treatment in the First Oncologist's clinic. During this time the specimen was analysed, provisional results were produced and these were discussed in a multidisciplinary meeting. After that, Miss Kemp's case was referred to the First Oncologist and the out-patient appointment was arranged.

300 I have considered the view of my Oncology Adviser that, overall, the time taken to investigate and diagnose Miss Kemp's disease was reasonable, although he thought perhaps investigations could have been expedited given that Miss Kemp was a vulnerable person. However, it seems to me that the only investigation which took some time to arrange was the CT scan. I appreciate that this wait must have been frustrating and worrying for Mrs Kemp, but at that time it appears doctors had no evidence to suggest Miss Kemp needed an urgent scan. Therefore, I consider it was reasonable to arrange for her to have the next available slot when an anaesthetist would be available in X-ray.

301 I now turn to Mrs Kemp's dissatisfaction with the way in which the investigations were carried out. I have found no evidence to suggest that the abdominal X-ray, the ultrasound or the biopsy caused Miss Kemp to become unduly distressed. I accept that Miss Kemp was unable to co-operate fully with the abdominal ultrasound but, in my view, it was not unreasonable for staff to assume she might co-operate with the procedure given she had allowed an abdominal X-ray to be taken on the previous day. I have considered the advice of my Learning Disability Adviser that the Consultant Surgeon's management of the biopsy showed he was sensitive to Miss Kemp's needs and appropriately adjusted his approach to take account of those needs. I agree with my Learning Disability Adviser that the Consultant Surgeon made reasonable adjustments which allowed him to carry out the biopsy successfully.

302 It is not clear what arrangements had been put in place for sedating or anaesthetising Miss Kemp for the first CT scan, although Mrs Kemp was under the impression that her daughter was going to have a general anaesthetic. However, records show that for the first attempt on 2 June 2004 Miss Kemp had not been starved and no premedication had been given, so it seems likely that the plan was to try sedation in the first instance. In the event Miss Kemp could not be persuaded to enter the scanner at the first attempt. The scan was rearranged for the following day and successfully performed under a general anaesthetic.

- 303 Mrs Kemp feels a general anaesthetic should have been given at the first attempt to scan her daughter and that because it was not Miss Kemp was distressed unnecessarily and the scan was delayed. I accept that the plan doctors had made to enable the scan to be performed had not been clearly communicated to Mrs Kemp and this caused her anxiety. However, given the generally well-known risks of anaesthesia, it does not seem unreasonable to me that the less risky option of sedation should have been tried first.
- 304 There are two recorded instances of appropriate application of best interest principles in decisions about investigations and tests during Miss Kemp's first admission to the Trust. These relate to the CT scan and the biopsy of the lump. In the knowledge that Miss Kemp had resisted a previous CT scan and did not like needles, the benefits of the investigations (diagnosing her disease, knowing more about the prognosis and making judgments about possible treatment) were weighed against factors including the distress the investigation would cause her. After discussion with the Trust's Legal Department, Mrs Kemp and/or the carers, doctors decided that the balance was in favour of carrying out the investigations and appropriate adjustments were made to allow the investigations to go ahead. Anaesthesia was used for the CT scan, while painkilling cream and distraction techniques enabled the Consultant Surgeon to biopsy the lump. The best interest decisions were correctly recorded on Consent Form 4 as set out in *Good practice in consent: Achieving the NHS Plan commitment to a patient-centred consent practice*.
- 305 Having considered the evidence and taken account of the advice of my Professional Advisers, in particular my Oncology Adviser who said that, given the circumstances, the investigations were carried out in a timely and reasonable way, I find no reason to criticise the Trust on this aspect of the complaint. Rather, I find that there was no undue delay in the investigation of Miss Kemp's cancer and that the time taken to investigate and diagnose her condition was in line with the target in the Cancer Plan.
- 306 Mrs Kemp has said the way the investigations were carried out showed Trust staff did not appreciate her daughter's needs or adapt their practice to meet those needs. I accept that Miss Kemp found the various procedures frightening and that Mrs Kemp would have undoubtedly found her daughter's anxiety distressing. However, having considered the evidence and the advice of my Professional Advisers, I find that, in the circumstances, the tests and examinations used to reach the diagnosis were on the whole carried out in a reasonable way. Best interest principles were appropriately applied and appropriate and reasonable adjustments were made to account for Miss Kemp's particular needs.
- 307 I find **no evidence of service failure** with regard to the time taken to investigate Miss Kemp's cancer or the way in which those investigations were carried out.
- Nutrition, hydration, pain relief and nursing care**
- 308 I now consider the general care and treatment which Miss Kemp received when she was admitted to the Trust. I focus on hydration, nutrition, pain relief and nursing care because these are Mrs Kemp's main areas of concern. Mrs Kemp maintains that Trust staff did not understand her daughter's needs and did not do enough to help her. She said care of her daughter was left to her and the carers. She has suggested that at times the Trust refused to meet her daughter's needs and that, as a result,

- Miss Kemp's physical condition deteriorated. Mrs Kemp believes this physical deterioration was one of the reasons why the Trust did not treat her daughter's cancer.
- 309 First, I consider Mrs Kemp's complaints about nutrition and hydration. Mrs Kemp appears to have been particularly concerned about her daughter's hydration. She was so concerned about this aspect of care and treatment that she sought legal help. In contrast, the Trust maintains there is no evidence that Miss Kemp was dehydrated.
- 310 Miss Kemp was first admitted to the Trust on 26 May 2004 because she was not eating and because she was losing weight. There were also concerns about how much she was drinking. During this admission her health records and information from the Daily Diary clearly show that she was eating irregularly and then only small amounts. The health records do not indicate how much Miss Kemp was drinking, but the Daily Diary suggests that she was accepting a range of drinks throughout her stay. My Professional Advisers have not said there was any indication that she needed urgent treatment because she lacked food or fluid at this time.
- 311 The reason for Miss Kemp's second admission on 23 June 2004 was principally her low fluid intake. The evidence suggests there were differences of opinion about whether or not Miss Kemp was clinically dehydrated on admission and over the following two days. The Trust's clinical team has stressed that there is an important difference between clinical dehydration, which they say is a serious situation requiring immediate intervention with treatment such as intravenous fluids, and a situation where a person is simply not drinking enough, when emergency intervention is not required.
- 312 On 23 June 2004 Mrs Kemp, Miss Kemp's carers and the GP were very concerned about Miss Kemp's low fluid intake. Mrs Kemp has said she considered her daughter was critically ill at this time and she understood this was the reason why the GP had arranged for her to be admitted. In contrast, the Second Oncologist has said that when he saw Miss Kemp on the evening of her admission he did not think she was dehydrated to a point where she needed emergency treatment. However, his contemporaneous note in the health record says that Miss Kemp was '*dehydrated*'. That said, his note also includes a remark about the need to work with the legal team and others the following morning to formulate a plan of treatment in Miss Kemp's best interests. Although Mrs Kemp thought her daughter was critically ill on the evening of 23 June 2004, it is clear the Second Oncologist did not consider Miss Kemp was seriously ill or significantly dehydrated because he did not believe it was necessary to instigate emergency treatment.
- 313 The Clinical Nurse Specialist, who saw Miss Kemp in the morning of 24 June 2004, has said that, in her opinion, Miss Kemp did not show signs of clinical dehydration because, although her mouth was dry, she was taking some fluid and had passed urine. Like the Second Oncologist, the Clinical Nurse Specialist did not consider emergency action was needed to correct serious dehydration. Her plan, the implementation and outcome of which is noted in the health record, was to try and improve the condition of Miss Kemp's mouth so she would find it easier to eat and drink. On 25 June 2004 a nursing care plan was written relating to hydration and nutrition.

- 314 Trust staff have said that they did not, as Mrs Kemp believes, withhold hydration and nutrition for her daughter during her second admission. They say that their intention was to assess and monitor her needs and try to make more detailed assessments, and plan appropriate interventions once she was settled.
- 315 It is clear from the limited evidence available that Miss Kemp's fluid and nutrition intake was low during both admissions to the Trust. Furthermore, my Professional Advisers have told me staff could have been more proactive in their approach to assessing and meeting Miss Kemp's hydration and nutrition needs. For example, there is no evidence that nurses used available tools, such as Essence of Care benchmarking, in their management of Miss Kemp's nutrition. Furthermore, my Oncology Adviser has suggested that had staff been more proactive in management in this regard it is possible that Miss Kemp may have been better able to co-operate with other interventions.
- 316 That said, I have found no evidence to suggest that at any time Miss Kemp was critically ill due to dehydration and nutrition such that she needed urgent or emergency medical intervention. My Professional Advisers have not suggested that this was the case at any point in her stays at the Trust.
- 317 I find that although Trust staff could have been more proactive in their approach to Miss Kemp's nutrition and hydration, there is no evidence that at any time Miss Kemp's condition was seriously compromised by lack of food or fluid, or that this led her to decline physically. Furthermore, there is no evidence that Trust staff refused to provide Miss Kemp with food or fluid.
- 318 Although there were some shortcomings in the Trust's approach to managing Miss Kemp's nutrition and hydration, I find these **do not amount to service failure**.
- 319 Secondly, I consider Mrs Kemp's complaints about pain relief.
- 320 Mrs Kemp says the Trust did not pay sufficient attention to her daughter's pain and did not provide adequate treatment to relieve it. She has expressed concerns about the way Trust staff approached this aspect of care and treatment during both admissions and at the out-patient appointment.
- 321 I recognise that it may not have always been obvious whether Miss Kemp was in pain because, for example, she was not able to express pain in a way which clinicians would immediately recognise as indicating she was suffering discomfort. I also recognise that Mrs Kemp was best placed to know when her daughter was in pain and I acknowledge her view that Trust staff showed insufficient attention to Miss Kemp's pain. In this regard, my Learning Disability Adviser told me staff did not always use resources available to them, such as the knowledge of her family and carers, to help them understand and meet Miss Kemp's pain needs. I have seen no evidence that Trust staff made attempts, as they should have done, to find effective ways of assessing Miss Kemp's need for pain relief.
- 322 That said, I have seen no evidence that Trust staff ignored Miss Kemp's pain needs. During the first admission the Daily Diary shows that there were some times when Miss Kemp appeared to be in pain. She was offered, and sometimes accepted, paracetamol to relieve her discomfort. I have found no evidence to suggest that

Miss Kemp was in severe pain during this first admission or that staff ignored her pain needs. At the out-patient appointment the clinical team have said there was no indication that Miss Kemp was in pain and they said they do not recall Mrs Kemp expressing concerns that her daughter was in pain. During the second admission there is again no record that Miss Kemp was suffering as a result of untreated pain or that the clinical team withheld pain relief, as Mrs Kemp has suggested. Actions which the team took at this time included, initially, provision of pain relief which had been prescribed by the GP and, subsequently, provision of alternative pain relief in the form of skin patches and cream. These were provided as a result of proactive pain management by the Clinical Nurse Specialist. In this regard, my Acute Nursing Adviser said the Consultant Nurse in Palliative Care gave reasonable and appropriate advice regarding pain and comfort and her recommendations were followed appropriately in the following days before Miss Kemp was transferred to the Rainbow Room.

323 Although there were some shortcomings in the Trust's approach to managing Miss Kemp's pain relief needs, I find these **do not amount to service failure**.

324 Given that I do not apply a test of perfection, and whilst recognising that other approaches to support Miss Kemp may have been possible, I am satisfied that in the circumstances the care and treatment provided for Miss Kemp in terms of hydration, nutrition, pain relief and nursing did not fall significantly below a reasonable standard.

Discharge from hospital on 7 June 2004

325 Mrs Kemp says it was not appropriate to discharge her daughter from hospital on 7 June 2004 because she was dehydrated and not eating. She also says that discharge arrangements were inadequate and she was given no guidance on how to manage Miss Kemp's nutrition, hydration and pain needs.

326 In considering this issue I have compared actions of Trust staff with national guidelines in Discharge from Hospital, the key points of which are set out at Annex B. I also note the Trust had its own discharge policy in place which reflected key aspects of the national guidelines.

327 My Professional Advisers said the Consultant Surgeon's decision to discharge Miss Kemp following her biopsy was appropriate because she did not have any acute health problems which could not be managed adequately in the community. However, they also advised me that it was not appropriate to discharge Miss Kemp without proper discharge planning and they have commented on the poor discharge documentation in the health record. I note that the discharge information sent to community services gave no information or advice about nursing care.

328 The Trust has said that on 28 May 2004 there was contact between Miss Kemp's carers and the Community Team for People with Learning Disabilities and as a result the potential need for additional support for Miss Kemp and her family was identified. Also, I note that although the Consultant Surgeon had said Miss Kemp could be discharged on Friday 4 June 2004, Miss Kemp was not discharged until the following Monday. Records show this was at least in part because Mrs Kemp was unhappy for her daughter to return to the Residential Home. As a result there

was some liaison between the Trust's nurses, Mrs Kemp and the Community Team for People with Learning Disabilities about discharge arrangements. The outcome of the debate was that Miss Kemp was discharged to her mother's home although Mrs Kemp has said, in the event, she did not know her daughter was going to be discharged until the last minute.

- 329 As I have said, national and local guidelines about discharge emphasise the importance of effective liaison, communication, multi-agency planning and documentation in ensuring safe, timely discharge. The importance of active involvement of families and carers is stressed.
- 330 I accept that Mrs Kemp was dissatisfied with the way in which arrangements were made for her daughter's discharge. I also appreciate that she would inevitably have had concerns about caring for Miss Kemp who had been in hospital for two weeks and who needed more than the usual level of support with eating and drinking. Furthermore, I was concerned to note that there were deficiencies in discharge documentation, particularly regarding nursing care. That said, Miss Kemp was judged fit to be discharged and there is also evidence that staff at the Trust made some reasonable adjustments in their approach to discharging Miss Kemp. In particular, Miss Kemp was kept in hospital for more than two days to allow time for alternative accommodation arrangements to be discussed and during this time there was discussion with community services and Mrs Kemp. Although arrangements for Miss Kemp's discharge were not ideal, I am not persuaded that, in the circumstances, they fell significantly below a reasonable standard.

- 331 Although there were some shortcomings in the Trust's approach to discharging Miss Kemp on 7 June 2004, I find these **do not amount to service failure**.

The decision not to treat Miss Kemp's cancer with chemotherapy

- 332 I now turn to the decision taken by the First and Second Oncologist that chemotherapy was not in Miss Kemp's best interests and, therefore, palliative care should be instigated. Mrs Kemp believes that Trust staff used her daughter's inability to consent as an excuse not to treat her cancer. She says treatment should at least have been tried but the doctors did not treat Miss Kemp purely because she had learning disabilities. Therefore, in considering this aspect of the complaint, I am particularly concerned with the question of whether decisions made by the clinical team reflected assumptions related to Miss Kemp's learning disability such that she received less favourable treatment.
- 333 First, I consider whether the Second Oncologist and his team had made assumptions about Miss Kemp and decided she should not receive chemotherapy before making a full assessment of her best interests. In his statement the Second Oncologist strongly refuted that this was the case.
- 334 It is clear from the Second Oncologist's note of the out-patient appointment and his subsequent letter to the Fifth GP that he recognised there would be considerable problems in treating Miss Kemp. In his letter to the Fifth GP of 23 June 2004 he said:

'... we have a major problem in offering her treatment be it radical or palliative.'

- 335 However, there is no suggestion in the records of that consultation or follow-up correspondence that either the First or Second Oncologist had already decided that Miss Kemp should not receive treatment. Rather, there is clear evidence that the Second Oncologist recognised the importance of working with Miss Kemp's family and his colleagues (for example, his letter to the Fifth GP included the suggestion of a multi-agency case conference) to try and address the issues involved in providing appropriate care and treatment. Furthermore, contemporaneous evidence shows that after the out-patient appointment he and his team immediately set about finding out what facilities might be available elsewhere which could best provide for Miss Kemp's needs. When Miss Kemp was readmitted on 23 June 2004, the need to make a decision about her treatment became more urgent and, as my Oncology Adviser has noted, the Second Oncologist made '*strenuous efforts to enlist the help of specialists*' in major cancer centres.
- 336 I find there is no evidence that the Second Oncologist had made assumptions about Miss Kemp related to her learning disability before events of 24 and 25 June 2004 when the best interest decision was made. Rather, the evidence suggests to me that he had recognised she had particular needs which would require a multi-agency approach and that the facilities available at the Trust were unlikely to be adequate to meet those needs.
- 337 I now turn to the way in which the Second and Third Oncologists made their decision regarding Miss Kemp's best interests. In Section 2 of this report I have summarised guidance in documents such as Good practice in consent, which sets out how clinicians should go about making best interest decisions. In essence, the guidance requires clinicians to take account of all relevant information and balance the benefits of treatment against the burdens of treatment.
- 338 Mrs Kemp does not dispute the fact that her daughter did not have the capacity to consent to treatment although she has questioned how doctors at the Trust established this. However, my Professional Advisers have said it would have been clear that Miss Kemp did not have capacity to consent and I consider it was reasonable for the clinical team to proceed on this basis without conducting and recording a formal assessment of capacity.
- 339 Contemporaneous evidence shows the Second Oncologist understood that once it had been established that Miss Kemp did not have the capacity to consent, the law required him to decide whether or not to give Miss Kemp chemotherapy, having regard to her best interests. To help him make that decision he asked the Third Oncologist to provide a second opinion and discussed the case with colleagues, including the Clinical Nurse Specialist and the Trust's Palliative Care Consultant, as well as oncologists at major cancer centres. It is clear from the health record and subsequent statements that the Second and Third Oncologists knew that a number of factors, including Miss Kemp's likely chance of survival with chemotherapy, the distress which treatment would cause her and the possible harm caused by the treatment itself and the side-effects of treatment, should be balanced carefully before they made a decision. There is evidence that both consultants also spent time discussing the situation with Miss Kemp's family and carers and documented that discussion in the health record. This was in line with guidance in *Good practice in consent: Achieving the NHS Plan commitment to a patient-centred consent practice*.

- 340 Mrs Kemp says she was told at the out-patient appointment of 18 June 2004 that her daughter had a 50% chance of survival if she underwent chemotherapy. There is no contemporaneous record of what the First and Second Oncologists told Mrs Kemp at this time and I have no reason to doubt what Mrs Kemp says. What the clinicians have said subsequently is that at the out-patient appointment they discussed treatment in broad terms with Mrs Kemp. The First Oncologist said she is likely to have told Mrs Kemp that for a *'straightforward lymphoma the chances of survival at 5 years are between 40% and 50%'*, but that she could not give a more precise figure without further investigations.
- 341 It is not possible to establish precisely what was said at the out-patient appointment. However, from the information I have seen and the advice I have received it is clear that, in reality, there is a range of evidence and opinion about the likelihood of survival from a large, diffuse B cell non Hodgkins lymphoma if a full course of chemotherapy is given.
- 342 My Oncology Adviser said research indicates there is a range of possible outcomes from active treatment of the type of lymphoma which Miss Kemp had developed, depending on a variety of prognostic indicators. He also said it is not possible to be certain about Miss Kemp's chances of survival, partly because there was no definitive information about the nature of the cancer and the stage to which it had developed by June 2004. However, he thought that, given what was known about Miss Kemp's tumour, a full course of treatment could have resulted in a 32 to 37% chance of her surviving. This matches reasonably closely with the estimates of one in three and 30 to 40% quoted by the First, Second and Third Oncologists in their responses to my enquiries.
- 343 When making their decision about whether treatment was in Miss Kemp's best interests the Second and Third Oncologists considered the likely distress and harm which treatment might cause her. Contemporaneous evidence, in particular the Third Oncologist's note in the health record of 25 June 2004, indicates that the two consultants were particularly mindful and concerned about the likely harmful impact of the consequences of chemotherapy. The Third Oncologist recorded his opinion that it was likely the chemotherapy would cause Miss Kemp *'considerable and unwarranted distress'* and that the *'chances of causing harm, or indeed death as a result of treatment'* were high. Subsequently, in their responses to my enquiries, the consultants have given further explanation about the nature of the distress and harm which they thought could have resulted from treating Miss Kemp. They explained that they were particularly concerned, not only with the potential detrimental impact of administering the treatment itself, which would have required Miss Kemp to be sedated or anaesthetised for prolonged periods over about six months, but also with the likely adverse impact of potential side-effects of treatment, particularly life-threatening infection. They said this was why they told Mrs Kemp that the overall chance of her daughter surviving even with treatment was around 10%. They also said they considered that giving a single cycle of treatment in an attempt to palliate Miss Kemp's symptoms would have carried the same risks of distress and harm.
- 344 My Oncology Adviser took a different view. He acknowledged that there were likely to be potentially serious consequences and side-effects from administering R-CHOP chemotherapy. However, he said these problems could be predicted and dealt with using a range of available measures. He told me that, in his

view, the side-effects of R-CHOP chemotherapy would not have been unduly burdensome for Miss Kemp. He added that if appropriate treatment and medical care had proved possible in the correct specialised environment Miss Kemp would have had a realistic chance of remission or even cure. He said he would not have made the decision which the Second and Third Oncologists made and he would at least have tried to administer one cycle of chemotherapy. Although he did add the caveat that in his opinion, in the circumstances of this case, this could only have been done in a major cancer centre. Nonetheless, my Oncology Adviser accepted that the decision taken by the Second and Third Oncologist was within the spectrum of reasonable clinical decisions.

345 My Learning Disability Adviser told me that, ideally, a formal best interests meeting should have been convened at which the possibility of treating Miss Kemp's cancer could have been more fully discussed. She said such a meeting might have resulted in a decision to try to administer one cycle of chemotherapy; treatment which she thought would have been '*difficult but not impossible*'. However, although she thought the decision not to treat Miss Kemp could have been made in a more considered way, my Learning Disability Adviser told me that, in the circumstances, she believed the doctors had acted in Miss Kemp's best interests. She also told me that, in her view, the doctors' decision was not affected by Miss Kemp's learning disabilities per se.

346 I also note that the Trust's Independent Medical Adviser said the decision not to treat Miss Kemp's cancer was correct. He agreed with the Second and Third Oncologists about the potential harm and distress which chemotherapy would probably have caused Miss Kemp. He considered

the risks of treatment outweighed the benefits and, in his view, Miss Kemp would have been unlikely to survive her cancer whether or not she received treatment.

347 I am in no doubt that the decision which faced the Second and Third Oncologists was not easy. All the advice and opinion which I have seen confirms this. There is no dispute that the appropriate treatment for Miss Kemp's cancer was R-CHOP and the only way that this could be administered was in several cycles of intensive treatment over a period of several months. The difficult question which they had to address was whether the benefits of treating Miss Kemp outweighed the potential harm and distress which that treatment might cause her.

348 As a lay Ombudsman it is not for me to have a clinical opinion about whether or not Miss Kemp should have received treatment for her cancer. The question I ask is whether, in all the circumstances, she received a reasonable standard of care and treatment.

349 First, I find that the Second and Third Oncologists acted in line with relevant ethical, legal and professional guidance on how they should act in a situation where a patient lacks the capacity to consent to treatment. In particular, they consulted with a wide range of colleagues, weighed up the risks and benefits of treatment and involved Mrs Kemp in their decision.

350 Secondly, I find that in the circumstances the decision which the Second and Third Oncologists made was not unreasonable. In making this finding I have taken account of the fact that there are significant differences of opinion, even between clinical experts, on whether or not Miss Kemp should have been treated.

351 Thirdly, I find there is no evidence that in making their decision the Second and Third Oncologist treated Miss Kemp less favourably with regard to her learning disabilities. That is not to say that, if Miss Kemp had not had learning disabilities, the decision in relation to her best interests would have been the same. Rather, that they considered the challenges that existed as a result of her learning disabilities, and the adjustments that could reasonably be made to address those challenges, and concluded that the risk of harm and distress that was likely to be caused by the treatment outweighed the benefit that was likely to be obtained. In different circumstances those assessments of risk and benefit might well have been different, but these were the circumstances that the Second and Third Oncologist were faced with in Miss Kemp's case.

352 Therefore, I **do not find service failure** with regard to the decision not to treat Miss Kemp's cancer with chemotherapy.

Care and treatment at the Trust: my conclusion

353 I have carefully considered Mrs Kemp's complaints about the care and treatment provided for her daughter by the Trust. Having considered all the available evidence, including Mrs Kemp's recollections and views, and taken account of the advice of my Professional Advisers, I conclude that:

(i) Miss Kemp's condition was appropriately investigated and reasonable adjustments were made with regard to her learning disabilities to enable the investigations to take place;

(ii) there were shortcomings in the way the Trust managed Miss Kemp's needs for hydration, nutrition and pain relief and in the way in which they made arrangements for her discharge, but these failings were not so serious as to amount to service failure; and

(iii) the decision not to treat Miss Kemp's cancer was made in an appropriate and reasonable way and was itself not unreasonable.

354 I consider the standard of care and treatment provided for Miss Kemp by the Trust did not fall significantly below a reasonable standard in the circumstances. Therefore, I conclude there was **no service failure** in this regard.

355 Therefore, I **do not uphold** this aspect of Mrs Kemp's complaint against the Trust.

Complaint (e): accommodation and facilities

356 As well as her dissatisfaction with the way the Trust managed her daughter's care and treatment Mrs Kemp is unhappy about the accommodation and facilities provided during Miss Kemp's second admission from 23 to 28 June 2004.

Key events

357 As I have previously described, on 23 June 2004 Miss Kemp was sent to hospital from the Respite Home as an emergency by a GP. She was initially admitted to the Clinical Decision Unit where patients are assessed before being discharged or transferred to other areas of the Trust. Records show there was discussion between the Second Oncologist and community services. As a result, the Respite Home agreed to look after

Miss Kemp if they could find additional staff. However, additional staff could not be found and a decision was taken that she should stay in hospital. The Second Oncologist felt Miss Kemp would be distressed in the busy atmosphere of the Clinical Decision Unit, so he arranged for her to go to a single room on the Second Ward. She stayed in that room until she was transferred to the Rainbow Room on 28 June 2004.

Mrs Kemp's recollections and views

358 Mrs Kemp told my investigator that she believed her daughter was critically ill when she was admitted to the Trust on 23 June 2004. She also said it was only when she refused to take Miss Kemp home that the Second Oncologist took action to find her the room on the Second Ward.

359 Mrs Kemp was dissatisfied about various aspects of the single room. She contacted the Legal Representative and a letter was written to the Trust setting out Mrs Kemp's areas of concern. This letter formed part of Mrs Kemp's complaint to the Trust which I consider in more detail later in the report. An entry in Mrs Kemp's Diary of Events from April 2004 sums up how she felt about the accommodation:

'You entered the room via a store cupboard, there was no peace. There was no bed for me or the carer. The blinds did not work on the window and there was no plug in the sink (which was just hanging on the wall). Despite repeated requests by family to staff they did not find Emma a shower.'

360 Subsequently, Mrs Kemp has questioned why her daughter was admitted to a general medical ward, rather than a specialist adult oncology ward.

The Trust's position

361 The Second Oncologist has described how he returned to the Trust after he had finished work for the day because he heard about Miss Kemp's admission and knew he was best placed to review her condition and decide about her ongoing care. He saw her in the Clinical Decision Unit and realised that this would not be the best environment for her because it was hot, noisy and busy. He said he knew it would be difficult to protect Miss Kemp's dignity and that of her family and carer if she stayed there. Therefore, he organised a single room for her, which happened to be the only one available in the Trust at that time. He said he had no intention of discharging her until a satisfactory management plan could be arranged.

362 The Trust has explained that when Miss Kemp was admitted on the evening of 23 June 2004 the oncology ward was full and there were no single rooms available on that specialist ward. The most suitable single room which could be found was the one on the Second Ward, which was next to the oncology ward. An alternative bed in a four-bedded bay on an orthopaedic ward was considered inappropriate as it was elsewhere in the hospital, a quarter of a mile away from the oncology ward.

The advice of the Professional Advisers

363 My Oncology Adviser said, given Miss Kemp had been diagnosed as having advanced cancer, the most appropriate location for her would have been a single room on an adult oncology or haematology ward with specialist staff and facilities. He said even after the decision had been taken not to instigate chemotherapy, the expertise of oncology trained nurses would have

been beneficial. He felt Miss Kemp should have been moved to a single room on the oncology ward at the earliest opportunity.

- 364 My Acute Nursing Adviser said it was preferable for Miss Kemp to be moved from the busy Clinical Decision Unit to a single room even when that room was not an ideal location for her. However, she considered Miss Kemp should have been moved to an oncology ward at the first available opportunity.

My findings

- 365 There remains a difference of opinion between Mrs Kemp and the Second Oncologist about events on the evening of 23 June 2004. Mrs Kemp has said the Second Oncologist only admitted her daughter because she refused to take her home, whereas the Second Oncologist maintains he wanted to put a plan in place before discharging her. The health record shows that the Second Oncologist did explore the possibility of Miss Kemp returning to the Respite Home and, therefore, he was certainly considering whether she could be discharged. However, the Respite Home could not find additional staff and the Second Oncologist recognised that the Clinical Decision Unit was not a suitable environment for Miss Kemp, so he made special arrangements for her to be admitted to a single room on a ward.
- 366 There is evidence that the Second Oncologist was prepared to discharge Miss Kemp to the Respite Home if additional staff could be found and, to this extent, I accept Mrs Kemp's assertion that the Second Oncologist was prepared to discharge her daughter on the evening of 23 June 2004. However, I am persuaded that when it became clear that Miss Kemp could not be safely discharged, the Second Oncologist did

recognise she needed more space, quiet and privacy than would be provided on the Clinical Decision Unit and took action to find a more suitable environment.

- 367 I can fully understand why Mrs Kemp was dissatisfied with the accommodation and facilities provided for her daughter during the second admission. I have no reason to doubt her description of the environment where Miss Kemp spent five nights before she was transferred to the Rainbow Room. I can only imagine how difficult and frustrating this situation was for Miss Kemp, her mother and her carers.
- 368 I have considered the advice of my Oncology Adviser and my Acute Nursing Adviser that it would have been preferable if Miss Kemp had been admitted to a single room in a specialist ward. I have also considered my Oncology Adviser's view that, even though no suitable room was immediately available, Miss Kemp should have been moved to such accommodation as soon as possible. However, it seems no such room became available before she left the Trust on 28 June 2004.

Accommodation and facilities at the Trust: my conclusion

- 369 There are aspects of events on the evening of 23 June 2004 which remain unresolved. While I do not doubt Mrs Kemp's version of events, I conclude that the Second Oncologist did make reasonable adjustments to try and manage what was undoubtedly a difficult situation. In particular, he came back to the hospital outside his normal working hours and, once it was clear that Miss Kemp could not be safely discharged, he made efforts to find her suitable accommodation in the hospital.

370 In terms of the accommodation which was provided, I accept that the oncology ward was full, a suitable single room on a specialist ward was not available and a single room on a general ward was more appropriate than a bed in the Clinical Decision Unit. I note Trust staff have said that by choosing a single room near the oncology ward for Miss Kemp they were attempting to make appropriate arrangements for her, her family and her carer.

371 Having considered the evidence, including Mrs Kemp's recollections and views, and taken account of the advice of my Professional Advisers I conclude that the standard of accommodation and facilities during Miss Kemp's second admission were not ideal but, in all the circumstances, this **does not amount to service failure**.

372 Therefore, I **do not uphold** this aspect of Mrs Kemp's complaint against the Trust.

Complaint (f): complaint handling by the Trust

373 Mrs Kemp remains dissatisfied with the way the Trust handled her complaint.

Key events

374 On 8 July 2004 Mrs Kemp wrote to the then Leader of the Opposition outlining her concerns about the care and treatment her daughter had received at the Trust. She raised several specific issues all of which related to her daughter's care and treatment at the Trust between 26 May and 28 June 2004. The key matters she complained about related to: poor nursing care during the first admission; delay in arranging a CT scan; the decision to discharge Miss Kemp on 7 June 2004 and to send her home after the out-patient

appointment of 18 June 2004; the Second Oncologist's reluctance to readmit Miss Kemp on 23 June 2004 when she was dehydrated and in pain; accommodation and facilities during the second admission; lack of attention to nutrition and hydration; and the decision not to treat Miss Kemp's cancer.

375 This letter was sent on to Mrs Kemp's own constituency MP, who sent it to the Trust on 28 July 2004.

376 The Legal Representative had also written a letter to the Trust's Solicitor on 30 June 2004 which was forwarded to the Trust on 7 July 2004. This set out why the accommodation and facilities provided during the second admission were inadequate. The points she raised included: problems with the furniture and fittings; the shower did not work and alternative arrangements were not made; the anteroom was used as a storage area; facilities for the carers were inadequate; and it was noisy at night.

377 On 1 September 2004 Mrs Kemp sent the Trust a copy of her Diary of Events from April 2004 which gave a more detailed chronological account of her concerns. In addition to the points raised in her letter of 8 July 2004 and the Legal Representative's letter of 30 June 2004, she complained about: lack of concern shown by Trust staff about Miss Kemp's distress and pain during her first admission; the way Miss Kemp was prepared for and taken to the CT scan on 2 June 2004; the wait to hear the result of the biopsy and what to do next; the lack of advice about care or pain relief during the out-patient appointment on 18 June 2004; the Second Oncologist's attitude on 23 June 2004; the lack of consideration shown by Trust staff for Miss Kemp's anxiety throughout her hospital experience; and the lack of facilities available for Miss Kemp to receive treatment for her cancer.

378 The Trust's Complaints Co-ordinator collated comments from the First Oncologist, the Lead Sister for the Second Ward, the Consultant Surgeon, and the Head of Legal Services and Corporate Risk. The Second Oncologist declined to provide a response to the complaint explaining that he regarded it as 'malicious' and that Emma was actually under the First Oncologist's care. The Third Oncologist was only involved to the extent that he approved a draft of the Trust's final response.

379 On 7 September 2004 the Deputy Chief Executive responded to Mrs Kemp (via her MP) on behalf of the Trust. The letter set out the sequence of events as they related to the points of complaint and said that: Miss Kemp was reluctant to be examined and refused tests and interventions; a CT scan was obtained under sedation on 2 June 2004; the Consultant Surgeon had discharged Miss Kemp because she had no acute symptoms and there was no plan for immediate treatment; and the Second Oncologist had spent many hours with Miss Kemp on 24 June 2004.

380 In relation to Miss Kemp's cancer, the Trust said that: '*under normal circumstances*' a patient with a high grade B cell non Hodgkin's lymphoma '*would have a 40% chance of cure with chemotherapy*'; chemotherapy can only be delivered intravenously; an adult oncology ward was not an appropriate place for Miss Kemp, but facilities were not available at other trusts; and after discussion about Miss Kemp's treatment on 25 June 2004 a '*successful conclusion*' was reached.

381 Responding to Mrs Kemp's complaints about the failure to meet Miss Kemp's nutrition and hydration needs the Trust said:

'At all times we recognise[d] that if Emma continued to refuse to drink or eat, and refused all approach[es] to provide intravenous hydration, she would deteriorate. However, we found ourselves in a very difficult position. As you are aware it is not possible in law to force treatment upon patients. In this case Emma [was] clearly unable to consent to that treatment and there is not another party who can consent. In the absence of a Declaration to Treat, which was being actively considered, in such a situation we are only able to instigate life saving treatment. Had we not been able to reach agreement on her care and she had deteriorated significantly, we would have been able to impose such care.'

and

'... we are unable to impose treatment of any nature upon an individual who is clearly unable to give informed consent, and indeed in Emma's case, who has dissented by her behaviour in an obvious and sometimes violent manner.'

382 Trust records show that these specific paragraphs were drafted by the Head of Legal Services and Corporate Risk.

383 The Trust apologised for the standard of accommodation and facilities provided during the second admission and advised Mrs Kemp to write back to the Trust, or approach the Healthcare Commission if she was dissatisfied with the response.

384 On 20 October 2004 Mrs Kemp wrote to the Trust saying she was dissatisfied with the response to her complaint, and that she had written to the Healthcare Commission. She

said she did not agree with some of the Trust's explanation and she enclosed a second copy of the Diary of Events from April 2004. In particular, she said Miss Kemp refused to be examined because she was frightened and she was never violent as the Trust had said.

385 On 11 November 2004 the Trust responded apologising for the use of the term '*violent*', accepting that this was an incorrect description of Emma's behaviour. It also said it had tried to address all the issues mentioned in Mrs Kemp's Diary of Events from April 2004 in its response dated 7 September 2004.

The Trust's position

386 The Trust has accepted that the response to Mrs Kemp's complaint did not address all the matters she raised and, in particular, the Chief Executive has accepted that the section which dealt with legal issues was '*incomplete*', and did not fully set out the correct legal position.

387 The Trust also informed me that since the events complained about it has '*fully reviewed and amended*' its complaints policy.

My findings

388 Mrs Kemp complained to the Trust in June 2004 when procedures for handling complaints against the NHS were set out in various Directions, as I have explained in Section 2 of this report. However, by the time the Trust responded in September 2004 the Regulations which I have also described in Section 2 had been in force for over a month. Therefore, I have compared the Trust's actions with the requirements of the Regulations.

389 I find the Trust's Complaints Co-ordinator acted reasonably in seeking comments from Trust staff involved and her action in this regard was in line with the Regulations. However, I find it entirely unacceptable that the Trust did not question the fact that the Second Oncologist had declined to participate in the complaints process. Instead, the Trust allowed the First Oncologist to respond to the complaint even though she had not been involved in the key events complained about. The Trust should have explored the Second Oncologist's reluctance to co-operate with the complaints process more fully.

390 I am not satisfied that the Trust's responses adequately addressed the issues raised by Mrs Kemp.

391 The Regulations require the body complained about to make sure they understand the nature of the complaint, identify the issues of the complaint and address all the key issues in a clear way which is easy for the complainant to understand.

392 As I have explained, Mrs Kemp's complaint to the Trust arrived between 30 June and 1 September 2004 in three separate letters: the letter from the Legal Representative about accommodation and facilities on the Second Ward; Mrs Kemp's letter to the then Leader of the Opposition; and the Diary of Events from April 2004. The Trust did not act in line with the Regulations because it did not establish the precise nature of the issues of complaint. Had it contacted Mrs Kemp to clarify exactly what she was complaining about it is more likely that the response would have gone at least some way towards addressing her concerns. As it was, the response left many matters either completely or partially unanswered. For example, the response

did not address Mrs Kemp's specific concerns about lack of preparation for the CT scan, the time taken to provide the biopsy results, the lack of consideration for Miss Kemp's anxiety, or Mrs Kemp's concern that Emma was simply sent home after the out-patient appointment without advice about her ongoing care or the management of her pain. The Trust's letter contained only partial responses to some issues, including discharge arrangements and accommodation and facilities on the Second Ward.

393 In addition, the Trust glossed over some issues including Mrs Kemp's specific complaint about the Second Oncologist's attitude on 23 June 2004, simply saying he had spent a long time with Miss Kemp and managed to find her a single room. The response also contained factual inaccuracies, including the date of the CT scan and the date of the second admission.

394 I was especially concerned that the Trust did not identify that Mrs Kemp's primary concern was the decision not to treat Miss Kemp's cancer. This meant the response to this aspect of the complaint was wholly inadequate. The Trust's Complaints Co-ordinator should have assembled information, such as statements from the Second and Third Consultants, which allowed her to explain the reason why they decided it was not in Miss Kemp's best interests to instigate chemotherapy. She did not do this and consequently the response was limited, weak and vague.

395 I also find there were errors in the explanations given by the Trust about the legal and ethical principles about providing care and treatment for people who lack capacity to consent, despite the fact that these are clearly set out in documents available at the time. I have set out the correct legal position in Section 2 of this

report. I am especially concerned that evidence in the complaint letter suggests the Head of Legal Services and Corporate Risk and the Deputy Chief Executive did not understand the legal position correctly.

396 The Trust's inaccurate and inadequate explanation probably led Mrs Kemp and Mencap to believe, at least in part, that the Trust had not treated Miss Kemp's cancer because she could not consent to treatment. In their report *Death by indifference*, 2007, Mencap summarised Miss Kemp's case as follows:

'Emma died of cancer on 25 July 2004, aged just 26. She had a severe learning disability, which meant that she sometimes exhibited challenging behaviour and had difficulty in communicating how she felt. The hospital delayed treating her because they said she would not co-operate with treatment and therefore could not consent to treatment.'

Complaint handling by the Trust: my conclusion

397 I conclude that there were major failings in the way the Trust handled Mrs Kemp's complaint. Specifically, the Trust:

(i) failed to ensure it understood the complaint correctly;

(ii) failed to adequately address all the issues raised;

(iii) failed to obtain sufficient relevant evidence;

(iv) failed to ensure that key individuals, in particular the Second Oncologist, participated in the investigation and contributed to the response;

(v) failed to provide a factually accurate response; and

(vi) provided inaccurate and misleading information about the legal and ethical position regarding adults who lack capacity to consent.

398 In these respects the Trust failed to comply fully with the applicable Regulations. Its actions did not accord with principles of good administration and it did not provide an appropriate or adequate remedy. These failings meant the Trust missed the opportunity to explain the reasons why the clinical team had made the decision not to treat Miss Kemp's cancer and to explain further why it considered this decision was in her best interests.

399 These failings amount to **maladministration**. However, I have found no evidence which indicates that the Trust's maladministration in handling Mrs Kemp's complaint was for disability related reasons. Mrs Kemp has had to pursue her complaint over many years in order to obtain the explanations she sought and this undoubtedly caused her distress. This was an **injustice** which arose in consequence of the maladministration I identified.

400 Therefore, I **uphold** Mrs Kemp's complaint about complaint handling by the Trust.

Recent action by the Trust

401 In information provided during my investigation, the Trust's Chief Executive described actions which the Trust has taken since the events complained about which are aimed at addressing issues raised in the course of the complaints process.

402 She said that in June 2006 the Trust formed a Learning and Multi-Disability Working Group with the aims of '*improving care delivery for all patients with learning disabilities, raising awareness within the Trust and developing appropriate systems*'. She described some of the work of the group which includes: reviewing a risk assessment tool; developing a business case for employing a specialist learning disabilities liaison nurse; developing training materials and setting up resource links; and involving service users in the everyday running of the hospital.

403 The Chief Executive also described *Information about me* documentation which has been developed in liaison with a community learning disabilities nurse and how sessions related to learning disabilities have been introduced as part of the induction programme for healthcare staff.

404 During the investigation the Trust has accepted that the response to Mrs Kemp's complaint was not complete. In particular, it said the paragraph of the response which dealt with legal issues was '*incomplete*', and did not set out the '*full legal position*'.

405 The Chief Executive confirmed that the complaints policy has been reviewed in the light of feedback from complainants and a new policy has been developed which focuses on timely and effective local resolution.

406 The Chief Executive also said she hoped to meet with Mrs Kemp when my investigation is complete.

My recommendation

407 I note that after the Healthcare Commission identified failures in the Trust's complaint handling the Trust apologised to Mrs Kemp for those failings. I also note the recent actions by the Trust to review and improve its complaints process. Furthermore, the Chief Executive has offered to meet with Mrs Kemp after my investigation. I consider the Trust has provided appropriate remedy for the injustice I identified in my investigation of Mrs Kemp's complaint about complaint handling by the Trust. The Trust's actions were in line with my *Principles for Remedy*.

408 Therefore, I make **no recommendation** regarding this aspect of Mrs Kemp's complaint against the Trust.

My investigation of the complaint against the Healthcare Commission

Complaint (g): the complaint against the Healthcare Commission

409 Mrs Kemp is dissatisfied with the way the Commission handled her complaint. She says the Commission's review of her complaint took too long and did not provide her with the answers she sought.

The basis for my determination of the complaint

410 The regulations and standards which apply to the Commission's handling of complaints are set out in Section 2 of this report. When assessing the way in which the Commission handled Mrs Kemp's complaint I have regard to those regulations and standards and to my own *Principles of Good Administration* and *Principles for Remedy*.

My jurisdiction and role

411 Section 1 of this report sets out the basis of my jurisdiction in relation to complaints made to me that a person (or body) has sustained injustice or hardship in consequence of maladministration by the Commission in the exercise of its complaint handling function.

412 When complaints have already been reviewed by the Commission, I do not normally carry out an investigation of the original complaint, but investigate the way in which the Commission has conducted its review. Specifically, I consider whether:

- there were any flaws in the Commission's review process which makes the decision unsafe;
- the Commission's decision at the end of the review process was reasonable; and
- the service the Commission provided was reasonable and in line with its own service standards.

413 When I uphold a complaint about the Commission's complaint handling, because I find the review process was flawed, or the decision unreasonable, I normally refer the complaint back to the Commission for it to remedy the failure by conducting a further review.

My decision

414 For reasons given below, I **do not uphold** Mrs Kemp's complaint about the Commission's complaint handling.

The Commission's reviews

Key events

415 On 20 October 2004 Mrs Kemp complained to the Commission about the care and treatment provided to Miss Kemp. Her complaints included the time it had taken to diagnose her daughter's cancer and the treatment which she received after the diagnosis of cancer had been made. Mrs Kemp also raised her concerns about the capability of nursing and medical staff to care for a patient with learning difficulties and she said staff were very insensitive and '*had no idea how to handle [her] daughter*'. Mrs Kemp referred to particular comments which she said had been made, for example, that '*there is no point in treating someone with severe learning difficulties*'.

416 During its review of her complaint, the Commission wrote to Mrs Kemp on five occasions to update her on progress and to apologise for the delay in concluding its review.

The Commission's first decision

417 On 21 December 2005 the Commission wrote to Mrs Kemp with its decision. No clinical advice had been sought as part of the Commission's review. The Commission divided Mrs Kemp's complaints into seven issues and decided to refer all but one of those issues back to the Trust for further local resolution. The Commission did not consider the Trust had provided an adequate response and some of the issues raised had not been raised with the Trust previously. The issue which the Commission did not refer back to the Trust was Mrs Kemp's concern that the Trust had not offered her daughter different methods of chemotherapy. Having reviewed documentation from the Trust, the Commission's Case Manager noted that the Trust had said that, although there were other methods of chemotherapy available, they were not administered because they needed to be given orally and Miss Kemp

could not swallow. The Case Manager considered this to be a reasonable position and concluded that on this specific issue no further action on the Trust's part was required. He also concluded that Miss Kemp's CT scan was undertaken within an acceptable time limit.

The Commission's final decision

418 On 25 January 2006 Mencap contacted the Commission detailing their concerns about the Commission's response of 21 December 2005. In their view, Mrs Kemp's questions had not been answered and there had been no detailed investigation. They also expressed concern that no clinical advice had been sought when assurances had been given to the contrary. The Commission accepted the criticisms Mencap had made and agreed to reconsider Mrs Kemp's complaint. The Commission wrote to Mencap in May 2006 to inform them that the case had been allocated to a Case Manager for review.

419 During the review process, the Commission updated Mrs Kemp on progress on five occasions.

420 As part of its review, the Commission had regard to the following information sources:

- *Understanding the patient safety issues for people with learning disabilities* issued by the National Patient Safety Agency;
- The Commission's strategic plan for 2005-2008 which says the Commission is determined to make a difference for people with learning disabilities;
- Valuing People; and
- The Department of Health's core standards. Specifically, that organisations challenge discrimination, promote equality and respect human rights.

421 The Commission obtained clinical advice from two professional advisers: a consultant in clinical oncology (the Commission's Medical Adviser) and a registered nurse (the Commission's Nursing Adviser). The Commission's Medical Adviser concluded that:

- Miss Kemp had an aggressive form of lymphoma with a low cure rate and poor prognosis;
- the time taken to make a diagnosis of cancer was not unreasonable. The Trust did its best to ensure that the CT scan and the other investigations which were carried out as part of the diagnostic process were carried out in the shortest possible length of time;
- Miss Kemp's symptoms were dealt with appropriately;
- following Miss Kemp's diagnosis of cancer, medical staff had considered all treatment paths appropriately and there were no other known treatment options which the Trust might have employed;
- all guidelines within the National Service Framework for cancer had been appropriately followed;
- the Trust had sought the relevant expertise and followed accepted practice to determine whether Miss Kemp had the mental capacity to provide consent;
- the Trust's position that, in the light of Miss Kemp's poor prognosis, radical treatment was neither feasible nor desirable, was reasonable; and

- it was because of Miss Kemp's problems with communication and her needle phobia that she was treated differently, rather than because of her learning disabilities.

422 The Commission's Nursing Adviser concluded that:

- there were no entries within the clinical records which suggested that nursing staff provided inappropriate care. The notes indicated that staff sought support from a learning disability nurse particularly around discharge planning, nutritional assessments were undertaken and appropriate care plans were developed;
- there were a number of entries in the notes which showed there was communication between staff and Miss Kemp's family about how best to manage her care. However, there should have been better documentation about what Miss Kemp's learning difficulties actually were. The Nursing Adviser would, for example, have expected nursing staff to have documented what Miss Kemp's normal abilities and behaviours were and what a change to the norm would be; and
- staff did as much as they were able to do to help Miss Kemp understand and co-operate with treatment. In all the circumstances, nursing staff cared for Miss Kemp appropriately as a patient with learning difficulties. Miss Kemp did not receive a lower standard of care with regard to her learning difficulties.

423 On 8 March 2007 the Commission issued its second decision. On the basis of the professional advice it received, the Commission decided that no further action was necessary in relation to Mrs Kemp's central complaints about the time it had taken to diagnose her daughter's cancer and the treatment which she received after the diagnosis of cancer had been made. The Commission did, however, make some recommendations to the Trust, including that the Trust should consider recruiting or training an existing nurse to specialise in learning disabilities, and that it should review the standard and appropriateness of the communication which took place between staff and Miss Kemp and Mrs Kemp, and disseminate any lessons learnt.

My professional advice

424 I asked my Professional Advisers for their views about the clinical advice which the Commission obtained. My Oncology Adviser said the clinical issues in this case were difficult. In his view, the Commission should have referred the case to a senior haemato-oncologist who had expertise of dealing with the management of complex lymphoma cases in a major centre. He disagreed with the Commission's clinical advice in a number of respects.

425 My Acute Nursing Adviser said the Commission obtained nursing advice from a suitably qualified adviser who referred to appropriate practice standards. However, my Acute Nursing Adviser said her overall conclusion differed significantly from that of the Commission's Nursing Adviser in that she did not feel that staff did everything they could to support Miss Kemp.

My findings

426 I have explained that I assess the way in which the Commission has conducted its review by considering the review process, the decision and whether the service provided was reasonable.

427 I find that the process leading to the Commission's first decision was flawed. The Commission concluded that, with the exception of one issue (the suitability of different methods of chemotherapy treatment), the Trust should take further action to resolve Mrs Kemp's complaint. The Commission, therefore, referred all but one of Mrs Kemp's complaints back to the Trust for further investigation. The Commission decided that Miss Kemp's CT scan was performed within an acceptable time limit.

428 The Regulations give the Commission the discretion to recommend that an NHS body take further action to resolve a complaint. I agree that, in this case, there was scope for the Trust to investigate matters further and I do not consider it was inappropriate that the Trust was given the opportunity to do this.

429 I am, however, critical that in reaching this decision, the Commission did not seek any clinical advice, relying instead on a lay view. The Commission may take any advice which is needed for it to make a decision. I would expect that when the Commission reviews complaints which involve clinical matters, it would obtain appropriate advice from professional advisers with the relevant experience and expertise. Determinations about chemotherapy options and the timing of a CT scan clearly had a clinical focus and, to address those matters properly, it was necessary to have advice from a suitably qualified clinician. The Commission's failure to do that renders its initial decision unreliable and unsafe. This was **maladministration**.

430 I turn now to the Commission's second and final decision. I expect the Commission to obtain appropriate advice from professional advisers with the relevant experience and expertise. To inform its second review, the Commission sought advice from an oncologist. My Oncology Adviser considers the Commission should have sought advice from a haemato-oncologist who had expertise in dealing with complex lymphoma cases. I am, however, not persuaded that the Commission's choice of adviser was wholly inappropriate. Oncology was the relevant specialty in this case, and the Commission was, in my view, entitled to expect the adviser it had appointed to say if he felt the matters he was being asked to consider fell outside his area of expertise. Furthermore, although my Oncology Adviser did not agree with all the advice provided by the Commission's Medical Adviser this does not in itself make it wrong advice. As I have explained previously in this report, during my investigation I have seen a range of clinical opinion about Miss Kemp's care and treatment.

431 My Acute Nursing Adviser has said that the Commission's Nursing Adviser was appropriately qualified to provide advice and referred to appropriate practice standards. However, she expressed her concerns about the advice itself. Again, this does not in itself make it wrong advice.

432 The Commission's second decision letter did contain some inaccuracies. However, on the whole I consider it:

- was comprehensive and clear;
- set out each complaint, referring to Mrs Kemp's view of events (and Mencap's view) as well as the facts from the health records;

- referred to relevant standards;
- referred to action taken by the Trust to resolve the complaint; and
- explained the rationale for each of its decisions using the clinical advice it had received.

433 Overall, the Commission's second response was reasonable and in line with Regulations.

434 I do not find that the service which the Commission provided was poor. It took the Commission ten months to complete the first review and approximately a year to conclude the second review. I have said I do not think it was unreasonable for the Commission to have referred Mrs Kemp's complaint back to the Trust in the first instance. The Commission's service standard at the time was that, in the majority of cases, the review process should take no longer than six months. Whilst the Commission did not complete either of its reviews within the general service standard target, I do not think the time taken in either case was so long in the circumstances of such a complex and sensitive case as to constitute maladministration.

435 I am also mindful that during both of its reviews, the Commission updated Mrs Kemp at regular intervals on the progress it was making with her complaint. One of the six *Principles of Good Administration* (referred to in Section 2 of this report) is that public bodies should be customer focused, and specifically that they should tell people if things are going to take longer than they had said they would. In its update letters, the Commission apologised for its delay, explained what stage it had reached in its review, and when Mrs Kemp could expect to hear from it next. This reflects good administrative practice.

436 I conclude that there were failings in the Commission's handling of Mrs Kemp's complaint in relation to the Commission's first decision which amount to **maladministration**. I have found **no maladministration** by the Commission in the second decision.

Injustice

437 There was injustice arising from the Commission's maladministration in that its first decision did not provide Mrs Kemp with the review to which she was entitled. However, the Commission's second review did address the matters she raised in a reasonable way and was not maladministrative. Furthermore, I found no service failure in the Commission's handling of the complaint. I find **no unremedied injustice** relating to Mrs Kemp's complaint against the Commission.

438 Therefore, I **do not uphold** Mrs Kemp's complaint against the Commission.

Section 4: the Ombudsman's final comments

Introduction

- 439 Mrs Kemp's overarching complaint is that her daughter's death was avoidable and that she was treated less favourably for disability related reasons. She has told me she has not had full answers to all her questions about Miss Kemp's care and treatment and she hopes my investigation will provide her with those answers. She hopes other people will not go through the same experience as her daughter. In this final section of my report I address Mrs Kemp's overarching complaint.
- 440 In assessing the actions of the Trust I have taken account of relevant legislation and related policy and administrative guidance as described in Section 2 of this report. I have taken account of available evidence and considered the advice of my Professional Advisers.
- 441 I have found no service failure in terms of the care and treatment provided to Miss Kemp by the GPs who saw her between 3 and 26 May 2004.
- 442 I have not upheld the complaints about the Trust's diagnostic investigations, the decision not to treat Miss Kemp's cancer with chemotherapy, the care and treatment she received, and the standard of accommodation and facilities.
- 443 I have upheld Mrs Kemp's complaint about the way the Trust handled her complaint, but I have decided there is no outstanding injustice in this regard.
- 444 I have found no evidence that Miss Kemp was treated less favourably by any of the bodies complained about for reasons related to her disability.

Was Miss Kemp's death avoidable?

- 445 Mrs Kemp questions the decision not to treat her daughter's cancer with chemotherapy. She believes that had this treatment been provided her daughter would not have died.
- 446 In considering whether to make a finding about avoidable death I assess whether the injustice or hardship complained about (in this case Miss Kemp's death) arose in consequence of any service failure or maladministration I have identified.
- 447 Having considered all the evidence and taken account of Mrs Kemp's recollections and views as well the clinical advice I have received, I have found no service failure or maladministration relating to the decision not to treat Miss Kemp's cancer. On that basis, my finding is that Miss Kemp's death did not arise in consequence of any service failure or maladministration. Therefore, I do not conclude that her death was avoidable. It will never be known whether Miss Kemp would have survived had she received chemotherapy, or whether the intensive treatment which this involved or the side-effects of that treatment would in fact have hastened her death, but these issues were not the subject of my investigation.

Mrs Kemp's response to my draft report

- 448 Mrs Kemp was dissatisfied with the outcome of my investigation. Her response to my draft report contained many detailed points which I have addressed separately in liaison with Mencap. However, her dissatisfaction focused on my findings and conclusions about the actions of staff at the Trust, particularly with regard to her daughter's care and treatment and

the decision not to provide chemotherapy. Mrs Kemp continues to strongly believe that Miss Kemp did not receive a reasonable standard of care, that she should have been treated with chemotherapy and that the decision not to treat her cancer was for reasons related to her learning disability.

449 In her response Mrs Kemp said her daughter's condition had improved significantly when she was at the Rainbow Room and as a result the doctors there asked the oncologists at the Trust to review its decision not to treat Miss Kemp's cancer. Mrs Kemp said the oncologists had refused this request from the Rainbow Room. She asked me to investigate this issue. In response to Mrs Kemp's request I made specific enquiries about Miss Kemp's stay at the Rainbow Room. The information I received (which I have set out earlier in this report) did not support Mrs Kemp's recollections, and therefore had no impact on my findings.

450 On behalf of Mrs Kemp, Mencap sent me some clinical advice which they had received about Miss Kemp's care and treatment and specifically about the decision not to provide chemotherapy. The advice was provided to Mencap by two consultant psychiatrists, a consultant in palliative care and a Macmillan Nurse in Learning Disabilities. These clinicians had seen my draft report, but had not had access to all the evidence I had considered. I asked two of my Professional Advisers, Mrs Lawson and Dr Chandler, to assess the information provided by Mencap particularly in the light of Mrs Kemp's comments on my draft report. Both Advisers told me they found no new evidence in the papers provided by Mencap which would cause me to doubt the findings and conclusions set out in my report.

My concluding remarks

451 I acknowledge that Mrs Kemp does not agree with all of my findings and decisions. However, I can assure her that her views have been taken into account, her complaint has been thoroughly and impartially investigated and my conclusions have been drawn from careful consideration of the evidence, including the advice of independent professional advisers. I hope my report will draw what has been a long and complex complaints process to a close.



Ann Abraham
Parliamentary and Health Service Ombudsman

March 2009

ANNEX A

Good Medical Practice, 2001: relevant sections

The duties of a doctor

'Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- *make the care of your patient your first concern;*
- *treat every patient politely and considerately;*
- *respect patients' dignity and privacy;*
- *listen to patients and respect their views;*
- *give patients information in a way they can understand;*
- *respect the rights of patients to be fully involved in decisions about their care;*
- *keep your professional knowledge and skills up to date;*
- *recognise the limits of your professional competence;*
- *be honest and trustworthy;*
- *respect and protect confidential information;*
- *make sure that your personal beliefs do not prejudice your patients' care;*

- *act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;*
- *avoid abusing your position as a doctor; and*
- *work with colleagues in the ways that best serve patients' interests.*

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.'

Providing a good standard of practice and care (sections 2 and 3)

'Good clinical care must include:

- *an adequate assessment of the patient's conditions, based on the history and symptoms and, if necessary, an appropriate examination;*
- *providing or arranging investigations or treatment where necessary;*
- *taking suitable and prompt action when necessary;*
- *referring the patient to another practitioner, when indicated.*

'In providing care you must:

- *recognise and work within the limits of your professional competence;*
- *be willing to consult colleagues;*
- *be competent when making diagnoses and when giving or arranging treatment;*

- *keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions made, the information given to patients and any drugs or other treatment prescribed;*
- *keep colleagues well informed when sharing the care of patients;*
- *provide the necessary care to alleviate pain and distress whether or not curative treatment is possible;*
- *prescribe drugs or treatment, including repeat prescriptions, only where you have adequate knowledge of the patient's health and medical needs. You must not give or recommend to patients any investigation or treatment which you know is not in their best interests, nor withhold appropriate treatments or referral;*
- *report adverse drug reactions as required under the relevant reporting scheme, and co-operate with requests for information from organisations monitoring the public health;*
- *make efficient use of the resources available to you.'*

Complaints and formal inquiries (section 30)

'You must co-operate fully with any formal inquiry into the treatment of a patient and with any complaints procedure which applies to your work. You must give, to those who are entitled to ask for it, any relevant information in connection with an investigation into your own, or another health care professional's conduct, performance or health.'

Working with colleagues (section 36)

'Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide. When working in a team, you must:

- *respect the skills and contributions of your colleagues;*
- *...*
- *communicate effectively with colleagues within and outside the team.'*

ANNEX B

Discharge from hospital: pathway, process and practice, 2003

The 'key messages' for all agencies involved in admission and discharge were:

- *'Understand your local community and balance the range of services to meet health, housing and social needs.'*
 - *Ensure individuals and their carers are actively engaged in the planning and delivery of their care.*
 - *Recognise the important role carers play and their own right for assessment and support.*
 - *Ensure effective communication between primary, secondary and social care to ensure that prior to admission and on admission each individual receives the care and treatment they need.*
 - *Agree, operate and performance manage a joint discharge policy that facilitates effective multidisciplinary working and between organisations.*
 - *On admission, identify those individuals who may have additional health, social and/or housing needs to be met before they can leave hospital and target them for extra support.*
 - *At ward level, identify and train individuals who can take on the role of care co-ordination in support of the multidisciplinary team and individual patients and their carers.*
 - *Consider how an integrated discharge planning team can be developed to provide specialist discharge planning support to the patient and multidisciplinary team.*
- *Ensure all patients are assessed for a period of rehabilitation before any permanent decisions on care options are made.*
 - *Ensure that the funding decision for NHS continuing care and care home placement are made in a way that does not delay someone's discharge.'*

The workbook contained two sections specifically about care for people with learning disabilities.

Section 5.6 draws attention to some of the common problems experienced by people with learning disabilities in an acute hospital setting. These include communication, consent, open ward environments and:

'the emphasis on rapid discharge limiting the time for thorough assessment and people's full needs are not always identified or treated. They may return to the community, or institutional care, with needs still not met; and

'care plans being made without vital information being obtained from those health, social care, family carers or housing services that are aware of their needs and current difficulties.'

Section 5.6 also draws attention to common difficulties for acute hospital services which may lead to incomplete and unrealistic discharge planning. These include poor links between acute and specialist mental health liaison services, delay in obtaining expert advice, and other patients' feelings about patients displaying agitation or challenging behaviour.

Section 5.6 includes suggestions for actions to be taken by commissioners, managers and practitioners to improve discharge planning for people with learning disabilities. It says that managers may wish to consider:

‘supporting the provision of training for acute staff in issues of consent, basic mental health, dealing with people who are confused and the impact of having a learning disability on physical functioning and communication;

‘developing protocols or guidelines for dealing with both emergency and planned admissions and presentations at A&E ... ;

‘providing active support and time for practitioners from learning disability and mental health teams to support individuals when in acute and physical health care sector;

...’

Practitioners may wish to consider:

‘... looking at each patient as an individual and understanding the anxieties he or she may have and working with staff in specialist services to alleviate these;

‘actively seeking the involvement of families and/or professional health or social care staff.’

Section 5.7 reminds hospitals of best practice with regard to people with learning disabilities including: preparing for admission, through making contact with the patient, reducing patient anxiety and involving the community team and GPs; using the hospital workbook; for an emergency admission, supporting and contacting parents and carers, using the hospital handbook, considering waiting areas and possibly fast-tracking patients through A&E; and, for admission to the ward, providing ongoing support and extra time for communication.

ANNEX C

Community care from 3 to 26 May 2004: Summary of key events (from health records and the Daily Diary)

26 April to 1 May 2004

Miss Kemp was quiet and 'off her food'. She had a 'bad stomach' and developed diarrhoea. Even when her appetite improved and she was feeling better she was 'still not right'.

3 May 2004

Mrs Kemp took her daughter to see the GP because she was concerned about her unusually poor appetite and diarrhoea. It was a Bank Holiday and an out of hours service was provided by NEWDOC.

The First GP recorded Miss Kemp's poor appetite. She examined her abdomen and suggested that if her symptoms persisted she should have a barium swallow (where the patient swallows a fluid before X-rays are taken to show up the structure of the gullet). She advised Mrs Kemp to take her daughter to see her usual GP (the Second GP) at Falkland Surgery if her poor appetite persisted.

5 May 2004

In the Daily Diary Miss Kemp was noted to have lost 12 pounds in around ten days. A note made by the Community Team for People with Learning Disabilities suggested the weight loss might be due to anxiety associated with moving home.

6 May 2004

Staff from the Residential Home took Miss Kemp to Falkland Surgery.

The Third GP recorded that Miss Kemp had been unwell for ten days, was off her food and seemed more tired than usual. She noted that Miss Kemp's recent diarrhoea had now settled and she was not vomiting. She also noted that her carers did not think Miss Kemp was in pain. Her examination of Miss Kemp's abdomen revealed no tenderness

or lumps. She recorded that Miss Kemp was well hydrated and there were no mouth ulcers or oral soreness. She prescribed sachets of rehydration salts to help replace substances which Miss Kemp would have lost during her bouts of diarrhoea and asked for a urine sample to be taken for analysis.

7 to 9 May 2004

On 7 May Miss Kemp refused to drink the rehydration salts or eat any meals, but she did drink milkshakes. She ate little while at home with her mother on 9 May.

10 May 2004

Staff from the Residential Home took Miss Kemp to Falkland Surgery.

The Fourth GP found nil of note in Miss Kemp's urine specimen. She recorded that Miss Kemp was not drinking, had a poor appetite and was active but experiencing dizziness. She noted that Miss Kemp had been upset by a quarrel at the Day Centre in late April and questioned whether the symptoms were linked to this. She made no specific follow-up plan.

13 May 2004

Mrs Kemp was dissatisfied with the actions of the GPs from NEWDOC and Falkland Surgery so she took her daughter to Eastfield House Surgery.

The Fifth GP knew Miss Kemp well. He recorded that she had not been eating for three weeks and questioned whether she had a swallowing problem. He noted that he could not examine Miss Kemp but he prescribed high protein milkshake supplements, requested some blood tests and made a referral for a barium swallow. He wrote to the X-ray department noting that they would need to make special arrangements for the investigation to meet Miss Kemp's needs. He asked to see Miss Kemp again in two weeks.

14 to 16 May 2004

Miss Kemp attended her father's wedding celebrations and a barbecue at her mother's home. Although she did drink some fluid, she ate little at either event. However, on 16 May 2004 her grandparents said she had eaten better and passed a very hard stool.

18 May 2004

Staff at the Residential Home contacted a GP surgery because Miss Kemp indicated she had stomach pain.

The Sixth GP made a home visit. She recorded that: Miss Kemp had non-specific abdominal pain; she had been crying in pain earlier in the day; she had a poor appetite and low fluid intake; she was not vomiting; and at the time she saw her she was not in pain and was moving comfortably. She examined Miss Kemp's abdomen, although she would not lie down for the examination, and found it soft and not tender. She concluded that she was probably constipated and planned to treat her with laxatives and oral fluids.

19 to 21 May 2004

Miss Kemp's appetite improved and when encouraged she drank more fluid. She opened her bowels and told staff at the Residential Home she was feeling better. However, correspondence between staff from the Day Centre and the Community Team for People with Learning Disabilities shows continuing concern about Miss Kemp's poor appetite and weight loss.

22 May 2004

Mrs Kemp took her daughter to the GP. It was a Saturday and an out of hours service was provided by NEWDOC.

The Seventh GP recorded that Miss Kemp had not been eating and had not had her bowels open properly for three weeks. He noted that she had been '*rolling on the floor at times*'. He examined her abdomen and felt a lump which he thought indicated constipation. He suggested admission to hospital but noted that Miss Kemp did not want this. He arranged for the community nurse to visit the next day to administer an enema.

During the evening Miss Kemp passed a large, hard stool.

23 to 25 May 2004

The community nurse suggested an oral laxative rather than an enema. Miss Kemp took some laxative but this did not work and on 25 May 2004 the community nurse administered an enema which resulted in a large stool. Miss Kemp ate little but drank some fluid. Later, she opened her bowels naturally.

26 May 2004

Staff at the Residential Home became worried about Miss Kemp because she was nauseous and pale. They also recorded that she had passed '*a considerable amount of blood*' with her stool. They contacted the community nurse who arranged for an emergency appointment at Eastfield House Surgery.

The Third GP examined Miss Kemp and recorded that her lower abdomen was tender and she found no sign of piles. She decided that Miss Kemp should be admitted to hospital for further investigation.

Mrs Kemp and a member of staff from the Residential Home took Miss Kemp to the Trust.

ANNEX D

Admission to the Trust from 26 May to 7 June 2004: summary of key events from Miss Kemp's health records

26 May 2004

Miss Kemp arrived on the First Ward.

A junior doctor recorded her learning disability and her recent history of loss of appetite, constipation and weight loss. He noted that she was difficult to examine and she had refused blood tests and observations. He also noted it was difficult to tell whether she was in pain although she looked '*reasonably comfortable*'. He identified a solid, fixed lump in her abdomen which he thought might be a hernia.

Another junior doctor also found it difficult to examine Miss Kemp but recorded the presence of a lump in her left groin. He thought it might be a hernia or an inflamed lymph node and suggested further tests including a CT scan and abdominal X-ray.

A registrar recorded that Miss Kemp was adequately hydrated and not in any obvious pain. Having reviewed the abdominal X-ray he thought the likely diagnosis was a hernia or inflamed lymph nodes. He asked for an ultrasound scan.

Nurses had difficulty in assessing Miss Kemp and recorded that they could not tell if she was in pain. Two nursing care plans were written relating to constipation and learning difficulties.

Miss Kemp's Legal Representative contacted the First Ward and suggested that if she needed tests staff should contact the Trust's legal team about acting in her best interests.

A staff nurse contacted the Trust's Legal Department and recorded the advice she received which was staff were not to force any treatment but were to wait for the result of a CT scan before making treatment decisions in Miss Kemp's best interests.

27 May 2004

An ultrasound was performed with difficulty because Miss Kemp would not lie down. The scan showed a lump in the groin, but more detailed information could not be seen.

28 May 2004

Doctors and nurses recorded that there were problems with investigations (such as taking blood) and observations. They did not think Miss Kemp was in pain.

A junior doctor saw Miss Kemp and her mother. He explained the difficulties in assessing Miss Kemp and arrangements which had been made for a CT scan on 2 June 2004. He recorded that Mrs Kemp was concerned about the wait and that he had explained Miss Kemp would need anaesthesia or sedation for the scan and this took more time to arrange.

A different junior doctor saw Miss Kemp in the afternoon and recorded Mrs Kemp's concern about her daughter's food and fluid intake. She recorded the plan to encourage oral fluids and liquid nutritional supplements with further review over the weekend. The junior doctor also discussed the scan with Mrs Kemp. He recorded that this would also provide an opportunity to take blood tests and establish an intravenous infusion.

There was also contact between the Mencap carers and the Community Team for People with Learning Disabilities, and the potential need for additional support for Miss Kemp and her family was identified.

29 and 30 May 2004

A junior doctor recorded that Miss Kemp was not eating but she was drinking.

Nurses recorded that Miss Kemp was mobile and appeared comfortable but had refused all care, treatment or intervention from staff.

31 May 2004 Bank Holiday Monday

Nurses noted that Miss Kemp was complaining of pain and pointing to the lump. She was given paracetamol.

1 June 2004

Doctors noted that Miss Kemp was drinking and had eaten some light soft food.

Nurses recorded that Miss Kemp had been offered medication but she had refused.

2 June 2004

Miss Kemp was taken to have a CT scan but she refused and returned to the Ward.

A doctor recorded that the scan would be rearranged for the following day to be performed under general anaesthetic. She considered Miss Kemp lacked capacity to consent but the scan was in her best interests because of the need to reach a diagnosis.

3 June 2004

Nurses and doctors recorded that Miss Kemp was refusing care and that she was not eating. She was given oral sedative in a drink and local anaesthetic cream was applied to the back of her hand so an intravenous cannula could be inserted. A CT scan was performed under intravenous sedation and it showed a 9 x 6cm lump in her groin.

The Radiologist thought the lump seemed more like a lipoma (non cancerous fatty lump) or liposarcoma (tumour originating in soft tissue) than a lymphoma.

4 June 2004

Nurses recorded that overnight Miss Kemp had vomited and complained of abdominal pain but had refused any medication.

Doctors discussed the plan to biopsy the lump with Miss Kemp's carers and suggested Miss Kemp might go home after the procedure.

A junior doctor sought advice from the Trust's Legal Department who advised her to proceed in Miss Kemp's best interests. She considered Miss Kemp lacked capacity to consent but the biopsy was in her best interests because she might have a life-threatening disease and a diagnosis was needed to make decisions about treatment and prognosis.

The Consultant Surgeon performed the biopsy and said Miss Kemp could go home because she was not acutely ill and no treatment was needed. However, Mrs Kemp was not happy for her daughter to be discharged to the Residential Home. After liaison between nurses, Mrs Kemp, the Community Team for People with Learning Disabilities and the Residential Home it was decided that Miss Kemp would stay in hospital over the weekend.

5 and 6 June 2004

Nurses noted that Miss Kemp had not complained of pain but she was not eating. They wrote a care plan about nutrition.

7 June 2004

Miss Kemp was discharged to her mother's home.

ANNEX E

Admission to the Trust from 23 June to 28 June 2004: summary of key events

23 June 2004

Miss Kemp arrived at the Trust around 7.00pm and was taken to the Clinical Decision Unit. The reason for admission was recorded as lymphoma, persistent nausea and dehydration.

Nurses recorded that she was flushed and agitated and refusing to let them take observations.

A junior doctor noted that Miss Kemp had not been drinking and was dehydrated although she appeared well, alert and mobile.

The Second Oncologist saw Miss Kemp. He noted her diagnosis of non Hodgkin's lymphoma and recorded that she was '*dehydrated*' and had not been eating or drinking properly for about six weeks. He noted that legal and social services advice would be needed to formulate a plan of care but the immediate plan was '*to find a safe place for Emma and her carer overnight*'.

Records show that there was discussion with community services about where Miss Kemp should spend the night and it was initially agreed that she would return to the Respite Home. However, they could not find additional staff and around 10.45pm she was admitted to the Second Ward.

24 June 2004

The Second Oncologist and the Clinical Nurse Specialist saw Miss Kemp. The Second Oncologist wrote to the Royal Marsden Hospital asking for advice and assistance, and suggesting Miss Kemp should be transferred immediately if the Royal Marsden were able to accept her.

25 June 2004

Nurses recorded that Miss Kemp was refusing food. They completed a nutritional risk assessment tool which showed she was at medium risk so nutritional supplements should be provided and her intake should be monitored. Three care plans were written relating to personal hygiene, hydration and nutrition.

The Nurse Consultant from the Supportive and Palliative Care Team visited Miss Kemp during the afternoon. She made several suggestions about alternative ways of managing her symptoms using different drugs given by various routes.

The Second Oncologist discussed the position with the Trust's Solicitor and asked for advice from the Trust's Consultant in Palliative Care. He spoke to Mrs Kemp, explained that he thought chemotherapy would not be appropriate for Miss Kemp and suggested palliative care should be instigated. He wrote that '*radical treatment is virtually doomed to failure and would actually add to Emma's distress*'. He contacted the Rainbow Room regarding palliative care. Subsequently, he asked the Third Oncologist to provide a second opinion on his decision.

The Third Oncologist saw Miss Kemp around 6.00pm. He recorded that he had discussed the situation in detail with the Second Oncologist and the Clinical Nurse Specialist and that his opinion was that palliative care was appropriate. He also recorded his subsequent discussion with Mrs Kemp.

26 to 27 June 2004

Miss Kemp began to receive pain relief via skin patches and gel and cream applied to her skin. She was described as '*settled*' and '*comfortable*' and she accepted sips of fluid.

28 June 2004

Miss Kemp was transferred to the Rainbow Room at Newbury.

PHSO-0006

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office

ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.

Six lives: the provision of public services to people with learning disabilities

Part five: the complaint made by Mrs Keohane

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Second report

Session 2008-2009

Presented to Parliament pursuant to
Section 14(4) of the Health Service Commissioners Act 1993

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-V
London: The Stationery Office
£64.15

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ISBN: 9 78 010295 8577

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Section 1: introduction and summary

1 This is the final report of our joint investigation into Mrs Keohane's complaints against Buckinghamshire Hospitals NHS Trust (the Trust), Tower House Surgery (the Surgery), Buckinghamshire County Council (the Council) and the Healthcare Commission. The report contains our findings, conclusions and recommendations with regard to Mrs Keohane's areas of concern.

The complaint

2 Mr Edward Hughes, Mrs Keohane's brother, was a 61 year old man with severe learning disabilities. He had lived in care for most of his adult life. Mrs Keohane told us her brother had been born in difficult circumstances during World War II and as a result he had suffered damage to his brain at birth. Mr Hughes also suffered from dementia, schizophrenia and heart problems. His verbal communication was limited to a few words and his behaviour could be challenging.

3 At the time of the events complained about Mr Hughes was living in accommodation provided by the Council at 309 Cressex Road in High Wycombe (the Care Home). He had been living there for many years and it was his settled place of residence.

4 On 5 May 2004 Mr Hughes was admitted to the Trust from the Care Home suffering from retention of urine (accumulation of urine in the bladder due to obstruction of the urethra – the tube down which urine passes from the bladder through the penis). Initially, he was catheterised (a tube was passed into his bladder through his penis to drain urine). However, he could not tolerate the catheter so doctors decided to operate on his enlarged prostate gland which was obstructing the flow of urine.

On 12 May 2004 he underwent transurethral resection of his prostate (where part of the prostate gland is removed via the penis using a telescopic surgical instrument). Post-operatively Mr Hughes developed heart and chest problems and his condition deteriorated. Doctors thought Mr Hughes had suffered a heart attack. On 16 May 2004 he was transferred to the Intensive Care Unit (the ICU). He recovered and returned to the Ward on 24 May 2004. At around 8.00pm on 26 May 2004, accompanied by a member of staff from the Care Home, he was discharged.

5 A member of staff from the Care Home accompanied Mr Hughes when he was admitted to hospital and staff visited him during his stay there. On occasions, they helped with his care and treatment. They also kept in contact with his family. Mrs Keohane and her brother, Mr Brian Hughes, visited Mr Hughes while he was on the Ward before he was transferred to the ICU and during his stay in the ICU.

6 When Mr Hughes was discharged, staff at the Care Home were concerned about him and stayed with him all night. On the following day they contacted the Surgery and asked for a home visit. That afternoon the GP called to see him. The GP examined Mr Hughes and decided no treatment was required and there was no reason to readmit him to hospital. That evening Mr Hughes ate a meal with the other residents, but at around 5.40pm (20 minutes after his meal) he got up and, while walking out of the dining area, he collapsed and vomited. An ambulance was called and Mr Hughes was taken to A&E at the Trust where he died at around 6.30pm.

7 A Coroner's post mortem was performed and the cause of death was recorded as: 1(a) organising pneumonia and 1(b) aspiration. Following a Coroner's inquest, held on

3 March 2005, this was changed to 1(a) acute on chronic aspiration. 'Organising pneumonia' refers to a situation where cellular processes which usually act to clear dead cells and other material formed as a result of a lung infection fail to work fully. This can lead to formation of fibrous tissue in the air sacs of the lungs. Aspiration occurs when fluids or solids do not pass normally down the gullet into the stomach, but instead they are inhaled into the respiratory passages and lungs. 'Acute on chronic aspiration' means that a person who has been aspirating over a period of time suffers an acute episode of aspiration.

- 8 Mrs Keohane is clear that she has no concerns about Mr Hughes' care and treatment before he was admitted to the ICU or during his stay in the ICU. She has told us her main concerns are about events around the time of his discharge from the Trust and his subsequent death. She says staff at the Trust *'just did not want him there because he was more difficult', 'they wanted rid of him' and 'pushed him out'*. She also says some of the healthcare professionals involved in Mr Hughes' care *'thought he wasn't worth saving'*.
- 9 Mrs Keohane has given permission for Mencap to act as her representative. Mencap were not involved in the original complaint to the Trust. They began assisting Mrs Keohane after the inquest when she decided to ask the Healthcare Commission to review her complaint.

The overarching complaint

- 10 Mrs Keohane believes her brother's death was avoidable and that he received less favourable treatment for reasons related to his learning disabilities. We have called these aspects of her complaint 'the overarching complaint'.

Complaint against the Trust

- 11 Mrs Keohane complains about:

Complaint (a): the care and treatment Mr Hughes received following his transfer from the ICU at the Trust to the Ward. In particular, Mrs Keohane feels strongly that the discharge arrangements made by the Trust were inadequate and did not take account of the fact that he had learning disabilities which meant he required long-term residential care. She says Mr Hughes was discharged too early, especially given his clinical condition and his swallowing problems, and his ability to swallow was not properly assessed before he was discharged. She questions whether correct discharge procedures were followed and what information was given to staff at the Care Home about caring for Mr Hughes when he was discharged.

Complaint (b): the accuracy of information which was given to the family about Mr Hughes' condition. Mrs Keohane says that after his death new information came to light about his heart condition and a second fall. She questions why the family were not told about Mr Hughes' heart condition and the fall when he was alive.

Complaint (c): the way in which the Trust responded to her complaints about Mr Hughes' care and treatment. In particular, she questions why evidence which emerged at the inquest was not examined in detail or included in the response to her complaint and why it took the Trust so long to respond to her complaint.

Complaint against the Surgery

12 Mrs Keohane complains about:

Complaint (d): the actions of a GP who visited Mr Hughes at his Care Home on the day he died. Mrs Keohane says the GP did not attend Mr Hughes quickly enough, did not examine him properly and should have readmitted him to the Trust.

Complaint (e): the way in which the Surgery responded to complaints about the GP's actions, including the time taken to respond to her complaint.

Complaint against the Council

13 Mrs Keohane complains about:

Complaint (f): the actions of staff at the Care Home when Mr Hughes was discharged from the Trust. She questions whether they followed advice which they received from the Trust.

Complaint against the Healthcare Commission

14 Mrs Keohane complains about:

Complaint (g): the way in which the Healthcare Commission handled her complaints. Mrs Keohane says the Healthcare Commission's reviews of her complaints took too long and did not provide her with the explanations she sought.

15 Mrs Keohane says she has not had answers to all her questions and she hopes the Ombudsmen's investigation will provide her with those

answers. She also hopes the outcome of her complaint will be that other people will not go through the same experience as Mr Hughes.

The Ombudsmen's remit, jurisdiction and powers

General remit of the Health Service Ombudsman

16 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In the exercise of her wide discretion she may investigate complaints about NHS bodies such as trusts, family health service providers such as GPs, and independent persons (individuals or bodies) providing a service on behalf of the NHS.

17 When considering complaints against an NHS body, she may look at whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the body, a failure by the body to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.

18 Failure or maladministration may arise from action of the body itself, a person employed by or acting on behalf of the body, or a person to whom the body has delegated any functions.

19 When considering complaints against GPs, she may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Again, such action may have been taken by the

GP himself or herself, by someone employed by or acting on behalf of the GP or by a person to whom the GP has delegated any functions.

- 20 The Health Service Ombudsman may carry out an investigation in any manner which, to her, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as she thinks fit.
- 21 If the Health Service Ombudsman finds that service failure or maladministration has resulted in an injustice, she will uphold the complaint. If the resulting injustice is unremedied, in line with her *Principles for Remedy*, she may recommend redress to remedy any injustice she has found.

Remit over the Healthcare Commission

- 22 By operation of section 3(1E) of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints about injustice or hardship in consequence of maladministration by any person exercising an NHS complaints function. As the Healthcare Commission is the second stage of the NHS complaints procedure set out in the *National Health Service (Complaints) Regulations 2004*, it is within the Health Service Ombudsman's remit.

General remit of the Local Government Ombudsman

- 23 Under the *Local Government Act 1974 Part III*, the Local Government Ombudsman has wide discretion to investigate complaints of injustice arising from maladministration by local authorities (local councils) and certain other

public bodies. He may investigate complaints about most council matters, including Social Services and the provision of social care.

- 24 If the Local Government Ombudsman finds that maladministration has resulted in an injustice, he will uphold the complaint. If the resulting injustice is unremedied he may recommend redress to remedy any injustice he has found.

Local Government Ombudsman - premature complaints

- 25 By section 26(5)(a) of the *Local Government Act 1974*, as amended, the Local Government Ombudsman may not generally entertain a complaint unless satisfied that it has been brought to the notice of the council concerned and that the council has had a reasonable opportunity to investigate the complaint and reply to the complainant.
- 26 However, section 26(5)(b) makes it clear that if, in the particular circumstances of any case, it is not reasonable to expect the complainant to take the complaint to the council, a Local Government Ombudsman may accept the case for investigation notwithstanding that the complaint has not been dealt with by the council.
- 27 In this instance, Mrs Keohane's concerns about the Council emerged out of her complaint about NHS services. At the time when she submitted her complaint against the Council the NHS components of the complaint had already been accepted for investigation by the Health Service Ombudsman. Therefore, with the aim of providing a timely, integrated response for the complainant, the Local Government Ombudsman exercised his discretion and accepted the case for investigation under the provisions of the Act which governs his work.

Powers to investigate a report jointly

- 28 The *Regulatory Reform (Collaboration etc between Ombudsmen) Order 2007* clarified the powers of the Health Service Ombudsman and the Local Government Ombudsman, with the consent of the complainant, to share information, carry out joint investigations and produce joint reports in respect of complaints which fell within the remit of both Ombudsmen.
- 29 In this case, the Health Service Ombudsman and the Local Government Ombudsman agreed to work together because the health and social care issues were so closely linked. A co-ordinated response consisting of a joint investigation leading to the production of a joint conclusion and proposed remedy in one report seemed the most appropriate way forward.
- 31 We obtained specialist advice from a number of professional advisers (our Professional Advisers): Professor J Vann Jones, a professor of cardiology (our Cardiology Adviser); Mr P C Gartell, a surgical consultant (our Surgical Adviser); Dr J Skoyles, a consultant anaesthetist with experience of ICU work (our Anaesthetic Adviser); Ms L Stewart, a senior acute nurse (our Acute Nursing Adviser); Ms L L Clark, a senior learning disability nurse (our Learning Disability Adviser); Dr J Cox, an experienced GP (our GP Adviser); and Ms H Crawford, a consultant speech and language therapist (our Speech and Language Therapy Adviser). Our Professional Advisers are specialists in their field and in their role as advisers to the Ombudsmen they are completely independent of any NHS body and the Healthcare Commission. Their role is to help the Ombudsmen and their investigative staff understand the clinical aspects of the complaint.

The investigation

- 30 During the investigation our investigator spoke with Mrs Keohane and her representatives to ensure we had a full understanding of her complaint. Relevant documentation about the case was examined including: Mr Hughes' health records from the Trust, the Surgery and the Care Home; complaint correspondence between Mrs Keohane, Mencap and the bodies complained about; papers related to attempted resolution of the complaint at local level and by the Commission; and papers about internal investigations conducted by the Trust and the Council which included details of actions taken by them to remedy failings which they identified. The Trust and the Council provided additional information in response to specific enquiries. Enquiries were made of the Buckinghamshire Coroner who conducted the inquest into Mr Hughes' death.
- 32 In this report we have not referred to all the information examined in the course of our investigation, but we are satisfied that nothing significant to the complaint or our findings has been overlooked.

Our decisions

- 33 Having considered all the available evidence related to Mrs Keohane's complaint, including her recollections and views and her comments on our draft report, and taken account of the clinical advice we have received, we have reached the following decisions.

Complaint against the Trust

- 34 The Health Service Ombudsman finds that the Trust provided inadequate care and treatment for Mr Hughes following his transfer from the ICU to the Ward. In particular, the Ward nurses made entirely inadequate attempts to assess Mr Hughes' needs and to plan and deliver care for him following his transfer from the ICU. She also finds that the arrangements for his discharge were inadequate and that the Trust discharged him when it was not safe to do so. That was **service failure**. The Health Service Ombudsman concludes that these failures in Mr Hughes' care and treatment were for disability related reasons. She also concludes that in some areas of their care and treatment of Mr Hughes the Trust failed to live up to human rights principles of dignity and equality.
- 35 In addition, the Trust failed to inform Mr Hughes' family of significant events in his care, in particular the fall and the plan to discharge him. That, too, was **service failure**.
- 36 Furthermore, the Trust's complaint handling was poor and Mrs Keohane was not provided with reasonable responses to her concerns. That was **maladministration**.
- 37 As a result of **service failure** and **maladministration** by the Trust, Mrs Keohane has suffered an **injustice**. That injustice has not been fully remedied. The Health Service Ombudsman **upholds** the complaint against the Trust.

Complaint against the Surgery

- 38 The Health Service Ombudsman finds that the GP provided a reasonable standard of care and treatment for Mr Hughes and that the Surgery responded appropriately to Mrs Keohane's complaints. She **does not uphold** the complaint against the Surgery.

Complaint against the Council

- 39 The Local Government Ombudsman finds that the Care Home staff provided a reasonable standard of care and treatment and he considers the Council responded appropriately following Mr Hughes' death. He **does not uphold** the complaint against the Council.

Complaint against the Healthcare Commission

- 40 The Health Service Ombudsman finds **maladministration** in the way the Healthcare Commission reviewed Mrs Keohane's complaint against the Trust. She **upholds** this aspect of the complaint against the Healthcare Commission. However, she found **no maladministration** in the way the Healthcare Commission reviewed Mrs Keohane's complaint against the Surgery. She **does not uphold** this aspect of the complaint against the Healthcare Commission.

The overarching complaint

- 41 The Health Service Ombudsman has concluded that some of the service failures in Mr Hughes' care and treatment were for disability related reasons and that the Trust's acts and omissions constituted a failure to live up to human rights principles of dignity and equality.
- 42 It has not been possible to establish beyond doubt why Mr Hughes collapsed and died. We have not found any evidence which points directly to a cause for his collapse. There is no post mortem evidence which shows that he collapsed due to any of the most common causes of collapse for a person of his age. That said, it does seem possible to us that he collapsed due to a sudden change in his heart rhythm which led to the other events associated with his death.
- 43 We have not found that Mr Hughes died in consequence of any service failure or maladministration we have identified. Therefore, we do not conclude that his death was avoidable.
- 44 In this report we explain the detailed reasons for our decisions and comment on the particular areas where Mrs Keohane has expressed concern to the Ombudsmen.

Section 2: the basis for our determination of the complaints

Introduction

- 45 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, the Ombudsmen generally begin by comparing what actually happened with what should have happened.
- 46 So, in addition to establishing the facts that are relevant to the complaint, we also need to establish a clear understanding of the standards, both of general application and which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. We call this establishing the overall standard.
- 47 The overall standard has two components: the general standard which is derived from general principles of good administration and, where applicable, of public law; and the specific standards which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.
- 48 Having established the overall standard we then assess the facts in accordance with the standard. Specifically, we assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard.
- 49 If so, we then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

- 50 The overall standard which we have applied to this investigation is set out below.

The general standard

Principles of Good Administration

- 51 Since it was established the Parliamentary and Health Service Ombudsman's Office has developed and applied certain principles of good administration in determining complaints of service failure and maladministration. In March 2007 the Parliamentary and Health Service Ombudsman published these established principles in codified form in a document entitled *Principles of Good Administration*.
- 52 The document organises the established principles of good administration into six Principles. These Principles are:
- Getting it right
 - Being customer focused
 - Being open and accountable
 - Acting fairly and proportionately
 - Putting things right, and
 - Seeking continuous improvement.
- 53 We have taken all of these Principles into account in our consideration of Mrs Keohane's complaint and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:¹

¹ *Principles of Good Administration* is available at www.ombudsman.org.uk

'Getting it right' means:

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

'Being customer focused' means:

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

'Being open and accountable' means:

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.

- Stating criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for actions.

'Acting fairly and proportionately' means:

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

'Putting things right' means:

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

‘Seeking continuous improvement’ means:

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Principles for Remedy

⁵⁴ In October 2007 the Parliamentary and Health Service Ombudsman published a document entitled *Principles for Remedy*.²

⁵⁵ This document sets out the Principles that we consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how we think public bodies should put things right when they have gone wrong. It also confirms our own approach to recommending remedies. The *Principles for Remedy* flows from, and should be read with, the *Principles of Good Administration*. Providing fair and proportionate remedies is an integral part of good administration and good service, so the same principles apply.

⁵⁶ We have taken the *Principles for Remedy* into account in our consideration of Mrs Keohane’s complaint.

The specific standards

Disability discrimination

Legal framework

Disability Discrimination Act 1995

⁵⁷ The sections of the *Disability Discrimination Act 1995* most relevant to the provision of services in this complaint were brought into force in 1996 and 1999 respectively. Although other parts of the *Disability Discrimination Act 1995* were brought into force in 2004 and further provisions added by the *Disability Discrimination Act 2005*, these changes either post-date or are not directly relevant to the subject matter of this complaint.

⁵⁸ Since December 1996 it has been unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified.

⁵⁹ Since October 1999 it has in addition been unlawful for service providers to fail to comply with the duty to make reasonable adjustments for disabled people where the existence of a practice, policy or procedure makes it impossible or unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

⁶⁰ It has also been unlawful since October 1999 for service providers to fail to comply with the duty to make reasonable adjustments so as to provide a reasonable alternative method of making the service in question available to disabled people where the existence of a physical feature makes it impossible or

² *Principles for Remedy* is available at www.ombudsman.org.uk

unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

- 61 Since October 1999 it has been unlawful for service providers to fail to comply with the duty to take reasonable steps to provide auxiliary aids or services to enable or facilitate the use by disabled people of services that the service provider provides, unless that would necessitate a permanent alteration to the physical fabric of a building or unless such failure is justified.

Policy aims

- 62 The *Disability Discrimination Act 1995* recognises that the disabling effect of physical and mental impairment will depend upon how far the physical and social environment creates obstacles to disabled people's enjoyment of the same goods, services and facilities as the rest of the public.
- 63 The key policy aim behind the legislation is to ensure that as far as reasonably possible disabled people enjoy access not just to the same services, but to the same standard of service, as other members of the public. In other words, those who provide services to the public, whether in a private or public capacity, are to do whatever they reasonably can to eradicate any disadvantage that exists for a reason related to a person's physical or mental impairment.
- 64 The critical component of disability rights policy is therefore the obligation to make 'reasonable adjustments', which shapes the 'positive accent' of the *Disability Discrimination Act 1995*. This obligation recognises that very often equality for disabled people requires not the same treatment as everyone else but different treatment. The House of Lords made

explicit what this means in a case (*Archibald v Fife Council*, [2004] UKHL 32, judgment of Baroness Hale), which although arising from the *Part 2* employment provisions of the *Disability Discrimination Act 1995*, has bearing on the *Part 3* service provisions also:

'The 1995 Act, however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment.'

- 65 As the Court of Appeal has also explained, specifically in respect of the *Part 3* service provisions of the *Disability Discrimination Act 1995* (*Roads v Central Trains* [2004] EWCA Civ 1451, judgment of Sedley LJ), the aim is to ensure 'access to a service as close as it is possible to get to the standard offered to the public at large'.

Policy and administrative guidance

Disability Rights Commission Codes of Practice

- 66 Between April 2000 and October 2007 the Disability Rights Commission had responsibility for the enforcement and promotion of disability rights in Britain. In that capacity, and by virtue of the provisions of the *Disability Rights Commission Act 1999*, it had a duty to prepare statutory codes of practice on the law. These statutory codes of practice, although not legally binding, are to be taken into account by courts and tribunals in determining any issue to which their provisions are relevant.
- 67 Before the establishment of the Disability Rights Commission in April 2000, the relevant Secretary

of State, on the advice of the National Disability Council, published a statutory code of practice on the duties of service providers under Part 3 of the *Disability Discrimination Act 1995* entitled *Code of Practice: Goods, Facilities, Services and Premises* (1999), itself a revision of an earlier code of practice published in 1996.

- 68 On its establishment in 2000, the Disability Rights Commission consulted on a further revised code of practice, which came into force on 27 May 2002 as the *Disability Discrimination Code of Practice (Goods, Facilities, Services and Premises)*. The revised code of practice not only updated the previous codes but anticipated the changes to the law that were due to come into effect in 2004, in particular with respect to the duty to remove obstructive physical features.
- 69 The 2002 code made it clear that a service provider's duty to make reasonable adjustments is a duty owed to disabled people at large and that the duty is 'anticipatory':

'Service providers should not wait until a disabled person wants to use a service which they provide before they give consideration to their duty to make reasonable adjustments. They should be thinking now about the accessibility of their services to disabled people. Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.'

- 70 It also drew attention to the pragmatic strain of the *Disability Discrimination Act 1995*. For example, in respect of the forthcoming 'physical features' duty, the code says:

'The Act does not require a service provider to adopt one way of meeting its obligations rather than another. The focus of the Act is on results. Where there is a physical barrier, the service provider's aim should be to make its services accessible to disabled people. What is important is that this aim is achieved, rather than how it is achieved.'

Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)

- 71 In 2001 the Department of Health published a White Paper, explicitly shaped by the relevant legislation (including the *Disability Discrimination Act 1995* and the *Human Rights Act 1998*), with a foreword written by the then Prime Minister, outlining the Government's future strategy and objectives for achieving improvements in the lives of people with learning disabilities.
- 72 The White Paper identified four key principles that it wanted to promote: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion (in the sense of being part of mainstream society and being integrated into the local community).
- 73 As the White Paper explained, the intention was that 'All public services will treat people with learning disabilities as individuals, with respect for their dignity'.
- 74 The fifth stated objective of the Government was to 'enable people with learning disabilities to access health services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary'.

75 The Department of Health also published in 2001 two circulars aimed jointly at the health service and local authorities, focusing on the implementation of Valuing People and including detailed arrangements for the establishment of Learning Disability Partnership Boards: *HSC 2001/016* and *LAC (2001) 23*.

76 The Department of Health has published a series of reports to help the NHS meet its duties under the *Disability Discrimination Act 1995*.

Signposts for success in commissioning and providing health services for people with learning disabilities (1998)

77 This was published by the Department of Health and was the result of extensive consultation undertaken with people with learning disabilities, carers and professionals with the aim of informing good practice. It was targeted at the whole NHS and emphasises the need for shared values and responsibilities, respecting individual rights, good quality information and effective training and development. It also encourages the use of personal health records. The accompanying executive letter *EL (98)3* informs chief executives of the availability of the guidance.

Doubly Disabled: Equality for disabled people in the new NHS – access to services (1999)

78 This Department of Health report, also aimed at the whole NHS, contains a specific section on learning disability. It provides guidance for managers with specific responsibility for advising on access for disabled patients to services and employment. It also provides information for all staff on general disability issues. The accompanying circular *HSC 1999/093* emphasises the purpose of the document saying:

‘... it will be essential for service providers to ensure that they have taken reasonable steps to ensure that services are not impossible or unreasonably difficult for disabled people to use.’

Once a Day: A Primary Care Handbook for people with learning disabilities (1999)

79 This was issued jointly by the Department of Health and the Royal College of General Practitioners, and was specifically aimed at primary care services. It draws attention to the interface between primary care and general hospital services and sets out actions which healthcare providers should take to facilitate equal access to health services for people with learning disabilities. The overall purpose of the handbook was described in the accompanying circular *HSC 1999/103* which says:

‘The purpose of this guidance, for GPs and primary care teams, is to enhance their understanding, improve their practice and promote their partnerships with other agencies and NHS services.’

In practice

80 The practical effect of the legal, policy and administrative framework on disability discrimination is to require public authorities to make their services accessible to disabled people. To achieve this objective they must take all reasonable steps to ensure that the design and delivery of services do not place disabled people at a disadvantage in their enjoyment of the benefits provided by those services.

81 Failure to meet this standard will mean not only that there is maladministration or service failure, but that there is maladministration or service failure for a disability related reason. This does not require a deliberate intention to treat disabled people less favourably. It will be enough that the public authority has not taken the steps needed, without good reason.

82 To be confident that it has met the standard, a public authority will need to show that it has planned its services effectively, for example, by taking account of the views of disabled people themselves and by conducting the risk assessments needed to avoid false assumptions; that it has the ability to be flexible, for example, by making reasonable adjustments to its policies, practices and procedures, whenever necessary; and by reviewing arrangements regularly, not just when an individual disabled person presents a new challenge to service delivery.

83 It should also be noted that a failure to meet the standard might occur even when the service in question has been specially designed to meet the needs of disabled people. This might be because, for example, the service design meets the needs of some disabled people but not others, or because good design has not been translated into good practice.

84 It is not for the Ombudsmen to make findings of law. It is, however, the role of the Ombudsmen to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsmen will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving disabled

people, such considerations are so integral to good administration and service delivery that it is impossible to ignore them.

Human rights

Legal framework

Human Rights Act 1998

85 The *Human Rights Act 1998* came into force in England in October 2000. The *Human Rights Act 1998* was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. To that extent, the *Human Rights Act 1998* did not so much create new substantive rights for UK citizens but rather established new arrangements for the domestic enforcement of those existing substantive rights.

86 It requires public authorities (that is, bodies which exercise public functions) to act in a way that is compatible with the *European Convention on Human Rights*; it requires the courts to interpret statute and common law in accordance with the *European Convention on Human Rights* and to interpret legislation compatibly with the *European Convention on Human Rights* wherever possible; and it requires the sponsors of new legislation to make declarations when introducing a Bill in Parliament as to the compatibility of that legislation with the *European Convention on Human Rights*.

87 Of particular relevance to the delivery of healthcare to disabled people by a public authority are the following rights contained in the *European Convention on Human Rights*:

- Article 2 Right to life
- Article 3 Prohibition of torture, or inhuman or degrading treatment
- Article 14 Prohibition of discrimination.

Policy aims

88 When the UK Government introduced the *Human Rights Act 1998*, it said its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new ‘*human rights culture*’ among public authorities and among the public at large.

89 A key component of that human rights culture is observance of the core human rights principles of Fairness, Respect, Equality, Dignity and Autonomy for all. These are the principles that lie behind the *Human Rights Act 1998*, the *European Convention on Human Rights* and human rights case law, both in the UK and in Strasbourg.

90 These principles are not new. As the Minister of State for Health Services remarked in her foreword to *Human Rights in Healthcare – A Framework for Local Action* (2007):

‘The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.’

91 The policy implications for the healthcare services are also apparent as one aspect of that aim of using human rights to improve service delivery. As the Minister of State also observed:

‘Quite simply we cannot hope to improve people’s health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people’s lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.’

92 At the time of the introduction of the *Human Rights Act 1998* in October 2000, the importance of human rights for disabled people was recognised. Writing in the Disability Rights Commission’s publication of September 2000 entitled *The Impact of the Human Rights Act on Disabled People*, the then Chair of the Disability Rights Commission noted that:

‘The Human Rights Act has particular significance for disabled people ... The withdrawal or restriction of medical services, the abuse and degrading treatment of disabled people in institutional care, and prejudiced judgements about the parenting ability of disabled people are just some of the areas where the Human Rights Act may help disabled people live fully and freely, on equal terms with non-disabled people.’

In practice

93 The practical effect of the legal, policy and administrative framework on human rights is to create an obligation on public authorities not only to promote and protect the positive legal rights contained in the *Human Rights Act 1998* and other applicable human rights instruments but to have regard to the practical application of the human rights principles of Fairness, Respect, Equality, Dignity and Autonomy in everything they do.

- 94 Failure to meet this standard will not only mean that the individual has been denied the full enjoyment of his or her rights; it will also mean that there has been maladministration or service failure.
- 95 To be confident that it has met the requisite standard, a public authority will need to show that it has taken account of relevant human rights principles not only in its design of services but in their implementation. It will, for example, need to show that it has made decisions that are fair (including by giving those affected by decisions a chance to have their say, by avoiding blanket policies, by acting proportionately and by giving clear reasons); that it has treated everyone with respect (including by avoiding unnecessary embarrassment or humiliation, by enabling individuals to make their own choices so far as practicable, and by having due regard to the individual's enjoyment of physical and mental wellbeing); that it has made genuine efforts to achieve equality (including by avoiding unjustifiable discrimination, by taking reasonable steps to enable a person to enjoy participation in the processes that affect them, by enabling a person to express their own personal identity and by actively recognising and responding appropriately to difference); that it has preserved human dignity (including by taking reasonable steps to protect a person's life and wellbeing, by avoiding treatment that causes unnecessary mental or physical harm, and by avoiding treatment that is humiliating or undignified); and that it has promoted individual autonomy (including by taking reasonable steps to ensure that a person can live independently).
- 96 It is not for the Ombudsmen to make findings of law. It is, however, the role of the Ombudsmen to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting

in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsmen will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving health and social care, such considerations are so integral to the assessment of good administration and good service delivery that it is impossible to ignore them.

Professional standards

The General Medical Council

- 97 The General Medical Council (the body responsible for professional regulation of doctors) publishes a booklet, *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet is clear that it represents standards which the General Medical Council expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of work. Key sections of the booklet are set out at Annex A.
- 98 Paragraph 5 of Good Medical Practice current at the time of this complaint says:

'The investigation or treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age, or social or economic status, to prejudice the treatment you arrange.'

The Nursing and Midwifery Council

99 The Nursing and Midwifery Council (the body responsible for professional regulation of nurses) publishes a booklet, *The Nursing and Midwifery Council code of professional conduct: standards for conduct, performance and ethics* (the Code of Conduct) which contains general and specific guidance on how nurses should approach their work. The booklet represents the standards which the Nursing and Midwifery Council expects nurses to meet.

100 Paragraph 1 of the Code of Conduct current in early 2004 said:

'You are personally accountable for your practice. This means that you are answerable for your actions and omissions, regardless of advice or directions from another professional.'

'You have a duty of care to your patients and clients, who are entitled to receive safe and competent care.'

101 Paragraph 2 of the Code of Conduct said:

'As a registered nurse, midwife or health visitor, you must respect the patient or client as an individual.'

'...

'You are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'

102 Paragraph 4 of the Code of Conduct emphasised the importance of teamwork and communication. It said:

'As a registered nurse, midwife or health visitor, you must co-operate with others in the team.'

'The team includes the patient or client, the patient's or client's family, informal carers and health and social care professionals in the National Health Service, independent and voluntary sectors.'

'You are expected to work co-operatively within teams and to respect the skills, expertise and contributions of your colleagues. You must treat them fairly and without discrimination.'

'You must communicate effectively and share your knowledge, skill and expertise with other members of the team as required for the benefit of patients and clients.'

'Health care records are a tool of communication within the team. You must ensure that the health care record for the patient or client is an accurate account of treatment, care planning and delivery.'

103 In *Making a Difference: strengthening the nursing, midwifery and health visiting contribution to health and healthcare* (Making a Difference), issued in 1999, the Chief Nursing Officer identified a need to focus on the fundamentals of nursing care. This led to the development of a set of benchmarking tools known as *The Essence of Care: Patient-focused benchmarking for health care practitioners* (the Essence of Care), (Department of Health, 2001). At the time of this complaint benchmarking tools were available for eight areas including

food and nutrition and the safety of clients with mental health needs in acute mental health and general hospital settings. NHS Trusts were expected to develop and implement local policies that ensured compliance with the benchmark standards.

- 104 In January 2003 the Department of Health published comprehensive guidelines about discharging patients from hospital called *Discharge from hospital: pathway, process and practice* (Discharge from Hospital). The lengthy guidelines are in the form of a workbook and include principles for good practice as well as introducing a range of tools to assist professionals involved in the discharge process. Some key details from the document are set out at Annex B. Amongst the document's 'key messages' are:

'Ensure individuals and their carers are actively engaged in the planning and delivery of their care.'

'...

'Agree, operate and performance manage a joint discharge policy that facilitates effective multidisciplinary working at ward level and between organisations.'

'On admission, identify those individuals who may have additional health, social and/or housing needs to be met before they can leave hospital and target them for extra support.'

'...

'Consider how an integrated discharge planning team can be developed to provide specialist discharge planning support to the patient and multidisciplinary team.'

- 105 Appendices 5.6 and 5.7 of the guidelines specifically address the needs of people with learning disabilities, mental health problems or dementia. The importance of meeting the special needs of these groups of patients by effective multidisciplinary and multi-agency working is threaded through the guidance.

Local policy at the Trust

- 106 The Trust provided us with a copy of their *Discharge Policy* which was in force in May 2004. Amongst the 'prime concerns' described in the policy are:

'That patients' interests are given paramount consideration in the planning & conduct of discharge.'

'...

'That patients ... and their carers have the right to know their diagnosis & prognosis & to understand the implication of their treatment & medications.'

'That procedures implemented must show due regard for individual patient choice, cultural characteristics & personal dignity.'

'Discharge planning & management must aim to ensure effective & efficient resource use, & whilst all patients must have an equal quality of service no one should be discharged into an unsafe or inadequate environment ...'

- 107 The policy goes on to set out the importance of liaison with home and community services to ensure that adequate facilities are ready for patients who are discharged. It recognises that some patients will require 'particular attention

when planning & delivering discharge/transfer of care' (including patients with continuing disability, psychiatric illness, confusion or loss of intellectual function) and emphasises the importance of a co-ordinated, multiprofessional approach. It concludes with the instruction:

'Patients MUST NOT be discharged until the Doctors/Midwives concerned have made the decision that they are medically fit for discharge & the Health & Social Care professionals are satisfied that the essential elements of the care programme are in place.'

Complaint handling

Council complaint handling

- 108 The *NHS and Community Care Act 1990* imposes on Social Services authorities a statutory duty to provide a complaints procedure. Statutory guidance has been issued by the Department of Health and authorities must have regard to it when managing complaints about their service. The statutory complaints process applicable to this complaint was that contained within the *Complaints Procedure Directions 1990* (these have now been superseded by the *Local Authority Social Services Complaints (England) Regulations 2006* and associated guidance, for complaints made after August 2006).
- 109 The 1990 Directions established a three-part process consisting of a first, informal, stage aimed at resolving the complaint at a local level, but which progressed to the formal second stage if the complainant remained dissatisfied. The matter was considered at the second stage by the designated complaints officer and an investigator might be appointed. If the complainant remained dissatisfied at the end

of this stage of the process, he had the right to request an independent review by a panel set up by the council to review the Stage 2 investigation. The panel did not carry out a fresh investigation, nor could it consider any aspect of the complaint that had not already been considered at an earlier stage. The panel had no power to make binding findings, but could make recommendations to the council to resolve the complaint. If the council rejected the findings it had to provide reasons for doing so.

NHS complaint handling

- 110 Prior to 2004 complaint handling in the NHS was subject to various Directions which required NHS bodies to have written procedures for dealing with complaints within their organisation (known as local resolution) and to operate the second element of the complaints procedure (independent review). Complaints against primary care providers were dealt with at the local level under practice-based complaints procedures required under the provider's terms of service.
- 111 However, on 30 July 2004 the *NHS (Complaints) Regulations 2004* (the Regulations) came into force, and created the procedure applicable to this complaint. These Regulations made detailed provision for the handling of complaints at local level by NHS bodies and, if a complainant was dissatisfied with local resolution, for the complaint to be given further consideration by the Healthcare Commission. Complaints against primary care providers continue to be dealt with at the local level by practice-based complaints procedures, but likewise move to the Healthcare Commission for the second stage of the process.

Complaints against NHS bodies

112 The Regulations (Regulation 3(2)) emphasise that complaint handling arrangements by NHS bodies at the local level must ensure that complaints are dealt with speedily and efficiently and that complainants are treated courteously and sympathetically and, as far as possible, involved in decisions about how their complaints are handled. The guidance issued by the Department of Health to support the Regulations emphasises that the procedures should be open, fair, flexible and conciliatory and encourage communication on all sides, with the primary objective being to resolve the complaint satisfactorily while being fair to all parties.

113 *Part II* of the Regulations (Regulations 3 to 13) sets out the statutory requirements for NHS bodies managing complaints at the local level and deals with such matters as who may make complaints, when they may be made and the matters which may be complained about. A dedicated complaints manager must be identified along with a senior person in the organisation to take responsibility for the local complaints process and for complying with the Regulations. Regulation 13 states that the response to the complaint, which must be signed by the Chief Executive where possible, must be sent to the complainant within 20 working days from when the complaint was made, unless the complainant agrees to a longer period. That response must also inform complainants of their right to refer the complaint to the Healthcare Commission.

Complaints against GPs

114 Guidance to GPs is found in the 1996 *Practice-based Complaints Procedures. Guidance for General practices*. This is intended to be a good practice guide and sets

out a model for a practice-based complaints procedure with sample resource leaflets and suggested forms. It is not intended to be prescriptive, so the only mandatory part of the guidance is that relating to the national criteria. These criteria, found in paragraph 3.1, are:

- Practice-based procedures should be managed by the practice.
 - One person should be nominated to administer the procedure.
 - The procedure must be in writing and must be publicised (and should include details of how to complain further).
 - Complaints should normally be acknowledged within two working days and an explanation normally provided within ten working days.
- 115 The aim of the practice-based complaints procedure is to make the process more accessible, speedier and fairer to everyone and to try to resolve most complaints at practice level. Detailed procedures are expected to be workable, flexible and 'user-friendly' for patients and practices alike.

Complaint handling by the Healthcare Commission

116 Complainants who are dissatisfied with the outcome of their complaint may ask the Healthcare Commission to consider the complaint, and *Part III* of the Regulations (Regulations 14 to 19) sets out the statutory requirements on the Healthcare Commission when considering complaints at this second level.

117 Regulation 16 states that the Healthcare Commission must assess the nature and substance of the complaint and decide as soon as it is reasonably practicable how it should be dealt with '*having regard to*' a number of matters including the views of the complainant and the body or person complained against and any other relevant circumstances. There is a wide range of options available to the Healthcare Commission for dealing with the complaint, apart from investigating it, including taking no further action, referring the matter back to the body complained about with recommendations as to action to resolve the complaint, and referring the matter to a health regulatory body.

118 If the Healthcare Commission does decide to investigate, it must send the proposed terms of reference to the complainant and the body or person complained about (and any other body with an interest in the complaint) for comment. Once the investigation begins, the Healthcare Commission has a wide discretion in deciding how it will conduct the investigation (Regulation 17) and this may include taking such advice as seems to it to be required, and requesting (not demanding) the production of such information and documents as it considers necessary to enable it properly to consider the complaint. The Healthcare Commission has established its own internal standards for the handling of complaints and although, for example, the Regulations do not specify the type of advice to be taken, the Healthcare Commission has acknowledged the need to seek appropriate guidance from a clinical adviser with relevant experience and expertise. Likewise, although the Regulations set no specific timescales for it to complete the investigatory process (Regulation 19 merely requires it to prepare a written report of its investigation

'as soon as is reasonably practicable'), the Healthcare Commission has said that it aims in the majority of cases to take no longer than six months to complete the process.

119 The report produced by the Healthcare Commission at the end of its investigation must summarise the nature and substance of the complaint, describe its investigations and summarise its conclusions, including any findings of fact, its opinion on the findings and the reasons for its opinion, and recommend what action should be taken and by whom to resolve the complaint or otherwise.

Section 3: the investigation

Background

¹²⁰ We have outlined the background to the complaint in Section 1 of this report. We say more about the key events associated with each aspect of the complaint in the relevant sections which follow.

The Health Service Ombudsman's investigation of the complaints against the Trust

Complaint (a): care and treatment by staff at the Trust

¹²¹ Mrs Keohane complains that the care and treatment provided for Mr Hughes by staff at the Trust from 24 to 26 May 2004 was inadequate. In particular, she says insufficient account was taken of his needs as a disabled person, his ability to swallow was not properly assessed, his discharge to the Care Home was poorly planned and he was discharged too early, especially as he had only just been transferred to the Ward from the ICU. She questions whether these events were related to his sudden death in the Care Home.

Key events

¹²² I have set out above the general background to Mr Hughes' care and treatment at the Trust. My Professional Advisers have studied Mr Hughes' health records from the Trust and other documents and established what happened to him from the day he was admitted to the evening he was discharged. At Annex C I have summarised the sequence of events from his admission on 5 May 2004 to his transfer from the ICU to the Ward on 24 May 2004. I now describe key events following Mr Hughes' return to the Ward.

Information from the Trust's records

¹²³ Trust records show that some time after 2.00pm on 24 May 2004 Mr Hughes was transferred from the ICU to the Ward. It is not clear precisely when he arrived there and I have found no information about his condition overnight. Nursing observations made during the morning of 25 May 2004 suggested that he had a high Early Warning Score (a measure of likely deterioration). A team of staff from the ICU visited Mr Hughes and around 10.30am nurses asked a junior doctor to review him because he appeared unwell and not very alert. The doctors found Mr Hughes should have been receiving oxygen, although the levels of oxygen in his blood were reasonable when he was breathing normal room air. They found he was agitated, would not keep his oxygen mask on and had pulled out his nasogastric tube (a tube passed through the nose into the stomach). His respiratory rate was very high and his heart rate was fast and irregular, although his blood pressure was within normal limits. The doctors ordered a series of tests including blood tests, an electrocardiogram (a tracing of the heart's electrical activity) and a chest X-ray. The ICU team visited Mr Hughes again around two hours later and found his heart rate was still fast and irregular. They also noted he was coughing when he tried to drink water and when the back of his mouth was cleared with a rigid plastic suction tube a thick creamy substance was obtained. The ICU team and the junior doctor recorded that they thought Mr Hughes might aspirate and that he was awaiting assessment by a speech and language therapist.

¹²⁴ Later on 25 May 2004 Mr Hughes was reviewed by a cardiology specialist registrar (a senior member of a consultant's team who specialised in heart conditions). This doctor studied Mr Hughes' recent medical history and reviewed

results of tests and investigations. He looked at the chest X-ray taken earlier in the day and he saw no evidence that Mr Hughes' lungs were blocked due to infection or inflammation, or that his heart was failing to pump adequately. He decided that Mr Hughes should receive various drugs to strengthen and control his heartbeat, control his blood pressure and guard against a possible heart attack. At about 5.00pm a senior doctor from a team specialising in chest care saw Mr Hughes and agreed with the cardiologist's treatment plan.

125 Mr Hughes was also seen on 25 May 2004 by a speech and language therapist who assessed his ability to swallow. She recorded that she could not carry out a full range of tests because Mr Hughes could not co-operate fully, for example, he could not seal his lips. She found Mr Hughes aspirated when given sips of water, but did not aspirate when given '*chilled purée*'. She recommended a diet of '*chilled purée*' only. Mr Hughes was also seen twice by a physiotherapist who used a rigid suction catheter to clear thick, white material which she thought might be yoghurt from the back of his throat. Later she recorded that Mr Hughes was walking around and '*coughing spontaneously*' (meaning he did not need encouragement to bring up secretions from his chest).

126 At around 2.30am on 26 May 2004 Mr Hughes fell when getting in or out of bed and sustained a small cut on the right side of his scalp. He was seen by a junior doctor who discussed the incident with a senior colleague. They decided that no treatment or specialist observations were needed. Later that morning Mr Hughes was seen by the Ward doctors, a microbiologist and the team from the ICU. The ICU team noted:

'The nurses feel unable to provide fully for the patient as he requires constant attention, pulls out all lines [tubes such as intravenous infusions], fell out of bed last night. Don't know what to suggest as patient unable to comply with therapy.'

127 Also on 26 May 2004 Mr Hughes was seen again by a speech and language therapist who assessed his ability to swallow, recommended a diet of '*thickened fluids (custard consistency) and puréed diet (warm and cold)*' and noted he would need follow-up speech and language therapy in the community. He was also seen by a physiotherapist who noted that the level of oxygen in his blood had improved, that he was coughing independently and did not require any treatment from her. During the evening he was discharged home accompanied by a member of staff from the Care Home.

128 There are no entries in the Trust records which note contact with the Care Home on 25 or 26 May 2004. There is an indication on a discharge tick list that a verbal handover was given by a nurse from the Ward to the person who collected Mr Hughes. However, there is no contemporaneous note of this conversation in Trust records. There is no evidence in Trust records of any written instructions provided to the Care Home by the Trust.

Information from the Surgery's records

129 I have only seen one document which contains information from the Trust for the community team. This is a proforma discharge letter to the Surgery which was apparently brought back to the Care Home by the person who went to fetch Mr Hughes from the Trust. This was given to the Surgery by Care Home staff on 27 May 2004 when they asked a GP to visit Mr Hughes. The proforma includes very brief

details about Mr Hughes' admission (his diagnosis and the operation he underwent, but no information about aftercare) and lists the drugs which he needed to take. There is no mention of his stay in the ICU or the possibility that he may have had a heart attack. There is no information at all about his nursing care, his diet or speech and language therapy recommendations. A copy of this document was not found in the Trust records.

Information provided by the Council and statements to the Coroner

- 130 The Council provided us with copies of records from the Care Home and a copy of the report of their investigation into events at the time of Mr Hughes' hospital admission and subsequent death. Their investigation was conducted soon after Mr Hughes died and their report was produced on 21 June 2004 so we consider it provides reasonably reliable evidence for our consideration of Mrs Keohane's complaint.
- 131 We have also seen copies of statements made by Trust and Care Home staff to the Coroner, who held his inquest on 3 March 2005. Although these statements were provided some months after Mr Hughes died they broadly confirm information in contemporaneous records and evidence given to the Council's inquiry.
- 132 From contemporaneous notes made by Care Home staff and from their statements to the Council's Investigator and the Coroner we know they were very concerned that Mr Hughes was being discharged back to their care.
- 133 Around lunchtime on 26 May 2004, the Locum Consultant Psychiatrist in Learning Disabilities for Buckinghamshire Learning Disabilities Services (the Consultant Psychiatrist) visited Mr Hughes at the Trust and discussed the planned discharge with Trust staff. There are no notes in the Trust records of his visit and it appears he made no contemporaneous notes in Care Home records. However, in his statement to the Coroner (dated 2 September 2004) and in evidence to the Council's inquiry, the Consultant Psychiatrist recalled speaking to a doctor (he understood she was a member of the urology team) and nurses about his concerns regarding the Care Home's ability to care adequately for Mr Hughes. In his statements he said the Trust doctor told him Mr Hughes did not need emergency medical or surgical care and was, therefore, fit for discharge. He recalled nurses telling him they were encountering problems with Mr Hughes' behaviour and this was affecting other patients on the Ward. The Consultant Psychiatrist said he felt he could not refuse to accept Mr Hughes back in the Care Home, despite his concerns. Therefore, he accepted his medical colleagues' opinion that Mr Hughes was fit to be discharged.
- 134 The Council's Investigator summarised the Consultant Psychiatrist's evidence on this matter as follows:
- [The Consultant Psychiatrist] (*interview*) made the decision to re-admit Mr Hughes to 309 Cressex Road on behalf of the Learning Disability Service. In making this decision, [the Consultant Psychiatrist] considered factors other than Mr Hughes' fitness for discharge. [The Consultant Psychiatrist] considered Mr Hughes' behaviour and its effect on the other patients in the hospital because he felt the hospital staff had "had enough". He was also concerned that Mr Hughes' situation could be interpreted as "bed blocking" and that this might have future repercussions for working relationships with the hospital. [The Consultant Psychiatrist] said that it was

difficult arguing with the hospital staff, although he did try to persuade them to keep Mr Hughes for an extra few days, to no avail, as he was aware that the nursing staff at 309 Cressex Road were apprehensive about re-admitting Mr Hughes so soon after ITU. [The Consultant Psychiatrist] felt he had to make a quick decision and that there were no other real options than to re-admit to 309 Cressex Road (interview and statement [the Consultant Psychiatrist]).'

135 The information in the Consultant Psychiatrist's retrospective statements is supported by contemporaneous records from the Care Home. Care Home staff wrote that the Consultant Psychiatrist had told them Mr Hughes was to be discharged, although he felt he should be transferred to another ward for a couple of days as he was not fully recovered. They recorded that the Consultant Psychiatrist had been told that the Trust had not been prepared to keep Mr Hughes in hospital because they could not provide the one-to-one care he needed and because they thought he would be better in his own environment.

136 The Care Home records for 26 May 2004 also note that staff from the Care Home had raised their concerns with the Ward because they believed it would be difficult for them to give Mr Hughes the nursing care he needed. The Care Home's Senior Charge Nurse spoke to the Deputy Sister of the Ward to discuss Mr Hughes' discharge. He recorded her response which was that she had concerns about other patients because Mr Hughes was restless and going to other patients' beds. During this conversation the Deputy Sister gave brief instructions about preparing Mr Hughes' diet which were recorded by the Senior Charge Nurse. My Speech and Language Therapy Adviser has analysed these instructions in her advice which I set out below.

137 During the Council's investigation the Care Home Charge Nurse said a yellow sign giving speech and language therapy recommendations had been sent home with Mr Hughes. He said this was to be put up in the Care Home kitchen. One of the Trust's speech and language therapists told the Council's Investigator that this was normal practice as speech and language therapists were not always available to contribute to the discharge letter. There is no copy of the yellow sign in the Care Home records or in any of the records which I have examined.

138 After Mr Hughes arrived back at the Care Home the records show staff contacted the Trust again because they thought Mr Hughes was '*confused and chesty*' and because they had further concerns about him being discharged. There is a note in the Care Home records that in her telephone conversation with the Care Home Charge Nurse the Deputy Sister of the Ward said she would contact the Senior Manager of South Buckinghamshire Learning Disability Service the following day.

139 In her statement to the Coroner (dated 15 September 2004) the Deputy Sister of the Ward said she had first nursed Mr Hughes when he was admitted with retention of urine. She said she was on holiday for part of the time when he was in the ICU but was on duty on late shifts (starting at 2.00pm) when he returned to the Ward on 24 May 2004, and on 26 May 2004 when Mr Hughes was discharged. In her statement she said:

'It was handed over that Ted could be discharged home and everything had been arranged and Cressex were very happy to care for him back in his own environment.'

'Ted was collected around 18.00 by a carer who cared for Ted and got him ready for discharge. I did stress to him to make sure Ted has a soft diet and his drinks had to be thickened (tin of thickener was supplied). As far as I know the drs [doctors] were happy to discharge Ted and the speech therapist was going to follow him up in the community.'

Findings, recommendations and outcome of the Council's inquiry

¹⁴⁰ The Council's Investigator looked in some detail at the way in which the Care Home staff responded to the news that Mr Hughes was to be discharged. He referred to the importance of multi-agency and multidisciplinary discharge planning and noted that in this case *'discharge planning was woefully inadequate and virtually non-existent'* and that *'this was an entirely unacceptable arrangement that should not have been permitted to occur'*.

¹⁴¹ In terms of the Care Home's responsibilities for discharge planning, he concluded that a key problem was that there was no clear agreement about the nature of the service provided by the Care Home (whether it provided a hospital ward environment or a home). He remarked that the Care Home's senior nurses had different views on the skills and competencies of their staff. He also concluded that an over-reliance had been placed on the Consultant Psychiatrist's unilateral decision to accept Mr Hughes back into the Care Home. He said the Consultant Psychiatrist did not fully consider some of the key implications of the discharge, including nursing skills needed to manage Mr Hughes and budgetary arrangements to support any increased staffing levels.

¹⁴² The Council's Investigator recognised that the Care Home staff were under pressure from the Trust to make a quick decision about taking Mr Hughes back. However, he said more time should have been taken to consult about arrangements for discharge and this should have resulted in a discharge meeting and discharge plan.

¹⁴³ The Council's Investigator recommended that a clear operational policy should be written which set out the type of service which residents could expect and the level of nursing skills and knowledge which would be needed to deliver this.

¹⁴⁴ The Council responded to the recommendations of its inquiry and an Operational Policy was drawn up which, amongst other matters, addresses the purpose of the Care Home and the level of nursing support available to residents. The Council also took a lead in developing a joint Admission and Discharge Policy with the Trust. This addresses problems identified in this case, including multi-agency and multidisciplinary working. It also includes a specific pathway to be followed when people with learning disabilities are admitted or discharged from an acute trust.

The advice of the Health Service Ombudsman's Professional Advisers

¹⁴⁵ My Surgical Adviser found no fault with Mr Hughes' initial care and treatment. Usually a patient with acute retention of urine would be sent home with an indwelling urinary catheter and a future date would be fixed for surgery to the prostate. However, Mr Hughes was not able to tolerate the urinary catheter and without this he would not be able to pass urine freely. My Surgical Adviser said because of Mr Hughes' situation, staff reorganised their schedules

to expedite his surgery as his care could not be planned and managed in the usual way for patients with urinary retention. He said the operation and Mr Hughes' initial recovery were uneventful and when he deteriorated he was immediately admitted to the ICU.

¹⁴⁶ My Cardiology Adviser provided information on Mr Hughes' heart condition and gave his opinion on changes which occurred during and after Mr Hughes' hospital stay. He said Mr Hughes was in atrial fibrillation when he was admitted to the Trust on 5 May 2004. He explained that atrial fibrillation is a common disorder of the heart rate and rhythm in people of Mr Hughes' age and that it was being appropriately treated with drugs.

¹⁴⁷ My Cardiology Adviser studied the evidence about what happened to Mr Hughes when he deteriorated and was admitted to the ICU. He said the doctors had considered whether Mr Hughes had suffered a heart attack. They did a test called 'serum troponin' which can give an indication of whether someone has had a heart attack. My Cardiology Adviser said the serum troponin was '*mildly elevated at a peak of 2.4*'. He noted that the Trust doctors thought this confirmed that Mr Hughes had suffered a small heart attack, so they arranged for a cardiologist to see him and appropriate treatment was organised. He also noted that an echocardiogram (an investigation where sound waves are used to examine the structure and function of the heart) had been performed in the ICU. This showed the left ventricle (one of the heart's four chambers) was functioning normally, but the right ventricle was dilated, although the pressure in the right side of the heart was normal. He said this possibly indicated that Mr Hughes had a mild cardiomyopathy (a disorder of the heart muscle). My Cardiology Adviser also studied the post mortem report

and said it showed no evidence that Mr Hughes had suffered a recent myocardial infarction (a heart attack).

¹⁴⁸ My Cardiology Adviser said that in an otherwise healthy person a serum troponin of 2.4 would indicate the person had suffered a heart attack. However, in a person like Mr Hughes, who at the time was suffering from a severe infection and a degree of kidney failure, other factors influence the serum troponin level. In these circumstances he would expect to see a much higher serum troponin (between 40 and 100) before he would say this indicated the person had suffered a heart attack.

¹⁴⁹ Summing up his thoughts on this aspect of Mr Hughes' condition, and noting that he had the benefit of hindsight, my Cardiology Adviser said:

'... there is no clear evidence that an acute cardiac event actually occurred during Mr Hughes' stay in hospital from 5-26 May 2004 although it is impossible to be completely certain but if a heart attack did occur it was small and not detectable at post mortem.'

and

'With the elevated troponin level it was reasonable to assume that a small heart attack had occurred and it was treated appropriately. As it happens treatment is more or less identical to what would have been prescribed for his possible mild cardiomyopathy and whether, as I think less likely, he had had a small heart attack, or whether, as I believe more likely, he had a pre-existing cardiomyopathy, the treatment given adequately covered both.'

- 150 My Cardiology Adviser said that in terms of Mr Hughes' heart problems, the doctors had assessed and treated him appropriately and it was appropriate to discharge him from the point of view of his heart condition. However, he said the discharge communication was 'weak'. He noted that doctors had only provided a standard, very brief discharge proforma and said *'in a patient with a very difficult and medically complex inpatient stay it would have been better for more detailed information to have been passed on in written [form] for immediate insertion in Mr Hughes' community health records'*.
- 151 My Anaesthetic Adviser said when Mr Hughes was moved from the ICU to the Ward he appeared to be breathing normally, coughing and swallowing safely. He also said staff on the Ward quickly arranged for Mr Hughes to be reviewed by specialist teams, including respiratory and heart specialists. My Anaesthetic Adviser noted that on 25 and 26 May 2004 nurses correctly recorded an Early Warning Score of 6 and 7. He said these scores usually prompt nurses to ask doctors to review the patient, which is what happened in this case. He explained that the Early Warning Score is a score derived from various observations which prompts early intervention when a patient's score shows them to be at risk of deterioration. However, he also said that in this case the Early Warning Score could have been skewed by Mr Hughes' fast heart rate, which was normal for him, and his fast respiratory rate, which Trust staff may have attributed to his agitation. My Anaesthetic Adviser said that, whatever the explanation for the raised Early Warning Score, nurses appropriately asked doctors to see Mr Hughes when they recorded the score and Mr Hughes was reviewed appropriately by several doctors after he was transferred from the ICU.
- 152 My Acute Nursing Adviser said after Mr Hughes was moved out of the ICU there was no documentary evidence of appropriate plans to manage his care and treatment. She found no complete nursing assessment and no plans for managing key activities such as communication, nutrition, hydration, mobility or behaviour. She noted that when problems were identified, such as the low oxygen levels and potential aspiration of food and fluid, no nursing care plans were put in place detailing how those problems should be addressed. In particular, she noted that it was not clear whether or not Mr Hughes was meant to be drinking after he left the ICU and, if he was not supposed to be drinking, there was no plan about how fluids were to be given. She also said there is no evidence to show that staff had considered ways of managing Mr Hughes' needs in these circumstances. For example, it is clear that Mr Hughes was thirsty – at one point he drank mouthwash which he mistook for Ribena and went to the kitchen where he drank milk and water – but there is no evidence that staff had found out how to try and manage his behaviour or communicate with him about eating and drinking restrictions.
- 153 My Acute Nursing Adviser said:
- 'There is no clear evidence of how to support communication with Mr Hughes. It is documented that he has learning disabilities but no assessment or plan of how to support Mr Hughes with this.'*
- 'There should have been a clearly documented assessment of his behaviours, basic cares, likes and dislikes, methods of communication, interpretation of noises, his use of body language. This is a minimum requirement for planning his care.'*

'The reviews undertaken by various members of the multidisciplinary team vary in the depth of assessment and recommendations. What is evident is that no one was taking an overall view of these opinions and planning the care for Mr Hughes.'

'The poor nursing documentation and assessment would make it very difficult for planning Mr Hughes' care and definitely would have contributed to the lack of continuity of care.'

'His learning disability seemed to be used as a reason for not undertaking a treatment or an assessment. There was no plan to manage his learning disabilities which would have facilitated treatments.'

'His care within the ward was fragmented with no clear guidance. This falls below the standard of care a patient should reasonably expect.'

154 My Acute Nursing Adviser found *'very little evidence of a planned approach to discharge'*. She said it was not clear whether all Mr Hughes' problems had been resolved so that he could be managed in the community.

155 In terms of a discharge plan, my Acute Nursing Adviser noted that the only evidence is a tick box single sheet which says that discharge information was given *'verbally to carer'*, but it does not say what this advice was. She also said that on this form there is an entry which implies information about Mr Hughes' diet was *'not applicable'* and this section was clearly wrongly completed.

156 My Acute Nursing Adviser said that although there is a record of an intention to contact the Care Home to discuss arrangements for Mr Hughes' discharge there is no evidence in Trust records of any such contact. In her view there should have been a multidisciplinary meeting including staff from the Care Home to discuss discharge arrangements and management of Mr Hughes' various needs. She said it would not have been unreasonable to delay the discharge until this meeting took place.

157 My Acute Nursing Adviser said there is no evidence that Trust staff followed any local policies about discharge and no evidence that they referred to Department of Health guidelines about discharge planning. She said that had these guidelines been followed it *'would have allowed both Mr Hughes' clinical and social circumstances to be taken into account and managed so that a controlled, timely and appropriate discharge could go ahead'*.

158 In summary, my Acute Nursing Adviser said after Mr Hughes was discharged from the ICU his care *'was not delivered to an acceptable standard'*. She said:

'Mr Hughes had clearly recognised learning disabilities and active steps were not taken to ensure that his care requirements were met. Instead, as incidents occurred these were managed, instead of his care being planned to prevent them happening.'

and

'I believe the absence of a planned assessment and management of Mr Hughes' learning disabilities definitely had an impact on the care and treatment that he received.'

159 My Learning Disability Adviser shared the concerns expressed by the Acute Nursing Adviser. She said that given Mr Hughes' complex problems, nursing assessments and care planning were *'inadequate'*. In particular, she said that there was no assessment of Mr Hughes' challenging behaviour or communication and no plans to meet his needs in these areas. In terms of discharge planning, my Learning Disability Adviser again agreed with the views of my Acute Nursing Adviser. She said the discharge appeared to be a *'spur of the moment event'* and *'discharge planning was inadequate'*. She expressed particular concern about poor records of liaison between the Ward and the Care Home and the fact that Trust staff did not appear to take account of concerns expressed by staff from the Care Home. She noted that had Trust staff understood that people with learning disabilities sometimes become agitated and challenging as a means of communication when they are physically unwell, they may have been better able to offer Mr Hughes appropriate care and treatment. As it was, she considered Mr Hughes' learning disability and communication problems were allowed to become *'a barrier to him receiving a standard of care that any patient could reasonably expect ...'*.

160 In general, my Speech and Language Therapy Adviser echoed the concerns of my Acute Nursing Adviser and my Learning Disability Adviser, especially with regard to the lack of integrated assessment and care planning. With regard to the actions of speech and language therapists at the Trust, she said they responded to the request for a pre-discharge speech and language therapy assessment in a *'timely and appropriate manner'*. She said that in terms of assessment the format appeared *'fairly standard'* and the speech and language

therapist provided *'a functional observational report, which is standard practice'*. However, she was concerned about the lack of clear speech and language therapy records of the assessments and lack of recorded rationale for actions and decisions. She said the lack of contemporaneous speech and language therapy records, separate from the main medical record, made it difficult for her to review the speech and language therapists' actions. For example, she could not tell why the speech and language therapists had decided not to perform some specific tests which she felt could have been indicated in his case.

161 My Speech and Language Therapy Adviser commented on information which was passed to the Care Home staff about Mr Hughes' eating and drinking needs. She said:

'There is no documentation of any recommendation or guidance having been given to the Care Home staff as to how to manage Mr Hughes' eating and drinking needs, ie the modification of his food and drink, either verbally or in written form. There are brief recommendations made in the medical notes as to "chilled purée" on 25.5.04 with no recommendations for fluid consistency trials, and for "thickened fluids (custard consistency) and puréed diet (warm and cold)" on 26.5.04. I am aware that the plan for discharge may have been sudden and the SLTs [Speech and Language Therapists] may have had little warning of the plan, but I would suggest that it would have been good practice to discuss recommendations with Care Home staff and nursing staff on the wards.'

and

'I appreciate that the timescales may not have allowed typed guidelines or a report to be produced. However, given Mr Hughes' vulnerability in terms of his health, and the urgency with which he required an adapted diet, ... some form of detailed handover to the Care Home should have taken place.

'The Care Home notes indicate that the [Trust] nursing staff provided information as to the food and drink consistency guidelines, but this information is not exactly as the SLT recommended. The Care Home record the information as told to them by the nursing staff as blended cold food and ice cold drinks from the fridge with thickener added to it whereas the final SLT recommendations were thickened fluids (custard consistency) and puréed diet (warm and cold).

'The nursing staff have provided incomplete information as to the recommended temperature of food and have provided no information as to the consistency of drink required. It is the responsibility of the SLT to ensure that their recommendations have been understood by the relevant key individuals.'

162 With regard to Mr Hughes' discharge, she said:

'... the lack of information provided in the medical notes in relation to all stages of Mr Hughes' discharge forces me to draw the conclusions that he was not thoroughly assessed for discharge, that it was not well planned, and that it was carried out in a hurried and untimely manner.'

The Health Service Ombudsman's findings

163 Mrs Keohane says that Mr Hughes received less favourable care at the Trust for reasons related to his learning disabilities. She has no complaints about his care and treatment until he was discharged to the Ward from the ICU on 24 May 2004. She believes that after he returned to the Ward his care and treatment were inadequate and, in particular, she believes he should not have been discharged. She feels strongly that Trust staff *'just did not want him there because he was more difficult'* and so they *'pushed [him] out'* to the Care Home.

164 I have considered evidence about the actions of Trust staff from various sources and I am satisfied that I have a reasonably clear picture of events from information in the different documents and accounts available to me. However, the poor nursing and speech and language therapy documentation has prevented my Professional Advisers from conducting a comprehensive review.

165 In assessing the actions of Trust staff I have taken account of relevant legislation and related policy, administrative guidance and professional standards as described in Section 2 and annexes to this report. In particular, I have referred to the requirements set out in Valuing People, Good Medical Practice, the Nursing and Midwifery Council's Code of Conduct, Discharge from Hospital and the *Disability Discrimination Act 1995*. I also refer to the Trust's own Discharge Policy.

166 Having studied the available evidence and taken into account the advice of my Professional Advisers, it is clear to me that between 24 and 26 May 2004 Mr Hughes did not receive a reasonable standard of care and treatment

and this led to his premature and poorly planned discharge to his Care Home. I also conclude that the failures in Mr Hughes' care and treatment were for disability related reasons.

167 First, I consider the way in which Trust staff assessed Mr Hughes' needs and planned and delivered his care and treatment.

168 I have described the actions of doctors who visited Mr Hughes after he was discharged from the ICU, including a microbiologist, a cardiologist and a respiratory doctor. He was also seen several times by Ward doctors and twice by specialists from the ICU. My Cardiology and Anaesthetic Advisers said Mr Hughes was assessed thoroughly and appropriately by those doctors who put in place an appropriate plan for medical management of his care, in particular his heart condition. They also said there was no reason why, from a purely medical point of view, Mr Hughes should have been kept in hospital. Having considered the evidence and taken account of the opinion of my Professional Advisers, I find no reason to criticise Trust doctors for their medical care and treatment of Mr Hughes from 24 to 26 May 2004.

169 I have also described how Mr Hughes was assessed on 25 and 26 May 2004 by the Trust's speech and language therapists. My Speech and Language Therapy Adviser said that the speech and language therapists responded promptly and appropriately to the requests for them to assess Mr Hughes' swallowing. I also note the Speech and Language Therapy Adviser's view that the speech and language therapy assessments appeared to be broadly in line with standard practice for their profession, although poor record keeping meant she could not tell why the speech and language therapists did not carry out further tests which might have been indicated. Having considered the evidence and

taken account of the opinion of my Professional Adviser, I find the Trust's speech and language therapists acted reasonably when assessing Mr Hughes' ability to swallow.

170 There is very little information about the Ward nurses' care and treatment of Mr Hughes following his discharge from the ICU. We know that they recorded some routine observations, such as blood pressure, respiration rate and heart rate. We also know they calculated an Early Warning Score, but we do not know precisely what they did as a result of their observations. I have seen no evidence which shows they assessed Mr Hughes' other needs such as nutrition, hydration, communication and safety. As my Acute Nursing Adviser has said, there is no evidence of a formal nursing assessment of Mr Hughes or any plan to meet his needs at this time. I have seen no evidence to show that, in caring for Mr Hughes, they recognised or took account of his needs as a person with learning disabilities.

171 What we do know is that the Ward nurses were finding Mr Hughes difficult to care for. They reported he was wandering around the Ward, approaching other patients and taking drinks from the kitchen. We also know that there was an incident when Mr Hughes fell and sustained a cut on his head, apparently because nurses were unable to manage him safely when he was getting in or out of bed. We also know from a record made by the visiting ICU team that the Ward nurses were having difficulty managing Mr Hughes because he could not comply with treatment. In addition, the Care Home records show that the Ward nurses felt they could not cope with Mr Hughes, even with some help and advice from Care Home staff. The Deputy Sister said to Care Home staff that Trust nurses were concerned for the safety of other patients and they wanted Mr Hughes to return to the Care Home.

- 172 Having considered the evidence and taken account of the opinion of my Learning Disability Adviser and my Acute Nursing Adviser, I find that the Ward nurses made entirely inadequate attempts to assess Mr Hughes' needs or plan or deliver care for him following his transfer from the ICU. Indeed, there is no record of any nursing care assessment or planning at this stage in Mr Hughes' stay at the Trust and little nursing record of his condition and progress. This clearly falls below the standard of care which any patient on the Ward should have received, let alone a patient with Mr Hughes' needs. It is clear to me that once he was transferred from the ICU, the Ward nurses had little idea how to look after Mr Hughes or make reasonable adjustments so they could manage his needs. Furthermore, aside from asking the Care Home staff to come into the Trust and actually carry out his care, they seemed to have had little idea where to seek help.
- 173 I find that in failing to provide the care and treatment Mr Hughes required, the Ward nurses failed to act in line with professional directives, in particular their Code of Conduct and the Essence of Care, or local, national or professional guidelines about caring for people with learning disabilities. The evidence I have seen strongly suggests the Trust had failed to respond to any of the guidance, such as Valuing People, Signposts for Success and Doubly Disabled, which had been in place for some years before Mr Hughes was admitted to the Trust in May 2004. These guidelines required the Trust to ensure arrangements were in place for appropriate care and treatment of people with learning disabilities. This was **service failure** which occurred for disability related reasons.
- 174 I now turn specifically to the way in which Mr Hughes' discharge was planned and carried out.
- 175 I have referred above and at Annex B to the Department of Health's guidelines, Discharge from Hospital, which were issued in January 2003. As I have said, this document provided comprehensive guidance and a toolkit for NHS bodies on all aspects of discharging patients. I also set out some of the key messages of that guidance. At Annex B I set out specific aspects of the guidance which refer to arrangements that should be made for people with learning disabilities.
- 176 I have referred above to the local discharge policy which was in place at the Trust in May 2004 and I set out some of the key points of that policy.
- 177 My medical Professional Advisers said Mr Hughes was medically fit for discharge because he no longer needed specialist medical care and because a plan to manage his main problem, his heart condition, had been put in place by Trust doctors. My Speech and Language Therapy Adviser said there is no evidence that the speech and language therapists acted unreasonably when assessing Mr Hughes' ability to swallow. Therefore, I have no reason to suggest that Mr Hughes was not fit for discharge from the perspective of his ability to swallow safely, as long as dietary restrictions were enforced. In this regard, I note that neither the Trust speech and language therapists, nor the physiotherapist suggested Mr Hughes was not fit for discharge because of a risk of aspiration. The physiotherapist reported that Mr Hughes did not need further physiotherapy and the speech and language therapist provided guidance on managing Mr Hughes' diet in the Care Home, which implied she thought he could be managed there. Neither said Mr Hughes needed further care or treatment in hospital.

- 178 I accept that Mr Hughes was medically fit for discharge, but I do not consider that it was safe to discharge him. I now set out the detailed reasons why I have reached this view.
- 179 My Acute Nursing Adviser, Learning Disability Adviser, and Speech and Language Therapy Adviser all said management of arrangements for discharging Mr Hughes was inadequate. My Cardiology Adviser's view was that communication between Trust doctors and community staff was '*weak*'. I have found no evidence whatsoever that Trust staff responsible for planning and arranging Mr Hughes' discharge referred to, or acted in accordance with, national or local guidance and/or policies about discharge which were in force at the time. In my view, the multidisciplinary team at the Trust who were responsible for Mr Hughes' care (including doctors, nurses and therapies staff) completely failed to enact even the most basic principles of good discharge as described in Discharge from Hospital or their own local policy.
- 180 I agree with Mrs Keohane and my Professional Advisers in that it seems each professional acted on their own, assessing Mr Hughes from the point of view of their own specialism, but failing to see him as a whole person with complex needs. I am especially critical of the Ward nurses who would normally play a central co-ordinating role in managing discharge arrangements. In this case, it seems to me that they found themselves unable to cope with Mr Hughes' needs and, therefore, took a simple, but wholly inappropriate route, which was to send him back to his Care Home as quickly as possible.
- 181 I do not propose to consider the Trust's failings against each and every aspect of national and local guidelines on discharge planning. However, I wish to draw particular attention to the Trust's failure to act in accordance with a key thrust of the guidelines – teamwork and close liaison with community services and carers. The national guidelines stress the importance of '*active engagement*', and '*effective communication*' between NHS trusts and primary care providers, as well as advocating the development of a joint discharge policy. The local policy stressed the need for a co-ordinated, multiprofessional approach to ensure adequate services were in place for vulnerable people who were to be discharged.
- 182 Given the clear national and local policy background, I was particularly concerned to find substantial evidence showing Trust staff ignored the views and representations of staff from the Care Home. Throughout Mr Hughes' stay at the Trust, Care Home staff demonstrated their professional concern and understanding of his needs. The Consultant Psychiatrist and the nurses visited him in hospital, advised on and assisted with his care, made a record of his progress and kept in contact with his family. However, when it came to arranging discharge, their opinions, including the Consultant Psychiatrist's personal representations to his medical colleagues, were disregarded. The Care Home staff were left with little choice but to accept Mr Hughes back into their care even though they had had no opportunity to discuss or plan for how they would meet his needs with the limited resources at their disposal. Trust staff showed no regard for the professional contribution of their community colleagues, giving them no chance to engage in the discharge planning process. Mr Hughes was unable to communicate his own views about his discharge. He could not express his needs and concerns, yet Trust staff rejected the contribution of those who knew him best and were best able to assess his needs and interpret his responses and reactions. This was completely unacceptable.

- 183 I was also concerned that staff at the Care Home did not utilise all the resources available to help them manage this situation when they clearly had concerns about their ability to adequately manage Mr Hughes' needs. I recognise they were put in a difficult position because the Consultant Psychiatrist had 'accepted' Mr Hughes back into the care of the learning disabilities service. Also, they were being pressed by the Trust to take Mr Hughes back as soon as possible, particularly because he was seen as a 'problem' for staff and patients on the Ward. It appears that they were given virtually no notice of the Trust's intention to discharge Mr Hughes. Evidence suggests that the Trust wanted to arrange discharge as quickly as possible on 26 May 2004. I also recognise that the Care Home staff knew Mr Hughes very well and cared about his welfare. This is clearly shown in the Care Home records, for example, in the personalised care plan which they devised for him only a month before he was admitted to the Trust. I understand that staff at the Care Home would have realised that Mr Hughes was distressed in the unfamiliar environment of the Ward and would have wanted to take him back to his own home where they could offer him the individualised care he required to meet his needs.
- 184 It is unfortunate that the Care Home staff did not seek help from other sources, such as the Community Learning Disability Team, or the Surgery (where Mr Hughes was well known to the GPs), or managers at the Council. Also, they could have sought more information from the Trust about Mr Hughes' medical needs on discharge to allow them to plan for his care and make any additional arrangements which might have been required. These issues were brought out clearly in the Council's inquiry. It seems the Care Home staff allowed themselves to be unreasonably pressurised by the Trust and this meant their approach to Mr Hughes' care at this time was reactive when it could have been proactive. They did not play as full a part as they could have done in multi-agency planning for discharge as described in Discharge from Hospital.
- 185 However, I note that the Council accepted the criticisms about discharge set out in the report of its inquiry and took swift action to remedy these failings. I also note that it was proactive in working with the Trust on developing the new Admission and Discharge Policy.
- 186 I have found specific evidence that the Trust had not responded effectively to national directives and guidelines about meeting the needs of people with learning disabilities. It seems that a local policy had been written in response to Discharge from Hospital, but this was ineffective in Mr Hughes' case. In terms of professional practice, Trust doctors did not comply with all the directives in Good Medical Practice. For example, they did not '*work with colleagues in the ways that best serve patients' interests*' (Duties of a Doctor) and they did not '*respect the skills and contributions of their colleagues*' or '*communicate effectively*' (section 36, see Annex A) with them. Trust nurses did not comply with their Code of Conduct, particularly paragraph 4, which emphasised the importance of teamwork and communication.
- 187 In conclusion, I find there was no effective multi-agency planning for Mr Hughes' discharge, despite the fact that this approach was clearly set out in national guidelines available at the time. In particular, no one took overall responsibility for ensuring he was safely discharged. In my view, although both medical and nursing staff from the Care Home did try to express concerns about Mr Hughes' discharge, and they were put under unreasonable pressure

from the Trust, they could have been more assertive in influencing discharge decisions and arrangements. That said, I have seen evidence that the Council subsequently took rapid and robust action to address the issues which led to this situation.

188 I find Trust staff completely disregarded representations from their community colleagues. In so doing they ignored the key principles of national and local guidance on safe discharge. I can understand that staff working on a busy surgical ward found Mr Hughes difficult to manage in an environment which was not ideal for his needs. I also do not doubt that they had genuine concern for the welfare of other patients in their charge. However, this did not absolve them from their responsibilities to ensure Mr Hughes was treated in the same way as any other patient who was medically fit for discharge, but whose needs meant they required extra time in hospital to ensure safe arrangements could be put in place in their home environment. In my view, the Trust's multidisciplinary team did not work together, or with colleagues in the community, as required by professional, national and local guidance and policy to ensure Mr Hughes was safely discharged.

189 The evidence I have seen leads me to agree with Mrs Keohane that Trust staff found Mr Hughes more difficult to care for than other patients who did not have his needs and, instead of trying to meet those needs in a professional way, they '*pushed [him] out*' to the Care Home. This was **service failure** which occurred for disability related reasons.

Complaint (b): communication with Mr Hughes' family

190 Mrs Keohane questions the accuracy of information which was given to her family about Mr Hughes' condition. She asks why staff at the Trust did not tell the family about his heart condition and the second fall. It seems likely to me that some of Mrs Keohane's concerns about this matter arise from information which she was given during the complaints process after Mr Hughes had died. I refer to the way in which Mr Hughes' possible heart attack was labelled in complaint correspondence by the technical term 'troponin positive acute coronary syndrome'. I deal with this issue in the section of the report about complaint handling by the Trust. Here I consider only the evidence about information which was given to Mrs Keohane and her family while Mr Hughes was alive.

Key events

191 Mr Hughes' condition deteriorated on 16 May 2004 and he was admitted to the ICU. Trust records show he was very ill. His blood pressure was low and his heart was beating quickly and irregularly. A series of investigations and tests were performed and Mr Hughes was sedated and connected to a ventilator which took over his breathing. He was given drugs and fluids to support his blood pressure and antibiotics to combat infection. The doctors thought that Mr Hughes had either aspirated and developed pneumonia or suffered a heart attack.

192 Mrs Keohane, her brother, Mr Brian Hughes, and sister-in-law visited Mr Hughes several times while he was in the ICU. Mrs Keohane arrived in England on 18 May 2004 and left to return to Ireland when Mr Hughes' condition was improving and he was due to return to the Ward.

193 The Trust's nursing records show a doctor spoke to Mr and Mrs Brian Hughes on 16 May 2004 and told them that the possible causes of Mr Hughes' deterioration were heart failure, bleeding into the stomach or a chest infection.

194 There is an entry in the medical record for 18 May 2004 which records a conversation between a doctor, Mrs Keohane and Mr Brian Hughes. The entry reads:

'I have talked to patients' relatives (sister and brother) and explained he has a source of infection ?chest (has aspirated) ?urinary. I told them his renal function has improved and that inotropic [drugs to support the heart] requirements are ↓ [down or decreasing] and his cardiac function is good although has had M.I. [myocardial infarction – a heart attack] I said we would continue at present and that his chances of survival should be better than 50%.'

195 This conversation is also recorded in the nursing records and the nurse wrote that Mr Hughes' family appeared to understand what was being said.

196 There is also a note of a conversation between a senior house officer (a junior doctor working in the ICU), Mrs Keohane and Mr Brian Hughes. The doctor recorded that he had discussed the likely source of Mr Hughes' infection, his current treatment and the plan to wean him off the ventilator as soon as possible. The doctor recorded that he mentioned Mr Hughes' need for inotropic drugs. As he was talking about drugs to support Mr Hughes' heart and circulation, I believe it is reasonable to assume that he spoke about Mr Hughes' heart condition.

197 Records from the Care Home show staff there were aware that Mr Hughes had possibly suffered a heart attack. For example, an entry for 17 May 2004 records that a staff nurse from the Care Home visited Mr Hughes in the ICU and discussed his condition with an ICU nurse. The record shows that the Care Home nurse contacted Mrs Keohane to tell her about Mr Hughes' condition.

The advice of the Health Service Ombudsman's Professional Advisers

198 My Anaesthetic Adviser said there are no Trust records aside from those made when Mr Hughes was in the ICU which provide any information about communication with Mr Hughes' family or his carers.

199 My Acute Nursing Adviser said there was evidence of 'close liaison' with the family and Care Home staff while Mr Hughes was in the ICU, but that when he returned to the Ward there is little evidence of communication with his family. She confirmed that there is no record to show that Mr Hughes' family were informed that he had fallen on the night of 25/26 May 2004, or that he had been discharged to the Care Home.

The Health Service Ombudsman's findings

200 Mrs Keohane complains that she was not told about Mr Hughes' heart condition, or that he had fallen on the night of 25/26 May 2004. She believes the way in which Trust staff communicated with her and her family about these matters was inadequate.

- 201 First, I consider whether Mrs Keohane was informed about her brother's heart condition. As I have noted above, Mr Hughes had atrial fibrillation which was being treated with drugs before he was admitted to the Trust in May 2004. I have described how, following Mr Hughes' deterioration on 16 May, Trust doctors carried out tests and investigations and decided it was likely that he had suffered a heart attack. They treated him for his heart condition with drugs. There is evidence in the Trust records that a junior doctor told Mr and Mrs Brian Hughes on 16 May that Mr Hughes may have deteriorated due to heart failure. There is also evidence that another doctor told Mrs Keohane and Mr Brian Hughes that the medical team thought Mr Hughes had suffered a heart attack. His contemporaneous entry in the medical notes is confirmed by an entry in the nursing notes. However, there is no further evidence of detailed discussion with Mr Hughes' family.
- 202 Therefore, I find that Mrs Keohane and Mr Brian Hughes were in fact told about the doctors' concerns about Mr Hughes' heart condition and their belief that he had suffered a heart attack. I also find that the doctors told Mrs Keohane and Mr Brian Hughes about some of the treatment Mr Hughes was receiving for his heart condition. I do not know whether this information was repeated or reinforced as there are limited records about subsequent communication with Mr Hughes' family. I also find that Trust nurses informed Care Home nurses about Mr Hughes' heart condition.
- 203 I consider there is sufficient evidence to show that doctors and nurses from the Trust made a reasonable attempt to inform Mr Hughes' family and his carers about changes in his heart condition. That said, I can fully understand why Mr Hughes' family may not remember the detail of individual conversations which they had with doctors and nurses at the Trust, especially as these took place when Mr Hughes was very ill and in the unfamiliar environment of the ICU.
- 204 I now turn to whether or not Mr Hughes' family were told about his fall on the night of 25/26 May 2004 and whether they should have been told about this. My Anaesthetic and Acute Nursing Advisers said there is no evidence of any communication with Mr Hughes' family after he returned to the Ward from the ICU. My Acute Nursing Adviser said there is no evidence that the family were told about his fall or that he was being discharged to the Care Home.
- 205 I consider it was unacceptable that neither doctors nor nurses communicated with Mr Hughes' family from the time when he left the ICU on 24 May 2004 to his discharge on 26 May. Given that Mr Hughes had been very ill and had just been transferred from the ICU, it was reasonable for Mrs Keohane to expect that either she or her brother would be informed of his progress and the plan to discharge him. I am persuaded that Trust staff did not keep Mr Hughes' family up to date at this important time in his stay at the Trust. Mrs Keohane and/or Mr Brian Hughes should have been told that Mr Hughes had fallen during the night, been informed of the consequences of that fall and any action which had been taken. This was **service failure** which was at least in part for disability related reasons.

Complaint (c): complaint handling by the Trust

206 Mrs Keohane complains about the way in which the Trust handled her complaint about Mr Hughes' care and treatment. In particular, she questions why evidence which emerged at the inquest was not examined in detail or included in the Trust's response and why it took the Trust so long to respond to her complaint.

207 In Section 2 of my report I have set out the key elements of the NHS complaints process. The sections of the Regulations which apply to this aspect of the complaint are those about local resolution – Regulations 3 to 13.

The complaint to the Trust

208 On 27 May 2004 Mrs Keohane rang the Trust to complain about Mr Hughes' care and she was advised to write to the Trust so that her concerns could be addressed. On the same day she wrote out her complaint. It appears she was writing just before her brother collapsed. She said she was happy with care in the ICU:

'But only a few hours back in the urinary ward and things became unsatisfactory. They did not want to have to care for him, too much trouble because he was handicapped and does not speak very much.'

209 On 13 June 2004 Mr Brian Hughes wrote to the Trust. He described events leading up to his brother's death. He said:

'In my opinion, my brother was discharged far too early and his best interests were not served so he met his death through a lack of care and attention.'

210 He also said insufficient attention had been paid to his brother's *'lack of communication skills along with his mental handicap and learning difficulties'*.

The Trust's response

211 On 28 June 2004 the then Chief Executive responded to Mrs Keohane. She copied her letter to Mr Brian Hughes. In summary, the main points of her response were:

- Mr Hughes had been admitted suffering from chronic urinary retention and the normal treatment would have been to catheterise him and discharge him with the catheter in situ. However, Mr Hughes was not able to tolerate the catheter so his *'special needs were taken into consideration'* and arrangements were made for him to stay as an in-patient for an emergency transurethral resection of his prostate. She said Mr Hughes was given priority over other patients.
- Urology Department staff *'continually liaised'* with carers from Mr Hughes' home and arranged for his carers to be with him after the operation.
- Mr Hughes had deteriorated, suffered a heart attack and was admitted to the ICU. He recovered and was transferred back to the Urology Ward.
- Mr Hughes was discharged to his home and *'At no point in the discharge process did the carer raise any queries or concerns that Mr Hughes was not ready for discharge'*.

- The care Mr Hughes received was ‘*of a very high standard*’ and staff ‘*made every effort to ensure Mr Hughes was treated with respect and they initiated special arrangements to ensure he was properly supported throughout his time in the hospital*’.
- 212 The Chief Executive’s response included a summary of information provided by the Council about events at the time Mr Hughes collapsed in the Care Home.

Further contact with the Trust

- 213 On 9 July 2004 Mrs Keohane telephoned the Trust and spoke to the Complaints Officer. She said she was unhappy with the Trust’s response. She raised issues about the decision to discharge Mr Hughes and mentioned the role of the Care Home. The Complaints Officer suggested that a meeting with Trust staff might resolve Mrs Keohane’s concerns. She also confirmed that information provided by the Care Home had been included in the investigation. However, she said Mrs Keohane would have to make a separate complaint about the Care Home if she wanted to raise further issues about Mr Hughes’ care there. This advice was correct, although the Complaints Officer could have been more helpful by putting Mrs Keohane in contact with the Council.
- 214 On 5 July 2004 Mr Brian Hughes wrote to the Trust asking if it had received his previous letter, although this letter did not arrive at the Trust until 20 July 2004. On 21 July 2004 the Trust replied outlining the action it had taken in responding to Mrs Keohane and explaining it was waiting for her further comments. A copy of the original response was enclosed.

- 215 It appears that neither Mrs Keohane nor Mr Brian Hughes contacted the Trust again or took up the Trust’s offer of a meeting. Mrs Keohane has since explained that this was because it was not practical for her to travel from Ireland for a meeting and she hoped the inquest would answer her outstanding questions. However, on 11 May 2005, around two months after the inquest, Mrs Keohane asked the Healthcare Commission to review her complaint to the Trust.

- 216 I consider the Healthcare Commission’s actions later in this report. In summary, the Healthcare Commission identified three key issues in the complaint to it: (i) the Trust’s response dated 28 June 2004; (ii) Mr Hughes’ fall on 15 May 2004; and (iii) whether Mr Hughes was discharged too early. The Healthcare Commission was highly critical of the Trust’s response of 28 June 2004 saying it ‘*failed to provide a complete and accurate picture and the statements and the investigation they undertook failed to bring to light issues which came out at the inquest*’. It referred all three issues back to the Trust for further action and made three recommendations. Two recommendations referred in general to the way the Trust should respond when an inquest had been held, including making further contact with the bereaved family. The third recommendation required the Trust to give a further response about events at the time of Mr Hughes’ discharge.

The Trust’s response to the Healthcare Commission’s decision letter

- 217 On 29 March 2007 (nine months after the Healthcare Commission issued its decision letter) the current Chief Executive wrote to Mrs Keohane with the Trust’s response to

the matters referred back by the Healthcare Commission. After setting out the background to the complaint the Chief Executive addressed specific issues raised by the Healthcare Commission.

218 She acknowledged that the Trust's response letter of 28 June 2004 did not cover all the aspects discussed at the inquest and *'did not provide a complete picture of everything that had happened with regard to Ted's care and treatment and discharge back to 309 Cressex Road'*. However, she said the Trust had followed usual practice after issuing a response because they had offered to meet Mrs Keohane or Mr Brian Hughes so any outstanding issues could be addressed.

219 The Chief Executive apologised that Mr Hughes' family had not been informed that Mr Hughes had fallen on 25/26 May 2004. She also reported on a further investigation of the incident which she said showed that Mr Hughes had not *'jumped over the bed'* and fallen as originally reported, but had jumped back onto the bed and fallen having got up to go to the toilet. She said the Trust had learnt from this incident and outlined the actions which had been taken to address the issue.

220 She acknowledged the Trust had not fully addressed Mrs Keohane's concerns about Mr Hughes' discharge. She gave an explanation of events which included descriptions of the assessments carried out on 25 and 26 May 2004 by doctors, speech and language therapists and physiotherapists. When discussing the cardiology assessment she said:

'It was felt that his troponin positive acute coronary syndrome should be treated conservatively with the decision for more invasive investigations if he developed chest pain or showed evidence of acute myocardial ischaemia (heart disease) in the future.'

221 She also said it was decided that Mr Hughes could be discharged, so staff telephoned the Care Home to arrange discharge to an environment where *'conservative treatment could be continued in a more comfortable and familiar setting with the staff specially trained to cater for his special needs'*.

222 The Chief Executive went on to say that at the inquest staff from the Care Home, including the Consultant Psychiatrist, had raised concerns about the discharge but these concerns were not recorded in Mr Hughes' Trust records. She noted that in his court statement the Consultant Psychiatrist had said he discussed his concerns with a female registrar and had mentioned that Mr Hughes appeared to be blocking a bed. However, she said there are no records of these conversations and, therefore, she could not *'shed any further light on this'*.

223 She also said:

'An acute hospital cannot, and does not, discharge any patient, whether this is to a family, or to a residential unit, without the surety that the patient will be accepted back home and that the patient will be either able to look after themselves or provided with the appropriate levels of support.'

224 In terms of complaint handling, the Chief Executive said the Trust had liaised with Adult Social Care, but they had been informed that Adult Social Care would be undertaking their own investigation. However, information from a statement from Adult Social Care was used in the original Trust response. She noted that no concerns were raised by Adult Social Care about Mr Hughes' care at the Trust. However, in their response to my specific enquiries, the Council told me that they had shared the outcome of their inquiry, but not the full report, with senior staff at the Trust (including the then Director of Nursing and her deputy) at an initial meeting on 3 September 2004 and at a wider meeting on 18 November 2004. They also said a new joint Admission and Discharge Policy had been developed as a result of discussion and joint working with the Trust.

225 The Chief Executive also said Trust records did not include instructions to the Care Home regarding Mr Hughes' diet, but the records did show that the Deputy Sister had discussed this with the carer who collected Mr Hughes and she had provided a tin of thickening powder.

226 She addressed the Healthcare Commission's view that following the inquest the Trust should have considered whether anything could be added to the complaint and, if so, they should contact the complainant. She said that she believed it *'was unacceptable to actively pursue a family that have had to endure an unexpected loss'* and that such an approach could be considered *'uncaring'* and *'imposing on their grieving process'*. She said the offer of a meeting following a response to a complaint is always open to complainants.

227 The Chief Executive apologised for the delay in providing the response.

Mencap's response

228 On 22 May 2007 Mencap wrote to the Trust setting out *'questions and concerns that remain outstanding'*. These were: the length of time taken by the total complaints process; emergence of information which was previously unknown to Mr Hughes' family (the second fall and his 'troponin positive acute coronary syndrome'); lack of action by the Trust in response to the inquest findings; and further issues about the complaints process (including the scope of the Trust's investigation regarding swallowing assessments, discharge arrangements, views of Care Home staff and the role of the GP and Mental Health Trust).

The Trust's response to Mencap

229 On 30 July 2007 the Chief Executive responded to Mencap's letter. In summary she:

- agreed that delays in the complaints process were unacceptable. She reiterated her apologies and said as a result of the complaint the Complaints Department had undergone a number of changes;
- apologised that Mrs Keohane had lost confidence in the complaints process and offered assurances about changes;
- reiterated that action had been taken to improve incident reporting;
- reported on a review by one of the Trust's consultant cardiologists who had said that 'troponin positive acute coronary syndrome' meant the same as having a heart attack and added that Mr Hughes' health record showed the family had been informed that he had suffered a heart attack; and

- explained that the inquest and the complaints process were two separate processes and reiterated her point that it would not be appropriate for the Trust to pursue the family following the inquest.

230 In terms of the robustness of the Trust's response to the complaint, the Chief Executive said the Trust did try to include the agency with responsibility for the Care Home in its response but they declined this opportunity. She also reported on a review of the action of the speech and language therapists by the Head of Therapies who had not been involved in Mr Hughes' care. She said this review showed that appropriate action had been taken, given the difficulties of assessing Mr Hughes. In terms of Mencap's concerns about Mr Hughes' discharge she reiterated the position taken in her previous response. In particular, she said the concerns raised by the Care Home staff did not come to light during the initial investigation and there was no record of the Consultant Psychiatrist's conversations with doctors at the Trust. She also said the Consultant Psychiatrist did not approach '*the relevant acute care consultant*'.

The review commissioned by the Trust

231 In April 2007 the Trust commissioned a review of the way in which it handled complaints related to patients with learning disabilities. The terms of reference, which were shared with Mrs Keohane and the Healthcare Commission, were: to analyse the process/thoroughness of the investigation into the complaint raised by Mrs Keohane following Mr Hughes' death; to identify whether the process of the complaints investigation on the Ward was robust enough to provide a response to the complainant; and to analyse a random selection of complaints to

assess whether there had been improvements in the complaint handling process. In the event, the review was not confined to complaint handling because, in the course of its investigation, the investigation team unearthed problems with Mr Hughes' management as a person with learning disabilities.

232 The investigation team included three senior staff from outside the Trust, including two people from the Ridgeway Partnership which by then had taken over responsibility for community mental health services in the area. The team was led by the Medical Director, Ridgeway Partnership. Other team members were the Governance Lead, Ridgeway Partnership, the Assistant Director Practice Development, Heatherwood and Wexham Park Hospitals NHS Foundation Trust and the General Manager of Medicine from the Trust.

233 The investigation team reported in July 2007. It described how it had created a process map to analyse the complaint about Mr Hughes. It identified 22 points of concern under the headings of: the complaint procedure; record keeping and documentation; involvement in the investigation process; critically reviewing patient care; and lessons learnt. It concluded that the investigation process carried out by the Ward was flawed in that it failed to identify facts which became known at a later date. It said '*staff in the urology team failed to take notes of key discussions and appeared not to have volunteered information in relation to Mr Hughes' discharge which must have been known to them at the time*'.

234 From the audit of complaints the investigation team identified key failings and concluded that '*work still needs to be done to improve the efficiency of complaint handling*'.

235 The investigation team made 12 recommendations about complaint handling in general and 7 recommendations specifically about Mrs Keohane's complaint. These are set out at Annex D.

236 On 26 July 2007 the Director of Nursing and Patient Standards wrote to Mrs Keohane enclosing a copy of the report. She offered her *'sincere apologies for the continuing distress'* which Mrs Keohane was experiencing. She did not offer specific apologies for the poor care and treatment Mr Hughes had received, but she said:

'Both me [sic] and my board colleagues ... found this a deeply distressing account both of the handling of your complaint and also the care Ted received.'

237 She also tried to telephone Mrs Keohane, but was unable to get through. She invited Mrs Keohane to meet her and other senior members of staff, either at the Trust or in Ireland, to discuss the report. So far, Mrs Keohane has not taken up this offer.

238 On 17 August 2007 the Trust's Governance Committee 'signed off' an action plan which had been developed to address the recommendations of the investigation. On 20 August 2007 the Director of Nursing and Patient Standards sent a copy of the plan to Mrs Keohane.

239 On 16 November 2007 the Director of Nursing and Patient Standards wrote to Mrs Keohane to inform her that the Trust had set up a multi-agency working group (including Mencap and a learning disabilities health liaison nurse) *'to review and approve training for staff to improve the care of patients with learning disabilities'*. She said the group would also take responsibility for work on the action plan.

The advice of the Health Service Ombudsman's Professional Advisers

240 My Acute Nursing Adviser observed that the recommendations from the review and the subsequent action plan would provide a clear audit trail of actions and accountabilities and *'should ensure that issues are effectively addressed in a transparent and timely way'*. She said the recommendations and action plan would provide a *'standard against which processes and interventions will be measured'*. My Learning Disability Adviser said the recommendations for future care of patients with learning disabilities appeared *'fairly robust'*. She made some specific suggestions for extending the ideas in the recommendations around managing patients with complex problems including challenging behaviour. These suggestions included: introducing training programmes for staff; using a standard risk assessment tool; using a standard format for detailed care planning; and liaising closely with community and mental health specialists through formal advice networks.

The Health Service Ombudsman's findings

241 Mrs Keohane remains dissatisfied with the way the Trust handled her complaint. Her main points are that the Trust took too long to respond and, even following their more detailed later responses, she feels they have not properly investigated her complaint or answered all her questions.

242 I can understand why Mrs Keohane is unhappy with the Trust's response to her complaint and why she feels the complaint process has been complex and prolonged. Although she first complained in May 2004, she did not receive detailed responses from the Trust until March and July 2007 – more than three years after

Mr Hughes died. However, despite the fact that there were serious failings in the Trust's approach to this complaint which I go on to explain, I find that an unfortunate combination of circumstances exacerbated the delay and complexity which Mrs Keohane experienced.

243 First, the fact that Mrs Keohane lives in Ireland undoubtedly made it more difficult for her to complain. As she said to my investigator, she did not know anything about the NHS complaints process. She began to write her initial letter of complaint to the Trust because she wanted to express concern about Mr Hughes' discharge, but while she was writing she received news of his death.

244 Secondly, the inquest and the actions of the Healthcare Commission influenced the progress of the complaint. One of Mrs Keohane's complaints about the Trust is that it did not include information which came to light at the inquest in its response to her complaint. This was partly because of the failings in the Trust's initial investigation but also simply because the inquest took place nine months after the Trust first responded to her complaint. Mrs Keohane has told us she did not take up the Trust's offer of a meeting to discuss her concerns about its response to her complaint partly because she lives far from the Trust and partly because she thought the inquest would provide her with the answers to her outstanding questions. Her decision was entirely reasonable. Unfortunately, it seems the inquest left her with more questions than answers. For example, new information came to light about the role and views of Care Home staff which led her to question further the Trust's decision to discharge Mr Hughes. Also, discussion of clinical information at the inquest left her with doubts about the actual reason why Mr Hughes died.

245 After the inquest Mrs Keohane could have returned to the Trust to ask for further information and explanation. I note the Trust's offer of a meeting was still open. However, Mencap suggested that Mrs Keohane asked the Healthcare Commission to review her complaint. Unfortunately, this decision may not have led to the clarity which Mrs Keohane naturally sought. Rather, because of flaws in the way the Healthcare Commission handled the review of the complaint, it led to further confusion and delay.

246 The Healthcare Commission's actions are considered in a later section of this report.

247 Having set out some of the factors which influenced the progress of Mrs Keohane's complaint to the Trust, I now consider the way in which the Trust responded to her complaint.

248 The Trust's response to Mrs Keohane's original complaint was prompt, within a month of receipt of her letter which was in line with the timeframe in the Regulations. However, there is evidence that the investigation was inadequate. The investigation was not conducted in accordance with the Regulations. In particular, there was no robust attempt to gather clinical information or question staff about their actions, there was an over-reliance on the fact that nothing was recorded in Trust records (especially interaction with Care Home staff) and the main issues, Mr Hughes' discharge and his learning disabilities, were barely addressed at all. Furthermore, the tone of the letter was defensive. The focus was on justifying the actions of Trust staff, rather than exploring and explaining those actions. This does not conform with the approach set out in Regulations 12 and 13. The poor investigation and response indicate to me that the Trust did not recognise the seriousness of the matters complained about.

- 249 It is not clear to me why it took the Trust nine months to respond to the Healthcare Commission's decision letter. I recognise that the Trust has apologised to Mrs Keohane for this delay, but I find that the Trust's inaction during this time is a further indication of its failure to recognise the seriousness of the matters complained about. The response indicates that some additional investigation had been conducted, for example there is more information about Mr Hughes' fall on 25/26 May 2004 and more detail about the assessments undertaken by staff before Mr Hughes was discharged. Unfortunately, in giving more detail about the assessment of Mr Hughes' heart condition, the Trust introduced the idea that he was suffering from 'positive troponin acute coronary syndrome' and suggested he might have developed serious complications as a result. This was apparently new clinical information (although in fact it was just a specialist medical description of his heart condition) which was included with no lay explanation. Understandably, this caused Mrs Keohane more anxiety and led her to believe that the Trust had not kept her fully informed about her brother's heart condition.
- 250 Moreover, the overall tone of the letter was still defensive. There was no recognition that the Trust may have been at fault. The Chief Executive's letter implies that because the Trust had no record that Care Home staff were concerned about Mr Hughes being discharged the Trust itself had no reason to be concerned. However, I have seen Care Home records which clearly document conversations between staff at the Trust and the Care Home in which the concerns of Care Home staff were recorded. Also, we know the Council's inquiry reported on 21 June 2004 and the summary results were shared with senior staff at the Trust on 3 September and 18 November 2004. I am not persuaded that the Trust took full account of this information when drawing up their response at this stage. That said, I agree with the Chief Executive's comments about the link between the inquest and the complaints process.
- 251 When Mencap wrote to the Chief Executive of the Trust in May 2007 with specific points about her letter of 29 March she took around two months to respond. Her letter indicated that she had sought some additional information to enable her to explain Mr Hughes' heart condition and the speech and language therapy assessments. However, she mainly focused on assuring Mencap that there had been improvements in complaint handling and incident reporting at the Trust. I particularly note that the Chief Executive did not change her position with regard to discharge arrangements for Mr Hughes. In fact, she reaffirmed her contention that there was no evidence that the Consultant Psychiatrist had expressed concerns to doctors at the Trust.
- 252 I can understand why the Chief Executive's responses to the Healthcare Commission's decision letter and Mencap's follow-up letter did little to address Mrs Keohane's concerns. In particular, the inadequate approach to investigating issues led to piecemeal, unconvincing responses. Key issues, including Mr Hughes' learning disabilities, were poorly addressed, the tone of the responses remained defensive and there was no acknowledgement that the Trust could be at fault, other than in terms of the complaints process. I am also concerned that the Trust failed to take appropriate account of the results of the Council's inquiry which were shared with it in autumn 2004. Rather, it continued to say that the Council was not co-operating with its investigation.

253 I am especially concerned by the lack of co-ordinated attention to the complaint after the Chief Executive's response of March 2007. In April 2007 the Trust instigated a review of events associated with Mrs Keohane's complaint. Mrs Keohane was informed about the review and on 26 July 2007 the Director of Nursing and Patient Standards wrote to her with a copy of the report of the review which was highly critical of the Trust's management of Mrs Keohane's complaint. The report also made seven recommendations, set out at Annex D of this report, about caring for people with learning disabilities. In my view these actions were appropriate. However, on 30 July 2007 the Chief Executive wrote to Mencap without any mention of the review or its outcome and without any acknowledgement or apology for the failures in care and treatment provided for Mr Hughes which the Trust's own review had revealed.

254 I find that there were significant failings in the way in which the Trust managed Mrs Keohane's complaint. In summary, the Trust:

- failed to recognise or address the most serious issues complained about;
- failed to conduct an appropriate investigation;
- adopted a defensive approach;
- failed to provide appropriate co-ordinated responses;
- at times, took too long to respond to correspondence; and
- failed to acknowledge and apologise for poor care and treatment.

255 These failings amount to **maladministration**. Furthermore, in key areas of their management of this complaint the Trust did not act in accordance with the Regulations or with the principles of good administration.

Complaints against the Trust: the Health Service Ombudsman's conclusion

256 I am in no doubt that after Mr Hughes was transferred from the ICU to the Ward, the Trust failed to recognise, take account of, or meet his needs as a person with learning disabilities. I agree with Mrs Keohane that Mr Hughes was discharged inappropriately to his Care Home because Trust staff found him difficult to manage. Furthermore, Trust staff failed to work as a team with colleagues in the community to secure his safe discharge. I found that Trust staff did tell Mr Hughes' family about his heart condition, but after his transfer from the ICU they failed to inform his family about significant events in his care, especially the fall on the night of 25/26 May 2004 and the fact that he was to be discharged. I conclude that there were **service failures** in the care and treatment the Trust provided for Mr Hughes after he was transferred from the ICU to the Ward.

257 The way in which the Trust managed Mrs Keohane's complaint was seriously flawed. This was **maladministration**.

Injustice

258 The Trust informed me of action which it took to address the shortcomings identified during its review of Mr Hughes' case and Mrs Keohane's complaint. I have set out this information above. My Professional Advisers have told me that this action would go some way towards addressing the failings identified, although my

Learning Disability Adviser thought the Trust could have taken more robust action in terms of care of people with learning disabilities. Some of her suggestions are covered in the Trust's subsequent actions.

259 In her response to my draft report the Chief Executive acknowledged the key failings I identified in my investigation and gave further details of recent action at the Trust aimed at addressing those failings. She said:

'I am mindful that this has been an extremely lengthy and distressing time for Mrs Keohane and other family members. The period since these very sad events is considerable and has spanned three different chief executives and management teams in this Trust. I wish once again, to personally reiterate on behalf of the Trust my sincere apologies to Mrs Keohane and the family that Mr Hughes did not receive the expected standard of care and discharge planning between the dates of 24th – 26th May 2004.'

260 The Chief Executive summarised the key actions taken by the Trust as follows:

- *'A Learning Disability Health Conference was held at the Trust in 2005.*
- *We commissioned an inquiry into the complaint handling of this case to help learn and inform the improvement made to our complaints handling processes.*
- *We have reviewed and updated relevant key policies such as the Discharge Policy and the Vulnerable Adults Policy and used the learning from these sad events to inform policy development.*

- *We are working in partnership with other agencies through a variety of groups and named links.*
- *A training programme open to all staff and volunteers has been put into place. Training will be delivered mainly by those who have learning disabilities.*
- *Each ward has a designated discharge co-ordinator and fortnightly meetings are held with key staff from across the health economy to ensure that any concerns regarding services or discharge arrangement can be raised and followed up on.*
- *Essence of Care has been re-launched.*
- *Matrons undertake formal rounds.*
- *Training in good record keeping is ongoing and regular audits are undertaken.*
- *Documentation on acute wards had now changed into a multidisciplinary care note.'*

261 The Chief Executive said:

'In our attempt to outline the actions that we have undertaken, we hope to demonstrate the lessons that we have learnt and the seriousness with which we have taken these events. It is also our aim that these actions will minimise the risk of reoccurrence.'

262 She also offered to meet Mr Hughes' family to discuss his care and the changes that have been made at the Trust.

263 Having considered the evidence put forward by the Trust about changes which have occurred since Mr Hughes was a patient there, I find that the Trust has now taken reasonable action to address the shortcomings identified by its own inquiry. I also find that its actions will address the failings identified in this report with regard to the care and treatment provided to Mr Hughes and to complaint handling.

264 That said, I consider Mrs Keohane still has reason to be aggrieved by the failings in the Trust's care and treatment of her brother, and in particular those failings which I have concluded occurred for disability related reasons. Furthermore, she should not have had to wait for an investigation by me to establish the facts about Mr Hughes' care and treatment. Partly due to failings at the Trust, Mrs Keohane has had to wait four years for answers to her questions – four years during which she wondered whether her brother's death was avoidable. That four year wait and that uncertainty is an injustice that has not been remedied.

265 I have found **service failure** in the care and treatment provided for Mr Hughes by the Trust and **maladministration** in the way the Trust handled Mrs Keohane's complaint. This has resulted in **injustice** for Mrs Keohane.

266 Therefore, I **uphold** Mrs Keohane's complaint against the Trust.

267 I make recommendations below to remedy the injustice to Mrs Keohane which I have described in paragraph 264 above. We say more about injustice in Section 4 of this report.

The Health Service Ombudsman's recommendations

268 I **recommend** that the Chief Executive of the Trust apologise to Mrs Keohane for the failings I have set out in this report.

269 I also **recommend** that the Trust offer compensation of £10,000 to Mrs Keohane in recognition of the injustice she has suffered in consequence of the service failure and maladministration I have identified.

The Trust's response

270 As I have said above, the Chief Executive of the Trust has acknowledged the failings identified in this report. She has also reiterated her sincere apologies to Mrs Keohane and offered to meet her and her family to discuss Mr Hughes' care and recent changes at the Trust. I have already commented that I find these actions are appropriate and I am reassured that lessons have been learnt from this case. The Chief Executive accepted my recommendation regarding a compensation payment.

The Health Service Ombudsman's investigation of the complaints against the Surgery

Complaint (d): care and treatment by the GP

271 Mrs Keohane believes that the GP did not respond quickly enough to the request from Care Home staff to visit Mr Hughes on 27 May 2004. Mencap have suggested that the GP did not arrive until 4.30pm, '*just over an hour*' before Mr Hughes died, when the request for a visit had been made in the morning. In their complaint to the Health Service Ombudsman Mencap said:

'Ted's GP prescribed further thickening powder, but then watched Ted sit down to a normal communal meal in the care home before he left.'

- 272 Mrs Keohane also says the GP did not examine Mr Hughes properly and that he was wrong not to readmit him to hospital.

Key events

- 273 Mr Hughes returned to the Care Home at around 8.00pm on 26 May 2004. Records from the Care Home show staff there were concerned about him as soon as he arrived. The Senior Charge Nurse wrote that Mr Hughes appeared *'confused and chesty even though staff at the hospital say his chest is clear'*.

- 274 The Team Leader on the night shift recorded that Mr Hughes was taken to bed around 10.00pm. He wrote that Mr Hughes was *'very unsteady'* and had to be showered using a shower chair which was used to wheel him back to his bed. The Team Leader also wrote that Mr Hughes was unable to settle and staff stayed with him all night. They were concerned he would injure himself because he was restless and unsteady. He wrote that Mr Hughes settled at about 3.00am but that he had a *'very chesty cough throughout the night and looks very pale'*.

- 275 During the morning of 27 May 2004 staff at the Care Home recorded that Mr Hughes was *'looking frail, staggering – but walking quite fast and opening his eyes quite wide. Ted is really a changed person'*. Their concern led them to contact the Surgery and ask for a visit from one of the GPs. This request is not recorded in the Care Home notes. However, records from the Surgery show that a compliments slip attached to the Trust's discharge summary was delivered to the Surgery some time on 27 May 2004. The

Senior Charge Nurse from the Care Home had written an untimed and undated note on the compliments slip. The note was addressed to Mr Hughes' usual GP and said:

'Edward Hughes has been discharged back to 309 and he is still not well, sounds chesty, unsteady on his feet, needs 1-1 constantly. Need thickener for his drinks so can we have it on Rx [prescription] please.'

*'Thanks Sen Charge Nurse.
Please can you come today to see Ted as he is not well still.'*

- 276 A different GP responded to the request for a visit to Mr Hughes because his usual GP was not available. The Care Home records say that the GP arrived *'around 15.00'*, examined Mr Hughes and said that he did not think Mr Hughes was chesty. The records also note that the GP asked for a specimen of urine to be collected for analysis.
- 277 The Surgery computer log shows that on 27 May 2004 the GP undertook home visits between finishing morning surgery at 12.11pm and starting afternoon surgery at 3.55pm. The computer record of the GP's visit notes that the Care Home staff were concerned by Mr Hughes' weak state and angered by the way he was discharged. It also notes that the GP considered whether Mr Hughes had a chest infection or a urinary tract infection. It also says that having examined Mr Hughes, the GP found his chest was clear and asked for a urine specimen to be taken. The record goes on to say that the GP contacted the Speech and Language Therapist at the Trust and confirmed the instructions for managing Mr Hughes' diet before prescribing drinks thickener and other medication.

The GP's statement to the Coroner

278 On 27 February 2005 the GP provided a statement for the Coroner. In this statement he noted that the request to visit Mr Hughes had been addressed to one of his colleagues, the lead doctor for the Care Home, but he was not available. The GP said he had met Mr Hughes 'several times before' and was aware of his social and medical history. He said:

'When I arrived to see Mr Hughes I initially discussed his problems with his carers who felt that he was much weaker than on admission to hospital ... On seeing and examining Mr Hughes I was led to the patient where he was sitting out of his room, on a chair. He wasn't notably short of breath at rest, and neither was he cyanosed [bluish coloured from lack of oxygen]. When I listened to his chest I felt there were no signs to suggest an acute chest infection. Indeed he was already on 3 medications to protect his chest from further aspiration. I wondered if his weakness was due to his rough peri-operative period [the time before, during and after surgery], but also whether in view of his recent prostate surgery he may have a urinary tract infection. When I saw him I did not feel his condition warranted readmission to hospital, but was planning to discuss the issue with the home manager the next day (he was off duty on the day I visited). I also spent quite a while tracking down his speech therapist to ensure I prescribed the correct food thickener and quantities.'

The Practice Manager's explanation

279 On 3 August 2006 the Practice Manager wrote to Mrs Keohane in response to her complaint about the GP's actions. She said she had discussed events with the GP who had:

'... observed Mr Hughes walk unaided, and noted he was not short of breath. Examination of the chest was clear. [The GP] considered a urinary tract infection, and requested a specimen of urine be sent to the laboratory for testing.'

280 The Practice Manager also said the GP did not admit Mr Hughes to hospital because:

'... his chest was clear, with no apparent infection, and although he appeared weak as you would expect from someone recovering from surgery and pneumonia, there was no sign of recent deterioration.'

The advice of the Health Service Ombudsman's Professional Adviser

281 My GP Adviser said there was no suggestion on the note which requested a home visit that the visit was more urgent than 'today', so it was reasonable for the GP to visit between his morning and afternoon surgery.

282 My GP Adviser said the GP's contemporaneous note of his visit shows that he obtained a history from Mr Hughes' carers and that he examined him. He also said the note goes on to acknowledge that Mr Hughes was at risk of aspiration. My GP Adviser said the Surgery's response to Mrs Keohane's complaint confirms that the GP saw Mr Hughes walk unaided, saw that he was not short of breath, examined his chest and asked for a urine specimen to be taken.

283 My GP Adviser said:

'Although there is a lack of detail in the clinical record about both the history taken and the physical examination findings, there is no evidence that [the GP's] assessment of Mr Hughes was either inadequate or inaccurate.

'[The GP's] diagnostic conclusion, that Mr Hughes was at risk of aspiration and that he might have a urine infection, were logical. By considering measures to reduce the risk of aspiration of food, prescribing a food thickener and [liaising with] a speech therapist, [the GP] went further than many GPs would have done in the circumstances.

'[The GP] also, correctly, continued Mr Hughes' treatment for atrial fibrillation (frusemide, metoprolol, perindopril) and infection (amoxicillin).

'[The GP] arranged for a speech therapist to assess Mr Hughes, requested that a urine sample be sent to the laboratory and arranged to discuss Mr Hughes' discharge from hospital with the Care Home Manager. These actions were appropriate and demonstrated a concern for both Mr Hughes and his carers.

'Mr Hughes had apparently been aspirating food chronically, ie over a period of time. His general weakness on discharge from hospital would almost certainly have made him more susceptible to aspiration. However, [the GP] could not have predicted that he would aspirate so severely later that day or that the consequences would be so serious.'

284 My investigator specifically asked my GP Adviser if the GP took sufficient account of Mr Hughes' learning disabilities and whether his actions were in line with relevant professional and national guidelines. My GP adviser said:

'[The GP] visited Mr Hughes in his home. There is no suggestion of any attempt to get Mr Hughes to travel to the surgery. [The GP] liaised with other professional people involved in his care, particularly Care Home staff and the speech therapist. [The GP] did not undertake any procedure or make any decision that would normally require explicit consent. The evidence is that [the GP] acted in Mr Hughes' best interests. There is no evidence that he discriminated against Mr Hughes because he suffered from learning difficulties, dementia or schizophrenia.'

285 Referring to the proposals in Valuing People my GP Adviser said:

'There is no evidence that Mr Hughes had any difficulty gaining access to GP care and there is evidence of integrated working between health professionals.'

and

'There is no evidence that [the GP] failed to comply with [GMC guidance] or that he discriminated against Mr Hughes in any way.'

286 My GP Adviser concluded that:

'I have no criticism of [the GP's] care of Mr Hughes on 27 May 2004. ... [The GP's] care and treatment of Mr Hughes was well above the minimum standard expected of a reasonable GP in similar circumstances.'

The Health Service Ombudsman's findings

- 287 Mrs Keohane believes that the GP's care and treatment of Mr Hughes on 27 May 2004 was inadequate. She believes that if the GP had acted differently, in particular taking more account of Mr Hughes' learning disabilities and recent discharge from hospital, he might not have died.
- 288 I can understand why Mrs Keohane finds it difficult to accept that Mr Hughes died only hours after he was seen by the GP and why, therefore, she feels the GP could have taken action to prevent his death. Unfortunately, it appears that, with the passage of time, some of the facts about the GP's visit, in particular the time he arrived at and left the Care Home, have become distorted. It seems to me that this may have understandably led Mrs Keohane to draw some conclusions about the GP's actions which are not supported by contemporaneous evidence.
- 289 I have considered evidence about the GP's actions from various sources and I have not found any significant inconsistencies in the different documents and accounts available to me. In assessing the GP's actions I have taken account of relevant legislation and standards. In particular, I have referred to the requirements set out in Valuing People and Good Medical Practice.
- 290 I have considered the advice of my GP Adviser who has made a detailed study of the contemporaneous evidence about the GP's visit. I find that there was no apparent urgency in the request for a GP to visit Mr Hughes and, therefore, it was reasonable for the GP to call on Mr Hughes in the afternoon during the time in his working day which was allocated to home visits. I also find that there is strong contemporaneous evidence to show that the GP called on Mr Hughes in the early afternoon (not just before Mr Hughes died as Mrs Keohane suggests, or at 4.30pm as Mencap have stated) because he was back in the Surgery seeing his first patient at 3.55pm. Also, the GP's time is then accounted for until his last patient left his consulting room at 6.13pm. This is corroborated by the Care Home notes which say the GP arrived there 'around 15.00'. In their document setting out the complaint to us, Mencap have said the GP was present when Mr Hughes ate his evening meal, but clearly this is not the case.
- 291 I also find that, although the record of the GP's actions is not particularly detailed, there is sufficient contemporaneous evidence to show the GP did examine Mr Hughes, including an examination of his chest, and did listen to what the Care Home staff said about Mr Hughes' condition and behaviour. I note my GP Adviser said the GP took appropriate steps to assess Mr Hughes' condition and that in so doing he took appropriate account of his needs. In particular, he liaised appropriately with his carers, recognising that they could provide him with their knowledgeable observations which would help him assess Mr Hughes' condition.
- 292 I have also considered my GP Adviser's view that, given the information which the GP had obtained from his own examination and observations, the observations of the Care Home staff and his knowledge of Mr Hughes' recent hospital stay, his diagnostic conclusions and subsequent actions were reasonable. In particular, I note my GP Adviser's opinion that *'there is no evidence to suggest that Care Home staff could not cope with his care or that Mr Hughes should be readmitted to hospital'*.

293 Furthermore, I have seen evidence which shows that the GP took particular care because he was alert to Mr Hughes' needs. He was aware that Mr Hughes was at risk of aspiration and personally took time to contact the Trust's speech and language therapy department to find out precisely what should be done to minimise the risk of Mr Hughes aspirating food. He then acted on the advice he obtained by appropriately prescribing thickener for Mr Hughes' drinks and took care to check that a follow-up speech and language therapy appointment had been made.

294 I particularly note that the GP showed concern not only for Mr Hughes, but also for the Care Home staff. They told him about their anxieties about caring for Mr Hughes and he agreed to speak with their Manager about this. I consider that, in recognising the importance of listening to and supporting the Care Home staff, the GP demonstrated an appropriate multidisciplinary approach to Mr Hughes' care. Furthermore, in agreeing to talk to the Care Home Manager he showed that he was concerned not only with Mr Hughes' immediate condition, but also with his future welfare.

295 Having considered all the evidence and taken account of the advice provided by my GP Adviser, I find there is no evidence to suggest the GP treated Mr Hughes less favourably for disability related reasons. Rather, I find he acted in accordance with professional and national guidelines on caring for patients with a learning disability. Moreover, in my view, the GP's actions demonstrated his awareness and commitment to working with patients with learning disabilities at the Care Home.

296 I conclude that there is **no evidence of service failure** in respect of the GP's care and treatment of Mr Hughes.

297 In their response to my draft report Mencap accepted they had made an incorrect assumption about the time of the GP's visit. They acknowledged that this assumption was based on their interpretation of one of the statements presented to the Coroner. Mencap asked me to note there had been no intention to mislead regarding this issue.

Complaint (e): complaint handling by the Surgery

298 In her complaint to the Health Service Ombudsman Mrs Keohane did not specifically complain about complaint handling by the Surgery. However, she did complain about the length and complexity of the complaints process and the fact that the process had not provided her with all the answers she sought. Therefore, I have considered the way in which the Surgery handled Mrs Keohane's complaint. This allows us to present a full picture of how her complaint was managed as a whole, as well as by the different bodies complained about.

299 Mrs Keohane did not complain to the Surgery until 15 June 2006. She explained that she had not complained previously because she thought the Healthcare Commission would investigate the GP's care of Mr Hughes as well as investigating her complaint against the Trust.

300 Mrs Keohane said that she recognised that time had passed since her brother's death and that the GP would have to rely on his written records. She asked about the circumstances leading to Mr Hughes' death and questioned why the GP did not admit Mr Hughes to hospital when he saw him on 27 May 2004.

301 I have set out the key elements of the NHS complaints process in Section 2 of this report. The sections of the Regulations which apply to this aspect of the complaint are those about local resolution – Regulations 3 to 13.

The Surgery's response

302 Two years had passed since Mr Hughes' death before Mrs Keohane complained to the Surgery. This meant that, according to Regulation 10, the Surgery could have refused to respond to her complaint because it was 'out of time'. In fact, the Practice Manager responded promptly to Mrs Keohane's letter. The Practice Manager's letter of 20 June 2006 opened with an expression of sadness about Mr Hughes' death and an offer of condolences. She went on to explain that it would take time to retrieve Mr Hughes' records and she enclosed a copy of the Surgery's complaints leaflet.

303 The tone of the second letter of 3 August 2006 was also sympathetic. The Practice Manager apologised for the delay in responding and said she had discussed Mrs Keohane's concerns with the GP and consulted the Surgery's records. I have outlined her explanation about the GP's actions and decision above. The Practice Manager was not defensive in her approach and she provided detailed, clear explanations. Furthermore, she invited Mrs Keohane to contact either herself or the GP if there were further issues she wanted to discuss.

304 On 25 August 2006 the Practice Manager wrote a follow-up letter to Mrs Keohane inviting her to contact her or the GP if she had any further queries.

305 It appears that Mrs Keohane did not contact the Surgery again because she was in correspondence with the Healthcare Commission about the GP's actions.

306 During the independent review of Mrs Keohane's complaint about the GP's care of Mr Hughes the Healthcare Commission contacted the Surgery to ask for information and the Practice Manager co-operated with its request. Subsequently, the Healthcare Commission informed the Practice Manager that Mrs Keohane had asked it to look into a second matter, namely the time of day when the GP saw Mr Hughes. The Practice Manager again answered promptly providing detailed information to assist the Healthcare Commission in dealing with the complaint. Correspondence which I have seen between the Practice Manager and the Healthcare Commission clearly shows that the Practice Manager was concerned for Mrs Keohane's welfare because of the protracted complaints process.

The Health Service Ombudsman's findings

307 Mrs Keohane is dissatisfied with the way in which the Surgery handled her complaint about the GP's actions.

308 The Surgery could have declined to respond to both complaints because they were 'out of time' according to the Regulations. Instead, taking into account the need to retrieve records from storage, the Practice Manager responded promptly and in detail. She responded to all aspects of the complaint. She also co-operated fully with the Healthcare Commission. Her approach was understanding, sympathetic and in line with the requirements of the Regulations. In particular, I note that, despite the time which had elapsed since the events complained about, the Practice Manager offered Mrs Keohane the opportunity to make further contact with her

or the GP. In my view, this clearly indicated a genuine willingness to help Mrs Keohane resolve her concerns.

- 309 I find Mrs Keohane's complaints were handled appropriately and reasonably. I conclude there is **no evidence of maladministration** in complaint handling by the Surgery.

Complaints against the Surgery: the Health Service Ombudsman's conclusion

- 310 I conclude that, in all the circumstances, the service provided to Mr Hughes by the GP on 27 May 2004 was of a reasonable standard. I find no reason to criticise the GP's actions, decisions or attitudes regarding his care and treatment of Mr Hughes. I also conclude that the Surgery handled Mrs Keohane's complaint promptly, appropriately and reasonably.
- 311 I conclude that there is **no evidence of service failure or maladministration** by the Surgery. Therefore, I **do not uphold** Mrs Keohane's complaints against the Surgery.

The Local Government Ombudsman's investigation of the complaint against the Council

Complaint (f): care by staff at the Care Home

Mrs Keohane's complaint

- 312 Mrs Keohane mentioned the actions of Care Home staff when she contacted the Trust on 9 July 2005 to discuss their response to her original complaint. Subsequently, Mencap mentioned the actions of Care Home staff in a telephone conversation with the Healthcare Commission in November 2006. On both

occasions correct advice was given – that the issues of concern should be raised with the Care Home in the first instance. In the event, neither Mrs Keohane, nor Mencap complained directly to the Care Home or the Council. Mrs Keohane did not formally complain about the actions of staff at the Care Home until she contacted the Local Government Ombudsman on 5 October 2007. The Local Government Ombudsman exercised his discretion to accept the complaint for investigation even though it had not been through preliminary stages of the complaints process.

- 313 Mrs Keohane is concerned about the actions of Care Home staff after Mr Hughes was discharged from the Trust at around 8.00pm on 26 May 2004. In particular, she wants to know more about the nature of his meals. She knows that special arrangements should have been made at the Care Home to reduce the risk of aspiration, yet the Coroner decided that acute aspiration was partly the reason for Mr Hughes' death. Therefore, she is concerned that special dietary arrangements were not made and as a result Mr Hughes aspirated his evening meal and died. In the complaint to the Health Service Ombudsman, Mencap say that on the evening he died Mr Hughes sat down to '*a normal communal meal*'. In Death by *indifference* Mencap said:

'Ted sat down and ate a communal meal. He began to vomit and then collapsed.'

- 314 Mrs Keohane wants to know whether appropriate arrangements were made for Mr Hughes' dietary needs and, if not, was this because inadequate information was given by the Trust to the Care Home or because the Care Home staff did not follow instructions they were given. She also wants to know more about the actions of Care Home staff when Mr Hughes collapsed.

Responsibility for management of the Care Home

315 The Council has explained that the Care Home is an NHS service (a 'small health home') providing in-patient and other services to people with learning disabilities and related needs. The service was operated by different NHS services until 2002 when the Council assumed responsibility for management of the service under the terms of a section 31 (*Health Act 1999*) agreement. This agreement utilised one of the *Health Act 1999* flexibilities to enable the local authority to manage the service on behalf of the NHS. The section 31 agreement provided for management of the staff and service by the Council. The home was close to capacity of 12 residents at the time of Mr Hughes' death. Short-stay accommodation had been phased out and Mr Hughes was one of the remaining long-stay residents. Buckinghamshire Mental Health NHS Trust (the Mental Health Trust) owned the premises and employed the staff who were seconded to the Council under the section 31 agreement. The agreement provided for management staff to be employed by either organisation, but in this case line managers and the most senior managers were Council employees and all staff accounted to the Council for their actions, whether employed by the NHS or the Council. The exception was doctors, who remained in the employment and management of the Mental Health Trust. The Council discharged its duties to the NHS through the section 31 agreement which provided for a Joint Advisory Board to oversee arrangements. The Care Home remained an in-patient service and its regulation was, therefore, the responsibility of the Healthcare Commission rather than the Commission for Social Care Inspection.

Mr Hughes' care plan

316 The Council provided me with a copy of Mr Hughes' care plan. The care plan was written at the end of April 2004. It starts with a description of a 'normal day' written from Mr Hughes' point of view. This includes information about his activities of daily living and his behaviours. There are then seven specific care plans addressing a range of Mr Hughes' needs such as personal hygiene, communication, community orientation and management of his heart condition. Each section sets out an overall goal, care objectives and an action plan to meet those objectives.

The Council's actions

- 317 After Mr Hughes' death the Council set up an inquiry under the Buckinghamshire Learning Disabilities Services' Serious Incident and Near Miss Policy. The remit of the inquiry was to investigate: the circumstances of Mr Hughes' first admission to the Trust; the circumstances of his discharge from the Trust; what specific discharge plan accompanied him and how that was followed by Care Home staff; the reason why he was accepted back at the Care Home; and first aid treatment provided by Care Home staff when he collapsed. The inquiry reported on 21 June 2004.
- 318 In response to my enquiries the Council explained why it had instigated an inquiry into events at the time of Mr Hughes' death, despite the fact that Mrs Keohane had not complained about the Care Home. The Council said that the investigation was a routine response to a 'Serious Incident'. It said:

'It is uncommon for a resident of Mr Hughes' age to die in our services and the fact that this death occurred during a period in which he had been admitted to hospital was a further cause for concern.'

319 I have seen a copy of the evidence collected for the inquiry as well as a copy of the detailed report of the investigation. The Council also provided me with an update on actions taken in response to the inquiry's recommendations. The Council told me the outcomes of the investigation had been shared with Mrs Keohane, the Mental Health Trust and the Trust and had been used to inform initiatives such as the joint Admission and Discharge Policy. The Council informed me that the findings of its inquiry had been shared with senior staff at the Trust in meetings on 3 September and 14 November 2004 and that discussion at the second meeting had been the catalyst for the joint Admission and Discharge Policy. I have seen a copy of the latter policy and a copy of the Operational Policy for the Care Home which includes responses to the report.

Key events

320 The events complained about by Mrs Keohane concern the actions of the Care Home staff from the point when Mr Hughes was discharged to their care from the Trust at around 8.00pm on 26 May 2004 to his collapse the following day.

321 The key evidence about what happened to Mr Hughes in the period between his arrival home and his death less than 24 hours later is provided by contemporaneous records from the Care Home and papers from the Council's inquiry. The Council's inquiry does not provide contemporaneous evidence. However, statements and information for the Council's

inquiry were collected and processed by 21 June 2004, which was within a month of Mr Hughes' death. Therefore, I consider the inquiry is a reasonably reliable source of evidence about events on 27 May 2004.

322 From available evidence, especially the Care Home records, we know that Care Home staff were very concerned about Mr Hughes right from the time he arrived back from the Trust. Their anxieties have been described in the sections of this report dealing with the assessment of whether Mr Hughes was safely discharged from the Trust and the consideration of the GP's actions. From contemporaneous records we know they ensured a member of staff was with him as much as possible (for example, he was provided with his own nurse during the night of 26/27 May 2004) and they appropriately asked a GP to visit because they were concerned about his condition. Their records also show their personal knowledge and understanding of Mr Hughes as an individual in their care. The nurse who cared for Mr Hughes during the morning of 27 May 2004 wrote:

'Ted is really a changed person.'

323 I have seen Mr Hughes' individual care plans and descriptions of his normal day at the Care Home, including his likes and dislikes, his personal habits and ways of understanding his behaviour. These documents were not specifically updated in the short time between Mr Hughes' discharge and his collapse, but progress notes indicate that staff were gathering information about his condition and attempting to meet his changing needs.

324 The information given to the Care Home staff by the Trust about arrangements for Mr Hughes' nutrition (or any other aspect of his care) was entirely inadequate. There is no record of any written instructions being given to Care Home staff about dietary arrangements. We know that some time during the afternoon or early evening of 26 May 2004 the Care Home staff were given verbal instructions by the Deputy Sister of the Ward about how to prepare Mr Hughes' meals and thicken his drinks. The Senior Charge Nurse at the Care Home made a contemporaneous record of the conversation in Care Home records. He said the Deputy Sister had told him Mr Hughes would be followed up by the speech therapist who had advised that *'he is to eat only blended cold food and ice cold drinks from the fridge with thickener added to it'*.

325 There are few entries in the Care Home notes about what Mr Hughes ate after he arrived home. The Team Leader caring for him overnight recorded that he had been given *'thickened up fluids'*. There is no contemporaneous record of what Mr Hughes ate and drank from the time the night staff went off duty in the morning of 27 May 2004 to the time when he ate his evening meal.

326 During the evening of 27 May 2004, after Mr Hughes had collapsed and been taken to hospital, the Senior Health Care Assistant who witnessed events recorded:

'Ted had his evening meal purified [sic] using 309's blender. Thickened drink given. Ted remained seated in the dining area after his meal. Around 17.40, Ted walked through the dining room door (leading to the male corridor) and collapsed onto the floor vomiting. [A Senior Health Care Assistant] rushed to Ted and supported his head so that Ted's vomit was not going back in his

mouth. Ted could hardly breath [sic]. [A Senior Health Care Assistant] quickly called for assistance and [the Charge Nurse] called for an ambulance. [A Senior Health Care Assistant] and [a 'bank' assistant] quickly came to Ted's aid. Pillows were put under Ted's head. [A Senior Health Care Assistant] kept on talking to Ted and calling his name. Ted slowly got limp and lifeless. The ambulance crew were quick to arrive and took over from the staff. For several minutes the ambulance crew tried to revive Ted before taking him to A&E.'

327 The Team Manager – Aylesbury Community Learning Disability Team (the Council's Investigator) carried out the Council's investigation. During the investigation he interviewed the Care Home staff who were on duty when Mr Hughes collapsed and died. He recorded their recollections in his report. I have studied the report of the investigation and the only significant additional information about events around the time of Mr Hughes' collapse is that Mr Hughes stayed in the dining room for about twenty minutes after he had finished his evening meal, which he ate fully, before he walked into the corridor.

328 The Council's Investigator noted that no first aid procedures were attempted by the Care Home staff *'apart from placing him in the semi-recovery position'*. He concluded that:

'... given the complexity of Mr Hughes' health status, the difficulty of performing resuscitation with a person vomiting and the level of experience and training of the staff involved, this was entirely appropriate. They did all that they could under the circumstances and no more could have been done.'

329 However, he also noted that even the senior staff at the Care Home had not received recent first aid training. The Charge Nurse on duty when Mr Hughes collapsed told the Council's Investigator that he had received no first aid training in the previous ten years. The Council's Investigator recommended that a plan for basic first aid training should be implemented at the Care Home, but he recommended caution around any decision to provide specialist first aid equipment, such as suction apparatus.

The advice of the Local Government Ombudsman's Professional Advisers

330 My Professional Advisers have had the opportunity to study records from the Trust and the Care Home. The Care Home records contain Mr Hughes' detailed individual care plans, medication charts, daily progress reports and other papers directly related to his healthcare. They have also seen the report of the Council's inquiry.

331 My Speech and Language Therapy Adviser said she could find no written advice to Care Home staff about Mr Hughes' diet. Having looked at records from the Trust and the Care Home she said:

'I can only find a telephone discussion with the ward sister documented, who verbally handed over some eating and drinking recommendations for Mr Hughes, which were not entirely accurate.'

332 My Speech and Language Therapy Adviser said she found it difficult to comment on how the Care Home staff interpreted dietary advice from the Trust because they were 'given very little instruction'. She noted that, for example, the Trust had not advised the Care Home about the appropriate texture of Mr Hughes' food or drinks.

333 My Anaesthetic Adviser said:

'An immediate impression is gained of a culture of caring and concern at 309 Cressex Rd. There are entries for each day of Ted's admission giving advice and on several occasions physically helping care for him on the urology ward. During his stay on ITU the home contacted the hospital each day and the level of care and interest is akin to that of a caring relative.'

334 There were some differences of view amongst my Professional Advisers about whether or not the Care Home staff should have attempted basic cardiopulmonary resuscitation when Mr Hughes collapsed.

335 My Anaesthetic Adviser said, given the level of training and experience, the Care Home staff acted reasonably when Mr Hughes collapsed. He said:

'As a residential home I am sure that there would be no shortfall in duty of care if they could not give more than basic life support.'

336 My Learning Disability Adviser said:

'It must be remembered that the staff dealing with the incident were Mental Health Nurses and not trained Adult Acute Nurses.'

'...'

'I feel that under the circumstances the staff at 309 Cressex Road did all that they could to help Mr Hughes given limited resources.'

The Local Government Ombudsman's findings

- 337 Mrs Keohane did not raise her concerns until October 2007 because her understanding of what happened to Mr Hughes has evolved as the complaints process has progressed. I can fully understand why she now wants to know what actions the Care Home staff took when Mr Hughes was discharged from the Trust and whether their actions had any influence on his death.
- 338 I have considered evidence from various sources about the actions of the Care Home staff and I have not found any significant inconsistencies in the relevant documents and accounts available to me. However, I note the 'story' about what happened around the time when Mr Hughes collapsed has changed over time and some of the known facts about events have become somewhat distorted. I have considered the advice of my Professional Advisers who have made a detailed study of the available evidence.
- 339 In assessing the actions of the Care Home staff I have taken account of relevant legislation and standards. In particular, I have referred to the requirements set out in Valuing People and the Code of Conduct.
- 340 First, it is clear to me that the Care Home staff were very concerned about Mr Hughes' welfare. I have seen evidence, particularly in the personalised and the Care Home records, that they had a professional understanding of his needs, a commitment to meeting those needs and a genuine concern for his welfare as a long-term resident in their care. My Anaesthetic Adviser remarked on the level of care and concern shown for Mr Hughes by the Care Home staff while he was a patient in the Trust. During this time they also kept in contact with Mrs Keohane.
- 341 In the short time between Mr Hughes' discharge from the Trust and his collapse the Care Home staff were very concerned about his welfare and safety. This is clearly demonstrated in their actions, such as arranging one-to-one care and contacting the GP, and their reports and assessment of his condition.
- 342 The evidence I have seen shows the Care Home staff were committed to the values and standards, especially the person-centred approach, described in documents such as Valuing People.
- 343 Secondly, I consider the instructions which the Care Home staff received about Mr Hughes' diet and the way they interpreted those instructions. I have seen no evidence that the Care Home staff received clear instructions from the Trust about how to prepare food and drinks for Mr Hughes. No written instructions were provided either by the Trust nurses or the speech and language therapy team. The Speech and Language Therapy Adviser has pointed out that the instructions written in the Care Home record by the Care Home Senior Charge Nurse following his conversation with the Deputy Sister at the Trust do not precisely match the instructions written in the Trust record by the speech and language therapist who saw Mr Hughes before he was discharged. I cannot say whether the Senior Charge Nurse was not given the correct instructions or whether he misinterpreted the information which was given to him. However, I note that the Care Home staff were alert to the importance of providing Mr Hughes with the correct diet because when they contacted the Surgery on 27 May 2004 they asked for drinks thickener to be prescribed for him. What I can say is that the Trust should have provided the Care Home with written information about Mr Hughes' diet and it was a failing on the part of the Trust (not the Care

Home) which led to any uncertainty about how to prepare his food and drinks.

344 The Care Home records do not give details of all the food and drinks which Mr Hughes consumed after his discharge. However, I consider there is enough information (in the record that he was given thickened drinks during the night of 26/27 May 2004 and his evening meal was puréed and he had a thickened drink on 27 May 2004) to show that Care Home staff were alert to the possibility that he might aspirate. The evidence also suggests Care Home staff took measures which were broadly in line with the imprecise verbal instructions they had received. In my view, given the limited instructions they had received, there is sufficient evidence to show the Care Home staff acted reasonably in managing Mr Hughes' diet.

345 I note that with the passage of time information about Mr Hughes' last meal has become distorted and this may have led in part to Mrs Keohane's concern about the actions of the Care Home staff. From complaint correspondence and Death by *indifference* we know Mencap and Mrs Keohane understood Mr Hughes ate a communal meal then got up, vomited and collapsed. In my view, this version of events implies that Mr Hughes ate the same meal as his fellow residents and very soon afterwards he vomited, inhaled food and died. I am clear that this was not the case. Although we cannot know exactly what Mr Hughes ate and there is little evidence about the texture and consistency of his meal, we do know from a contemporaneous entry in the Care Home record that his evening meal was puréed and his drink thickened. Furthermore, the evidence is that he did not vomit and collapse immediately after the meal, but some twenty minutes later. The evidence of the contemporaneous

record made by staff who were present when Mr Hughes' evening meal was prepared and eaten and when he collapsed suggests to me that the actions of the Care Home staff did not have any influence on his subsequent collapse and death.

346 Finally, I turn to the question of whether Care Home staff acted appropriately and reasonably when Mr Hughes collapsed. My Anaesthetic and Learning Disability Advisers said that, given the fact that staff apparently had no first aid or basic life support training, those present when Mr Hughes collapsed acted responsibly and reasonably. It is not clear whether or not Mr Hughes was turned into the 'recovery position' (lying face down with his head turned to the side and his upward-facing limbs bent) which is the recommended manoeuvre for anyone who had unexpectedly collapsed. The contemporaneous record describes how staff supported Mr Hughes' head to try and stop him inhaling vomit. In later descriptions, for example in the inquiry report, it is said that Mr Hughes was placed in a '*semi recovery position*', although it is not clear precisely what is meant by this. What is clear is that Care Home staff knew they should try and prevent Mr Hughes inhaling vomit and they attempted to stop this happening. In my view it would not have been appropriate for staff who had not been trained in cardiopulmonary resuscitation techniques to attempt to resuscitate Mr Hughes. I find that they acted appropriately and reasonably in calling for an emergency ambulance as soon as they realised the seriousness of the situation.

347 That said, I was concerned to learn that senior Care Home staff had apparently received little or no training in first aid. Given that they were responsible for a group of vulnerable adults

as well as a group of mostly unqualified staff, I find it was unacceptable that the senior staff had neither received, nor sought, training in first aid. I find this was an organisational failing because I would have expected basic first aid training to have been organised in the Care Home environment to allow staff to practise safely. I find the senior nurses at the Care Home should have taken personal professional responsibility for ensuring they were adequately trained. Their Code of Conduct stated that, as qualified nurses, they were responsible for their actions and omissions. However, I note that this failing has now been appropriately addressed as a result of the Council's inquiry. I have been assured that first aid training is now mandatory for all staff and this is regularly monitored, for example, through training records.

Complaint against the Council: the Local Government Ombudsman's conclusion

348 I conclude that the service provided to Mr Hughes by the Care Home staff after he was discharged from the Trust on 26 May 2004 was reasonable in the circumstances. I consider they acted broadly in accordance with national and professional guidelines on caring for patients with particular needs. I have taken into account the limited instructions which they had received from the Trust and their lack of first aid training and I find no reason to criticise their actions, decisions or attitudes regarding their care and treatment of Mr Hughes at and around the time of his death. I note that appropriate action has been taken to remedy the failing I identified regarding first aid training.

349 I conclude that any shortcomings which I have identified **do not amount to maladministration** by the Council. Therefore, I **do not uphold** Mrs Keohane's complaint against the Council.

350 At this point I would like to commend the Council's response to Mr Hughes' unexpected death. Although there was no complaint about the Care Home, the Council quickly instigated a thorough investigation of events and produced a detailed report aimed at learning lessons and improving services. I have seen evidence that it appropriately shared the learning from its investigation with partner organisations and with Mrs Keohane. I have also seen evidence about the actions taken as a result of that investigation which demonstrates that the Council has followed up on the recommendations made as a result of its investigation.

The Health Service Ombudsman's investigation of the complaint against the Healthcare Commission

Complaint (g): the Healthcare Commission's review of Mrs Keohane's complaints against the Trust and the Surgery

351 Mrs Keohane is dissatisfied with the way the Healthcare Commission (the Commission) handled her complaint. She says the Commission's reviews took too long and did not provide her with the explanations she sought.

The basis for the Health Service Ombudsman's determination of the complaints

352 The regulations and standards which apply to the Commission's handling of complaints are set out in Section 2 of this report. When assessing the way the Commission handled Mrs Keohane's complaint I have regard to those regulations and standards and to my own *Principles of Good Administration* and *Principles for Remedy*.

The Health Service Ombudsman's jurisdiction and role

- 353 Section 1 of this report sets out the basis of my jurisdiction in relation to complaints made to me that a person (or body) has sustained injustice or hardship in consequence of maladministration by the Commission in the exercise of its complaint handling function.
- 354 When complaints have already been reviewed by the Commission, I do not normally carry out an investigation of the original complaint, but investigate the way in which the Commission has conducted its review. Specifically, I consider whether:
- i. there were any flaws in the Commission's review process which make the decision unsafe;
 - ii. the Commission's decision at the end of the review process was reasonable; and
 - iii. the service the Commission provided was reasonable and in line with its own service standards.

355 When I uphold a complaint about the Commission's complaint handling, because I find that the review process was flawed, or the decision unreasonable, I normally refer the complaint back to the Commission for it to remedy the failure by conducting a further review.

The Health Service Ombudsman's decision

356 Mrs Keohane made two separate complaints to the Commission. Her first complaint was against the Trust, and following completion of the Commission's review of that complaint,

she made a second complaint against the Surgery. For the reasons given below, I **uphold** Mrs Keohane's complaint about the Commission's handling of her complaint against the Trust. However, I did not consider it appropriate to recommend a further review by the Commission and I therefore decided to investigate the complaint myself.

357 I **do not uphold** Mrs Keohane's complaint about the Commission's handling of her complaint against the Surgery.

The Commission's review of Mrs Keohane's complaint against the Trust

Key events

358 Mrs Keohane complained to the Commission on 11 May 2005, ten months after the Trust had responded to her complaint. The Commission initially decided that her complaint was out of time. However, Mrs Keohane subsequently contacted the Commission on 18 October 2005 to explain why she had not complained to it earlier, and, on 31 October 2005, the Commission informed her that it had agreed to accept her complaint for review.

359 Mrs Keohane's complaints were that:

- the Trust had failed in duty of care to Mr Hughes, given that he had fallen out of bed after his operation; and
- his discharge had been premature and inappropriate given his needs.

360 The Commission made no further contact with Mrs Keohane until 28 March 2006 when it apologised for the delay in allocating her case for review. On 12 April 2006 one of the Commission's Case Managers wrote to

Mrs Keohane to inform her that she would be responsible for reviewing her case and to explain how she would undertake her review. Mrs Keohane was, from that point onwards, kept regularly updated with the progress of her complaint.

- 361 The Commission did not take any clinical advice as part of its review.

The Commission's decision

- 362 On 21 June 2006 the Commission reported on Mrs Keohane's complaint. It concluded that the Trust's response to Mrs Keohane was inadequate and referred both aspects of her complaint back to the Trust for further local resolution. The Commission said that the Trust's response had *'failed to provide a complete and accurate picture and the statements and the investigation they undertook failed to bring to light issues which came out at the inquest'*. The Commission criticised the Trust for only mentioning one fall and failing to disclose the second and said that the Trust's investigation had not uncovered the fact that there was *'clear evidence that concerns were raised [by Trust staff] about the appropriateness of Ted's discharge'*. The Commission recommended that the Trust revisit Mrs Keohane's complaint. The Commission also made two further general recommendations about how the Trust should handle a complaint where an inquest had been held.
- 363 The Trust did not respond to the Commission's recommendations for nine months. There is no evidence to suggest that the Commission took any action during this period to follow up its recommendations.

The Health Service Ombudsman's findings

- 364 I have explained that I assess the way in which the Commission conducted its review by considering the review process, the decision and whether the service provided was reasonable.
- 365 I find that the Commission's decision that the Trust's response was inadequate was a reasonable one. I see no flaws in the process by which the Commission reached this decision. It reviewed the evidence and, rightly in my view, concluded that the Trust had failed to address the issues Mrs Keohane had raised. In particular, the Trust had failed to take account of the concerns expressed by staff regarding Mr Hughes' discharge. The Commission concluded the Trust's assessment of all the relevant available evidence was inadequate and, as such, that the Trust's response was unsound. In the light of this conclusion, the Commission did not go on to make any clinical determination of the substantive issues, deciding instead to refer the case back to the Trust to address the identified failings. This is an action which it has discretion to take.
- 366 I am, however, critical of the fact that there is no evidence to suggest that the Commission made any effort to follow up its recommendations to the Trust. The Commission had made significant criticisms of the Trust and, as it appears to have recognised, Mrs Keohane's complaint raised serious issues. In these circumstances, I consider the Commission should have followed up its recommendation that Mrs Keohane should receive a timely and satisfactory response from the Trust.

367 I also find that the service which the Commission provided was poor. The Commission's service standard at the time was that, in the majority of cases, the review process should take no longer than six months. The Commission took eight months to complete its review. Whilst I do not consider that this length of time would, in the circumstances, amount to poor service, I was concerned to note that the Commission did not make any contact with Mrs Keohane for a period of five months. One of the six *Principles of Good Administration* (referred to in Section 2 of this report) is that public bodies should be customer focused and, specifically, that they should deal with people helpfully and sensitively bearing in mind their individual circumstances. Failing to have made any contact with Mrs Keohane for such a significant period of time does not reflect good administrative practice or customer service.

368 I conclude that the failings I have identified in the Commission's handling of Mrs Keohane's complaint against the Trust amount to **maladministration**.

Injustice

369 The injustice arising from the Commission's maladministration is that Mrs Keohane's complaints about the Trust were not afforded the serious consideration which they warranted. She did not receive the answers she sought or get the proper review of her complaints to which she was entitled. She was also left, for a significant period of time, without any information about the progress of her complaint.

370 Therefore, I **uphold** this aspect of Mrs Keohane's complaint against the Commission.

The Health Service Ombudsman's recommendation

371 I **recommend** that the Commission apologise to Mrs Keohane for failing to carry out a proper review of her complaint against the Trust.

372 The Chief Executive has accepted my recommendation and she will write to Mrs Keohane to express her apologies once the final report has been issued.

The Commission's review of Mrs Keohane's complaint against the Surgery

Key events

373 On 16 August 2006 Mencap, on behalf of Mrs Keohane, complained to the Commission about the GP's actions when he visited Mr Hughes at the Care Home on 27 May 2004. Mrs Keohane was concerned about the way the GP reached his decision not to admit Mr Hughes to hospital. She believed that had the GP admitted Mr Hughes, his subsequent collapse and death might well have been avoided. On 8 September 2006 Mencap added a further point to the complaint. They said the GP had taken too long to respond to the request to visit Mr Hughes.

374 Mrs Keohane's complaint about delay in the GP's visit to the Care Home had not been raised previously with the Surgery. Therefore, in accordance with the Regulations which govern the NHS Complaints Procedure, the Commission could have referred it to the Surgery for them to respond in the first instance. However, in order to provide Mrs Keohane with a comprehensive response to her complaints, the Commission decided to incorporate both elements into its review.

375 The Commission took clinical advice. The Commission's Clinical Adviser did not consider that there had been any undue delay on the GP's part on 27 May 2004 in responding to what appeared to be a non-urgent request. He also concluded the GP's decision not to admit Mr Hughes to hospital at that time was reasonable. He did not think there was any further action that the GP should have taken and he considered his actions had been appropriate.

376 My GP Adviser has advised that the clinical advice which the Commission received was provided by an appropriately qualified clinician and that the decisions which the Commission's Adviser reached were reasonable.

The Commission's decision

377 On 30 November 2006 the Commission reported on Mrs Keohane's complaint. The Commission concluded that the care and treatment which Mr Hughes had received had been appropriate and that no further action was warranted.

The Health Service Ombudsman's findings

378 I have explained that I assess the way in which the Commission conducted its review by considering the review process, the decision and whether the service which it provided was reasonable.

379 I have found no fault in the Commission's review of Mrs Keohane's complaint against the Surgery. Because one part of Mrs Keohane's complaint to the Commission, the timing of the GP's visit on 27 May 2004, had not been considered by the Surgery, it was open to the Commission to have referred it back to the Surgery in the first instance. However, in order to provide

Mrs Keohane with a full response to her complaint, the Commission decided instead to incorporate both parts of her complaint into its review. One of the six *Principles of Good Administration* (referred to in Section 2 of this report) is that public bodies should be customer focused, and specifically that they should deal with people helpfully and sensitively bearing in mind their individual circumstances. The approach which the Commission took in this part of its review reflects good administration and customer service.

380 I would expect that when the Commission reviews complaints which involve clinical matters, it would obtain appropriate advice from professional advisers with relevant experience and expertise. I am satisfied that the Commission's Adviser was appropriately qualified and had the relevant experience and expertise. I am also satisfied that the Commission's decision, which was made on the basis of that advice, was reasonable.

381 The Commission completed the review within three months which is within the service standard prevailing at the time.

382 I conclude that there is **no evidence of maladministration** in respect of the Commission's review of Mrs Keohane's complaint against the Surgery.

383 Therefore, I **do not uphold** this aspect of Mrs Keohane's complaint against the Commission.

Section 4: the Ombudsmen's final comments

Introduction

- 384 Mrs Keohane's overarching complaint is that Mr Hughes' death was avoidable and that he was treated less favourably for disability related reasons. She told us she has not had answers to all her questions and she hopes the Ombudsmen's investigation will provide her with those answers. She also hopes that other people will not go through the same experience as Mr Hughes. In this final section of our report we address Mrs Keohane's overarching complaint.
- 385 In assessing the actions of the Trust, the Surgery, the Council and the Healthcare Commission we have taken account of relevant legislation and related policy and administrative guidance as described in Section 2 of this report. We have taken account of available evidence and considered the advice of our Professional Advisers.

Was Mr Hughes treated less favourably for reasons related to his learning disabilities? The Health Service Ombudsman's conclusions

- 386 Mrs Keohane believes her brother was treated less favourably for reasons related to his learning disabilities.
- 387 I have found service failure in respect of the inadequate care and treatment provided by the Trust to Mr Hughes following his transfer from the ICU to the Ward. In particular, I have concluded that the Ward nurses made entirely inadequate attempts to assess Mr Hughes' needs, and to plan and deliver care for him, following his transfer from the ICU. The arrangements for his discharge were inadequate and the Trust discharged him when it was not safe to do so.
- 388 I have also concluded that these failures in Mr Hughes' care and treatment were for disability related reasons. The Trust had not ensured that appropriate arrangements were in place for the care and treatment of people with learning disabilities. Also, the Ward nurses did not assess Mr Hughes' needs adequately, or at all, nor did they plan or deliver adequate care for him. The discharge arrangements were also inadequate for disability related reasons. Mr Hughes' behaviour, which was linked to his impairment, made him difficult to manage on the Ward and this encouraged staff to move him on. In Mr Hughes' case, and for reasons related to his impairment, there was particular need to convey to the receiving Care Home specific information about his condition and future care. This did not happen.
- 389 In Section 2 I set out my approach to human rights. On that basis, I also conclude that the Trust's actions and omissions constituted a failure to live up to human rights principles, especially those of dignity and equality.
- 390 By discharging Mr Hughes prematurely and without sufficient regard to his care, the Trust failed to have due regard to the need to safeguard his dignity and wellbeing in his future care by the Care Home, and to the observance of the principle of equality in the delivery of his care. There is no evidence of any positive intention to humiliate or debase Mr Hughes. Nevertheless, the standard of service does raise the question whether the Trust's actions constitute a failure to respect Mr Hughes' dignity.
- 391 In these respects, I conclude the service failures I have found demonstrated inadequate respect for Mr Hughes' status as a person.

Was Mr Hughes' death avoidable? The Ombudsmen's conclusions

- 392 Mrs Keohane believes that had her brother received appropriate and reasonable care from the Trust, the Surgery and the Council his death would have been avoided.
- 393 In considering whether to make a finding about avoidable death we assess whether the injustice or hardship complained about (in this case Mr Hughes' death) arose in consequence of the service failure or maladministration we have identified.
- 394 Mrs Keohane has told us she feels even after the inquest, the responses from the bodies complained about and the Healthcare Commission's reviews, she has not had a clear explanation about why her brother died. She remains concerned that Mr Hughes' death was avoidable. She asks the Ombudsmen whether they could help her understand what is likely to have happened to cause Mr Hughes to collapse when he died. To this end, she specifically asks whether there is anything in the A&E records relating to Mr Hughes' death.

Events when Mr Hughes collapsed

- 395 There is limited information available about Mr Hughes' death. However, we have looked at records made by the Care Home staff, the ambulance crew, A&E staff and the pathologist. We also sought additional information from the Coroner.

- 396 We know from the contemporaneous Care Home records which were made by the nurse who witnessed Mr Hughes collapse that at 5.40pm, around twenty minutes after eating a puréed meal, Mr Hughes got up and walked out of the dining area. The nurse recorded that Mr Hughes unexpectedly fell to the floor, hit his head and vomited. We also know from the ambulance record that when the ambulance crew reached Mr Hughes at 5.54pm his heart had stopped and, despite resuscitation attempts by the crew and staff in A&E, it could not be restarted.

The post mortem report

- 397 The Coroner ordered a post mortem to be performed. The pathologist who examined Mr Hughes' body made a series of detailed observations which she recorded in her report. Of specific relevance are the sections of her report relating to Mr Hughes' brain, lungs and heart.
- 398 The pathologist said there was no evidence in Mr Hughes' brain that suggested he had suffered a stroke. She also said that there was no evidence in his heart that he had suffered a heart attack. However, she did note that both ventricles (the lower chambers of the heart) were enlarged and there were some degenerative changes of two of the heart valves.
- 399 The pathologist found no clots in Mr Hughes' lungs. She found no bolus of food in the back of his throat, but she did find '*a large amount of partly digested food*' in the upper windpipe. She also found partly digested food in the respiratory passages leading into some areas of the lung tissue itself.

400 The pathologist concluded that Mr Hughes' heart showed evidence of heart failure (this is failure of the heart to pump adequately, not a heart attack) and cardiomyopathy (disease causing weakening of the cardiac muscle itself), but no evidence of a heart attack. She also concluded that there was some evidence that Mr Hughes had previously suffered from pneumonia although she saw no signs of acute pneumonia. She said:

'Continual aspiration of stomach contents over a prolonged period of time would have led to pulmonary [lung] damage with subsequent organising pneumonia leading to deteriorating lung function and eventual death. Coexistent heart failure would have accelerated death.'

401 In other words, probably principally on the basis of her examination of Mr Hughes' body, the pathologist concluded that he had died because he had been aspirating food over a period of time and this chronic problem, along with his heart failure, had led to pneumonia and death.

The Coroner's inquest

402 Where there is to be a Coroner's inquest, no death certificate is issued until the Coroner has determined the cause of death. It is the role of the Registrar of Births, Marriages and Deaths to issue the death certificate after the inquest. The Coroner has confirmed to us that he recorded a verdict of natural causes and notified the Registrar that the cause of death was acute on chronic aspiration. In Death by *indifference* Mencap said Mr Hughes' death certificate said he had died from a heart attack, but this was changed after the inquest to aspiration pneumonia. Unfortunately, this is not correct as the death certificate did not mention

a heart attack. The Coroner told us that having considered the evidence before him, including the pathologist's report which concluded that the causes of death were organising pneumonia and chronic aspiration, he decided that there was evidence to suggest that Mr Hughes had aspirated at the time of his death. This is why he instructed the Registrar that the cause of death was acute on chronic aspiration.

The opinion of the Ombudsmen's Professional Advisers

403 Our Anaesthetic Adviser said there is nothing in the A&E record of 27 May 2004 which sheds light on Mr Hughes' death. He said the record only shows that Mr Hughes' heart had stopped and that attempts to revive him were unsuccessful.

404 Our Anaesthetic Adviser told us about the most frequent reasons why an adult of Mr Hughes' age suddenly collapses and dies. He said that in these circumstances sudden death (when there is no accident or injury) is usually the result of either a stroke, a pulmonary embolism (where a blood clot blocks a major blood vessel or group of vessels in the lungs) or a cardiac event, such as a heart attack or significant change in heart rhythm. Our Anaesthetic Adviser said that a change in heart rhythm results from abnormal electrical impulses passing through heart muscle. This adversely affects the normal heart beat and may cause the heart to stop, but does not result in a change to heart muscle itself. Therefore, a change in heart rhythm cannot be detected at post mortem examination.

405 Our Anaesthetic Adviser explained that when a fully conscious adult vomits the natural body movements (for example, leaning forward) together with mechanisms in the throat, automatically stop them inhaling large amounts

of food which would otherwise cause them to choke and inhibit their breathing. He explained that it is only when a person is partly or fully unconscious that they cannot protect their respiratory system in this way. Our Anaesthetic Adviser said we know from the post mortem that Mr Hughes aspirated food into his upper windpipe before he died and, therefore, it follows that something must have caused Mr Hughes to lose consciousness before he vomited.

406 Our Cardiology and Anaesthetic Advisers do not dispute that Mr Hughes vomited and aspirated when he died. However, they have suggested that, given the information they have seen about events on 27 May 2004, especially the facts that 20 minutes had passed since Mr Hughes ate his evening meal and he was conscious and walking out of the dining room before he vomited, it is unlikely that the episode of vomiting was the direct cause of his collapse.

407 Both Advisers said they can only speculate in hindsight about what may have caused Mr Hughes to collapse. However, given Mr Hughes' history of problems with his heart rhythm, they suggested it is possible that an unexpected and unpredictable alteration in heart rhythm (which may have stopped his heart beating) caused him to collapse suddenly, vomit, aspirate, stop breathing and die. They agreed that if this is what occurred, there is nothing that could reasonably have been done to prevent him collapsing, or to save his life once he had collapsed. The Anaesthetic Adviser emphasised that if Mr Hughes had suffered this sudden change in his heart rhythm the Coroner would not have had evidence of the event because it would not have been detectable at the post mortem.

The Ombudsmen's finding

408 Mrs Keohane has asked whether we could find any additional information about the reason why Mr Hughes collapsed and died. We should make it clear that it is not possible to establish beyond doubt why Mr Hughes collapsed. We have not found any evidence which points directly to a cause for his collapse. As we have said, there is no post mortem evidence which shows he collapsed due to any of the most common causes of collapse for a person of his age. That said, in the light of the advice from our Cardiology and Anaesthetic Advisers, it does seem possible to us that he collapsed due to a sudden change in his heart rhythm which led to the other events associated with his death.

409 We hope Mrs Keohane may be able to take some comfort from the knowledge that it is likely nothing could have been done to prevent Mr Hughes collapsing and that the likelihood that Mr Hughes would have survived such an event, even in hospital, would have been low.

410 Our Professional Advisers have studied the evidence available to them and given their view about the likely cause of his collapse. However, we have not concluded that Mr Hughes' death occurred in consequence of any maladministration or service failure which we have found in the course of our investigation and, therefore, we do not conclude that his death was avoidable.

Mrs Keohane's response to the Ombudsmen's draft report

411 Mrs Keohane said trying to find out what had happened to her brother had been a '*long, frustrating and distressing time*'. She said our

investigation into Mr Hughes' death was thorough and at last enables his family to have a better understanding of what happened to him. She said it was a comfort to her to have the story clarified and presented so clearly. She also found comfort in the information provided about the standard of care in the Care Home.

412 However, Mrs Keohane does not accept the suggestion about the reason for her brother's collapse which has been put forward by our Professional Advisers. She feels strongly that he was prematurely discharged from the Trust and the GP should have readmitted him to hospital. She believes Mr Hughes collapsed because he vomited, choked and stopped breathing. In particular, she does not accept the Health Service Ombudsman's conclusion that there was no service failure in the care and treatment provided by the GP.

413 In response to Mrs Keohane's concerns the Health Service Ombudsman reviewed the available information about the GP's actions in the light of the professional advice she had received. However, the advice which she received was unequivocal and she found no new evidence which would cast doubt on her findings and decision on this matter.

414 Mrs Keohane also asked for a more detailed explanation about the mechanism of aspiration. In response our Anaesthetic Adviser provided further advice which is included above.

The Ombudsmen's concluding remarks

415 In earlier sections of this, our joint report, we have set out our investigation and findings with regard to the care and treatment and service Mr Hughes and his sister received from the Council, the NHS and the Healthcare Commission.

416 We acknowledge that Mrs Keohane does not agree with all of our findings and decisions. However, we can assure her that her complaints have been thoroughly and impartially investigated and that our conclusions have been drawn from careful consideration of detailed evidence, including the opinion of independent professional advisers.

417 We hope our report will provide her with the explanations she seeks and reassure her that lessons have been learnt and learning shared as a result of her complaint so others are less likely to suffer the same experiences as her and her brother. We also hope our report will draw what has been a long and complex complaints process to a close.



Ann Abraham
Parliamentary and Health Service Ombudsman



Jerry White
Local Government Ombudsman

March 2009

ANNEX A

Good Medical Practice, 2001: relevant sections

The duties of a doctor

'Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- *make the care of your patient your first concern;*
- *treat every patient politely and considerately;*
- *respect patients' dignity and privacy;*
- *listen to patients and respect their views;*
- *give patients information in a way they can understand;*
- *respect the rights of patients to be fully involved in decisions about their care;*
- *keep your professional knowledge and skills up to date;*
- *recognise the limits of your professional competence;*
- *be honest and trustworthy;*
- *respect and protect confidential information;*
- *make sure that your personal beliefs do not prejudice your patients' care;*

- *act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;*
- *avoid abusing your position as a doctor; and*
- *work with colleagues in the ways that best serve patients' interests.*

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.'

Providing a good standard of practice and care (sections 2 and 3)

'Good clinical care must include:

- *an adequate assessment of the patient's conditions, based on the history and symptoms and, if necessary, an appropriate examination;*
- *providing or arranging investigations or treatment where necessary;*
- *taking suitable and prompt action when necessary;*
- *referring the patient to another practitioner, when indicated.*

'In providing care you must:

- *recognise and work within the limits of your professional competence;*
- *be willing to consult colleagues;*

- *be competent when making diagnoses and when giving or arranging treatment;*
- *keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions made, the information given to patients and any drugs or other treatment prescribed;*
- *keep colleagues well informed when sharing the care of patients;*
- *provide the necessary care to alleviate pain and distress whether or not curative treatment is possible;*
- *prescribe drugs or treatment, including repeat prescriptions, only where you have adequate knowledge of the patient's health and medical needs. You must not give or recommend to patients any investigation or treatment which you know is not in their best interests, nor withhold appropriate treatments or referral;*
- *report adverse drug reactions as required under the relevant reporting scheme, and co-operate with requests for information from organisations monitoring the public health;*
- *make efficient use of the resources available to you.'*

Working with colleagues (section 36)

'Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide. When working in a team, you must:

- *respect the skills and contributions of your colleagues;*
- *...*
- *communicate effectively with colleagues within and outside the team.'*

ANNEX B

Discharge from hospital: pathway, process and practice

The 'key messages' for all agencies involved in admission and discharge were:

- *'Understand your local community and balance the range of services to meet health, housing and social needs.'*
 - *Ensure individuals and their carers are actively engaged in the planning and delivery of their care.*
 - *Recognise the important role carers play and their own right for assessment and support.*
 - *Ensure effective communication between primary, secondary and social care to ensure that prior to admission and on admission each individual receives the care and treatment they need.*
 - *Agree, operate and performance manage a joint discharge policy that facilitates effective multidisciplinary working between organisations.*
 - *On admission, identify those individuals who may have additional health, social and/or housing needs to be met before they can leave hospital and target them for extra support.*
 - *At ward level, identify and train individuals who can take on the role of care co-ordination in support of the multidisciplinary team and individual patients and their carers.*
- *Consider how an integrated discharge planning team can be developed to provide specialist discharge planning support to the patient and multidisciplinary team.*
 - *Ensure all patients are assessed for a period of rehabilitation before any permanent decisions on care options are made.*
 - *Ensure that the funding decision for NHS continuing care and care home placement are made in a way that does not delay someone's discharge.'*

The workbook contained two sections specifically about care for people with learning disabilities.

Section 5.6 draws attention to some of the common problems experienced by people with learning disabilities in an acute hospital setting. These include communication, consent, open ward environments and:

'the emphasis on rapid discharge limiting the time for thorough assessment and people's full needs are not always identified or treated. They may return to the community, or institutional care, with needs still not met; and

'care plans being made without vital information being obtained from those health, social care, family carers or housing services that are aware of their needs and current difficulties.'

Section 5.6 also draws attention to common difficulties for acute hospital services which may lead to incomplete and unrealistic discharge planning. These include poor links between acute and specialist mental health liaison services, delay in obtaining expert advice, and other patients' feelings about patients displaying agitation or challenging behaviour.

Section 5.6 includes suggestions for actions to be taken by commissioners, managers and practitioners to improve discharge planning for people with learning disabilities. It says that managers may wish to consider:

'supporting the provision of training for acute staff in issues of consent, basic mental health, dealing with people who are confused and the impact of having a learning disability on physical functioning and communication;

'developing protocols or guidelines for dealing with both emergency and planned admissions and presentations at A&E ... ;

'providing active support and time for practitioners from learning disability and mental health teams to support individuals when in acute and physical health care sector; ...'

Practitioners may wish to consider:

'... looking at each patient as an individual and understand the anxieties he or she may have and working with staff in specialist services to alleviate these;

'actively seeking the involvement of families and/or professional health or social care staff.'

Section 5.7 reminds hospitals of best practice with regard to people with learning disabilities including: preparing for admission, through making contact with the patient, reducing patient anxiety and involving the community team and GPs; using the hospital workbook; for an emergency admission, supporting and contacting parents and carers, using the hospital handbook, considering waiting areas and possibly fast-tracking patients through A&E; and for admission to the ward, providing ongoing support and extra time for communication.

ANNEX C

Sequence of key events during Mr Hughes' stay in the Trust

5 May 2004

Mr Hughes was admitted to the Trust suffering from a distended abdomen. He was found to be in urinary retention and was catheterised to allow urine to flow from his bladder and relieve his discomfort. When he was admitted he was taking drugs for his heart condition and anti-acid medicine to treat excess acid in his stomach.

12 May 2004

Mr Hughes could not tolerate the catheter so doctors could not follow the usual treatment pathway for his enlarged prostate. Normally patients with this condition would have been discharged home with a urinary catheter and readmitted at a later date for planned surgery. Therefore, Mr Hughes was treated as an urgent patient and part of his prostate gland was surgically removed. He returned to the Ward after his surgery.

16 May 2004

At 2.30am Mr Hughes fell on the floor while returning to bed. He sustained a laceration near his eyebrow. At this time, observations of his nervous system and circulation appeared stable but he had been suffering vomiting and diarrhoea. He was seen by two junior doctors. By 10.00am his condition had deteriorated. His blood pressure could not be recorded and the extremities of his body were cold. An anaesthetist saw him and admitted him to the ICU. When he arrived in the ICU Mr Hughes was found to have low blood pressure, he was agitated, breathing quickly and the levels of oxygen in his blood were low. The number of white cells in his blood was very high.

17 to 19 May 2004

By this time Mr Hughes had been connected to a ventilator and was receiving intravenous drugs to maintain his blood pressure. A troponin level was recorded as 2.5 which suggested that something had happened to his heart, possibly a heart attack.

21 May 2004

Blood and urinary infections were being treated and he was suffering respiratory problems.

22 to 24 May 2004

Mr Hughes gradually recovered. He needed less medication to support his blood pressure and the ventilator was disconnected. By 24 May the ICU doctors had decided that Mr Hughes was well enough to return to the Ward.

ANNEX D

Trust review: recommendations specific to Mrs Keohane's complaint

- Develop a protocol for the care and treatment of people with a learning disability in acute hospitals with reference to Discharge from Hospital. With particular reference to Appendix 5.7, *Guidelines for the acute sector when caring for someone with a learning disability*.
 - Examine admission and discharge procedures in terms of information available to patients and carers prior to admission and on discharge – quality and accessibility of information.
 - Review discharge procedures to ensure that discharge plans are written and available to patients and their carers.
 - For individuals with communication problems a senior member of the team should ensure that the plan and any aftercare or follow-up arrangements are explained to the patient and their carers.
 - Copies of these arrangements should be available on the day of discharge to be given to the patient and their carers and copies sent to the person's GP and local community team for people with a learning disability.
 - If at some stage a review of the care and treatment of a patient with a learning disability is indicated, for example, following a death or complaint, then this should include all the agencies involved.
- The needs of people with specific communication difficulties including people with a learning disability should be incorporated into staff training programmes.

PHSO-0006

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office

ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.

Six lives: the provision of public services to people with learning disabilities

Part six: the complaint made by Mrs Ryan

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Second report

Session 2008-2009

Presented to Parliament pursuant to
Section 14(4) of the Health Service Commissioners Act 1993

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-VI
London: The Stationery Office
£64.15

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ISBN: 9 78 010295 8577

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Section 1: introduction and summary

1 This is the final report of my investigation into Mrs Ryan's complaint against Kingston Hospital NHS Trust (the Trust). The report contains my findings, conclusions and recommendations with regard to Mrs Ryan's areas of concern.

The complaint

2 Mr Ryan was a 43 year old man with severe learning disabilities, Down's syndrome and epilepsy who lived in a residential care home (the Care Home). Mr Ryan's family described him as a charming, strong and energetic man who, before his stroke, was living happily with his carers. They said it took Mr Ryan a while to get to know people and it took people a while to get to know him. They thought this was probably because he could not communicate verbally and because his behaviour was different.

3 On 26 November 2005 Mr Ryan suffered a stroke. Care Home staff called an ambulance and he was admitted to the Trust accompanied by one of his carers. He arrived at the Accident and Emergency Department (A&E) at around 5.15am and was admitted to the Clinical Decision Unit before being transferred to the Ward later that day. The Ward was a general medical ward with 16 beds allocated to endocrine consultants and 14 beds allocated to respiratory consultants. The Ward had no specific facilities for the care of stroke patients. There was no stroke unit at the Trust. While Mr Ryan was in the Ward carers from the Care Home stayed with him and took responsibility for some of his basic care. However, the relationship between the carers and Ward staff broke down during the course of Mr Ryan's hospital stay. His Community Learning Disability Team Nurse, whose role was to look after Mr Ryan's health needs as a person with a learning disability, also visited him on several occasions.

4 The stroke affected Mr Ryan's ability to swallow and as a result he could not eat or drink normally. Over the weeks which followed he was seen and assessed by various members of the multidisciplinary team, including speech and language therapists, a consultant respiratory physician (the Consultant), and junior doctors and nurses. He also underwent tests and investigations. The clinical team found it difficult to assess and treat Mr Ryan because he could not co-operate fully with them. They waited until 12 December 2005 before deciding that Mr Ryan's ability to swallow had not returned and alternative feeding would be needed. However, no attempt was made to feed Mr Ryan nasogastrically or intravenously.

5 On 13 December 2005 doctors decided to insert a percutaneous endoscopic gastrostomy (PEG) feeding tube, so that Mr Ryan could be given liquid feed via a tube passed through the wall of his abdomen into his stomach. However, this has to be inserted during a formal operation, and by the time an appropriate slot could be found in the operating theatre timetable Mr Ryan had developed pneumonia and was too ill to undergo surgery. Doctors decided that Mr Ryan was unlikely to survive and palliative care was introduced. With palliative care the focus is on alleviating the symptoms of the illness, rather than treating the illness itself. Mr Ryan died five days later, on 21 December 2005, twenty-six days after he was admitted. The primary causes of death, as recorded on his death certificate, were '*aspirational pneumonia*' (pneumonia which developed because he inhaled stomach contents causing an infection) and '*cerebrovascular accident*' (a stroke). '*Down's Syndrome*' was recorded as a secondary factor.

- 6 Mrs Ryan says she was not worried about her son when he was admitted to hospital because she thought Trust staff would protect and care for him and he would be safe *'in good hands'*. However, she believes Trust staff had no understanding of people with learning disabilities and they may have been afraid of him. She says this led them to ignore him so his needs were not met and he *'starved to death'*. Mr Ryan's sister says the Trust *'didn't bother feeding [him] because he had Down's Syndrome'*.
- 7 Mrs Ryan acknowledges that the Trust has worked hard to find out what happened to Mr Ryan and that the Trust has been open and transparent about failings it identified in his care and treatment. She also recognises that the Trust has acknowledged and apologised for those failings. However, she does not agree with all the Trust's explanations. In particular, she does not agree with the Trust's position that the acknowledged failings in Mr Ryan's case were not specifically related to his learning disabilities.
- 8 Mrs Ryan has given permission for Mencap to act as her representative. Mencap have assisted Mrs Ryan since she first complained to the Trust in February 2006.

The overarching complaint

- 9 Mrs Ryan believes her son's death was avoidable and that he received less favourable treatment at the Trust for reasons related to his learning disability. I have called these aspects of her complaint *'the overarching complaint'*.

Complaint against the Trust

- 10 Mrs Ryan complains that:

Complaint (a): the Trust failed to meet Mr Ryan's basic needs because he was not fed for 26 days. She wants to know why her son's nutritional needs were not properly assessed, why he was not referred to a dietician and why no action was taken to feed him during this time.

Complaint (b): staff at the Trust failed to communicate effectively with each other and she wants to know why this occurred.

Complaint (c): Mr Ryan *'starved to death'* and his death was avoidable.

Complaint (d): the Trust failed to respond appropriately to her complaints about Mr Ryan's care and treatment. Mrs Ryan wants to know why it took the Trust so long to give her an explanation about how her son died and why it did not classify his death as a Serious Untoward Incident as soon as he died.

- 11 Mrs Ryan says she has not had full answers to all her questions about Mr Ryan's care and treatment and she hopes the Ombudsman's investigation will provide her with those answers. Mrs Ryan also wants to know if the actions taken by the Trust following its investigation of the circumstances of Mr Ryan's death are appropriate and whether they will prevent a recurrence of similar events.
- 12 She also hopes the outcome of her complaint will be that other people will not go through the same experience as Mr Ryan.

The Ombudsman's remit, jurisdiction and powers

General remit of the Health Service Ombudsman

- 13 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In the exercise of my wide discretion I may investigate complaints about NHS bodies such as trusts, family health service providers such as GPs, and independent persons (individuals or bodies) providing a service on behalf of the NHS.
- 14 When considering complaints against an NHS body, I may look at whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the body, a failure by the trust to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.
- 15 Failure or maladministration may arise from action of the body itself, a person employed by or acting on behalf of the body, or a person to whom the body has delegated any functions.
- 16 I may carry out an investigation in any manner which, to me, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as I think fit.
- 17 If I find that service failure or maladministration has resulted in an injustice, I will uphold the complaint. If the resulting injustice is unremedied, in line with my *Principles for Remedy*, I may recommend redress to remedy any injustice I have found.

Premature complaints

- 18 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Health Service Ombudsman may not generally investigate any complaint until the NHS complaints procedure has been invoked and exhausted, and this is the approach I take in the majority of NHS complaints made to me.
- 19 However, section 4(5) makes it clear that if, in the particular circumstances of any case, the Ombudsman considers it is not reasonable to expect the complainant to have followed the NHS route, I may accept the case for investigation notwithstanding that the complaint has not been dealt with under the NHS complaints procedure. This is a matter for my discretion after proper consideration of the facts of each case.
- 20 In this instance, Mrs Ryan's complaint has not been considered by the Healthcare Commission. However, the complaint is one of a group of six cases submitted to me by Mencap about care and treatment of people with learning disabilities. Therefore, I decided it was in the public interest for the complaint to be considered as one of a group of those linked cases under the provisions of the Act which governs my work.

The investigation

- 21 During the investigation my investigator met Mrs Ryan, her family and her representatives to ensure I had a full understanding of her complaint. I also examined all relevant documentation about the case including: Mr Ryan's health records from the Trust; complaint correspondence between Mrs Ryan,

Mencap and the Trust; papers related to the attempted resolution of the complaint; and papers about an internal inquiry conducted by the Trust which included details of actions taken by it to remedy failings which it identified. The Trust also provided additional information in response to my specific enquiries.

- 22 I obtained specialist advice from a number of professional advisers (my Professional Advisers): Dr A G Rudd, a consultant physician specialising in stroke care (my Medical Adviser); Ms E Onslow, a senior nurse with experience in acute nursing (my Acute Nursing Adviser); Ms M Bering and Ms L L Clark, senior learning disability nurses (my Learning Disability Nursing Advisers); and Ms H Crawford, a consultant speech and language therapist (my Speech and Language Therapy Adviser).
- 23 My Professional Advisers are specialists in their field and in their role as my advisers they are completely independent of any NHS body. Their role is to help me and my investigative staff understand the clinical aspects of the complaint.
- 24 In this report I have not referred to all the information examined in the course of my investigation, but I am satisfied that nothing significant to the complaint or my findings has been overlooked.

My decision

- 25 Having considered all the available evidence related to Mrs Ryan's complaint, including her recollections and views and her comments on the draft report, and taken account of the clinical advice I have received, I have reached the following decisions.

Complaint against the Trust

- 26 I have found **service failures** in the care and treatment provided by the Trust for Mr Ryan. These included failings in stroke care, clinical leadership, communication and multidisciplinary team working as well as failings in care and treatment; in particular, the failure to feed Mr Ryan.
- 27 Furthermore, there was **maladministration** by the Trust in its handling of Mrs Ryan's complaint. The Trust did not fully recognise or acknowledge its failures. As a consequence, Mrs Ryan was not given complete answers to her questions about her son's care and treatment. In addition, the response to her complaint was unreasonably delayed. However, I have not found that this maladministration was for disability related reasons.

The overarching complaint

- 28 I have concluded that in many respects the service failures I identified occurred for disability related reasons and that the Trust's acts and omissions constituted a failure to live up to human rights principles of dignity, equality and autonomy.
- 29 I have also concluded that, had the service failures which I have identified not occurred, it is likely Mr Ryan's death could have been avoided.
- 30 As it is likely their son's death could have been avoided, Mr Ryan's parents have suffered an **injustice** which can never be remedied. I **uphold** Mrs Ryan's complaint.
- 31 In this report I explain the detailed reasons for my decision and comment on the areas where Mrs Ryan has expressed particular concern.

Section 2: the basis for my determination of the complaint

Introduction

- 32 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, I generally begin by comparing what actually happened with what should have happened.
- 33 So, in addition to establishing the facts that are relevant to the complaint, I also need to establish a clear understanding of the standards, both of general application and which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. I call this establishing the overall standard.
- 34 The overall standard has two components: the general standard which is derived from general principles of good administration and, where applicable, of public law; and the specific standards which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.
- 35 Having established the overall standard I then assess the facts in accordance with the standard. Specifically, I assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard.
- 36 If so, I then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

- 37 The overall standard which I have applied to this investigation is set out below.

The general standard

Principles of good administration

- 38 Since it was established my Office has developed and applied principles of good administration in determining complaints of service failure and maladministration. In March 2007 I published these established principles in codified form in a document entitled *Principles of Good Administration*.
- 39 The document organises the established principles of good administration into six Principles. These Principles are:
- Getting it right
 - Being customer focused
 - Being open and accountable
 - Acting fairly and proportionately
 - Putting things right, and
 - Seeking continuous improvement.
- 40 I have taken all of these Principles into account in my consideration of Mrs Ryan's complaint and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:¹

¹ *Principles of Good Administration* is available at www.ombudsman.org.uk

'Getting it right' means:

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

'Being customer focused' means:

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

'Being open and accountable' means:

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.

- Stating criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for actions.

'Acting fairly and proportionately' means:

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

'Putting things right' means:

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

‘Seeking continuous improvement’ means:

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Principles for remedy

- 41 In October 2007 I published a document entitled *Principles for Remedy*.²
- 42 This document sets out the Principles that I consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how I think public bodies should put things right when they have gone wrong. It also confirms our own approach to recommending remedies. The *Principles for Remedy* flows from, and should be read with, the *Principles of Good Administration*. Providing fair and proportionate remedies is an integral part of good administration and good service, so the same principles apply.
- 43 I have taken the *Principles for Remedy* into account in my consideration of Mrs Ryan’s complaint.

The specific standards

Disability discrimination

Legal framework

Disability Discrimination Act 1995

- 44 The sections of the *Disability Discrimination Act 1995* most relevant to the provision of services in this complaint were brought into force in 1996 and 1999 respectively. Although other parts of the *Disability Discrimination Act 1995* were brought into force in 2004 and further provisions added by the *Disability Discrimination Act 2005*, these changes either post-date or are not directly relevant to the subject matter of this complaint.
- 45 Since December 1996 it has been unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified.
- 46 Since October 1999 it has in addition been unlawful for service providers to fail to comply with the duty to make reasonable adjustments for disabled people where the existence of a practice, policy or procedure makes it impossible or unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.
- 47 It has also been unlawful since October 1999 for service providers to fail to comply with the duty to make reasonable adjustments so as to provide a reasonable alternative method of making the service in question available to disabled people where the existence of a physical feature makes it impossible or

² *Principles for Remedy* is available at www.ombudsman.org.uk

unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

- 48 Since October 1999 it has been unlawful for service providers to fail to comply with the duty to take reasonable steps to provide auxiliary aids or services to enable or facilitate the use by disabled people of services that the service provider provides, unless that would necessitate a permanent alteration to the physical fabric of a building or unless such failure is justified.

Policy aims

- 49 The *Disability Discrimination Act 1995* recognises that the disabling effect of physical and mental impairment will depend upon how far the physical and social environment creates obstacles to disabled people's enjoyment of the same goods, services and facilities as the rest of the public.
- 50 The key policy aim behind the legislation is to ensure that as far as reasonably possible disabled people enjoy access not just to the same services, but to the same standard of service, as other members of the public. In other words, those who provide services to the public, whether in a private or public capacity, are to do whatever they reasonably can to eradicate any disadvantage that exists for a reason related to a person's physical or mental impairment.
- 51 The critical component of disability rights policy is therefore the obligation to make 'reasonable adjustments', which shapes the 'positive accent' of the *Disability Discrimination Act 1995*. This obligation recognises that very often equality for disabled people requires not the same treatment as everyone else but different treatment. The House of Lords made

explicit what this means in a case (*Archibald v Fife Council*, [2004] UKHL 32, judgment of Baroness Hale), which although arising from the *Part 2* employment provisions of the *Disability Discrimination Act 1995*, has bearing on the *Part 3* service provisions also:

'The 1995 Act, however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment.'

- 52 As the Court of Appeal has also explained, specifically in respect of the *Part 3* service provisions of the *Disability Discrimination Act 1995* (*Roads v Central Trains* [2004] EWCA Civ 1451, judgment of Sedley LJ), the aim is to ensure 'access to a service as close as it is possible to get to the standard offered to the public at large'.

Policy and administrative guidance

Disability Rights Commission Codes of Practice

- 53 Between April 2000 and October 2007 the Disability Rights Commission had responsibility for the enforcement and promotion of disability rights in Britain. In that capacity, and by virtue of the provisions of the *Disability Rights Commission Act 1999*, it had a duty to prepare statutory codes of practice on the law. These statutory codes of practice, although not legally binding, are to be taken into account by courts and tribunals in determining any issue to which their provisions are relevant.
- 54 Before the establishment of the Disability Rights Commission in April 2000, the relevant Secretary of State, on the advice of the National

Disability Council, published a statutory code of practice on the duties of service providers under Part 3 of the *Disability Discrimination Act 1995* entitled *Code of Practice: Goods, Facilities, Services and Premises* (1999), itself a revision of an earlier code of practice published in 1996.

- 55 On its establishment in 2000 the Disability Rights Commission consulted on a further revised code of practice, which came into force on 27 May 2002 as the *Disability Discrimination Code of Practice (Goods, Facilities, Services and Premises)*. The revised code of practice not only updated the previous codes but anticipated the changes to the law that were due to come into effect in 2004, in particular with respect to the duty to remove obstructive physical features.
- 56 The 2002 Code made it clear that a service provider's duty to make reasonable adjustments is a duty owed to disabled people at large and that the duty is 'anticipatory':

'Service providers should not wait until a disabled person wants to use a service which they provide before they give consideration to their duty to make reasonable adjustments. They should be thinking now about the accessibility of their services to disabled people. Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.'

- 57 It also drew attention to the pragmatic strain of the *Disability Discrimination Act 1995*. For example, in respect of the forthcoming 'physical features' duty, the Code says:

'The Act does not require a service provider to adopt one way of meeting its obligations rather than another. The focus of the Act is on results. Where there is a physical barrier, the service provider's aim should be to make its services accessible to disabled people. What is important is that this aim is achieved, rather than how it is achieved.'

Valuing People – A New Strategy for Learning Disability for the 21st Century (2001)

- 58 In 2001 the Department of Health published a White Paper, explicitly shaped by the relevant legislation (including the *Disability Discrimination Act 1995* and the *Human Rights Act 1998*), with a foreword written by the then Prime Minister, outlining the Government's future strategy and objectives for achieving improvements in the lives of people with learning disabilities.
- 59 The White Paper identified four key principles that it wanted to promote: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion (in the sense of being part of mainstream society and being integrated into the local community).
- 60 As the White Paper explained, the intention was that 'All public services will treat people with learning disabilities as individuals, with respect for their dignity'.
- 61 The fifth stated objective of the Government was to 'enable people with learning disabilities to access health services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary'.

62 The Department of Health also published in 2001 two circulars aimed jointly at the health service and local authorities, focusing on the implementation of Valuing People and including detailed arrangements for the establishment of Learning Disability Partnership Boards: *HSC 2001/016* and *LAC (2001) 23*.

63 The Department of Health has published a series of reports to help the NHS meet its duties under the *Disability Discrimination Act 1995*.

Signposts for success in commissioning and providing health services for people with learning disabilities (1998)

64 This was published by the Department of Health and was the result of extensive consultation undertaken with people with learning disabilities, carers and professionals with the aim of informing good practice. It was targeted at the whole NHS and emphasises the need for shared values and responsibilities, respecting individual rights, good quality information and effective training and development. It also encourages the use of personal health records. The accompanying executive letter *EL (98)3* informs chief executives of the availability of the guidance.

Doubly Disabled: Equality for disabled people in the new NHS – access to services (1999)

65 This Department of Health report, also aimed at the whole NHS, contains a specific section on learning disability. It provides guidance for managers with specific responsibility for advising on access for disabled patients to services and employment. It also provides information for all staff on general disability issues. The accompanying circular *HSC 1999/093* emphasises the purpose of the document, saying:

‘... it will be essential for service providers to ensure that they have taken reasonable steps to ensure that services are not impossible or unreasonably difficult for disabled people to use.’

In practice

66 The practical effect of the legal, policy and administrative framework on disability discrimination is to require public authorities to make their services accessible to disabled people. To achieve this objective they must take all reasonable steps to ensure that the design and delivery of services do not place disabled people at a disadvantage in their enjoyment of the benefits provided by those services.

67 Failure to meet this standard will mean not only that there is maladministration or service failure, but that there is maladministration or service failure for a disability related reason. This does not require a deliberate intention to treat disabled people less favourably. It will be enough that the public authority has not taken the steps needed, without good reason.

68 To be confident that it has met the standard, a public authority will need to show that it has planned its services effectively, for example, by taking account of the views of disabled people themselves and by conducting the risk assessments needed to avoid false assumptions; that it has the ability to be flexible, for example, by making reasonable adjustments to its policies, practices and procedures, whenever necessary; and by reviewing arrangements regularly, not just when an individual disabled person presents a new challenge to service delivery.

69 It should also be noted that a failure to meet the standard might occur even when the service in question has been specially designed to meet the needs of disabled people. This might be because, for example, the service design meets the needs of some disabled people but not others, or because good design has not been translated into good practice.

70 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsman will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving disabled people, such considerations are so integral to good administration and service delivery that it is impossible to ignore them.

Human rights

Legal framework

Human Rights Act 1998

71 The *Human Rights Act 1998* came into force in England in October 2000. The *Human Rights Act 1998* was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. To that extent, the *Human Rights Act 1998* did not so much create new substantive rights for UK citizens but rather established new arrangements for the domestic enforcement of those existing substantive rights.

72 It requires public authorities (that is, bodies which exercise public functions) to act in a way that is compatible with the *European Convention on Human Rights*; it requires the courts to interpret statute and common law in accordance with the *European Convention on Human Rights* and to interpret legislation compatibly with the *European Convention on Human Rights* wherever possible; and it requires the sponsors of new legislation to make declarations when introducing a Bill in Parliament as to the compatibility of that legislation with the *European Convention on Human Rights*.

73 Of particular relevance to the delivery of health care to disabled people by a public authority are the following rights contained in the *European Convention on Human Rights*:

Article 2 Right to life

Article 3 Prohibition of torture, or inhuman or degrading treatment

Article 14 Prohibition of discrimination.

Policy aims

74 When the UK Government introduced the *Human Rights Act 1998*, it said its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new 'human rights culture' among public authorities and among the public at large.

75 A key component of that human rights culture is observance of the core human rights principles of Fairness, Respect, Equality, Dignity and Autonomy for all. These are the principles that lie behind the *Human Rights Act 1998*, the *European Convention on Human Rights* and human rights case law, both in the UK and in Strasbourg.

76 These principles are not new. As the Minister of State for Health Services remarked in her foreword to *Human Rights in Healthcare – A Framework for Local Action* (2007):

‘The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.’

77 The policy implications for the healthcare services are also apparent as one aspect of that aim of using human rights to improve service delivery. As the Minister of State also observed:

‘Quite simply we cannot hope to improve people’s health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people’s lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.’

78 At the time of the introduction of the *Human Rights Act 1998* in October 2000, the importance of human rights for disabled people was recognised. Writing in the Disability Rights

Commission’s publication of September 2000 entitled *The Impact of the Human Rights Act on Disabled People*, the then Chair of the Disability Rights Commission noted that:

‘The HRA has particular significance for disabled people ... The withdrawal or restriction of medical services, the abuse and degrading treatment of disabled people in institutional care, and prejudiced judgements about the parenting ability of disabled people are just some of the areas where the Human Rights Act may help disabled people live fully and freely, on equal terms with non-disabled people.’

In practice

79 The practical effect of the legal, policy and administrative framework on human rights is to create an obligation on public authorities not only to promote and protect the positive legal rights contained in the *Human Rights Act 1998* and other applicable human rights instruments but to have regard to the practical application of the human rights principles of Fairness, Respect, Equality, Dignity and Autonomy in everything they do.

80 Failure to meet this standard will not only mean that the individual has been denied the full enjoyment of his or her rights; it will also mean that there has been maladministration or service failure.

81 To be confident that it has met the requisite standard, a public authority will need to show that it has taken account of relevant human rights principles not only in its design of services but in their implementation. It will, for example, need to show that it has made decisions that are fair (including by giving those affected by

decisions a chance to have their say, by avoiding blanket policies, by acting proportionately and by giving clear reasons); that it has treated everyone with respect (including by avoiding unnecessary embarrassment or humiliation, by enabling individuals to make their own choices so far as practicable, and by having due regard to the individual's enjoyment of physical and mental wellbeing); that it has made genuine efforts to achieve equality (including by avoiding unjustifiable discrimination, by taking reasonable steps to enable a person to enjoy participation in the processes that affect them, by enabling a person to express their own personal identity and by actively recognising and responding appropriately to difference); that it has preserved human dignity (including by taking reasonable steps to protect a person's life and wellbeing, by avoiding treatment that causes unnecessary mental or physical harm, and by avoiding treatment that is humiliating or undignified); and that it has promoted individual autonomy (including by taking reasonable steps to ensure that a person can live independently).

- 82 It is not for the Ombudsman to make findings of law. It is, however, the role of the Ombudsman to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsman will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving health and social care, such considerations are so integral to the assessment of good administration and good service delivery that it is impossible to ignore them.

Professional standards

The General Medical Council

- 83 The General Medical Council (the body responsible for professional regulation of doctors) publishes a booklet, *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet represents the standards which the General Medical Council expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of work. Key sections of the booklet current at the time of this complaint are set out at Annex A.

- 84 Paragraph 5 of Good Medical Practice, 2001, says:

'The investigation or treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about patients' lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age, or social or economic status, to prejudice the treatment you arrange.'

The Nursing and Midwifery Council

- 85 The Nursing and Midwifery Council (the body responsible for professional regulation of nurses) publishes a booklet, *The Nursing and Midwifery Council code of professional conduct: standards for conduct, performance and ethics* (the Code of Conduct), 2004, which contains general and specific guidance on how nurses should approach their work. The booklet

represents the standards which the Nursing and Midwifery Council expects nurses to meet.

- 86 Section 2 of the Code of Conduct current in 2005 says:

'You are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'

- 87 Amongst other issues, the Code of Conduct sets out nurses' duty to minimise risk to patients and to maintain clear and accurate records. It also stresses the importance of teamwork. Section 4 says:

'You must communicate effectively and share your knowledge, skill and expertise with other members of the team as required for the benefit of patients and clients.'

- 88 In *Making a Difference: strengthening the nursing, midwifery and health visiting contribution to health and healthcare* (Making a Difference), issued in 1999, the Chief Nursing Officer identified a need to focus on the fundamentals of nursing care. This led to the development of a set of benchmarking tools known as *The Essence of Care: Patient-focused benchmarking for health care practitioners* (the Essence of Care), (Department of Health, 2001). At the time of the events complained about benchmarking tools were available for eight areas, including food and nutrition, and the safety of clients with mental health needs in acute mental health and general hospital settings. NHS Trusts were expected to develop and implement local policies that ensured compliance with the benchmark standards.

Standards for the management of stroke patients

- 89 At the time Mr Ryan was admitted to hospital specific national and professional standards were in place which described benchmarks for the care and treatment of people who had suffered strokes. The *National Clinical Guidelines for Stroke* was issued by the Royal College of Physicians in 2000 and 2004. Key extracts from the 2004 guidelines are set out at Annex B. The *National Service Framework for Older People* issued in 2001 also included standards for stroke services. These documents set out, for example, standards for the development of specialist stroke units, guidelines for testing and investigating patients and requirements for multidisciplinary working.

- 90 In summary, the chronology of the Department of Health's expectations with regard to stroke care services were:

- April 2002 – every general hospital caring for people with stroke should have plans to introduce a specialised stroke service.
 - April 2003 – every hospital caring for older people with stroke should have established clinical audit systems to ensure delivery of the *National Clinical Guidelines for Stroke*.
 - April 2004 – primary care groups/trusts should have ensured that 100% of all general hospitals caring for people with stroke would have a specialised stroke service as described in the stroke service model.
- 91 The national and professional guidelines describe arrangements which should be in place for the care of stroke patients. Even where a stroke unit is not available, the guidelines are clear that patients should receive focused care

and treatment to meet their needs as a person who has suffered a stroke. Mrs Ryan's complaint particularly concerns nutrition. On this aspect of care, whether a patient is in a specialist unit or a general ward, the guidelines (when considered together with prevailing standards of practice described by the Professional Advisers) suggest the care pathway should be the same. A standard swallowing test should be performed by a suitably qualified person as soon as possible after admission. If this shows swallowing is impaired nothing should be given by mouth until swallowing returns. At this stage only intravenous fluids should be given for hydration.

- 92 The Medical Adviser said that until National Institute for Clinical Excellence (NICE) guidelines were introduced in 2006, there was no set time which should be allowed to elapse before alternative methods of feeding should be considered. However, he suggested that the body of medical opinion would agree that if there is no sign of improvement in swallowing after about a week, medical staff should put a plan in place for alternative feeding. He said usually this involves short-term nasogastric feeding (providing liquid food via a tube – a nasogastric tube – passed through the nose into the stomach), although intravenous feeding (providing sterile liquid containing nutrients through drips into the blood stream) can be considered, with a longer-term plan for percutaneous endoscopic gastrostomy (PEG) feeding. He also said feeding via a PEG feeding tube can be expedited if there are problems with nasogastric or intravenous feeding.

Local policy at the Trust

- 93 The Trust had not established a stroke unit at the time Mr Ryan was admitted, although it was negotiating with the local primary care trust (the PCT) on this issue. However, a draft stroke pathway had been drawn up and agreed with the PCT. This was based on services which were available at the Trust and existing arrangements for transferring stroke patients who needed rehabilitation to local hospitals with specialist facilities. The draft pathway includes some elements from the *National Clinical Guidelines for Stroke*, such as the timeframes for brain scanning and prescription of aspirin. It mentions '*multidisciplinary rehabilitation and assessment*', but gives no detail on areas such as swallowing assessments or feeding and there are no specific links to policies such as the Trust's Eating and Drinking Policy.
- 94 The Trust's detailed Eating and Drinking Policy was drawn up by a working party involving speech and language therapists from the Trust and the PCT and was in place at the time Mr Ryan was admitted to the Ward. The policy focuses on the role of speech and language therapists and includes guidelines on assessment and management of eating and drinking problems, procedures and quality standards, legal and ethical issues, including consent, as well as training and professional competences. Proformas for various speech and language therapy activities are also included.
- 95 The policy stresses the importance of multidisciplinary team working (including doctors, dieticians, other therapists and community staff) and the role of speech and language therapists within that team. The first core standard is:

'Speech and Language Therapists will not work in isolation in the management of Eating and Drinking Difficulties, but will work as part of a multi-disciplinary team (MDT) and liaise closely with other professionals and relatives involved in the care of the client/patient.'

- 96 The policy also states that where there is unresolved disagreement amongst the team about the management of eating and drinking and where there is risk to the individual patient, the speech and language therapist should escalate the issue to the line manager.

Complaint handling

NHS complaint handling

- 97 Prior to 2004 complaint handling in the NHS was subject to various Directions which required NHS Trusts to have written procedures for dealing with complaints within their organisation (known as local resolution) and to operate the second element of the complaints procedure (independent review).
- 98 However, on 30 July 2004 the *NHS (Complaints) Regulations 2004* (the Regulations) came into force, and created the procedure applicable to this complaint. These Regulations made detailed provision for the handling of complaints at local level by the bodies complained about and, if the complainant was dissatisfied with this local resolution, for the complaint to be given further consideration by the Healthcare Commission.
- 99 The Regulations (Regulation 3(2)) emphasise that complaint handling arrangements by NHS bodies at the local level must ensure that complaints are dealt with speedily and

efficiently and that complainants are treated courteously and sympathetically and, as far as possible, involved in decisions about how their complaints are handled. The guidance issued by the Department of Health to support the Regulations emphasises that the procedures should be open, fair, flexible and conciliatory and encourage communication on all sides, with the primary objective being to resolve the complaint satisfactorily while being fair to all parties.

- 100 *Part II* of the Regulations (Regulations 3 to 13) sets out the statutory requirements for NHS bodies managing complaints at the local level and deals with such matters as who may make complaints, when they may be made and the matters which may be complained about. A dedicated complaints manager must be identified along with a senior person in the organisation to take responsibility for the local complaints process and for complying with the Regulations. Regulation 13 states that the response to the complaint, which must be signed by the Chief Executive where possible, must be sent to the complainant within 20 working days from when the complaint was made, unless the complainant agrees to a longer period. That response must also inform complainants of their right to refer the complaint to the Healthcare Commission.

Serious Untoward Incidents

- 101 A Serious Untoward Incident can arise from clinical or non-clinical circumstances. In clinical practice such an event usually relates to a situation where a failure in clinical care, such as poor standards of care and treatment or a clinical error, had resulted in serious harm to a patient, or had put them at risk of harm.

Section 3: the investigation

Background

102 I have outlined the background to the complaint in Section 1 of this report. I say more about the key events associated with each aspect of the complaint in the relevant sections which follow.

Mr Ryan's stroke

103 Information about the nature, cause and likely outcome of Mr Ryan's stroke is central to an understanding of his disabilities and is relevant to my consideration of all aspects of Mrs Ryan's complaint. Therefore, I now set out some clinical information about strokes in general, followed by the Medical Adviser's assessment of available information about Mr Ryan's stroke.

Clinical information about strokes

104 Every year around 150,000 people in the UK suffer a stroke. Most people are over 65, but anyone can have a stroke, including children and even babies. A stroke is the third most common cause of death in the UK and the single most common cause of disability (*What is a stroke?*, The Stroke Association, May 2007).

105 A stroke happens when the blood supply to part of the brain is cut off and this means that brain cells can be damaged or destroyed. Because the brain controls everything the body does, damage to the brain will affect body functions such as movement, swallowing and speech. A stroke can also affect mental processes, such as thinking, learning and communication.

106 A stroke can cause brain tissue to die. This is called cerebral infarction and an infarct can be tiny or affect a larger part of the brain.

107 There are two main causes of stroke. The most common type of stroke is a blockage (an ischaemic stroke) which happens when a clot blocks an artery that carries blood to the brain. The second type of stroke is a bleed when a blood vessel bursts causing bleeding into the brain (haemorrhagic stroke).

The nature, cause and likely outcome of Mr Ryan's stroke

108 My Medical Adviser studied Mr Ryan's health record. He said:

'The stroke that Mr Ryan sustained was due to a blocked artery in the right side of the brain. Assessment of the severity of a stroke is made by a detailed clinical assessment of the deficits the patient has as well as seeing the amount of brain tissue affected on the brain scan. Unfortunately, there is little detail in the medical notes as to precisely what the impairments were that Mr Ryan had. It is reported that he had a paralysis of his left side and he had difficulties swallowing but it is not indicated whether he had some of the other features associated with right sided brain lesions [abnormalities] such as loss of vision on the left, loss of sensation (one brief mention in the notes suggesting that this may have been a problem) or problems with perception. Clinical examination was clearly difficult because of the learning disabilities but examination by a neurologist or stroke physician may have been helpful in determining the nature of the stroke more precisely.'

'I have seen the report of the scan but not the scan itself. On the basis of the report the amount of damage to the brain was significant but not very extensive. It sounds like the sort of stroke that one would normally expect the patient to survive, although often with long-term residual neurological deficits [problems with physical and mental functions]. Up to 50% of stroke patients have swallowing difficulties on admission to hospital. The majority of these do recover within the first few weeks. Some people take several months to recover and others are left with long-term difficulties. There is no literature that I am aware of that describes the natural history of stroke in people with Down's syndrome. I would not expect Down's syndrome to have a major impact on survival rates, however, as in this case the ability of the patient to participate in rehabilitation may well have a negative effect on recovery of function.'

'No explanation was found to explain why Mr Ryan had his stroke at such a young age.'

Complaint against the Trust

Complaints (a) and (b): failure to feed Mr Ryan and communication between staff

Key events

- 109 The basic facts about Mr Ryan's stay at the Trust are set out above. A more detailed chronology of key events extracted from Mr Ryan's health records is provided at Annex C.
- 110 Mrs Ryan complains to me about two specific aspects of Mr Ryan's clinical care – the Trust's failure to feed him and the failures in communication between different members of Trust staff. The facts about why Mr Ryan was not fed and why there were communication failures are inseparable from information about his overall care as a person disabled by a stroke. Therefore, I have considered these aspects of the complaint together because the key issues and available evidence are fundamentally linked.
- 111 Mrs Ryan complains that the Trust failed to meet Mr Ryan's basic needs because they did not feed him for 26 days after he suffered a stroke. She wants to know why her son's nutritional needs were not properly assessed, why he was not referred to a dietician and why no action was taken to feed him during this time. Mrs Ryan is also concerned that staff at the Trust failed to communicate effectively with each other about Mr Ryan's care and treatment.

Information from records of the actions of key individuals and groups of staff

- 112 Mr Ryan was admitted to the Trust on 26 November 2005. Later that day it was noticed that he may have aspirated and from that point onward he was given no food or fluid by mouth.
- 113 A junior doctor saw Mr Ryan during the evening of 26 November 2005. He recorded the probable aspiration and ordered that Mr Ryan should be given nothing by mouth. Over the following ten days Mr Ryan was seen on various occasions by junior doctors who noted that he was still not eating or drinking. During this time he was also reviewed by the Consultant on three occasions. However, there is no record that the Consultant made any assessment or decisions about feeding Mr Ryan as part of these reviews. On 7 December 2005 a junior doctor recorded

his view that alternative feeding methods should be considered and on the following day a junior doctor wrote that feeding should be discussed with the Specialist Registrar (the Specialist Registrar). However, there is no record of any such conversation and it was not until 12 December 2005 that the Specialist Registrar wrote in the notes that feeding would be discussed with the Consultant the following day.

114 On 13 December 2005 (the 18th day of Mr Ryan's admission) the Consultant decided that a gastroenterologist (a consultant specialising in disorders of the stomach and intestine) should be asked to insert a PEG feeding tube. It seems that a medical student was asked to liaise with the gastroenterologist because on 15 December 2005 a medical student recorded that there would be no space in the operating theatre for five days. He also recorded that he had discussed the possibility of inserting a nasogastric tube with the speech and language therapist. The medical student wrote that in his view a nasogastric tube should be inserted. Later that evening Mr Ryan deteriorated and the following day (the 21st day of his admission) the Consultant reviewed Mr Ryan's condition and decided that palliative care should be introduced.

115 The nursing records do not contain any assessment of Mr Ryan's nutritional needs, apart from an incomplete Malnutrition Universal Scoring Tool (an assessment process used to measure whether a person is at risk of malnutrition) completed on the day he was admitted. Nor was there any plan to ensure that he received hydration or nutrition. There is no evaluation of his nutritional status during his stay; for example, it appears he was never weighed. The only nursing records about hydration and nutrition are frequent remarks that drips were running and that Mr Ryan was to be given nothing orally. There is no note in the

nursing record of any concern about Mr Ryan's hydration or nutrition. There is no written record which shows that any nurse expressed concerns about the fact that Mr Ryan was receiving no nutrition whatsoever.

116 Mr Ryan was referred to the speech and language therapist (the Speech and Language Therapist) on 29 November 2005 and she first assessed him the following day. She found there was a high risk that he would aspirate and said he should be given nothing by mouth. Subsequently, the Speech and Language Therapist reviewed Mr Ryan on eight occasions. When Mr Ryan was able to co-operate with her assessment, she recorded that he was at risk of aspiration and that he should be given nothing by mouth. On 7 December 2005 she clearly wrote a request in the notes for the team to consider alternative feeding methods because by that time Mr Ryan had received no nutrition for 12 days. Five days later she attended a meeting with ward staff, carers and staff from the Community Learning Disability Team. She again noted her concerns that Mr Ryan had been given no nutrition. Her final review was on 16 December 2005, the day on which the decision was made to offer Mr Ryan palliative care only.

117 Mr Ryan was never formally referred to a dietician. By chance, a dietician noticed him when she was carrying out an audit on the Ward. On 12 December 2005 she discussed the situation with the Speech and Language Therapist, noting that Mr Ryan had been without food for 16 days. On the following day, the day on which the Consultant decided a PEG feeding tube should be inserted, the dietician reviewed him again and recorded that she would provide a feeding regime once the PEG feeding tube had been inserted. Mr Ryan was not seen again by a dietician.

- 118 On 28 November 2005 the Community Learning and Disability Nurse visited Mr Ryan. She wrote in the medical notes asking to be involved in decisions about his care and treatment. She visited again on 30 November 2005 and wrote in the notes asking doctors to review Mr Ryan's hydration and nutrition. She asked if intravenous feeding could be considered. She also participated in the meeting about Mr Ryan on 12 December 2005, when concerns about nutrition were discussed with the Speech and Language Therapist and ward staff, and in the meeting with the Consultant on 16 December 2005 when palliative care arrangements were discussed.
- 119 I have seen no evidence which shows what actions were taken by Mr Ryan's carers who were with him most of the time he was in hospital. However, Mr Ryan's family have said the carers raised their concerns about hydration and nutrition with ward staff.

Information from staff interviews conducted for the Trust's internal inquiry

- 120 The Trust provided summaries of interviews with staff which were held as part of the internal inquiry into the circumstances of Mr Ryan's stay at the Trust. I say more about the internal inquiry later in this report. The interviews were conducted by the full inquiry panel on 6 and 8 December 2006 (almost a year after Mr Ryan died). The summaries are not direct transcripts, but appear to be typed records of notes made during the interviews. I have not reproduced the interview records in full, but have selected extracts where information sheds additional light on what happened to Mr Ryan, particularly in terms of stroke care, nutrition and communication.
- The Consultant*
- 121 The Consultant told the internal inquiry that ideally Mr Ryan would have been admitted to a stroke unit where the multidisciplinary team would have been able to meet his needs. He suggested that such multidisciplinary arrangements were not in place on the Ward which was a busy, general ward. With hindsight, he recognised that there should have been a multidisciplinary team approach to Mr Ryan's care.
- 122 The Consultant was asked why no one became concerned about Mr Ryan's nutrition. He said he relied on the Speech and Language Therapist to tell the doctors when a stroke patient could be fed. He said the Speech and Language Therapist did not speak to anyone, she only wrote in the notes and junior doctors may not have picked up on this. He also said he thought Mr Ryan would not tolerate a nasogastric tube because he was pulling out his drips and was not tolerating suction to clear his upper respiratory tract. However, he thought that the nurses had attempted to pass a nasogastric tube. He would normally expect nurses to realise that doctors expected them to attempt to pass a nasogastric tube from reading the medical notes. The Consultant explained that it was usual to wait for five to seven days for a PEG feeding tube to be fitted, but the situation was more complicated for Mr Ryan because he could not give consent.
- The Specialist Registrar*
- 123 The Specialist Registrar explained to the internal inquiry that he had only become involved in Mr Ryan's care when he returned from leave on 12 December 2005. He said when he saw Mr Ryan on that day he recognised he was very ill and nutritionally depleted and it was on the following day that the Consultant decided

that a PEG feeding tube should be inserted. He recognised that multidisciplinary team working had been poor and that relations with Mr Ryan's carers had been strained. He did not think the way he had communicated with Mrs Ryan about the decision to initiate palliative care had been poor.

The Matron

124 The Matron told the internal inquiry that she covered several wards. She said she supported ward staff but her role focused on bed management and discharge. She said she had not been made aware of any concerns about Mr Ryan until there was a dispute with his carers. She explained that the wards were starting nutrition benchmarking and she would have expected concerns about the Malnutrition Universal Scoring Tool assessment to be raised through this route.

125 The Matron also confirmed that in her experience junior doctors often conducted ward rounds without senior doctors, and patients were not seen by doctors at weekends.

The Ward Sister

126 The Ward Sister told the internal inquiry that she thought Mr Ryan was not fed because there was a breakdown in communication. She said all staff were very concerned but they thought the Speech and Language Therapist was talking to the doctors. She said she remembered talking to doctors, but they said they would be reviewing the situation. She also confirmed that doctors had not asked for a nasogastric tube to be passed and no attempt was made by nurses to pass a nasogastric tube.

127 The Ward Sister said that Mr Ryan's carers helped with his hygiene needs. She felt that the ward staff had a good relationship with Mr Ryan's Community Learning Disability Team Nurse, but that the carers did not communicate very proactively with the ward team. She would have expected carers to raise any concerns with her, but she did not remember them approaching her with concerns about Mr Ryan. With hindsight, she wished she had communicated better with the Community Learning Disability Team.

The Speech and Language Therapist

128 The Speech and Language Therapist who was interviewed was not the person who had provided care for Mr Ryan. However, she said her colleague who had provided that care had liaised with doctors who told her they were escalating the issue of feeding. She confirmed that her colleague had taken no further action to escalate her concerns although she realised that nothing was happening about feeding Mr Ryan.

The Community Learning Disability Team staff

129 Two members of the Community Learning Disability Team were interviewed together by the internal inquiry panel. One of these was Mr Ryan's Community Learning Disability Team Nurse who had visited Mr Ryan several times at the Trust. They explained that the Team did not use a care facilitator model because the facilitative role was shared amongst team members. They also explained that they had not taken on the role of Mr Ryan's care manager because he had been placed at the Care Home by Haringey Social Services (not the local social services agency) who retained responsibility for care management. Also, the carers did not report to them. They said the role of the Community Learning Disability Team was to look after Mr Ryan's health needs.

130 They also explained that the carers told them Mr Ryan was in hospital about two days after he was admitted. They said when a learning disability client is in hospital the Community Learning Disability Team try to help doctors and nurses, particularly by communicating about the client's needs. They said that at that time they would not have challenged the hospital's decisions, but subsequently they had developed an escalation protocol. They also said the hospital may have misinterpreted the role of the carers, who would not necessarily have had clinical experience.

131 The Community Learning Disability Team Nurse said she knew Mr Ryan would be phobic in a hospital environment and that he would try to resist attempts to insert tubes and would pull them out. She noted his behaviour was less challenging than usual because he had suffered a stroke. However, she said that, in her judgment, he would have pulled out a nasogastric tube.

132 The Community Learning Disability Team Nurse said it had been more difficult to liaise with doctors than with the nurses. She had left messages in the notes for doctors and tried to bleep them, but she found it very difficult to get in touch with them. They did not attend the multidisciplinary meeting which was set up at her request and did not respond to her request to contact her after that meeting.

133 The Community Learning Disability Team Nurse said carers did not make her aware of their concerns about Mr Ryan's care until some time around 14 December 2005 and she was surprised to learn how relationships with ward staff had deteriorated.

The Trust's explanation about what happened to Mr Ryan

134 The Trust's initial explanations about what happened to Mr Ryan were given in response to Mrs Ryan's complaint and follow-up correspondence between the Trust and Mencap. I consider the way in which the Trust responded to the complaint later in this report. In this part of the report I am concerned with the Trust's subsequent position on the care and treatment provided for Mr Ryan, that is, the explanations it has given Mrs Ryan following the internal inquiry which reported in January 2007.

135 On 8 September 2006 the Trust set up an internal inquiry. The purpose of the inquiry was:

'To examine all the relevant circumstances surrounding the care and treatment of Martin Ryan following his admission to [the Trust] on 26 November 2005 up to his death on 21 December 2005. To assess the adequacy of the care provided and to report findings and recommendations. To understand and consider the failure to escalate the complaint within the organisation.'

136 The members of the inquiry panel were: the Medical Director at the Trust; a Non-Executive Director at the Trust; the Head of Governance at the Trust; the Director of Nursing at St George's NHS Trust; and a Consultant in Learning Difficulties at South London and the Maudsley NHS Trust. The panel reviewed documents, conducted interviews with staff and noted developments since Mr Ryan's death.

137 The inquiry panel's final report set out their opinion about what had happened to Mr Ryan. The findings of the internal inquiry are set out in detail at Annex D. The key findings about Mr Ryan's clinical care were: care was inadequate because Mr Ryan's nutritional needs were not met; there was a lack of continuity of care; medication was not given on time; communication with Mr Ryan's family and between members of the multidisciplinary team was poor; there was friction between staff on the Ward and the carers; expert help offered by the Community Learning Disability Team was rejected; no one acted as Mr Ryan's advocate; medical care was fragmented; there was no clinical leadership from the Consultant or the Ward Sister; the Speech and Language Therapist had a limited view of her role; and there was no co-ordinated multidisciplinary approach to care and clinical decision making. Furthermore, there was no stroke unit and no body of staff trained to care for stroke patients.

138 The report concluded that:

'The care afforded to [Mr Ryan] fell well short of that which should have been expected, ...'

139 The inquiry panel made nine recommendations about clinical care. Subsequently the Trust Board added six more recommendations. The recommendations are set out at Annex E and I consider them in more detail later in the report when I discuss the actions taken by the Trust in response to the internal inquiry.

140 In February 2007 copies of the report were sent to Mr Ryan's parents and Mencap. The Trust also met with them to discuss the report and actions which had been taken as a result of the inquiry recommendations.

Additional information from the Consultant

141 In response to the draft report the Consultant has drawn my attention to the fact that he was on leave from 6 to 12 December 2005.

The advice of my Professional Advisers

142 My Professional Advisers reviewed Mr Ryan's health records. They also studied all available information about: the complaint to the Trust (including complaint correspondence and papers related to the investigation into the complaint, such as statements from clinical staff); and the Trust's inquiry (including background information, interview notes, notes of meetings – including Trust Board meetings – the report itself and information about follow-up action).

The advice of my Medical Adviser

143 My Medical Adviser compared the care and treatment Mr Ryan received with national standards for stroke care in place at the time. He said that in addition to the guidance on care for stroke patients set out in the *National Clinical Guidelines for Stroke* and the *National Service Framework for Older People*, there were other international guidelines available, for example those produced for the European Union. However, he noted that *'few recommendations were followed in this case'* and *'many aspects of the care that Mr Ryan received were below acceptable standards'*.

144 My Medical Adviser said:

'I do not think that the care Mr Ryan received met acceptable standards for a patient with stroke. There were many aspects that did not accord with national guidelines as available in November 2005.'

'Mr Ryan was not admitted to a stroke unit at any stage of his illness nor was there involvement, as far as I can tell from the notes, by any physician with expertise in stroke during the admission. Stroke unit care has been shown in multiple randomised controlled trials to reduce mortality and disability compared to general medical care. This evidence formed the basis of the recommendation that all patients with stroke should be managed on a stroke unit in the National Clinical Guidelines (2000 and 2004) and led to the National Service Framework for Older People setting a milestone that by April 2004 all hospitals in England should have a specialist stroke service.

'There is no evidence through his stay of any effective multidisciplinary working, objective or goal setting. These processes are central to stroke rehabilitation and the failure to undertake these basic clinical practices was I believe central to the subsequent failures in management.

'There was a delay in brain imaging after admission of 3 days (the 2004 National Clinical Guidelines recommend a maximum of 24 hours unless there is indication for more urgent scanning). In retrospect, however, I do not think that this resulted in any harm to the patient.

'No secondary prevention [treatment to try and prevent a further stroke] was given to Mr Ryan throughout his stay. He should have received aspirin within 48 hours of admission (once the scan had confirmed that the stroke was due to ischaemia [reduced blood flow] rather than haemorrhage). In fact although the drug was prescribed it was never given because it was

written to be given orally and Mr Ryan was "nil by mouth". There is no reason why the drug could not have been given rectally.

'The failure to carry out a swallowing assessment on admission (as recommended in many guidelines and statements of good practice) led to Mr Ryan being allowed access or [sic] food and fluid over the first 24 hours, which probably contributed to his first chest infection within 24 hours of admission.

'There was unacceptable delay in considering Mr Ryan's nutritional needs. It was clear from shortly after admission that he was unable to swallow safely. At the time of his admission there were no definitive NICE nutritional guidelines or stroke guidelines defining precisely how long it was reasonable to delay the provision of alternative sources of nutrition in dysphagic patients [patients who are unable to swallow safely]. However, my view, and I suspect the view of the majority of stroke clinicians, would have been that if after a week there was no sign of recovery of a safe swallow then alternative means of feeding should have been introduced. The medical team did not appear to even consider the issue of nutrition until day 12 when the Pre-Registration House Officer [a junior doctor] wrote a comment in the notes that he would discuss it with the registrar. Four days later it was written that the registrar would discuss feeding with the consultant the following day and only then was a referral made for a gastrostomy tube to be inserted.

'...

'The only circumstance where withholding food is acceptable is where a decision has been made that palliative care is the appropriate course; this was not the situation in Mr Ryan's case. I accept that nasogastric feeding may have been difficult or impossible and [the Community Learning Disability Team Nurse] who knew him well stated in her evidence to the internal inquiry that she thought he probably would not have tolerated the tube but I do not think that failure should have been assumed and therefore used as a reason not to attempt tube insertion. The alternative of using intravenous feeding would have been a possibility but was not apparently considered. Use of restraints to allow nasogastric feeding is controversial but is used in some units for restless and confused patients. Early referral for gastrostomy insertion would I believe have been justified. It is not a major procedure and the tube is easy to remove once swallowing returns. The primary responsibility for deciding on feeding policy for a patient lies with the medical team; however, effective multidisciplinary teamworking would have led to the issue being addressed much earlier than it was in this case, even where the medical team was failing to deal with the problem. The medical records do indicate that [the Community Learning Disability Team Nurse] and the speech and language therapist wanted the issue of nutrition addressed. From the evidence given by [the Consultant] it would appear that he did not read the notes and was dependent upon his junior staff to be kept informed of developments. This is not a satisfactory situation where there are no multidisciplinary team meetings.'

¹⁴⁵ In terms of the way in which professionals communicated with each other and with Mr Ryan's family, my Medical Adviser said:

'Involving families and other carers in the management of stroke patients is essential for effective care. This is especially important where the stroke patient is unable to speak for himself. There were clearly problems in this case with communication, especially between the physicians and the family and this undoubtedly contributed to the dissatisfaction that has been expressed following Mr Ryan's death. I saw no evidence in the notes that the consultant met or even [tele]phoned the family until 16 December at which stage the decision to switch to palliative care had already been made. The Speech Therapist and Physiotherapist did meet with the carers earlier in the course of the admission however it is not clear that they were able to provide the family with a comprehensive picture of management.'

'...

'Interprofessional communication does not appear to have been effective. Although there was good quality [medical] note keeping there was little evidence that the team acted upon recommendations made by the individual clinicians. In my view by far the most effective way that this can be avoided in the future is to have at least weekly multidisciplinary meetings attended by senior clinicians (including the consultant physician).'

The advice of my Acute Nursing Adviser

¹⁴⁶ My Acute Nursing Adviser agreed with the Medical Adviser that, in all the circumstances, the Trust did not provide Mr Ryan with a reasonable standard of care. Having reviewed the nursing records she identified shortcomings in assessment, care planning, record keeping, communication, leadership, lack of proactive nursing and a failure to meet Mr Ryan's nutritional needs. She said:

'The admission assessment was superficial and there is no evidence in the clinical records to indicate that attempts were made to complete the nursing assessment at any time during Mr Ryan's hospital stay. There are two core care plans indicating risk of convulsions and impaired respiratory function. Neither of these reflects the individual and specific needs of Mr Ryan which were complex.

'...

'As Mr Ryan was unable to communicate his own needs it would have been good practice to have discussed his usual activities of daily living with his family and carers. It is clear to me that ... if assessment had been more thorough then a more robust and person-centred plan of care could have been developed.'

¹⁴⁷ My Acute Nursing Adviser noted that the Malnutrition Universal Scoring Tool assessment was poorly completed (it was not signed or dated). She also said that because Mr Ryan's height and weight were estimated and no attempt was made to use alternative methods to assess his nutritional state accurately, it was an unreliable measurement. However, she did note that the tool appeared to show

that Mr Ryan was at high risk of malnutrition and should have been referred to a dietician and reassessed in two days. My Acute Nursing Adviser said there is no evidence that anyone carried out either of these actions. She noted the *'almost daily entries in the nursing records'* that Mr Ryan was *'NBM'* (to have nothing to eat or drink by mouth) but there was no evidence that nurses raised concerns about this or took any proactive action about this aspect of Mr Ryan's care. She said:

'I would have expected any ward manager to have taken ownership of the situation and instigated appropriate initiatives to ensure that Mr Ryan had a clear management plan that reflected his needs. It would have been reasonable (and good practice) to have sought advice and direction from senior nursing and legal advisers in relation to the legal and ethical dilemmas surround[ing] this case but I cannot see that to have taken place.'

¹⁴⁸ With regard to the failure to feed Mr Ryan my Acute Nursing Adviser said:

'It appears that a decision had been made to try NG [nasogastric] feeding although there was no management plan with regard to this in the medical notes. From the documentation of nursing care it appears nursing staff were not aware of this decision. They also considered that attempting to pass an NG tube would be impossible. This appears to be related to the fact that previous attempts at passing a nasopharyngeal airway [a plastic tube to allow secretions to be suctioned from the respiratory tract] by the physiotherapist had proved to be difficult, that Mr Ryan had removed his intravenous cannula on a number of occasions and the

Learning Disabilities Team had apparently advised that he would not tolerate an NG or PEG feeding tube. There appears to be no evidence of any discussion regarding alternative methods of fluid administration, for example, the use of subcutaneous route.

'In my opinion, the lack of any attempt to pass an NG tube was wholly unacceptable. The communication between all members of the multidisciplinary team was also extremely poor and contributed significantly to the fact that Mr Ryan was not fed for 26 days. The decision to insert a feeding tube was not discussed until the consultant ward round on 13 December and it is my opinion that this discussion should have taken place earlier in view of Mr Ryan's lack of dietary intake.'

149 She also noted that standards for record keeping set out by the Nursing and Midwifery Council were not met because *'documentation in relation to the nursing care of Mr Ryan [was] poor'* and nurses failed to meet requirements in the Code of Conduct. She specifically said the nurses did not behave as required by the Code of Conduct because they did not take action to minimise the risk to Mr Ryan associated with poor nutrition.

150 My Acute Nursing Adviser agreed with my Medical Adviser that there is evidence of poor multidisciplinary communication. She said this was particularly significant in terms of the misunderstanding between doctors and nurses about passing a nasogastric tube. She found no evidence that nurses attended medical ward rounds (which she regards as essential to ensuring continuity of care through multidisciplinary interaction) and no evidence that they knew how to escalate clinical concerns.

She noted that the Code of Conduct requires nurses to raise concerns when they believe a patient's care is being compromised, but the ward nurses did not do this in Mr Ryan's case.

151 My investigator specifically asked my Acute Nursing Adviser for her view on professional liaison between Trust staff and Mr Ryan's carers. She said it appeared that the carers provided basic, personal care while he was on the Ward. However, she noted that following the stroke Mr Ryan's needs would have changed and it would have been good practice for the Trust nurses to have established the level of care which the carers were able to provide as soon as possible following his admission. She also said the carers' nursing interventions should have been incorporated into an individualised care plan, shared care should have been encouraged and Trust nurses should have been proactive in supporting the carers. In her view this would have allowed difficult issues, such as the use of restraint and the rationale for carers taking notes, to be discussed openly. She concluded that Trust nurses and carers did not engage effectively with each other and this led to failings in the nursing care Mr Ryan received.

The advice of my Speech and Language Therapy Adviser

152 My Speech and Language Therapy Adviser had no criticisms of the standard of care provided by the Trust's Speech and Language Therapist. She said: the response to the referral was *'timely and appropriate'*; the assessment appeared to be *'as detailed as possible and appropriate to Mr Ryan's presentation'*; the review schedule was regular; and the same speech and language therapist saw Mr Ryan on eight out of nine of his contacts with a speech and language therapist which is *'good practice and ensures continuity of care'*. She also said:

'The recordings in the case notes were clear, decisive and unambiguous. Throughout the management of Mr Ryan the SLT [Speech and Language Therapist] states clearly, repeatedly and unequivocally, that the recommendations for non-oral feeding should be considered.'

153 My Speech and Language Therapy Adviser also noted that the Speech and Language Therapist took part in the first multidisciplinary meeting when Mr Ryan was in hospital. She said it was regrettable that there was no doctor present and that there appeared to have been no forum for discussion with members of the multidisciplinary team and no pathway or protocol for actioning recommendations for alternative feeding. My Speech and Language Therapy Adviser did say there was no documented evidence that the Trust's Speech and Language Therapist had contacted her community colleague. However, she noted that from evidence presented to the Trust's inquiry, it appears contact did take place.

154 My Speech and Language Therapy Adviser agreed with my other Professional Advisers in their opinion that, in all the circumstances, Mr Ryan did not receive a reasonable standard of care. She said:

'The care and treatment did not appear to be multidisciplinary in a "joined up" way, holistically focused, or person centred way. The individuals treating Mr Ryan worked in an isolated, individual way. They did not appear to work as a functional multidisciplinary team.'

155 She also said 'no-one was competently and holistically taking responsibility for decision making and for co-ordinating care and treatment for Mr Ryan' and that Trust staff did not utilise the expertise offered by the Community Learning and Disability Team staff.

The advice of my Learning Disability Nursing Advisers

156 My First Learning Disability Nursing Adviser said it was not in question that Mr Ryan did not receive a reasonable standard of care. She confirmed that communication between Trust staff and staff from the Care Home was poor and had apparently broken down to such an extent that there was animosity between the two groups. She also noted that the learning disability nurses would probably not have had experience in nursing stroke patients, especially in a general hospital setting.

157 My First Learning Disability Nursing Adviser identified key failings in Mr Ryan's care. In her view, these were that he was not admitted to a stroke unit and there had been a breakdown in communication between members of the multidisciplinary team.

158 My Second Learning Disability Nursing Adviser said the primary causes of the substandard service which Mr Ryan received at the Trust were failures in basic care and treatment, including communication and nutrition. She particularly pointed to poor communication with learning disability specialists in the community team.

My findings

159 As I have previously said, the fact that Mr Ryan received inadequate care is not disputed by the Trust. Their internal inquiry uncovered major clinical failings which I have set out at

Annex D. These have been openly accepted and acknowledged by the Trust. Mrs Ryan and Mencap have seen a full copy of the report of the internal inquiry and have discussed the findings with the Chief Executive. However, Mrs Ryan still has some specific outstanding questions about Mr Ryan's care and treatment. She wants to know more about why staff on the Ward failed to feed her son and why communication between staff was so poor.

160 In Section 2 I have set out the legal and policy framework which is relevant to this complaint; also, and at Annex B, I have described the care and treatment that national and professional guidelines say should have been provided for Mr Ryan. I have also outlined above aspects of the multidisciplinary nutritional care the Trust's own Eating and Drinking Policy says should have been provided for him.

161 It is clear from the evidence I have seen that what policy, guidelines and professional standards say should have happened to Mr Ryan after he suffered a stroke, particularly in terms of his nutritional care, did not happen. I now consider how failure to comply with those national, professional and local standards resulted in key failings in Mr Ryan's care and treatment and led to the failure to feed him.

Failings in stroke care

162 My Professional Advisers all said the standard of care and treatment which Mr Ryan received as a stroke patient constituted a failure of service. My Medical Adviser also said a major failing in Mr Ryan's case was the fact that the Trust had not responded to national and international recommendations on stroke care, especially those set out in the *National Clinical Guidelines for Stroke*. Possibly the key recommendation of these guidelines is:

'Stroke services should be organised so that patients are admitted under the care of a specialist team for their acute care and rehabilitation.'

163 My Medical Adviser said the advantages of stroke units had been mentioned in the 2000 clinical guidelines and a milestone had been set in the *National Service Framework for Older People* that all English hospitals should have a stroke unit by April 2004. It is indisputable that because there was no stroke unit at the Trust until early 2006, the Trust failed to meet the requirements of the *National Clinical Guidelines for Stroke* and the *National Service Framework for Older People* on this key point.

164 At the time when Mr Ryan was admitted in November 2005, services for stroke patients at the Trust were fragmented. As a consequence, Mr Ryan was admitted to a busy general medical ward where the focus was mainly on respiratory and endocrine disorders. He was placed under the care of a consultant who specialised in respiratory medicine and who had no special expertise in stroke care.

165 The Trust had agreed a draft stroke pathway with the PCT. This did show that the Trust was trying to cope with deficits in its stroke services by setting up links with other local healthcare organisations. However, the draft pathway included only some aspects of essential stroke care set out in the *National Clinical Guidelines for Stroke* and did not include information, or directions about where to find additional information, about meeting stroke patients' basic needs, such as nutritional care. Therefore, the draft stroke pathway fell short of professional and national expectations in terms of planning for a stroke unit.

166 My Medical Adviser told me Mr Ryan did not receive effective stroke care because the Trust failed to organise services to provide effective care and treatment for stroke patients. As my Medical Adviser has said, Mr Ryan was not assessed or treated according to existing guidelines. For example, he was never assessed by a senior clinician with an interest in stroke, such as a neurologist, and, although he should have had a brain scan within 24 hours of admission, he was not scanned until day 4 of his stay. Also, the guidelines said Mr Ryan should have received aspirin to try and prevent a second stroke. However, as my Medical Adviser noted, aspirin was prescribed, but never given because Mr Ryan was not able to take anything by mouth. Apparently, there was no attempt to administer aspirin rectally which my Medical Adviser said would have been a suitable alternative route. Furthermore, there was no team of experts skilled in the management of the needs of stroke patients, for example speech and language therapists, dieticians and nurses, who could identify and meet Mr Ryan's basic needs, including his nutritional needs. This was **service failure**.

167 My Professional Advisers agree that in addition to the failings directly associated with stroke care, major problems in Mr Ryan's case were those identified by the Trust's internal inquiry – lack of clinical leadership, inadequate communication and poor multidisciplinary team working. They suggest that these were at the heart of the shortcomings in Mr Ryan's care and led directly to the failure to feed him. In their advice, my Professional Advisers cite many instances of these three key failings. I now set out some of these detailed examples to explore Mrs Ryan's questions about why her son was not fed.

Failings in clinical leadership

168 My Medical Adviser and my Acute Nursing Adviser said neither the Consultant nor the Ward Sister provided effective clinical leadership either for their professional group, or the ward team as a whole. For example, the health records and evidence to the internal inquiry show that neither of the lead professionals had set up effective systems of organising care and treatment. Crucially, the internal inquiry identified that the nursing shift patterns did not encourage continuity of care and medical cover was fragmented with no effective arrangements at weekends. Most worrying is the clear fact that neither of the lead professionals recognised that the basic standard of care which doctors and nurses in their charge were providing for a very ill man was inadequate.

169 In terms of the Consultant's leadership role in ensuring Mr Ryan was adequately nourished, I note my Medical Adviser said:

'The primary responsibility for deciding on feeding policy for a patient lies with the medical team.'

170 However, it is clear to me that the Consultant did not fulfil his role as the person with overall responsibility for Mr Ryan's care and I agree with the Medical Adviser that there is evidence that his clinical leadership was poor in this regard.

171 On the day of admission a junior doctor recorded that Mr Ryan could not swallow and correctly said he should be given nothing by mouth. I note that no formal swallowing assessment was performed on the day of admission as required by the *National Clinical Guidelines for Stroke*. However, I note that my Speech and Language Therapy Adviser said that, subsequently, the Speech and Language

Therapist performed appropriate assessments of swallowing, discussed her findings with nurses, junior doctors and Mr Ryan's carers, and repeatedly wrote her findings and advice in the health record.

- 172 Despite the Speech and Language Therapist's assessment that Mr Ryan would need alternative feeding because his swallow was not returning, the medical team, led by the Consultant, did not make a decision about alternative feeding until Mr Ryan had been in hospital for 18 days. Soon after this, Mr Ryan became too ill to undergo the operation to insert the PEG feeding tube.
- 173 In my criticism of the Consultant's clinical leadership, I also draw attention to his evidence to the internal inquiry. It seems he focused on the roles of other professionals regarding failings in Mr Ryan's nutritional care, rather than accept his own shortcomings. For example, in relation to the failure to feed Mr Ryan, he suggested the Speech and Language Therapist should have told him Mr Ryan's swallow was not returning and that nurses should have attempted to pass a nasogastric tube. However, it is clear that the Consultant did not fulfil his lead responsibility to assess Mr Ryan's nutritional state, to respond to the Speech and Language Therapist's specialist advice and devise a plan about Mr Ryan's nutrition which other professionals could follow. This was a fundamental failing in care and treatment and a major reason why Mr Ryan was not fed.
- 174 As I have said in paragraph 141 and in Annex C of this report, the Consultant was on leave for part of the time during Mr Ryan's stay at the Trust. I accept that this means the Consultant could not have been personally involved in Mr Ryan's care and treatment during this period of leave. However, as I have set out in Annex A,
- 'Good Medical Practice' requires a doctor who is responsible for a patient's care to ensure that *'arrangements are in place to provide cover at all times'*. It is clear to me that such suitable arrangements were not in place as regards Mr Ryan's medical care.
- 175 The shortcomings in the clinical leadership by the Consultant were **service failure**.
- 176 In terms of nursing leadership, I note the Matron's evidence to the internal inquiry suggests she was able to give little support to the Ward Sister because her role was mainly as a bed manager for several wards. The only evidence of the Matron's direct involvement in Mr Ryan's case is a record of the dispute which arose between ward staff and carers two days before Mr Ryan died. There is no evidence that she fulfilled her senior clinical role to guide the Ward Sister or advise on care and treatment or facilitate developments in nursing. For example, in her evidence to the internal inquiry she said that benchmarking on nutrition was just being introduced. However, as I have said above, the Essence of Care guidance had been in place since 2001.
- 177 Having remarked on the inadequate support provided by the Matron to the Ward Sister, I note the advice of my Acute Nursing Adviser that there is also no evidence that the Ward Sister herself provided even basic clinical leadership in this case. There is no indication that she took the lead, as she should have done, in monitoring and managing Mr Ryan's care and condition. There is no evidence that she supervised the actions of nurses in her team, or that she had put in place arrangements to guide or support team members. Moreover, it appears she was not aware of the nursing failings which the Acute Nursing Adviser identified in this

case, including the poor assessments (such as the incomplete Malnutrition Universal Scoring Tool assessment), inadequate care plans and substandard delivery and evaluation of nursing care. In particular, I note the advice of my Acute Nursing Adviser that there is no evidence of any nursing action specifically aimed at meeting Mr Ryan's nutritional needs. In her evidence to the internal inquiry the Ward Sister said nurses were concerned about Mr Ryan's nutrition. I have seen no evidence that she took a lead in managing those concerns, such as taking independent action within her professional boundaries or escalating the situation to senior clinical or management staff. The shortcomings in the clinical leadership by the Matron and the Ward Sister were **service failure**.

Failings in communication and multidisciplinary team working

- 178 The multidisciplinary team comprises all professionals involved in the care of an individual patient or a group of patients. Membership will vary depending on the nature of a person's illness and their specific needs. For a stroke patient the multidisciplinary team would usually include doctors, nurses, speech and language therapists, dieticians and other specialist therapists, such as physiotherapists. The wider multidisciplinary team would include community professionals, such as community nurses, and carers.
- 179 National, professional and local policy and guidelines stress the importance of multidisciplinary team working in stroke care. However, the evidence I have seen shows how poor communication and team working between professionals meant that the approach to Mr Ryan's care, including his nutrition, was fragmented, unplanned and ineffective. I will describe some examples to show how different

members of the multidisciplinary team failed to communicate effectively and how this impacted on Mr Ryan's nutritional care.

- 180 The Consultant held no formal multidisciplinary meetings on the Ward and it seems he and his team regarded the Consultant ward round as the only clinical discussion and decision forum, despite the fact that other professionals involved in Mr Ryan's care could not always attend the ward round. Some examples, including the Consultant's own actions and omissions, show how ineffective the notes and ward rounds were in this regard.
- 181 The health records suggest the Consultant only saw Mr Ryan six times during his 26-day stay on the Ward (although I note he was on leave for about a week during that time). Therefore, I was particularly concerned that all clinical decision making seemed to hinge on the Consultant's ward round. It appears that everyone, even the Specialist Registrar, waited until the Consultant arrived on the Ward before making key treatment decisions. The Medical Adviser has pointed out that even when the Consultant did review Mr Ryan it seems he did not use the information he received to inform his decision making. If he had, he would have seen the concerns expressed by the Community Learning Disability Team, the Speech and Language Therapist and the junior doctors. In fact, the Medical Adviser has suggested the Consultant relied on his junior doctors to tell him what was happening and then expected them to write in the notes on his behalf. The Consultant only wrote personally in the notes following the meeting on 16 December 2005 about palliative care.

- 182 During his interview with the internal inquiry panel the Consultant said he expected the nurses to read the notes to find out about his plan for Mr Ryan's nutritional care. He suggested that had they done so they would have seen that a nasogastric tube should have been passed. In contrast, he said he expected the Speech and Language Therapist to talk to him rather than rely on writing in the notes. In fact, as I have said, the notes do not contain any plan to manage Mr Ryan's nutrition, such as an instruction to attempt nasogastric feeding, until 13 December 2005 when Mr Ryan had already been in hospital for 18 days. On that day a junior doctor recorded the Consultant's decision about the PEG feeding tube. This evidence shows that poor communication led to confusion about what actions nurses and others had taken, or should have taken, with regard to feeding Mr Ryan.
- 183 On the basis of information from the Trust's internal inquiry my Medical Adviser questioned whether the Consultant was in the habit of reading the medical notes to see what colleagues had written there. The Consultant disputes this. However, the key point is not whether the Consultant did or did not read the medical notes. Rather, it is whether those notes were used effectively as a tool for communication and multidisciplinary teamwork. It is clear that, in terms of Mr Ryan's nutrition, relevant information in the medical notes was not acted upon until it was too late to instigate effective artificial feeding for him.
- 184 I find that multidisciplinary communication methods were not in place or failed to work effectively. This was **service failure**.
- 185 In her interview with the internal inquiry the Ward Sister said nurses were very concerned about Mr Ryan's nutrition and talked to doctors about their concerns. There is no record of this. Also, I have seen no evidence that nurses contributed to discussion at the Consultant's ward round, or that they used any other means to communicate their concerns either to each other (for example, via care plans), or to senior clinicians or managers. This was **service failure**.
- 186 As I have said, the Speech and Language Therapist was a key member of the team responsible for Mr Ryan's care. Essentially her role was to assess whether Mr Ryan could swallow safely and to advise on deterioration or improvement in his swallowing.
- 187 In the findings of the Trust's internal inquiry the Speech and Language Therapist is criticised for not escalating her concerns about Mr Ryan's nutrition. I agree that she did not act in line with the Trust's own Eating and Drinking Policy which said that if there was difficulty or disagreement with feeding decisions a speech and language therapist should involve senior staff. That said, she was the first professional who recognised and recorded that alternative feeding should be considered and she did this within a week of admission. Also, she did attend a meeting with the Community Learning Disability Team Nurse and ward nurses where nutrition was discussed. Regrettably, no doctor attended that meeting and, in fact, no action about nutrition was taken as a result of the discussion.
- 188 Normally a dietician would contribute expertise to the team caring for a stroke patient. The dietician's role is mainly to ensure individual patients, or groups of patients, receive the correct diet to meet their nutritional needs. Mrs Ryan has asked specifically why a dietician

was not involved in discussions and decisions about her son's nutrition. The simple answer is that no one informed the dieticians about Mr Ryan's feeding problems. The Malnutrition Universal Scoring Tool assessment which should have led to a request for dietetic advice was poorly completed and not actioned. That said, there is probably little the dietician could have offered because other team members had not established a way of feeding Mr Ryan. There would have been no point in the dietician advising on the nature and content of his diet when there was no way of feeding it to him.

189 As I have said, community staff are also part of the multidisciplinary team. In Mr Ryan's case, his carers appropriately alerted Community Learning Disability Team staff that he was in hospital two days after he was admitted. Community Learning Disability Team staff had a responsibility to help Trust staff understand and meet his health needs while he was in hospital and Trust staff had a responsibility to seek out and respect that input. As my Acute Nursing Adviser has suggested, it seems there was an over-reliance on Mr Ryan's carers to fulfil this role, when it is likely they had very little experience of acute healthcare. The Community Learning Disability Team Nurse did visit Mr Ryan on several occasions and there is evidence that she tried to influence decisions about his nutrition by writing in the notes, asking for a multidisciplinary meeting and attempting to contact doctors. Trust staff did not respond to her or actively seek her advice and in so doing failed in their professional duty as set out in the Nursing and Midwifery Council's Code of Conduct and the General Medical Council's Good Medical Practice to work effectively with colleagues to plan and deliver optimum care for Mr Ryan. This was **service failure**.

Failure to feed Mr Ryan and communication between staff: my conclusion

- 190 I conclude that the key reasons for the significant shortcomings in Mr Ryan's care and treatment, and in particular his nutritional care, were failings in provision of stroke services as well as failings in clinical leadership, communication and multidisciplinary team working.
- 191 The Trust's failure to comply with national directives on the development of a stroke unit or to organise existing services to provide effective stroke care, is at the heart of this case. Had such co-ordinated services existed there would have been more chance that Mr Ryan would have received care and treatment organised and provided by a group of clinical staff who, although experts in their own field, would come together to deliver effective care focused on the needs of a stroke patient.
- 192 In the absence of a specialist stroke facility, the Trust's professional healthcare and management staff should have worked together and with community colleagues and organised available resources to ensure they delivered a reasonable standard of care for Mr Ryan. Sadly, this did not happen. Instead, the staff who cared for Mr Ryan appeared to work in isolation from each other and no one took the lead in managing his care. In particular, the medical team, led by the Consultant, failed to comply with the standards set out in Good Medical Practice and the nursing team, led by the Ward Sister, failed to comply with their professional Code of Conduct.
- 193 As a result of the Trust's organisational failings and the flawed actions and omissions of Trust staff, Mr Ryan was not fed for 26 days. This was **service failure** which was at least in part for disability related reasons.

Complaint (c): malnutrition and starvation

- ¹⁹⁴ One of the conclusions of the Trust's internal inquiry was that Mr Ryan's death could not be attributed to the poor care and treatment he received. Subsequently, the Trust has put forward a view, based on its analysis of academic papers carried out after the event, that there was a high chance that Mr Ryan would have died as a result of the stroke.
- ¹⁹⁵ Mrs Ryan does not accept the Trust's explanation about the reasons why Mr Ryan died. She believes that he '*starved to death*' and she wants to know whether he would have survived if he had received adequate nutrition.
- ¹⁹⁶ I can fully understand why Mrs Ryan believes her son '*starved to death*'. He was not fed for 26 days and it is an indisputable fact that people need food to live and that without sufficient food people weaken and eventually die. However, the questions which I have to address are whether there is sufficient evidence to support Mrs Ryan's view of the reason why Mr Ryan died and whether his death could have been avoided. To assess these questions I turn to the expert advice of my Medical Adviser. In the light of his advice, I look at information about the severity of Mr Ryan's stroke and consider the impact of the lack of specialist stroke care and malnutrition on his chances of survival.

The advice of my Medical Adviser

- ¹⁹⁷ In terms of the severity of Mr Ryan's stroke, my Medical Adviser said information about the nature of Mr Ryan's stroke and the physical and mental consequences for Mr Ryan were not fully documented. For example, it was clear that Mr Ryan could not move his left side and could not swallow, but there was no firm evidence

about any other possible effects of the stroke, such as loss of sensation or vision. However, from the limited documentary evidence that he had seen (including the report of the brain scan), he thought damage to Mr Ryan's brain was '*significant but not very extensive*'. My Medical Adviser cautiously said it seemed Mr Ryan had suffered the sort of stroke which he would normally expect a patient to survive. However, he also said that patients who do survive such strokes usually have long-term mental and physical problems.

- ¹⁹⁸ In terms of the medical facilities provided for Mr Ryan, my Medical Adviser pointed to the recommendations in the *National Clinical Guidelines for Stroke*. These guidelines were drawn up on the basis of carefully conducted and validated research and, as I have previously said, the overarching recommendation about organisation of stroke services was that they should be grouped into a stroke unit. My Medical Adviser said there is evidence that the mortality rate and level of disability amongst stroke patients who are admitted to specialist stroke units is lower than amongst those who are admitted to general medical wards.
- ¹⁹⁹ My Medical Adviser said there is sufficient evidence to show that Mr Ryan became malnourished during his time in hospital. In terms of the impact of malnutrition on likely survival the Medical Adviser said:

'Prolonged starvation would in my view have made it less likely that [Mr Ryan] would have made a neurological recovery, made him more susceptible to infection and less able to combat infection when it occurred. I think therefore that there is a real possibility that delay in feeding contributed to his death.'

and

'I think it is likely that malnutrition contributed to Mr Ryan's death although this is impossible to prove.'

- 200 My Medical Adviser considered all the representations made in response to my draft report and he found nothing which persuaded him to change his original advice.

My findings

- 201 I have taken account of my Medical Adviser's opinion. Based on this advice it seems reasonable to assume that, even though he suffered a severe stroke, Mr Ryan would have had a better chance of survival if he had been admitted to a hospital where stroke services were organised in the way described in the *National Clinical Guidelines for Stroke*.
- 202 Also, it is clear from my Medical Adviser's advice that Mr Ryan would have been less likely to develop infections if he had been fed. However, my Medical Adviser said that it is impossible to prove that malnutrition either contributed to or caused Mr Ryan's death.

Malnutrition and starvation: my conclusion

- 203 Given the magnitude of the failings in Mr Ryan's care and treatment I, like Mrs Ryan, find it difficult to accept the Trust's position that those failings did not contribute to his death. My Medical Adviser told me that the evidence suggests Mr Ryan had a 'significant' stroke and, as I have said in paragraph 104, according to the Stroke Association, stroke is the third most common cause of death in the UK. Therefore, I do not doubt that Mr Ryan was at risk of dying as a result of impairments caused by the stroke.

One of those impairments was his inability to swallow safely. It cannot be disputed that this led directly to the need to ensure he received adequate nutrition by artificially feeding him. To my mind, especially given the limited information we have about the nature of the stroke itself, it is not possible to separate the direct impact of Mr Ryan's stroke from the life-threatening consequences of that stroke, such as the inability to eat normally.

- 204 In the light of the opinion of my Medical Adviser, I conclude that it is impossible to say for certain whether Mr Ryan would have survived if he had been fed. However, what I can say is that because of the failings of Trust staff, Mr Ryan was not fed for 26 days and this undoubtedly placed him at considerable risk of harm. I conclude that although it is impossible to prove that malnutrition and starvation contributed to or caused Mr Ryan's death, it is likely that the failure to feed him for a prolonged period was one of a number of failings which led to his death. This was **service failure** which was at least in part for disability related reasons.

Complaint (d): complaint handling by the Trust

- 205 Mrs Ryan is dissatisfied with the way in which the Trust handled her complaint about her son's care and treatment. She says the Trust failed to respond appropriately to her complaints and she wants to know why it took the Trust so long to give her an explanation about how her son died. She also wants to know why the Trust did not classify his death as a Serious Untoward Incident as soon as he died. She believes this may have been for reasons related to his learning disabilities. Mrs Ryan also wants to know

whether the changes which the Trust has put in place following Mr Ryan's death will make a difference to the care and treatment of other patients in similar circumstances.

Key events

- 206 On 23 January 2006 three staff from the Community Learning Disability Team and the Care Home wrote to the Chief Executive asking for a meeting to discuss their concerns with the aim of finding ways to work more collaboratively with Trust staff. On 22 March 2006 a meeting took place where the Community Learning Disability Team staff put forward a number of concerns, including staffing levels, breakdown in communication, lack of feeding, medication not being given on time and liaison with the Community Learning Disability Team and Mr Ryan's carers.
- 207 Meanwhile, on 27 February 2006, Mencap complained to the Trust on behalf of Mrs Ryan. They raised concerns about the treatment Mr Ryan received in hospital and '*lack of communication with his family about his condition and possible treatments*'. They listed five specific areas of concern with multiple questions in each area. The key areas were: insertion of a feeding tube; communication with the family; epilepsy medication; lack of skills in dealing with people with learning disabilities; and inclusion of Down's syndrome on the death certificate.
- 208 On 26 April 2006 the Trust responded giving details about Mr Ryan's care and treatment. The response included a description of the sequence of speech and language assessments as well as information on decisions about nasogastric feeding and inserting a PEG feeding tube.
- 209 The Trust said there was '*no delay in appropriately considering the feeding tube*' and that there was liaison with the Community Learning Disability Team, Mr Ryan's carers and his family about feeding. It also explained that it had not always been possible to give epilepsy medication on time because staff resources were limited and there were difficulties in keeping an intravenous cannula in place. It also said that when Mr Ryan's condition deteriorated, the way in which staff had communicated with his family and the Community Learning Disability Team had been appropriate.
- 210 The Trust said nurses on the Ward had received training on caring for vulnerable adults, but not in caring for patients with learning disabilities. However, it said Mr Ryan's carers had provided specialist knowledge to support the ward nurses. In terms of the death certificate the Trust explained that the Consultant (who had not written the certificate) thought the information '*would help in the recording of accurate statistics reflecting the morbidity and mortalities associated with this syndrome*'.
- 211 The Trust offered to meet with Mrs Ryan to discuss her concerns.
- 212 On 15 May 2006 Mencap wrote again to the Trust raising some points about accuracy and validity of some information in the Trust's letter of 26 April 2006. They also asked the Trust to comment about why no attempt was made to feed Mr Ryan and why the Community Learning Disability Team had not been consulted about the possibility of using '*minimal restraint*' to help the Speech and Language Therapist with her assessments. They also questioned the Trust's response about communication with Mrs Ryan because she did not remember speaking to the Palliative Care Team and she

said no doctor or nurse spoke to her when she arrived on the Ward on 16 December 2005.

- 213 On 12 July 2006 the Trust responded to Mencap's second letter. In this response the Trust admitted there had been a breakdown in communication between the Consultant and the ward nurses because the Consultant thought nurses were attempting to insert a nasogastric tube when they were not. However, nurses thought the Community Learning Disability Team had advised that Mr Ryan would not tolerate a nasogastric tube so this method of feeding would not be possible. Therefore, they had not attempted to insert a tube. The Trust reported that the Head of Speech and Language Therapy had reviewed the actions of the Speech and Language Therapist who had assessed Mr Ryan and found no fault with her actions. The Trust also said the Consultant did not believe the medical team were at fault because they had followed usual procedures for arranging insertion of a PEG feeding tube. The Trust maintained that it would have been '*clinically inappropriate to force Mr Ryan to eat with any restraint*'.
- 214 In terms of communication with Mrs Ryan at the time when palliative care was introduced, the Trust said there was a record that the Palliative Care Team had spoken to her and the medical team spent '*a considerable amount of time contacting Mrs Ryan at home and speaking to her on the telephone*'. It said the Consultant would have been available to speak to her had she asked to meet him.
- 215 On 31 July 2006 Mencap wrote to the Trust for a third time. On this occasion Mencap said the failure to feed Mr Ryan was one of the direct causes of his death. They raised further points about feeding (lack of communication, risk/benefit of using restraint, whether or not nasogastric feeding was attempted, national guidelines on feeding and the Trust's Eating and Drinking Policy) and made some points about treating patients who lack capacity to consent.
- 216 The Trust tried to arrange a meeting with Mencap and Mr Ryan's parents in October 2006, but this offer was declined. On 18 October 2006 the Trust responded to Mencap's third letter. Its response included the draft report of a 'mini review' which had been conducted by the Trust's Medical Directorate.
- 217 The 'mini review' included an acknowledgement that multidisciplinary communication on the Ward had been poor, especially between doctors and nurses. It described action which had been taken to address this problem, for example, the introduction of weekly multidisciplinary meetings. It also included an acknowledgement that there was poor communication between the multidisciplinary team about feeding Mr Ryan and no one had taken responsibility for raising concerns or taking action about those concerns. Furthermore, the 'mini review' found there was no nutritional management plan in the medical notes and there had been confusion between doctors and nurses about whether or not an attempt had been made to pass a nasogastric tube. The Trust acknowledged it had been '*wholly unacceptable*' that no attempt had been made to pass a nasogastric tube. It also acknowledged the failure to complete the Malnutrition Universal Scoring Tool assessment, saying this was also unacceptable and contributed to Mr Ryan's lack of nutrition. The Trust also said staff had lacked understanding about appropriate use of restraint.

- 218 The Trust's response included the Chief Executive's apologies for delay, inaccuracies and confusion arising from previous responses. She also offered her *'heartfelt apologies to Mr Ryan's parents for the poor treatment that Mr Ryan received'* and she offered to meet with his family. The Chief Executive also told Mencap that she had reported Mr Ryan's death as a Serious Untoward Incident to the strategic health authority and launched an internal inquiry into his care and treatment.
- 219 On 9 November 2006 Mencap wrote a fourth letter to the Trust. This raised one principal query about Mr Ryan's congenital heart condition which was mentioned in the 'mini review'. Mencap said neither Mr Ryan's parents nor his carers knew about this condition and they questioned whether this had influenced the decision not to insert a PEG feeding tube.
- 220 On 22 November 2006 the Trust responded explaining that the doctor who had admitted Mr Ryan had heard an abnormal heart sound and wondered whether this resulted from congenital heart disease. However, Mr Ryan's heart function was found to be normal and this had no bearing on the decision not to insert a PEG feeding tube.
- 222 The findings of the inquiry are set out at Annex D. Key findings on management of the complaint included: there was a reasonable conclusion to the complaint from the Community Learning Disability Team; responses to Mencap showed inconsistencies and inaccuracies; significant delay in providing the first response; no challenge to written statements; failure to trigger a Serious Untoward Incident; and no developed governance framework in the Directorate of Medicine.
- 223 The report made nine recommendations which I have set out at Annex E. In summary, they related to clinical leadership; medical cover in the Directorate of Medicine; the work of the Trust's Nutritional Review Group; arrangements for Clinical Governance in the Directorate of Medicine; use of a nursing staff dependency tool; the relationship of ward staff to carers; speech and language therapy team working; whistle-blowing; and review of specific aspects of the complaints policy.
- 224 On 8 January 2007 an informal seminar was held by the Trust Board to consider the results of the inquiry. By this time several developments had already occurred including: establishment of a Nutritional Working Group; the stroke unit had been opened; the Ward Sister had revised the system of nursing handover and was going to attend a leadership course; the Consultant had attended a course on the care of people with learning disabilities; a regular multidisciplinary morbidity and mortality meeting had been set up and Mr Ryan's case had been discussed there; changes to organisation of services, including 'Hospital at Night'; and initiation of joint working with the local Community Learning Disability Teams.

The internal inquiry

- 221 I have described above the nature and purpose of the Trust's internal inquiry. One of the aims of the internal inquiry was:

'To understand and consider the failure to escalate the complaint within the organisation.'

225 On 31 January 2007 the Trust Board reviewed the report and accepted its conclusions and recommendations. It also added six more recommendations which included: disciplinary hearings for key staff; further action on ensuring nutritional standards were met; Trust-wide review of governance arrangements; complete review of the complaints procedure; review of the Trust's overall approach to patients with learning disabilities; and development of a formal action plan to address all the recommendations.

226 Throughout 2007 the Trust Board monitored actions taken in response to the recommendations. In January 2008 the Board accepted the final report on the action plan which showed that all actions had been completed.

227 The Trust met with Mr Ryan's parents in March 2007 to discuss the internal inquiry and, since then, it has continued to update them about changes and improvements resulting from the findings and recommendations. Most recently, the Chief Executive wrote to Mencap setting out progress against the action plan. Her letter included achievements in improving nutritional care across the Trust against Essence of Care benchmarks. She also sent information about the outcome of collaborative working between the Trust and the Community Learning Disability Team which has included development of a 'Joint protocol to support people with learning disabilities to access acute hospital services' and a 'Health Passport' for people with learning disabilities.

The advice of my Professional Advisers

228 My investigator specifically asked my Professional Advisers for their views on the Trust's explanations about the failures in Mr Ryan's care and treatment, including the finding of the internal inquiry. She also asked for their views on whether the recommendations of the internal inquiry and the subsequent action taken by the Trust would address those failings and, where possible, prevent a recurrence of what happened to Mr Ryan.

229 My Medical Adviser said he agreed with the findings of the internal inquiry. He also said that there is evidence that the Trust is addressing the problems; for example, there is now a stroke unit. He said:

'I am reassured by the statement that multidisciplinary meetings are now a regular feature of care.'

230 My Acute Nursing Adviser said the internal inquiry was thorough and identified key aspects about failings in Mr Ryan's clinical care. In terms of the Trust's actions to address failings it identified she said:

'It is my opinion that the Trust has made considerable effort to learn from this case and has worked hard to put measures in place to address the failings identified. There is clear evidence encompassed in the recommendations of the internal inquiry panel and further recommendations of the Trust Board to demonstrate that the Trust are taking appropriate actions to address the clinical failings identified by the internal inquiry.'

231 My Acute Nursing Adviser also reviewed additional information about the latest action taken by the Trust. She said the Trust has *'made really good progress'* and she commented that using the matrons and site managers as points of reference and expertise when people with learning disabilities are admitted was a particularly good idea. She also said the Trust had developed a clear pathway to escalate concerns and there was *'clear evidence of collaborative working'* between Trust staff and the Community Learning Disability Team.

232 My First Learning Disability Nursing Adviser said:

'I believe the Trust has done everything possible to address this complaint and have taken full responsibility for their actions ...'

233 My Second Learning Disability Nursing Adviser said the Trust has:

'... really taken on board the lessons learnt from the tragedy regarding Mr Ryan and have pulled out all the stops to ensure people with learning disabilities get a better service in the future. The report back to their Board indicates they took the incident seriously and have put a lot of effort into getting things right for the future.'

234 She also said that the Trust's protocol about admissions and discharges is *'excellent'* and *'should go a long way to improving things dramatically for people with learning disabilities'*. Furthermore, she said the *'patient passport'* which the Trust had developed is in line with national standards. In addition, she remarked on the positive relationship which had developed between the Trust and the PCT, particularly in terms of agreeing additional funding for services.

My findings

235 Mrs Ryan remains dissatisfied with the way in which the Trust handled her complaint. Her main points are that the Trust failed to respond appropriately to her complaints and took too long to give her an explanation about how her son had died. She also wants to know why the Trust did not classify Mr Ryan's death as a Serious Untoward Incident as soon as he died. She believes this may have been for reasons related to his learning disabilities.

236 I can understand why Mrs Ryan is unhappy with the Trust's response to her complaint and why she feels the complaints process has been complex and prolonged. Although she first complained about Mr Ryan's care and treatment in February 2006, Mrs Ryan did not receive an open and comprehensive response from the Trust until it shared the results of the internal inquiry with her in March 2007. Even then, as we have seen, she has some outstanding queries, particularly relating to Mr Ryan's learning disabilities.

237 First, I consider the way in which the Trust responded to Mrs Ryan's complaint.

238 I have studied all the evidence about complaint handling by the Trust, including complaint correspondence and background papers provided by the Trust. I have assessed the Trust's actions against the Regulations, the *Principles of Good Administration* and *Principles for Remedy* and it is clear that there were significant failings in the Trust's management of this complaint.

239 In my view, the most serious shortcoming in complaint handling was the failure to recognise the seriousness of the matters complained about – the fact that the complaint concerned

the death of a man who had not been fed for 26 days. The significance of the complaint was not fully recognised until the Chief Executive declared a Serious Untoward Incident in September 2006 – over six months after the Trust received Mrs Ryan’s first complaint letter. The internal inquiry panel recognised the significance of this failing and explored the reasons why the complaint was not singled out as being particularly serious and significant. Although the initial complaint investigation and response followed the basic process set out in the Regulations, there were failings in the way in which the investigation was conducted.

240 In particular, it is clear that the investigating officer did not have the medical experience or authority to conduct an effective, in-depth investigation involving senior clinicians. This is illustrated in the first two responses from the Trust (26 April and 12 July 2006). The content of the letters is apparently based mainly on the Consultant’s view of events. It seems there was some input from the speech and language therapy team, but very little input from the senior nurses, especially the Ward Sister, who should have had a key role in responding to the complaint. Furthermore, it appears that the investigating officer did not challenge the Consultant’s contention that there had been no failings in Mr Ryan’s care and treatment, when the most basic failing, lack of nutrition, would have been obvious to anyone reviewing the case. However, it appears the investigator did not question the Consultant’s view. This meant that, in its first response, the Trust even denied there had been a delay in inserting a feeding tube. In the second response the Trust accepted there had been a breakdown in communication about feeding, but continued to maintain that the medical team was not at fault regarding the failure to feed Mr Ryan. Instead, a series of different explanations, such as limited

resources, problems with consent and Mr Ryan’s deteriorating physical condition, were put forward as reasons why he was not fed. It is clear that the investigation was not carried out in line with the requirements of Regulations 12 and 13. This was **maladministration**.

241 Turning to the nature of the responses themselves, I find the tone of the first two letters was inappropriate and very defensive. This is illustrated by the responses about communication with Mr Ryan’s family. Based principally on the Consultant’s view, the Trust condoned the frank way in which the Specialist Registrar had informed Mrs Ryan over the telephone that her son was dying. Moreover, the Trust robustly defended the Consultant’s approach to communication, saying he had been available when the decision to commence palliative care was made, but the family had not asked to speak to him. At this stage, the Trust did not acknowledge any major failings and its approach was far from conciliatory. The Trust’s responses were not in line with the overall thrust of the Regulations which focus on effective local resolution or the specific instructions on responses to complaints in Regulation 13. This was **maladministration**. In these circumstances I do not find it at all surprising that Mrs Ryan declined a local resolution meeting.

242 Mencap recognised that there were inaccuracies and inconsistencies in the Trust’s first two responses, for example, about whether or not nurses had attempted to pass a nasogastric tube and the length of time Mr Ryan had been without food. This led them to question other aspects of the Trust’s responses, including explanations about epilepsy medication. Inaccuracy and inconsistency were key failings in the initial management of this complaint. This was **maladministration**.

- 243 It is clear that the Trust's initial investigation into Mrs Ryan's complaint was wholly inadequate and its first two responses to the serious matters complained about were wholly inappropriate. I find that, up to this point, its approach to complaint investigation and response was not in line with that set out in the detail of the Regulations or the *Principles of Good Administration*.
- 244 Having made these criticisms of the initial attempts to address Mrs Ryan's complaint, it seems to me that some time in the summer of 2006 there was a turning point in the Trust's approach. This was when the 'mini review' was instigated. It is not entirely evident who or what prompted the 'mini review', but it is clear that the findings of this second investigation led the Trust to recognise the major failings in Mr Ryan's care and treatment. As a direct result the Chief Executive contacted the strategic health authority about Mr Ryan's death and set up the internal inquiry.
- 245 Following the 'mini review' there was a turnaround in the Trust's approach. The Trust's letter of 18 October 2006 is very different in content and tone from its previous two letters. It included detailed explanations, acknowledged failings, offered apologies and provided information about the internal inquiry.
- 246 I have studied the Trust's subsequent actions in depth and I have found no further faults with its approach to managing the complaint. On the contrary, I agree with Mencap and my Professional Advisers that, once it realised the seriousness of the issues complained about, the Trust was open and transparent about its failings. In terms of the inquiry itself, I draw attention to the appropriate senior independent advisers who were asked to join the inquiry panel, the range of papers they studied, the in-depth interviews they conducted and the clear, concise report they produced.
- 247 In terms of the Trust's response to the outcome of the internal inquiry, I note the effort which has been made to implement the expanded recommendations and the keen interest of the Trust Board in tracking progress with actions to meet those recommendations. I also note that the Chief Executive has maintained her personal interest in the case and has remained the key contact for Mr Ryan's parents and Mencap. Mencap have acknowledged that the Trust has worked hard to correct the failings identified in this case. Following the internal inquiry, the Trust has openly acknowledged failings, offered sincere personal apologies to Mrs Ryan and kept her and Mencap informed of progress with initiatives to address the failings identified. At this stage its actions reflected the *Principles of Good Administration*.
- 248 Secondly, I consider whether the failure to declare Mr Ryan's death as a Serious Untoward Incident at an earlier stage was related to his learning disabilities.
- 249 The Trust should have reported Mr Ryan's death to the strategic health authority as soon as he died because events associated with his death fulfilled the criteria to trigger a Serious Untoward Incident (which I have set out above). The Trust missed a second trigger when it received Mrs Ryan's complaint in February 2006. However, in my view, the Trust's failure to report Mr Ryan's death was due to the failings in both clinical and management systems which I have described in detail elsewhere in this report. In reviewing the sequence of events in the Trust's management of the complaint, I have seen no evidence to suggest that this failing, or any of the shortcomings in complaint handling, were related to Mr Ryan's learning disabilities.

Complaint management: my conclusion

250 In conclusion, I agree with Mrs Ryan that there were major failings in the way in which the Trust handled her complaint. Specifically, these were:

- i. failure to recognise the seriousness of the matters complained about, in particular the failure to feed Mr Ryan;
- ii. failure to declare a Serious Untoward Incident at an early stage;
- iii. failure to conduct a proper, in-depth investigation; and
- iv. failure to provide appropriate responses which were accurate and consistent.

251 In these respects the Trust failed to comply fully with the applicable Regulations; its actions did not accord with principles of good administration; and it did not provide an appropriate or adequate remedy. These failings amount to **maladministration**.

252 However, I have found no evidence which indicates that the Trust's maladministration in the handling of Mrs Ryan's complaint was for disability related reasons.

Section 4: the Ombudsman's final comments and overall conclusion

Introduction

253 Mrs Ryan's overarching complaint is that her son's death was avoidable and that he was treated less favourably for disability related reasons. She has told me she has not had full answers to all her questions about Mr Ryan's care and treatment and she hopes my investigation will provide her with those answers. She seeks recognition for her view of events and she hopes other people will not go through the same experiences as her son. In this final section of my report I address Mrs Ryan's overarching complaint and set out my overall conclusion.

254 In assessing the actions of the Trust I have taken account of relevant legislation and related policy and administrative guidance as described above. I have taken account of available evidence and considered the advice of my Professional Advisers.

Was Mr Ryan treated less favourably for reasons related to his learning disabilities?

255 Mrs Ryan believed her son was treated less favourably for reasons related to his learning disabilities.

256 I have found service failure in respect of the inadequate care and treatment provided to Mr Ryan by the Trust. I have concluded that the key reasons for the significant shortcoming in Mr Ryan's care and treatment, and in particular his nutritional care, were failings in provision of stroke services, as well as failings in clinical leadership, communication and multidisciplinary team working.

257 In addition I have found maladministration in the way in which the Trust handled Mrs Ryan's complaint.

258 The Trust does not dispute the fact that Mr Ryan received inadequate care and treatment. However, when the Trust's internal inquiry looked at whether Mr Ryan was disadvantaged with regard to his learning disability it concluded:

'There was no evidence supplied which led the Panel to believe that [Mr Ryan's] care was hampered by the nature of his learning disability. Many of his behaviours (including agitation intolerance of IV cannulation etc) would be typical of many stroke patients who might be agitated and confused.'

259 Mrs Ryan does not accept the Trust's conclusion on this issue. Mr Ryan's sister said she thought the Trust *'didn't bother feeding [Mr Ryan] because he had Down's Syndrome'*.

260 I have described above the nature of Mr Ryan's learning disabilities and some of the possible mental and physical consequences for people who have suffered a stroke. We do not know the precise impact of the stroke on Mr Ryan's mental and physical health. However, it is clear that during his admission to the Trust he was not only disabled for reasons related to his learning disabilities, but also because of his stroke.

261 I am not persuaded by the Trust's argument that Mr Ryan was not disadvantaged for reasons related to his disabilities. Rather, from the evidence I have seen and the advice I have received, I conclude that the acknowledged failings in care and treatment cannot be separated from the fact that Trust staff did not attempt to make any reasonable adjustments to

the way in which they organised and delivered care and treatment to meet his complex needs. Trust staff failed to meet Mr Ryan's needs as a person disabled by his learning disabilities and his stroke. Therefore, I conclude that in some significant respects the Trust's service failures were for disability related reasons.

262 The evidence I have seen strongly suggests that the Trust failed to respond to any of the guidance such as Valuing People, Signposts for Success and Doubly Disabled which had been in place for some years before Mr Ryan was admitted to the Trust in November 2005. As I have explained in Section 2, this guidance required the Trust to ensure arrangements were in place for appropriate care and treatment of people with learning disabilities.

263 In Section 2 I set out my approach to human rights. On that basis, I also conclude that the Trust's actions and omissions constituted a failure to live up to human rights principles, especially those of dignity, equality and autonomy.

264 By failing to care properly for Mr Ryan, in particular by not feeding him, the Trust failed to have due regard to his status as a person, to the need to avoid the infringement of his dignity and wellbeing that would arise from a lack of attention to his needs, in particular his need for food, and to observance of the principle of equality in the way these rights were to be protected. There is no evidence of any positive intention to humiliate or debase Mr Ryan. Nevertheless, the standard of service does at the very least constitute a failure to respect Mr Ryan's human dignity.

265 In these respects the service failures I have found touched upon and demonstrated inadequate respect for Mr Ryan's status as a person.

Was Mr Ryan's death avoidable?

266 Mrs Ryan believes that her son '*starved to death*' because staff at the Trust failed to feed him for 26 days. I can fully understand why she takes that view and I share her concerns.

267 In considering whether to make a finding about avoidable death I assess whether the injustice or hardship complained about (in this case Mr Ryan's death) arose in consequence of any service failure or maladministration I have identified.

268 I have concluded that it is impossible to say for certain whether Mr Ryan would have survived if he had been fed. However, whilst I cannot categorically say that Mr Ryan died because he was not fed, I am not persuaded that the Trust can categorically say that this was not the reason for his death.

269 My Medical Adviser has told me that on the basis of available information the stroke which Mr Ryan suffered '*sounds like the sort of stroke that one would normally expect the patient to survive, although often with long-term [problems with physical and mental functions]*'. The combination of failures in Mr Ryan's care and treatment, particularly the lack of specialist stroke services and the clinical failings in leadership, communication and multidisciplinary team working, put him at risk. Added to this the Trust's failure to feed him meant he was more likely to develop infections and less likely to survive them.

270 Taking into account the professional advice I have received, I conclude that, had the care and treatment Mr Ryan received not fallen so far below the standards which I have identified earlier in this report, it is likely that his death could have been avoided.

Injustice

271 The Trust's internal inquiry established failings in the service provided for Mr Ryan and it openly acknowledged and apologised for those failings in a face-to-face meeting with Mr and Mrs Ryan. The Trust informed me of the actions it took to address the shortcomings identified as well as subsequent developments, in particular improvements related to services for people with learning disabilities. I have set out these actions above. My Professional Advisers have told me that these actions and initiatives were appropriate and would address the key failings in Mr Ryan's care and treatment identified at that time.

272 In her response to my draft report the Trust's Chief Executive said she would like to give:

'... the Trust's sincere apologies for the shortcomings identified in your Report. Many of these were the conclusions of the Internal Review established by the Trust and to that extent reflect the dismay experienced in the hospital for the distress and sadness that we are aware has been experienced by Mr and Mrs Ryan.'

273 She also offered to meet Mr Ryan's parents if they wished.

274 She went on to detail further changes which the Trust has made including changes to the complaints procedure and developments in services for people with learning disabilities. These included collaborative working with the Community Learning Disability Team and participation in the London Network for Learning Disability Nurses. She also gave details of the ways in which the Trust's focus on nutrition has impacted on staff and patients. Her examples included recruitment of a nutritional nurse specialist, staff training, policy review and audit.

275 Having considered the evidence put forward by the Trust about changes which have occurred since Mr Ryan was a patient there I find the Trust has taken and continues to take, reasonable action to address the shortcomings identified by its own inquiry. In particular, I recognise that the Trust has, as Mencap have acknowledged, taken an open and honest approach to the failings in the service provided for Mr Ryan. I also find that its actions will address many of the failings identified in this report with regard to the care and treatment provided for Mr Ryan and to complaint handling.

276 That said, I consider Mr Ryan's parents still have reason to be aggrieved by the failings in the Trust's care and treatment of their son and, in particular, those failings which I have concluded occurred for disability related reasons. Furthermore, they should not have had to wait for an investigation by me to fully establish the facts about the service provided for their son. Partly due to failings at the Trust, Mr Ryan's parents have had to wait over two years for answers to their questions. These findings represent **unremedied injustice**.

My overall conclusion

- 277 I have found **service failure** and **maladministration** which have led to an **unremedied injustice** to Mr Ryan and his family. In the avoidable death of their son, Mr Ryan's family have suffered an injustice which can never be remedied.
- 278 Therefore, I **uphold** Mrs Ryan's complaint against the Trust.

My recommendations

- 279 I recognise that the Chief Executive of the Trust has already met with Mr Ryan's parents and with Mencap to apologise for failings identified by the Trust's own internal inquiry, and that she has offered her apologies for those failings. However, my investigation has uncovered significant additional failings, particularly in relation to Mr Ryan's death, his human rights and his learning disabilities. These failings have not previously been recognised by the Trust. Therefore, I **recommend** that the Chief Executive of the Trust apologise to Mr Ryan's parents for all the failings I have set out in my report.
- 280 I also **recommend** that the Trust offer compensation of £40,000 to Mr Ryan's parents in recognition of the injustice they have suffered in consequence of the service failure and maladministration I have identified.

The Trust's response to my recommendations

- 281 The Chief Executive of the Trust acknowledged the failings identified in this report and said:

'The Trust unreservedly apologises to Mr and Mrs Ryan for the failings identified in the Ombudsman's report. We know that nothing can be done to take away the pain and anguish caused to their family, but hope that our commitment to have learnt from our mistakes will offer some comfort. The Trust accepts the remedy proposed by the Ombudsman.'

I have outlined above some of the actions taken by the Trust in respect of its failings. I have already commented that I find these actions appropriate and I am reassured that lessons have been learnt from this case. The Chief Executive accepted my recommendation regarding a compensation payment and offered to make that payment as soon as possible.

Mr Ryan's parents' response to my report

- 282 Mr Ryan's family and Mencap have said the outcome of my investigation is that *'justice has been done'* because my report exposes the failures that led to Mr Ryan's death. They also welcomed my conclusion that some of the failures in care and treatment were for disability related reasons. They told me they believe my report will have a positive impact on future care of people with learning disabilities. In particular, they have said that my report shows how *'proper care, using multidisciplinary working, personalised care planning and good communication within teams and with families and carers would greatly improve the outcome for people with a learning disability in our hospitals'*.

283 Mr Ryan's family have also welcomed the information provided by the Trust regarding changes which have been put in place to prevent a similar event occurring and they hope this work can be used to benefit other hospitals. Mr Ryan's family welcomed the personal apology which they received from the Chief Executive of the Trust.

My concluding remarks

284 Mrs Ryan's complaints have been thoroughly and impartially investigated and my conclusions have been drawn from careful consideration of the detailed evidence, including the opinion of independent professional advisers. I hope my report will provide Mrs Ryan with the answers she seeks and will reassure her that lessons have been learnt and learning shared so that others are now less likely to suffer the same experiences as Mr Ryan and his family. I also hope that my report will draw what has been a long and complex complaints process to a close.



Ann Abraham
Parliamentary and Health Service Ombudsman

March 2009

ANNEX A

Good Medical Practice, 2001: relevant sections

The duties of a doctor

'Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- *make the care of your patient your first concern;*
- *treat every patient politely and considerately;*
- *respect patients' dignity and privacy;*
- *listen to patients and respect their views;*
- *give patients information in a way they can understand;*
- *respect the rights of patients to be fully involved in decisions about their care;*
- *keep your professional knowledge and skills up to date;*
- *recognise the limits of your professional competence;*
- *be honest and trustworthy;*
- *respect and protect confidential information;*
- *make sure that your personal beliefs do not prejudice your patients' care;*
- *act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;*

- *avoid abusing your position as a doctor; and*
- *work with colleagues in the ways that best serve patients' interests.*

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.'

Providing a good standard of practice and care (sections 2 and 3)

'Good clinical care must include:

- *an adequate assessment of the patient's conditions, based on the history and symptoms and, if necessary, an appropriate examination;*
- *providing or arranging investigations or treatment where necessary;*
- *taking suitable and prompt action when necessary;*
- *referring the patient to another practitioner, when indicated.*

'In providing care you must:

- *recognise and work within the limits of your professional competence;*
- *be willing to consult colleagues;*
- *be competent when making diagnoses and when giving or arranging treatment;*
- *keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions*

made, the information given to patients and any drugs or other treatment prescribed;

- keep colleagues well informed when sharing the care of patients;
- provide the necessary care to alleviate pain and distress whether or not curative treatment is possible;
- prescribe drugs or treatment, including repeat prescriptions, only where you have adequate knowledge of the patient's health and medical needs. You must not give or recommend to patients any investigation or treatment which you know is not in their best interests, nor withhold appropriate treatments or referral;
- report adverse drug reactions as required under the relevant reporting scheme, and co-operate with requests for information from organisations monitoring the public health;
- make efficient use of the resources available to you.'

Working with colleagues (section 36)

'Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide. When working in a team, you must:

- respect the skills and contributions of your colleagues;
- ...
- communicate effectively with colleagues within and outside the team.'

Leading teams (section 37)

'If you lead a team, you must ensure that:

- medical team members meet the standards of conduct and care set out in this guidance;
- any problems that might prevent colleagues from other professions following guidance from their own regulatory bodies are brought to your attention and addressed;
- all team members understand their personal and collective responsibility for the safety of patients, and for openly and honestly recording and discussing problems;
- each patient's care is properly co-ordinated and managed and that patients know who to contact if they have questions or concerns;
- arrangements are in place to provide cover at all times;
- regular reviews and audit of the standards and performance of the team are undertaken and any deficiencies are addressed;

...'

Arranging cover (section 39)

'You must be satisfied that, when you are off duty, suitable arrangements are made for your patients' medical care. These arrangements should include effective hand-over procedures and clear communication between doctors.'

ANNEX B

National Clinical Guidelines for Stroke, 2nd Edition, 2004 (extracts)

Organisation of stroke services

a. Stroke services should be organised so that patients are admitted under the care of a specialist team for their acute care and rehabilitation.

b. Stroke services should have:

- a geographically identified unit as part of the in-patient service
- a co-ordinated multidisciplinary team that meets at least once a week
- staff with specialist expertise in stroke and rehabilitation
- educational programmes for staff, patients and carers
- agreed protocols for common problems
- access to brain and vascular imaging services.

Assessment of acute stroke

a. Brain imaging should be undertaken as soon as possible in all patients, at least within 24 hours of onset.

b. The diagnosis should always be reviewed by an experienced clinician with expertise in stroke.

c. If the underlying pathology is uncertain, or the diagnosis of stroke is in doubt after computed tomography scan, magnetic resonance imaging should be considered.

d. The patient should be assessed on admission for:

- their risk of aspiration, using a validated 50ml water screening tool, administered by an appropriately trained professional
- their needs in relation to moving and handling, and their risk of developing pressure sores.

Acute interventions

a. Blood glucose, arterial oxygen concentration, hydration and temperature should be maintained within normal limits.

b. Blood pressure should only be lowered in the acute phase where there are likely to be complications from hypertension, for example hypertensive encephalopathy, aortic aneurysm with renal involvement.

c. Patients should be mobilised as soon as possible.

d. Aspirin (300mg) orally or rectally should be given as soon as possible after the onset of stroke symptoms if a diagnosis of primary haemorrhage has been excluded.

ANNEX C

Summary of key events (from medical and nursing records)

26 November 2005

Day 1

Mr Ryan was admitted to the Trust at around 5.45am, after he had suffered a stroke.

Mr Ryan was reviewed by an A&E junior doctor and later by another junior doctor. Tests and investigations, including a chest X-ray and blood tests, were carried out.

Mr Ryan was reviewed by a consultant (not the Consultant) at 8.00am and transferred to the Ward at 12.30pm. He was reviewed by a junior doctor at 6.00pm. This junior doctor decided Mr Ryan may have aspirated after eating, and therefore should be designated 'nil by mouth'. A course of antibiotics was started and a weakness was noted on Mr Ryan's left side.

28 November 2005

Day 3

A junior doctor saw Mr Ryan because he was drowsy but 'awake and rousable'. He was also not moving his left side. This junior doctor asked for an urgent CT scan, and a repeat chest X-ray. Intravenous infusion and antibiotics were continued and a speech and language therapy review was suggested.

The Community Learning Disability Team Nurse made an entry in the notes in which she explained that she was Mr Ryan's community nurse and provided two telephone contact numbers. In her note she asked to speak to the Consultant, expressed concern about the fact the CT scan had not been done and asked if she could liaise with a speech and language therapist and a physiotherapist after the CT scan had been done.

29 November 2005

Day 4

Mr Ryan was referred to speech and language therapy.

Mr Ryan was reviewed by the Consultant.

The Specialist Registrar in Radiology reported that the CT scan showed a recent infarct in the right side of Mr Ryan's brain.

30 November 2005

Day 5

A junior doctor noted that he had discussed the CT report with the Community Learning Disability Team Nurse but there is no record of what was said.

The physiotherapist reviewed Mr Ryan's position in bed.

A senior house officer said that Mr Ryan should remain nil by mouth and the intravenous infusions should continue. He also ordered further blood tests.

With his carer present, Mr Ryan was reviewed by a physiotherapist. Mr Ryan was unable to co-operate with chest exercises.

Also, while his carer was present, Mr Ryan was reviewed by a speech and language therapist and a note was made of Mr Ryan's normal eating and drinking habits. Mr Ryan tried to take sips of thin and syrupy fluids, but his swallowing was difficult to assess because Mr Ryan could not co-operate with instructions. Mr Ryan also coughed immediately following attempting to drink thin fluids. This speech and language therapist decided there was a high risk of aspiration and Mr Ryan should be given nothing orally.

The Community Learning Disability Team Nurse made an entry in the notes. She asked the medical team to review Mr Ryan's hydration and nutrition, and suggested that there had been breaks in the intravenous fluid regime. She said she thought the intravenous infusion should run continuously. She also asked if intravenous feeding could be considered.

1 December 2005

Day 6

Mr Ryan was reviewed by a junior doctor who said he should continue nil by mouth and should have physiotherapy. This junior doctor ordered additional tests, including tests of heart activity. He made note of a conversation with Mr Ryan's parents during which he had discussed '*diagnosis and management*' with them. There are no recorded details of this conversation.

2 December 2005

Day 7

The consultant reviewed Mr Ryan and said he should be given aspirin.

Mr Ryan was reviewed again by a speech and language therapist who tried him with teaspoons of creamy thick fluid. She decided there was still a high risk of aspiration and he should remain nil by mouth. She questioned whether Mr Ryan would tolerate alternative feeding methods.

Mr Ryan was reviewed twice by a physiotherapist who thought he may be aspirating his chest secretions. She also tried to seat him in a wheelchair but this was unsafe and the Care Home were asked to bring in his own wheelchair.

5 December 2005

Day 10

A speech and language therapist tried to assess Mr Ryan but was unable to because he was drowsy.

6 December 2005

Day 11

Following review, the Consultant decided Mr Ryan should sit out of bed during the day. Subsequently, the Consultant went on leave. He next saw Mr Ryan on 13 December 2005.

A speech and language therapist tried Mr Ryan with teaspoons of yoghurt. She decided there was still a high risk of aspiration and he should remain nil by mouth.

Mr Ryan was reviewed by a physiotherapist who transferred him into his wheelchair.

7 December 2005

Day 12

A junior doctor carried out a review of Mr Ryan and noted that alternative feeding methods should be considered.

A physiotherapist noted no change in Mr Ryan's condition.

A speech and language therapist again reviewed Mr Ryan and decided he should remain nil by mouth. She wrote:

'Team pls [please] consider this pts [patient's] long term nutrition as pt has been on NBM for 11 days with no improvement to swallow so far.'

8 December 2005

Day 13

Mr Ryan was reviewed by a junior doctor who noted a further improvement in movement in Mr Ryan's left arm. He decided to keep Mr Ryan nil by mouth and to discuss the situation with the Specialist Registrar.

A speech and language therapist tried to review Mr Ryan but he was too drowsy to co-operate.

A junior doctor noted he discussed the result of a heart test with Mr Ryan's sister. There are no recorded details of the discussion.

9 December 2005

Day 14

A junior doctor reviewed Mr Ryan and noted he would discuss his feeding with the Consultant.

A speech and language therapist tried to review Mr Ryan but he was too drowsy to co-operate.

A chest X-ray was taken.

12 December 2005

Day 17

A speech and language therapist reviewed Mr Ryan and wrote that she had discussed his condition with the Community Learning Disability Team Nurse, the Community Social Worker, the Manager of the Care Home and the Ward Sister. She said they had talked about feeding and a discharge destination for Mr Ryan. She explained her role and her opinion about the danger of aspiration. She said she was concerned about Mr Ryan's nutrition and that the team was going to discuss this with the Consultant the following day, with a view to alternative feeding methods.

A speech and language therapist saw Mr Ryan again and tried him with teaspoons of yoghurt. She noted that he did not try to swallow at all, but coughed on the yoghurt. She decided the risk of aspiration remained high and mentioned she was waiting for a decision about alternative feeding.

A Specialist Registrar reviewed Mr Ryan's condition and noted that the intravenous infusion should continue, Mr Ryan should remain nil by mouth and the Consultant would conduct a review the following day.

Mr Ryan's situation was reviewed by a dietician who had discussed him with a speech and language therapist. The dietician noted that Mr Ryan had been without food for 16 days.

13 December 2005

Day 18

The Consultant reviewed Mr Ryan and decided that he should be referred to gastroenterologists for the placement of a PEG feeding tube. A dietician noted that a senior dietician would provide a feeding regime once the PEG feeding tube had been inserted.

14 December 2005

Day 19

Mr Ryan was reviewed by a speech and language therapist who tried him with teaspoons of yoghurt but decided he was severely dysphagic and at high risk of aspiration.

A junior doctor noted that he had discussed the plan to insert a PEG feeding tube with Mrs Ryan.

15 December 2005

Day 20

A medical student recorded that he had been told there was no space in the operating theatre schedule for five days. He had therefore discussed the possibility of feeding Mr Ryan using a nasogastric feeding tube with a speech and language therapist who had told him this would not increase the risk of aspiration but Mr Ryan might pull the tube out. This medical student suggested a nasogastric tube should be used to try to feed Mr Ryan.

A review was carried out by a junior doctor at 11.30pm because Mr Ryan had suddenly deteriorated, with a raised temperature, sudden shortness of breath and increased agitation. This junior doctor noted Mr Ryan had either developed

an aspiration pneumonia, become overloaded with fluid or suffered a pulmonary embolism [clot in the lung]. He arranged blood tests and prescribed antibiotics and oxygen.

16 December 2005

Day 21

The Consultant carried out a review and decided Mr Ryan's condition had deteriorated so much he was now not fit enough to have the PEG feeding tube inserted and so palliative care should be instituted.

A Specialist Registrar discussed Mr Ryan's condition with Mrs Ryan in a telephone conversation. He recorded that:

'She agrees that despite our best efforts over the last 19 days he has not improved + had in fact deteriorated despite our best efforts.'

He recorded that he went on to discuss specific decisions with Mrs Ryan including the palliative care decision (no antibiotics, no intravenous infusion, no PEG feeding tube, no Intensive Care Unit or resuscitation) and that Mrs Ryan agreed with these decisions.

Mr Ryan was reviewed by the Palliative Care Team who suggested intravenous fluids should be stopped, and sedation and pain relief given.

Mr Ryan was also reviewed by a speech and language therapist and a physiotherapist who decided no further intervention from them was appropriate because of the decision to give palliative care only.

Mr Ryan's care was reviewed by a palliative care consultant who spoke to staff from the Care Home and noted their concerns about the decisions which had been taken. A palliative care nurse telephoned Mrs Ryan and also spoke with Mr Ryan's carers.

A case conference was held, involving the Consultant, his Specialist Registrar, staff from the Care Home, the Social Worker and the Ward Sister. An entry was made in the medical notes by the Consultant. It said:

'Aim: to discuss care of patient + future mgt [management].

'Concerns from care staff regarding timely admin [administration] of IV fluids + attempts to feed patient. Explained that due to excessive work demands, there may be occ [occasional] delays in putting up IV fluids but this has never affected his medical health or prognosis.

'Feeding – (Ward Sister) reports attempts to pass NG tube were aborted due to patient's physical refusal + lack of understanding. Further attempts not carried out due to the need for restraint, risk of NG being pulled out + the risk of aspiration. In light of this a PEG was being planned but took extra time due to involvement of family, carers, GI [gastrointestinal] consultant + patient's fitness for procedure. However this was actively being pursued at all times.

' – We are all in agreement that palliative measures should be continued in light of his obvious distress + agitation, + the likely poor prognosis + low chance of recovery from stroke. The carers will discuss amongst themselves regarding whether they wish to complain about the feeding issue and IV fluids.'

17 December 2005**Day 22**

Nurses recorded that Mr Ryan's family had visited him until late in the evening.

19 December 2005**Day 24**

Mr Ryan's care was reviewed by a junior doctor who noted the view of Care Home staff that they were unhappy with Mr Ryan's care and that they said the palliative care plan should be reviewed as Mr Ryan had survived the weekend.

A junior doctor discussed Mr Ryan's care with the Community Learning Disability Team Nurse on the telephone. This doctor noted that the Community Learning Disability Team Nurse said she was unhappy with the outcome of the decision taken at the case conference and that there were discrepancies between the doctors and nurses regarding nasogastric feeding. He also noted that she asked if the management plans should be reviewed because Mr Ryan had survived the weekend.

The Matron noted that the ward nurses were intimidated by Mr Ryan's carers who were making notes of what was happening to him.

20 December 2005**Day 25**

Following review, the Consultant decided palliative care should continue.

21 December 2005**Day 26**

Mr Ryan's death was confirmed at 1.10am.

ANNEX D

The Trust's internal inquiry: summary of findings

The findings about clinical care and treatment were:

- there was no stroke unit and there was no cohort of staff trained to respond to the specific needs of stroke patients;
- care was inadequate because Mr Ryan's nutritional needs were not met, for example there was no overall plan to meet these needs, there was an over-reliance on the hope that swallowing would return, and instructions about passing a nasogastric tube were unclear;
- no co-ordinated, multidisciplinary approach to Mr Ryan's overall needs and a '*complete lack of focus*' on the importance of basic nutrition;
- over-reliance on the outcome of speech and language therapy assessments in decision making about nutrition;
- a lack of continuity in both medical and nursing care, for example there were no daily ward rounds by senior doctors, information about test results was not passed on or actioned, the nursing shift pattern meant the nurse in charge had a caseload of patients as well as a co-ordinating role and the Modern Matron focused on bed management rather than care standards;
- communication difficulties both internally between members of the multidisciplinary team and externally with Mr Ryan's family and the Community Learning Disability Team;
- friction between Trust staff and carers, a possible confusion of responsibilities and a failure to grasp the benefits which the Community Learning Disability Team offered;
- no one acted as the patient's advocate because staff worked within their own professional roles and escalated their concerns; for example, the Speech and Language Therapist did not take a proactive approach to Mr Ryan's overall condition or care;
- medical care was fragmented; for example, there were no routine medical ward rounds at weekends; and
- there was no clear clinical leadership from the Consultant or the Ward Sister; for example, they did not recognise the need to seek advice or involvement from learning disability experts, or to find out about standards about stroke care.

The findings about complaint handling were:

- the complaint by the Community Learning Disability Team seemed to reach a reasonable conclusion;
- the Trust was too slow to recognise the seriousness of the issues complained about, in particular the basic issue of lack of nutrition;
- the Consultant persisted in maintaining Mr Ryan's care had been clinically appropriate and the investigating officer did not challenge this, or statements from other clinicians, possibly because she did not have a clinical background;
- there was a backlog of complaints and, although the basic steps of the complaints policy were followed, investigation of the original complaint was protracted and poorly organised;

- there were inaccuracies and inconsistencies in the responses to Mencap;
- a Serious Untoward Incident was not triggered early enough because clinical staff did not consider there had been significant failures in care (the usual trigger for a Serious Untoward Incident). Further triggers were also missed, specifically when Mencap became involved and during the Directorate of Medicine's 'mini inquiry'; and
- there was no evidence of a developed governance framework and no embedded system of multidisciplinary inquiry.

ANNEX E

The Trust's internal inquiry: recommendations

The report of the internal inquiry should be circulated to all those involved and the Medical Director should personally discuss its findings with the Consultant. The report should also be discussed with the Ward Sister. Arrangements should be made to discuss the findings with Mr Ryan's parents and Mencap.

1. Clinical leadership is essential to the wellbeing of all patients and was clearly lacking in this case. The Trust should:

- consider what additional skills in terms of clinical leadership, developing team working and the care of patients with needs the individual Consultant and Ward Sister require in this area. This might include mentorship;
- review the current arrangements for leadership development and their adequacy in respect of all clinical staff groups; and
- review and clarify the relative roles and responsibilities of the Head of Nursing, Matron and Ward Sisters with the Directorate of Medicine to ensure nursing leadership and the appropriate focus on quality. Ensure that the lead responsibility for quality is clarified.

2. The Trust should review the arrangements for medical staff cover with Medicine, considering the necessity for daily ward rounds of doctors of a suitable seniority, arrangements for annual leave and the adequacy of weekend cover.

3. The Nutritional Review Group should be charged with expediting its work and there should be a formal report back on progress to the Governance Committee at each meeting. This should include a rolling audit of Malnutrition Universal Scoring Tool, which should take place at least biannually until the Trust is assured it is fully embedded in practice.

4. The clinical governance arrangement within the Division of Medicine should be reviewed. This should include systems to assure that learning from complaints and incidents is identified and shared. A review of the triggers for clinical incidents should be undertaken with the Directorate and all staff reminded of the importance of incident reporting.

5. A review of the need for nursing staff dependency tools should take place.

6. A protocol should be developed to help define the relationship of ward staff to formal carers to ensure a mutual understanding of roles.

7. The complaints policy should be reviewed with a view to:

- assessing the value of grading complaints;
- reviewing the role and competencies for investigating officers, and the training available to them;
- considering the circumstances where peer review might be appropriate; and
- considering triggers for escalating complaints when the policy standards are not being complied with.

8. The Speech and Language Therapy Department should review its approach in relation to team working. There should be no hesitancy of bringing to the attention of clinicians any concerns in relation to a patient's care plan, or otherwise escalating concerns.

9. All staff should be encouraged to make known, in non-intimidating circumstances, any concerns that they may have about the clinical care of patients. This includes awareness of channels including the Whistle-Blowing Policy.

On 31 January 2007 the Trust Board added six more recommendations. These were:

1. That a formal disciplinary hearing should take place involving the Consultant and the Ward Sister.
2. That external advice should be sought to validate the Trust's approach to ensuring high nutritional standards for patients.
3. A thorough review of the complaints procedure should take place.
4. A review of the governance arrangements across all Clinical Divisions should take place.
5. That the Report should be presented to Mencap and the parents of Mr Ryan by the Chief Executive and Medical Director and that support from Mencap should be sought in undertaking a review of the Trust's overall approach to the care of patients with a learning disability.
6. That a formal action plan should be developed to address all the recommendations.

PHSO-0006

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office

ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.

Six lives: the provision of public services to people with learning disabilities

Part seven: the complaint made by
Mr and Mrs Wakefield

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Second report

Session 2008-2009

Presented to Parliament pursuant to
Section 14(4) of the Health Service Commissioners Act 1993

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-VII
London: The Stationery Office
£64.15

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ISBN: 9 78 010295 8577

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Section 1: introduction and summary

1 This is the final report of our joint investigation into Mr and Mrs Wakefield's complaint against West Street Surgery (the Surgery), Cheltenham and Tewkesbury Primary Care Trust, now the Gloucestershire Primary Care Trust (the PCT)¹, Gloucestershire County Council (the Council), Gloucestershire Partnership NHS Foundation Trust (the Partnership Trust)², Gloucestershire Hospitals NHS Foundation Trust (the Acute Trust) and the Healthcare Commission. This report contains our findings, conclusions and recommendations with regard to their areas of concern.

The complaint

2 Tom Wakefield was a sociable young man with profound and multiple learning disabilities. He could understand speech and was able to communicate in a variety of ways. He used self-harming behaviour (tearing his face and scalp) to communicate and as a means of getting what he wanted. His school records describe him as having a happy smile and liking simple humour. He enjoyed people-watching and going on outings, including going to the pub. He also liked time by himself. His mother said that until 2001 Tom had been well and had a good appetite. She described him as being big and strong, '*a meat and two veg person*'.

3 Tom's gastrointestinal problems began when he was young. At six months he had repeated haematemesis (vomiting blood). An endoscopy when he was 15 months old revealed severe oesophageal ulceration. He had operations to correct a hiatus hernia (when the upper part of the stomach pushes up into the opening in the diaphragm through which the gullet passes) and a pyloroplasty (when the opening between the

stomach and the intestine is widened to help the stomach empty more quickly). He continued to suffer from oesophageal reflux, a condition that allows the stomach's contents to flow upwards, causing irritation to the oesophagus. It can also sometimes cause aspiration (where stomach contents are inhaled into the lungs). Tom's scoliosis led to postural problems which, combined with his oesophageal reflux and ulceration, gave him pain. However, it appears that until 2001 his pain was well controlled by standard medication.

4 From the age of six Tom attended Penhurst School. While at school his health needs were the responsibility of a team of professionals including school nurses, a speech and language therapist and a GP. Tom should have transferred in July 2003, when he was 19 years old, to suitable adult accommodation. In this period of transition planning, a social worker and representatives of the Community Learning Disability Team were also involved in his care. Because the Council had not found a place for Tom by the date he was due to transfer, it was agreed that he could remain at the school until he was 20 years old.

5 From 2002 Tom's health deteriorated and from early 2003 he was displaying increasing signs of distress and was losing weight. The school thought his behaviour resulted primarily from his unhappiness with his environment. His parents were convinced that his behaviour represented his attempts to communicate pain. From March 2003 Tom was reviewed regularly at a hospice for children and adolescents by consultants with expertise in pain management and in children's medicine. His GP tried unsuccessfully to obtain psychologist or psychiatrist input to help assess Tom's behaviour.

¹ Cheltenham and Tewkesbury PCT, Cotswold and Vale and West Gloucestershire PCT merged in 2006 to form Gloucestershire PCT

² Services now provided by Together Foundation Trust for Gloucestershire

- 6 In the autumn of 2003 Tom's health and behaviour deteriorated further and the school felt that it was no longer able to cope with his needs. On 3 October 2003 he was given six weeks' notice to leave.
- 7 On 20 November 2003 Tom was admitted to an NHS in-patient unit, the Windrush Unit, part of the Partnership Trust. The Windrush Unit served a dual purpose and housed a number of people on a longer-term basis as well as providing an assessment service. The Partnership Trust had recognised that the quality of the environment at the Windrush Unit was poor and the Unit has since closed. When Tom was there the longer-stay patients were being resettled in other accommodation. The usual length of stay for assessment patients was about 12 weeks. Tom was there for just under 14 weeks before permanent accommodation became available towards the end of February 2004. During this period he continued to lose weight and his health and behaviour worsened. In January 2004 he sustained an injury to his ear which became infected and had to be drained under anaesthetic.
- 8 At the end of February 2004 Tom moved to Prospect Place, an adult care home.
- 9 On 2 March 2004 Tom was admitted to a hospital (an event which is not the subject of this complaint) suffering from severe constipation and was discharged within a few days. In April 2004 he was admitted to the Acute Trust. He was found to have an ulcerated oesophagus and an impaired swallow reflex. During this admission a percutaneous endoscopic gastrostomy (PEG) was performed to allow a feeding tube to be passed directly into his stomach.
- 10 Tom died on 25 May 2004. His death certificate records the cause of death as aspiration pneumonia, reflux oesophagitis, scoliosis and cerebral palsy.
- 11 Mr and Mrs Wakefield told the Ombudsmen that they spent over a year trying to persuade NHS organisations and the Council to listen to their concerns about their son. Despite their efforts, they feel that in the last months of his life he was in pain and did not receive the care and support he needed. Throughout this period they felt they were not listened to.
- 12 Three years after Tom's death, his parents say all they have are six separate sets of responses. They still do not have a full account of his care and treatment. Nor do they consider that they have confirmation that organisations have really understood and reflected on what happened to Tom and his family. They believe the bodies concerned have failed to acknowledge the extent of their failings, and have not taken sufficiently robust action to prevent a recurrence.
- 13 Mr and Mrs Wakefield have given permission for Mencap to act as their representative.

The overarching complaint

- 14 Tom's parents believe their son's death was avoidable, that he suffered unnecessarily and that he received less favourable treatment for reasons related to his learning disabilities. We have called these aspects of the complaint 'the overarching complaint'.

Complaint against the Surgery

15 Mr and Mrs Wakefield complain that:

Complaint (a): the care and treatment provided by the Surgery was inadequate. In particular, they consider that the Surgery failed to deal adequately with their son's pain and weight loss and failed to act upon medical advice to refer him for an endoscopy (examination of the gullet and stomach using a telescopic instrument). They consider that had his weight and pain been better managed, and had the endoscopy been performed, the course of events might have been different.

Complaint (b): the Surgery did not provide a reasonable response to their complaint.

Complaint against the Council

16 Mr and Mrs Wakefield complain that:

Complaint (c): the Council failed to plan for, or commission, new provision for their son, or to deal appropriately with his transition into adult accommodation. In particular, they are concerned about the failure by his social worker to pass on information regarding the offer in October 2003 of a suitable permanent placement. They also complain about the way the Council responded to their complaints about Tom's transition to adult care. Although their complaint was investigated at Stage 2 of the Council's complaints procedure, Tom's parents consider that they have not had an adequate response and remain uncertain of the actions taken by the Council in the light of its investigation.

Complaint against the PCT

17 Mr and Mrs Wakefield complain that:

Complaint (d): the PCT failed to liaise appropriately with the Council in planning for their son's transition into adult accommodation.

Complaint (e): the PCT did not provide a reasonable response to their complaint.

Complaint against the Partnership Trust

18 Mr and Mrs Wakefield complain that:

Complaint (f): their son's admission to the Windrush Unit was inappropriate. They also complain that while at the Unit he received inadequate care and treatment (including specific failures to investigate an injury to his ear), that he was generally at risk and he was in a poor physical environment. They also complain that his discharge from the Windrush Unit was badly managed.

Complaint (g): the Partnership Trust did not provide a reasonable response to their complaint.

Complaint against the Acute Trust

19 Mr and Mrs Wakefield complain that:

Complaint (h): the care and treatment provided for their son, particularly with regard to pain management, hydration and nutrition, from his admission in April 2004 until his death the following month was inadequate.

Complaint against the Healthcare Commission

20 Mr and Mrs Wakefield complain about:

Complaint (i): the way the Healthcare Commission handled their complaint, including the time taken to respond.

21 Mr and Mrs Wakefield hope the Ombudsmen's investigation will provide the answers they seek and that their hurt and suffering will be acknowledged. They have said they are aware that nothing will bring Tom back, but they hope other families would benefit from changes brought about as a result of their complaint. They do not want others to go through the same experiences as them and their son.

The Ombudsmen's remit, jurisdiction and powers

General remit of the Health Service Ombudsman

22 By virtue of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints against the NHS in England. In the exercise of her wide discretion she may investigate complaints about NHS bodies such as trusts, family health service providers such as GPs, and independent persons (individuals or bodies) providing a service on behalf of the NHS.

23 When considering complaints against an NHS body, she may look at whether a complainant has suffered injustice or hardship in consequence of a failure in a service provided by the body, a failure by the body to provide a service it was empowered to provide, or maladministration in respect of any other action by or on behalf of the body.

24 Failure or maladministration may arise from action of the body itself, a person employed by or acting on behalf of the body, or a person to whom the body has delegated any functions.

25 When considering complaints against GPs, she may look at whether a complainant has suffered injustice or hardship in consequence of action taken by the GP in connection with the services the GP has undertaken with the NHS to provide. Again, such action may have been taken by the GP himself or herself, by someone employed by or acting on behalf of the GP or by a person to whom the GP has delegated any functions.

26 The Health Service Ombudsman may carry out an investigation in any manner which, to her, seems appropriate in the circumstances of the case and in particular may make such enquiries and obtain such information from such persons as she thinks fit.

27 If the Health Service Ombudsman finds that service failure or maladministration has resulted in an injustice, she will uphold the complaint. If the resulting injustice is unremedied, in line with her *Principles for Remedy*, she may recommend redress to remedy any injustice she has found.

Remit over the Healthcare Commission

28 By operation of section 3(1E) of the *Health Service Commissioners Act 1993*, the Health Service Ombudsman is empowered to investigate complaints about injustice or hardship in consequence of maladministration by any person exercising an NHS complaints function. As the Healthcare Commission is the second stage of the NHS complaints procedure set out in the *National Health Service (Complaints) Regulations 2004*, it is within the Health Service Ombudsman's remit.

Health Service Ombudsman - premature complaints

29 Section 4(5) of the *Health Service Commissioners Act 1993* states that the Health Service Ombudsman generally may not investigate any complaint until the NHS complaints procedure has been invoked and exhausted, and this is the approach taken by the Ombudsman in the majority of NHS complaints made to her.

30 However, section 4(5) makes it clear that if, in the particular circumstances of any case, the Health Service Ombudsman considers it is not reasonable to expect the complainant to have followed the NHS route, she may accept the case for investigation notwithstanding that the complaint has not been dealt with under the NHS complaints procedure. This is a matter for the Health Service Ombudsman's discretion after proper consideration of the facts of each case.

31 In this instance, Tom's parents had not previously complained to the Acute Trust. Nevertheless, they had asked the Healthcare Commission to consider their son's care while in the Acute Trust but this had not happened. They explained that they had become exhausted by the complaints process and had lacked the energy to pursue matters further. They had, however, remained concerned about the care provided to their son while he was a patient at the Acute Trust and feel that without an investigation of his care while he was there they will still not fully understand what happened to him. Taking these matters into account, the Health Service Ombudsman exercised her discretion to investigate the complaint against the Acute Trust under the provisions of the Act which governs her work.

General remit of the Local Government Ombudsman

32 Under the *Local Government Act 1974 Part III*, the Local Government Ombudsman has wide discretion to investigate complaints of injustice arising from maladministration by local authorities (local councils) and certain other public bodies. He may investigate complaints about most council matters, including Social Services and the provision of social care.

33 If the Local Government Ombudsman finds that maladministration has resulted in an injustice, he will uphold the complaint. If the resulting injustice is unremedied, he may recommend redress to remedy any injustice he has found.

Powers to investigate and report jointly

- 34 *The Regulatory Reform (Collaboration etc. between Ombudsmen) Order 2007* clarified the powers of the Health Service Ombudsman and the Local Government Ombudsman, with the consent of the complainant, to share information, carry out joint investigations and produce joint reports in respect of complaints which fell within the remit of both Ombudsmen.
- 35 In this case, the Health Service Ombudsman and the Local Government Ombudsman agreed to work together because the health and social care issues were so closely linked. A co-ordinated response consisting of a joint investigation leading to the production of a joint conclusion and proposed remedy in one report seemed the most appropriate way forward.

The investigation

- 36 During the investigation, our investigator met Mr and Mrs Wakefield and their representative to ensure we had a full understanding of their complaint. The investigator also examined relevant documentation including: Tom's health records from the Surgery, the Partnership Trust and the Acute Trust; the complaint files relating to the attempted local resolution of the complaints by all the bodies complained about; and the complaint files from the Healthcare Commission. Health records were also obtained from a hospice (the Hospice), which Tom attended for assessment in 2003, and the former Medical Director of the Hospice (the Hospice's Medical Director) responded to our specific enquiries. Further comments and information have been provided by the GP, the Partnership Trust, the Acute Trust, the PCT and

the Council. In addition, our investigative staff met staff from the Partnership Trust and the Acute Trust.

- 37 We obtained specialist advice from a number of our professional advisers (the Professional Advisers): Dr I Barrison and Dr R Barry, two consultant gastroenterologists (the First Gastroenterology Adviser and the Second Gastroenterology Adviser); Dr E Ward, a GP (the GP Adviser); Dr N Evans, a consultant psychiatrist (the Psychiatry Adviser); Ms C McFarlane, a senior acute nurse (the Nursing Adviser); Ms N Trenowden, a learning disability nurse (the Learning Disability Nursing Adviser); and Professor C Butler, a professor of pharmacy (the Pharmacy Adviser).
- 38 The Professional Advisers are specialists in their field and in their roles as advisers to the Ombudsmen they are completely independent of any NHS body and the Healthcare Commission. Their role is to help the Ombudsmen and their investigative staff understand the clinical aspects of the complaint.
- 39 In this report we have not referred to all the information examined in the course of our investigation, but we are satisfied that nothing significant to the complaint or our findings has been overlooked.

Our decisions

- 40 Having considered all the available evidence related to Mr and Mrs Wakefield's complaint, including their recollections and their response to our draft report, and taken account of the clinical advice we have received, we have reached the following decisions.

Complaint against the Surgery

41 The Health Service Ombudsman finds that the care and treatment provided by the Surgery, including the management of Tom's pain and weight loss, and the decision not to refer him for an endoscopy, did not fall significantly below a reasonable standard in the circumstances. She finds the failings she identified **do not amount to service failure**. She finds **no maladministration** in the way the Surgery handled Mr and Mrs Wakefield's complaint. She **does not uphold** the complaint against the Surgery.

Complaint against the Council

42 The Local Government Ombudsman finds that the Council's arrangements for Tom's transition to adult accommodation fell significantly below a reasonable standard. This was **maladministration** which contributed to the **injustice** suffered by Tom and his family. It will never be known if, had everything been in place, his life would have been longer or if he could have had some improved enjoyment of his life in his last year. The Local Government Ombudsman has concluded that some of the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons. He **upholds** the complaint about the provision of facilities for Tom and his transition to adult accommodation. The Local Government Ombudsman also finds that Mr and Mrs Wakefield were not provided with an adequate response to their complaint, nor have they received adequate assurance about actions taken subsequently. This was **maladministration** which would have compounded the distress caused to them. He **upholds** the complaint about complaint handling.

Complaint against the PCT

43 The Health Service Ombudsman finds that there were shortcomings in the way the PCT fulfilled its responsibilities with regard to planning for the health needs of people with profound and multiple learning disabilities. This was **service failure**. She recognises that the Council had lead responsibility for planning for transition to adult care, but concludes nonetheless that it is impossible to know what difference it would have made to Tom and his family in terms of his transition to adult accommodation if the PCT had fulfilled its responsibilities to people with profound and multiple learning disabilities. This unanswered question remains a cause of distress for Tom's parents which has yet to be acknowledged and is an **unremedied injustice**. The Health Service Ombudsman also concludes that the service failure by the PCT was for disability related reasons. She finds **maladministration** in the way the PCT handled Mr and Mrs Wakefield's complaint. Given the **unremedied injustice** resulting from service failure she **upholds** the complaint against the PCT.

Complaint against the Partnership Trust

44 The Health Service Ombudsman finds that the admission to the Windrush Unit was appropriate. She also finds that, whilst the Partnership Trust made a reasonable assessment of Tom's needs, the plans set out for him were not implemented. He was not provided with reasonable nursing care. The arrangements for his discharge to his adult care home were inadequate. This **service failure** by the Partnership Trust contributed to the **injustice** of unnecessary distress and suffering for Tom and his family. The Health Service Ombudsman concludes that some of the service failures by

the Partnership Trust in terms of managing his discharge and his care and treatment were for disability related reasons. She also concludes that the Partnership Trust's acts and omissions constituted a failure to live up to human rights principles of dignity and equality. In addition, she finds **maladministration** in the way the Partnership Trust handled Mr and Mrs Wakefield's complaint. She **upholds** the complaint against the Partnership Trust.

Complaint against the Acute Trust

45 The Health Service Ombudsman finds that the nursing and medical care provided by the Acute Trust fell below a reasonable standard. This **service failure** by the Acute Trust contributed to the **injustice** of unnecessary distress and suffering for Tom and his family. The Health Service Ombudsman concludes that some of the service failures by the Acute Trust in terms of care and treatment were for disability related reasons. She also concludes that the Trust's acts and omissions constituted a failure to live up to human rights principles of dignity and equality. She **upholds** the complaint against the Acute Trust.

Complaint against the Healthcare Commission

46 The Health Service Ombudsman finds **maladministration** in the way the Healthcare Commission handled Mr and Mrs Wakefield's complaints, which led to the **injustice** that they were denied a reasonable review of their complaints. She **upholds** the complaint against the Healthcare Commission.

The overarching complaint

47 The Health Service Ombudsman concludes that some of the service failures by the Partnership Trust in terms of managing Tom's discharge, and by both the Partnership Trust and the Acute Trust in terms of his care and treatment, were for disability related reasons. She also concludes that the Trusts' acts and omissions constituted a failure to live up to human rights principles of dignity and equality. She also concludes that the service failure by the PCT was for disability related reasons. The Local Government Ombudsman concludes that some of the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons.

48 The Ombudsmen conclude that there was **service failure** by most, although not all, of the bodies complained about. That service failure resulted in **unremedied injustice** for Tom's parents. They will never know if, had appropriate arrangements been in place for their son's transition to adult care, his life would have been longer or more enjoyable in his last year. **Service failure** by NHS bodies and **maladministration** by the Council have resulted in the **unremedied injustice** of unnecessary distress and suffering for Tom's family. Poor complaint handling has compounded their distress.

49 We conclude that **maladministration** by the Council and **service failure** by the PCT, the Partnership Trust and the Acute Trust resulted in unnecessary suffering for Tom in the final months of his life. The resulting distress for his family is an injustice which remains unremedied.

- 50 We have not found that Tom died in consequence of the maladministration or service failure we identified and, therefore, we cannot say that his death was avoidable.
- 51 In this report we explain the detailed reasons for our decisions and comment on the particular areas where Mr and Mrs Wakefield have expressed concerns to the Ombudsmen.

Section 2: the basis for our determination of the complaints

Introduction

52 In simple terms, when determining complaints that injustice or hardship has been sustained in consequence of service failure and/or maladministration, the Ombudsmen generally begin by comparing what actually happened with what should have happened.

53 So, in addition to establishing the facts that are relevant to the complaint, we also need to establish a clear understanding of the standards, both of general application and which are specific to the circumstances of the case, which applied at the time the events complained about occurred, and which governed the exercise of the administrative and clinical functions of those bodies and individuals whose actions are the subject of the complaint. We call this establishing the overall standard.

54 The overall standard has two components: the general standard which is derived from general principles of good administration and, where applicable, of public law; and the specific standards which are derived from the legal, policy and administrative framework and the professional standards relevant to the events in question.

55 Having established the overall standard we then assess the facts in accordance with the standard. Specifically, we assess whether or not an act or omission on the part of the body or individual complained about constitutes a departure from the applicable standard.

56 If so, we then assess whether, in all the circumstances, that act or omission falls so far short of the applicable standard as to constitute service failure or maladministration.

57 The overall standard which we have applied to this investigation is set out below.

The general standard

Principles of Good Administration

58 Since it was established the Office of the Parliamentary and Health Service Ombudsman has developed and applied certain principles of good administration in determining complaints of service failure and maladministration. In March 2007 the Parliamentary and Health Service Ombudsman published these established principles in codified form in a document entitled *Principles of Good Administration*.

59 The document organises the established principles of good administration into six Principles. These Principles are:

- Getting it right
- Being customer focused
- Being open and accountable
- Acting fairly and proportionately
- Putting things right, and
- Seeking continuous improvement.

60 We have taken all of these Principles into account in our consideration of Mr and Mrs Wakefield's complaint and therefore set out below in greater detail what the *Principles of Good Administration* says under these headings:³

³ *Principles of Good Administration* is available at www.ombudsman.org.uk

'Getting it right' means:

- Acting in accordance with the law and with regard for the rights of those concerned.
- Acting in accordance with the public body's policy and guidance (published or internal).
- Taking proper account of established good practice.
- Providing effective services, using appropriately trained and competent staff.
- Taking reasonable decisions, based on all relevant considerations.

'Being customer focused' means:

- Ensuring people can access services easily.
- Informing customers what they can expect and what the public body expects of them.
- Keeping to commitments, including any published service standards.
- Dealing with people helpfully, promptly and sensitively, bearing in mind their individual circumstances.
- Responding to customers' needs flexibly, including, where appropriate, co-ordinating a response with other service providers.

'Being open and accountable' means:

- Being open and clear about policies and procedures and ensuring that information, and any advice provided, is clear, accurate and complete.

- Stating criteria for decision making and giving reasons for decisions.
- Handling information properly and appropriately.
- Keeping proper and appropriate records.
- Taking responsibility for actions.

'Acting fairly and proportionately' means:

- Treating people impartially, with respect and courtesy.
- Treating people without unlawful discrimination or prejudice, and ensuring no conflict of interests.
- Dealing with people and issues objectively and consistently.
- Ensuring that decisions and actions are proportionate, appropriate and fair.

'Putting things right' means:

- Acknowledging mistakes and apologising where appropriate.
- Putting mistakes right quickly and effectively.
- Providing clear and timely information on how and when to appeal or complain.
- Operating an effective complaints procedure, which includes offering a fair and appropriate remedy when a complaint is upheld.

‘Seeking continuous improvement’ means:

- Reviewing policies and procedures regularly to ensure they are effective.
- Asking for feedback and using it to improve services and performance.
- Ensuring that the public body learns lessons from complaints and uses these to improve services and performance.

Principles for Remedy

- 61 In October 2007 the Parliamentary and Health Service Ombudsman published a document entitled *Principles for Remedy*.⁴
- 62 This document sets out the Principles that we consider should guide how public bodies provide remedies for injustice or hardship resulting from their service failure or maladministration. It sets out how we think public bodies should put things right when they have gone wrong. It also confirms our own approach to recommending remedies. The *Principles for Remedy* flows from, and should be read with, the *Principles of Good Administration*. Providing fair and proportionate remedies is an integral part of good administration and good service, so the same principles apply.
- 63 We have taken the *Principles for Remedy* into account in our consideration of Mr and Mrs Wakefield’s complaints.

The specific standards

Disability discrimination

Legal framework

Disability Discrimination Act 1995

- 64 The sections of the *Disability Discrimination Act 1995* most relevant to the provision of services in this complaint were brought into force in 1996 and 1999 respectively. Although other parts of the *Disability Discrimination Act 1995* were brought into force in 2004 and further provisions added by the *Disability Discrimination Act 2005*, these changes either post-date or are not directly relevant to the subject matter of this complaint.
- 65 Since December 1996 it has been unlawful for service providers to treat disabled people less favourably than other people for a reason relating to their disability, unless such treatment is justified.
- 66 Since October 1999 it has in addition been unlawful for service providers to fail to comply with the duty to make reasonable adjustments for disabled people where the existence of a practice, policy or procedure makes it impossible or unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.
- 67 It has also been unlawful since October 1999 for service providers to fail to comply with the duty to make reasonable adjustments so as to provide a reasonable alternative method of making the service in question available to disabled people where the existence of a physical feature makes it impossible or

⁴ *Principles for Remedy* is available at www.ombudsman.org.uk

unreasonably difficult for disabled people to make use of a service provided, unless such failure is justified.

- 68 Since October 1999 it has been unlawful for service providers to fail to comply with the duty to take reasonable steps to provide auxiliary aids or services to enable or facilitate the use by disabled people of services that the service provider provides, unless that would necessitate a permanent alteration to the physical fabric of a building or unless such failure is justified.

Policy aims

- 69 The *Disability Discrimination Act 1995* recognises that the disabling effect of physical and mental impairment will depend upon how far the physical and social environment creates obstacles to disabled people's enjoyment of the same goods, services and facilities as the rest of the public.
- 70 The key policy aim behind the legislation is to ensure that as far as reasonably possible disabled people enjoy access not just to the same services, but to the same standard of service, as other members of the public. In other words, those who provide services to the public, whether in a private or public capacity, are to do whatever they reasonably can to eradicate any disadvantage that exists for a reason related to a person's physical or mental impairment.
- 71 The critical component of disability rights policy is therefore the obligation to make 'reasonable adjustments', which shapes the 'positive accent' of the *Disability Discrimination Act 1995*. This obligation recognises that very often equality for disabled people requires not the same treatment as everyone else but different treatment. The House of Lords made

explicit what this means in a case (*Archibald v Fife Council*, [2004] UKHL 32, judgment of Baroness Hale), which although arising from the *Part 2* employment provisions of the *Disability Discrimination Act 1995*, has bearing on the *Part 3* service provisions also:

'The 1995 Act, however, does not regard the differences between disabled people and others as irrelevant. It does not expect each to be treated in the same way. It expects reasonable adjustments to be made to cater for the special needs of disabled people. It necessarily entails an element of more favourable treatment.'

- 72 As the Court of Appeal has also explained, specifically in respect of the *Part 3* service provisions of the *Disability Discrimination Act 1995* (*Roads v Central Trains* [2004] EWCA Civ 1451, judgment of Sedley LJ), the aim is to ensure 'access to a service as close as it is possible to get to the standard offered to the public at large'.

Policy and administrative guidance

Disability Rights Commission Codes of Practice

- 73 Between April 2000 and October 2007 the Disability Rights Commission had responsibility for the enforcement and promotion of disability rights in Britain. In that capacity, and by virtue of the provisions of the *Disability Rights Commission Act 1999*, it had a duty to prepare statutory codes of practice on the law. These statutory codes of practice, although not legally binding, are to be taken into account by courts and tribunals in determining any issue to which their provisions are relevant.

- 74 Before the establishment of the Disability Rights Commission in April 2000, the relevant Secretary of State, on the advice of the National Disability Council, published a statutory code of practice on the duties of service providers under Part 3 of the *Disability Discrimination Act 1995* entitled *Code of Practice: Goods, Facilities, Services and Premises* (1999), itself a revision of an earlier code of practice published in 1996.
- 75 On its establishment in 2000 the Disability Rights Commission consulted on a further revised code of practice, which came into force on 27 May 2002 as the *Disability Discrimination Code of Practice (Goods, Facilities, Services and Premises)*. The revised code of practice not only updated the previous codes but anticipated the changes to the law that were due to come into effect in 2004, in particular with respect to the duty to remove obstructive physical features.
- 76 The 2002 code made it clear that a service provider's duty to make reasonable adjustments is a duty owed to disabled people at large and that the duty is 'anticipatory':
- 'Service providers should not wait until a disabled person wants to use a service which they provide before they give consideration to their duty to make reasonable adjustments. They should be thinking now about the accessibility of their services to disabled people. Service providers should be planning continually for the reasonable adjustments they need to make, whether or not they already have disabled customers. They should anticipate the requirements of disabled people and the adjustments that may have to be made for them.'*
- 77 It also drew attention to the pragmatic strain of the *Disability Discrimination Act 1995*. For example, in respect of the forthcoming 'physical features' duty, the code says:
- 'The Act does not require a service provider to adopt one way of meeting its obligations rather than another. The focus of the Act is on results. Where there is a physical barrier, the service provider's aim should be to make its services accessible to disabled people. What is important is that this aim is achieved, rather than how it is achieved.'*
- Valuing People: A New Strategy for Learning Disability for the 21st Century (2001)**
- 78 In 2001 the Department of Health published a White Paper, explicitly shaped by the relevant legislation (including the *Disability Discrimination Act 1995* and the *Human Rights Act 1998*), with a foreword written by the then Prime Minister, outlining the Government's future strategy and objectives for achieving improvements in the lives of people with learning disabilities.
- 79 The White Paper identified four key principles that it wanted to promote: legal and civil rights (including rights to education, to vote, to have a family and to express opinions); independence; choice; and inclusion (in the sense of being part of mainstream society and being integrated into the local community).
- 80 As the White Paper explained, the intention was that 'All public services will treat people with learning disabilities as individuals, with respect for their dignity'.

81 The fifth stated objective of the Government was to *'enable people with learning disabilities to access health services designed around individual needs, with fast and convenient care delivered to a consistently high standard, and with additional support where necessary'*.

82 The Department of Health also published in 2001 two circulars aimed jointly at the health service and local authorities, focusing on the implementation of Valuing People and including detailed arrangements for the establishment of Learning Disability Partnership Boards: *HSC 2001/016* and *LAC (2001) 23*.

83 The Department of Health has published a series of reports to help the NHS meet its duties under the *Disability Discrimination Act 1995*.

Signposts for success in commissioning and providing health services for people with learning disabilities (1998)

84 This was published by the Department of Health and was the result of extensive consultation undertaken with people with learning disabilities, carers and professionals with the aim of informing good practice. It was targeted at the whole NHS and emphasises the need for shared values and responsibilities, respecting individual rights, good quality information and effective training and development. It also encourages the use of personal health records. The accompanying executive letter *EL (98)3* informs chief executives of the availability of the guidance.

Doubly Disabled: Equality for disabled people in the new NHS – access to services (1999)

85 This Department of Health report, also aimed at the whole NHS, contains a specific section on learning disability. It provides guidance for managers with specific responsibility for advising on access for disabled patients to services and employment. It also provides information for all staff on general disability issues. The accompanying circular *HSC 1999/093* emphasises the purpose of the document saying:

'... it will be essential for service providers to ensure that they have taken reasonable steps to ensure that services are not impossible or unreasonably difficult for disabled people to use.'

Once a Day: A Primary Care Handbook for people with learning disabilities (1999)

86 This was issued jointly by the Department of Health and the Royal College of General Practitioners, and was specifically aimed at primary care services. It draws attention to the interface between primary care and general hospital services and sets out actions which healthcare providers should take to facilitate equal access to health services for people with learning disabilities. The overall purpose of the handbook was described in the accompanying circular *HSC 1999/103* which says:

'The purpose of this guidance, for GPs and primary care teams, is to enhance their understanding, improve their practice and promote their partnerships with other agencies and NHS services.'

In practice

- 87 The practical effect of the legal, policy and administrative framework on disability discrimination is to require public authorities to make their services accessible to disabled people. To achieve this objective they must take all reasonable steps to ensure that the design and delivery of services do not place disabled people at a disadvantage in their enjoyment of the benefits provided by those services.
- 88 Failure to meet this standard will mean not only that there is maladministration or service failure, but that there is maladministration or service failure for a disability related reason. This does not require a deliberate intention to treat disabled people less favourably. It will be enough that the public authority has not taken the steps needed, without good reason.
- 89 To be confident that it has met the standard, a public authority will need to show that it has planned its services effectively, for example, by taking account of the views of disabled people themselves and by conducting the risk assessments needed to avoid false assumptions; that it has the ability to be flexible, for example, by making reasonable adjustments to its policies, practices and procedures, whenever necessary; and by reviewing arrangements regularly, not just when an individual disabled person presents a new challenge to service delivery.
- 90 It should also be noted that a failure to meet the standard might occur even when the service in question has been specially designed to meet the needs of disabled people. This might be because, for example, the service design meets the needs of some disabled people but not others, or because good design has not been translated into good practice.

- 91 It is not for the Ombudsmen to make findings of law. It is, however, the role of the Ombudsmen to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsmen will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving disabled people, such considerations are so integral to good administration and service delivery that it is impossible to ignore them.

Human rights

Legal framework

Human Rights Act 1998

- 92 The *Human Rights Act 1998* came into force in England in October 2000. The *Human Rights Act 1998* was intended to give further effect to the rights and freedoms already guaranteed to UK citizens by the *European Convention on Human Rights*. To that extent, the *Human Rights Act 1998* did not so much create new substantive rights for UK citizens but rather established new arrangements for the domestic enforcement of those existing substantive rights.
- 93 It requires public authorities (that is, bodies which exercise public functions) to act in a way that is compatible with the *European Convention on Human Rights*; it requires the courts to interpret statute and common law in accordance with the *European Convention on Human Rights* and to interpret legislation compatibly with the *European Convention on Human Rights* wherever possible; and it

requires the sponsors of new legislation to make declarations when introducing a Bill in Parliament as to the compatibility of that legislation with the *European Convention on Human Rights*.

- 94 Of particular relevance to the delivery of healthcare to disabled people by a public authority are the following rights contained in the *European Convention on Human Rights*:

Article 2 Right to life

Article 3 Prohibition of torture, or inhuman or degrading treatment

Article 14 Prohibition of discrimination.

Policy aims

- 95 When the UK Government introduced the *Human Rights Act 1998*, it said its intention was to do more than require government and public authorities to comply with the *European Convention on Human Rights*. It wanted instead to create a new ‘*human rights culture*’ among public authorities and among the public at large.

- 96 A key component of that human rights culture is observance of the core human rights principles of Fairness, Respect, Equality, Dignity and Autonomy for all. These are the principles that lie behind the *Human Rights Act 1998*, the *European Convention on Human Rights* and human rights case law, both in the UK and in Strasbourg.

- 97 These principles are not new. As the Minister of State for Health Services remarked in her foreword to *Human Rights in Healthcare – A Framework for Local Action* (2007):

‘The Human Rights Act supports the incorporation of these principles into our law, in order to embed them into all public services. These principles are as relevant now as they were over 50 years ago when UK public servants helped draft the European Convention on Human Rights.’

- 98 The policy implications for the healthcare services are also apparent as one aspect of that aim of using human rights to improve service delivery. As the Minister of State also observed:

‘Quite simply we cannot hope to improve people’s health and well-being if we are not ensuring that their human rights are respected. Human rights are not just about avoiding getting it wrong, they are an opportunity to make real improvements to people’s lives. Human rights can provide a practical way of making the common sense principles that we have as a society a reality.’

- 99 At the time of the introduction of the *Human Rights Act 1998* in October 2000, the importance of human rights for disabled people was recognised. Writing in the Disability Rights Commission’s publication of September 2000 entitled *The Impact of the Human Rights Act on Disabled People*, the then Chair of the Disability Rights Commission noted that:

‘The Human Rights Act has particular significance for disabled people ... The withdrawal or restriction of medical services, the abuse and degrading treatment of disabled people in institutional care, and prejudiced judgements about the parenting ability of disabled people are just some of the areas where the Human Rights Act may help disabled people live fully and freely, on equal terms with non-disabled people.’

In practice

- ¹⁰⁰ The practical effect of the legal, policy and administrative framework on human rights is to create an obligation on public authorities not only to promote and protect the positive legal rights contained in the *Human Rights Act 1998* and other applicable human rights instruments but to have regard to the practical application of the human rights principles of Fairness, Respect, Equality, Dignity and Autonomy in everything they do.
- ¹⁰¹ Failure to meet this standard will not only mean that the individual has been denied the full enjoyment of his or her rights; it will also mean that there has been maladministration or service failure.
- ¹⁰² To be confident that it has met the requisite standard, a public authority will need to show that it has taken account of relevant human rights principles not only in its design of services but in their implementation. It will, for example, need to show that it has made decisions that are fair (including by giving those affected by decisions a chance to have their say, by avoiding blanket policies, by acting proportionately and by giving clear reasons); that it has treated everyone with respect (including by avoiding unnecessary embarrassment or humiliation, by enabling individuals to make their own choices so far as practicable, and by having due regard to the individual's enjoyment of physical and mental wellbeing); that it has made genuine efforts to achieve equality (including by avoiding unjustifiable discrimination, by taking reasonable steps to enable a person to enjoy participation in the processes that affect them, by enabling a person to express their own personal identity and by actively recognising and responding appropriately to difference);

that it has preserved human dignity (including by taking reasonable steps to protect a person's life and wellbeing, by avoiding treatment that causes unnecessary mental or physical harm, and by avoiding treatment that is humiliating or undignified); and that it has promoted individual autonomy (including by taking reasonable steps to ensure that a person can live independently).

- ¹⁰³ It is not for the Ombudsmen to make findings of law. It is, however, the role of the Ombudsmen to uphold the published *Principles of Good Administration*. These include the obligation to 'get it right' by acting in accordance with the law and with regard for the rights of those concerned. Where evidence of compliance is lacking, the Ombudsmen will be mindful of that in determining the overall quality of administration and service provided in the particular case. In cases involving health and social care, such considerations are so integral to the assessment of good administration and good service delivery that it is impossible to ignore them.

Health and social care

Legal framework

National Health Service Act 1977

- ¹⁰⁴ The *National Health Service Act 1977* made it a duty for the NHS to promote services to improve health. Section 1 of the Act confers a duty on the Secretary of State to secure improvements in the physical and mental health of the population. Section 22 creates a duty of co-operation between NHS bodies and local authorities in exercising their respective functions.

National Health Service and Community Care Act 1990

- 105 The *National Health Service and Community Care Act 1990* clarified that local authorities have a duty to assess the individual community care needs of any person who, in their view, requires services and then have to decide what services should be provided. The Act also required health authorities to assist in the assessment of need in cases where the person appeared to require the services of the NHS.

Health Act 1999

- 106 The *Health Act 1999* enabled the establishment of primary care trusts and described their functions.

Care Standards Act 2000

- 107 The main purpose of the Act was to reform the regulatory system for care services in England and Wales. For the first time, local authorities were to be required to meet the same standards as independent sector providers. In England the Act provided for an independent National Care Standards Commission to undertake a regulatory function to ensure that standards were met.

The Care Homes regulations, amended 2003, incorporating National Minimum Standards for Social Care

- 108 These regulations and standards form the basis of the regulatory framework established under the *Care Standards Act 2000* for the conduct of care homes and were drafted following consultation with service users, providers and regulators. The regulations contain a statement of national minimum standards published by the Secretary of State under section 23(1) of the *Care Standards Act 2000* applicable to care homes (as defined by section 3 of that Act) which provide accommodation, together with nursing or personal care, for adults (aged 18-65).

Standard 2 of the National Minimum Standards Care Homes Regulations (*Care Homes for Adults (18-65)*), states:

'2.1 New service users are admitted only on the basis of a full assessment undertaken by people competent to do so, involving the prospective service user, using an appropriate communication method and with an independent advocate as appropriate.'

'2.2 For individuals referred through Care Management, the registered manager obtains a summary of the single Care Management (health and social services) assessment – integrated with the Care Programme Approach (CPA) for people with mental health problems – and a copy of the single Care Plan.'

Community Care (Delayed Discharges etc) Act 2003

- 109 The *Community Care (Delayed Discharges etc) Act 2003* placed a duty upon local authorities to enable timely, well planned discharges from hospital for people who had a need for social care. It required the NHS to alert social services departments to patients who may need social care support to enable discharge from hospital.

Policy aims

- 110 By the end of the 1990s the Government had become concerned about a number of failures in social care and in the co-ordination of care across health and social services. Accordingly, further legislation (which built on early legislation) was introduced to underline the requirement for proper assessment of needs and planning of health and social care for whole communities and for individuals. The Government also introduced legislation

to raise the quality, safety and consistency of services provided to people with complex health and social care needs and to ensure that people with complex needs were discharged from hospital safely and without unnecessary delay.

Policy and administrative guidance

Governing the NHS: A Guide for NHS Boards

111 This document was issued jointly by the Department of Health and the NHS Appointments Commission in 2003 and summarises the main functions of primary care trusts as being to:

- identify the health needs of the population
- maintain an effective public health function
- work to improve the health of the community
- lead local planning
- secure the provision of a full range of services
- manage and develop primary healthcare services
- develop and improve local services
- lead the integration of health and social care
- deliver services within their remit.

Moving into the Mainstream, the report of a national inspection of services for adults with learning disabilities

112 This report was issued to local authorities by the Chief Inspector of the Social Services Inspectorate (SSI) in 1998 and set out best practice guidance for local authorities about the planning and provision of services for people with learning disabilities.

HSC 2001/016 and LAC (2001) 23: Valuing People: A New Strategy for Learning Disability for the 21st Century: implementation

113 Valuing People drew on the legislation and guidance described above and clarified how it was to be applied to people with learning disabilities. HSC 2001/016 and LAC (2001) 23 circulars laid out specifically what was expected of the NHS and local authorities. Local authorities would, by October 2001, have established learning disability partnership boards that would develop integrated plans and services for people with learning disabilities, taking account of the health needs of the population, resources and service users' and carers' views. Councils were expected to take the lead role with the learning disability partnership boards for ensuring appropriate plans were drawn up and provision was made for people with learning disabilities to whom councils had a duty of care. Primary care trusts would be the lead NHS organisations on the partnership board and would take account of the partnership board's plans in exercising their duties to assess the health needs of people with learning disabilities and in commissioning an appropriate range of services. The partnership boards would, by 2002, have a framework in place for planning services to address the needs of young people making the transition to adult services and would take action to ensure that people with learning disabilities could obtain fair benefit from mainstream policy. A quality framework would be in place by April 2002 to improve service quality amongst all agencies, with particular attention for people with complex needs such as those with profound and multiple learning disabilities.

114 By winter 2002 people with learning disabilities who made substantial and long-term use of publicly funded services were to have a named person to act as their service co-ordinator. This person was to pay particular attention to achieving effective organisation and monitoring of services provided by all agencies. A health facilitator was to be available to help people to access the healthcare they needed and to help healthcare providers develop appropriate skills – especially in primary and secondary care.

LAC (2003) 13, Fair access to care services: guidance on eligibility criteria for adult social care

115 In this circular the Department of Health reminded councils of their duties under section 47 of the *NHS and Community Care Act 1990* and said that they should develop strategies to fill gaps and improve the range, accessibility and effectiveness of adult social care services. It says that prior to admission to adult care, a care plan should be developed and agreed with the individual. There should be a written record of a care plan that should encompass, as a minimum, a note of eligible needs, the preferred outcome of service provision, contingency plans to manage emergency changes and a review date.

116 The *National service framework for mental health: modern standards and service models* (the National Service Framework for Mental Health) (Department of Health, 1999) reiterated the importance of the Care Programme Approach (CPA) as a means for systematically assessing an individual's health and social care and for drawing up plans to address those needs. The CPA required close working between health and social services and the involvement of users and carers. It stressed the need for anticipatory planning to enable better decision making at times of change and to try to avoid crisis.

117 In *Making a Difference: strengthening the nursing, midwifery and health visiting contribution to health and healthcare* (Making a Difference), issued in 1999 by the Department of Health, the Chief Nursing Officer identified a need to focus on the fundamentals of nursing care. This led to the development of a set of benchmarking tools known as *The Essence of Care: Patient-focused benchmarking for health care practitioners* (the Essence of Care), (Department of Health, 2001). At the time of this complaint benchmarking tools were available for eight areas including:

- Food and nutrition
- Personal hygiene and mouth care
- Continence and bladder and bowel care
- Record keeping
- Safety of patients with mental health needs
- Privacy and dignity
- Communication.

NHS trusts were expected to develop and implement local policies that ensured compliance with the benchmark standards.

118 In January 2003 the Department of Health published comprehensive guidelines about discharging patients from hospital called *Discharge from hospital: pathway, process and practice* (Discharge from Hospital). The lengthy guidelines are in the form of a workbook and include principles for good practice as well as introducing a range of tools to assist professionals involved in the discharge process. Amongst other things, it expects organisations

to have arrangements to ensure that people can be safely transported home or to another setting and that relevant information, such as discharge summaries and care plans, transfer on a timely basis. Amongst the document's 'key messages' are:

'Ensure individuals and their carers are actively engaged in the planning and delivery of their care.'

'...

'Agree, operate and performance manage a joint discharge policy that facilitates effective multidisciplinary working at ward level and between organisations.'

'On admission, identify those individuals who may have additional health, social and/or housing needs to be met before they can leave hospital and target them for extra support.'

'...

'Consider how an integrated discharge planning team can be developed to provide specialist discharge planning support to the patient and multidisciplinary team.'

- 119 Appendices 5.6 and 5.7 of the guidelines specifically address the needs of people with learning disabilities, mental health problems or dementia. The importance of meeting the special needs of these groups of patients by effective multidisciplinary and multi-agency working is threaded through the guidance.

Professional standards

The General Medical Council

- 120 The General Medical Council (the body responsible for professional regulation of doctors) publishes *Good Medical Practice* (Good Medical Practice), which contains general guidance on how doctors should approach their work. This booklet is clear that it represents standards which the General Medical Council expects doctors to meet. It sets out the duties and responsibilities of doctors and describes the principles of good medical practice and standard of competence, care and conduct expected of doctors in all areas of their work. Key sections of the booklet current at the time of this complaint are set out at Annex A.

- 121 Paragraph 5 of Good Medical Practice, 2001, says:

'The investigation and treatment you provide or arrange must be based on your clinical judgement of patients' needs and the likely effectiveness of treatment. You must not allow your views about a patient's lifestyle, culture, beliefs, race, colour, gender, sexuality, disability, age, or social or economic status, to prejudice the treatment you arrange.'

The Nursing and Midwifery Council

- 122 The Nursing and Midwifery Council (the body responsible for professional regulation of nurses) publishes a booklet, *The Nursing and Midwifery Council code of professional conduct* (the Code of Conduct), which contains general and specific guidance on how nurses should approach their work. The booklet represents the standards which the Nursing and Midwifery Council expects nurses to meet.

123 Paragraph 1 of the Code of Conduct current in 2004 said:

'You are personally accountable for your practice. This means that you are answerable for your actions and omissions, regardless of advice or directions from another professional.'

'You have a duty of care to your patients and clients, who are entitled to receive safe and competent care.'

124 Paragraph 2 of the Code of Conduct said:

'As a registered nurse, midwife or health visitor, you must respect the patient or client as an individual.'

'...

'You are personally accountable for ensuring that you promote and protect the interests and dignity of patients and clients, irrespective of gender, age, race, ability, sexuality, economic status, lifestyle, culture and religious or political beliefs.'

125 Paragraph 4 of the Code of Conduct emphasised the importance of teamwork and communication. It said:

'As a registered nurse, midwife or health visitor, you must co-operate with others in a team.'

'The team includes the patient or client, the patient's or client's family, informal carers and health and social care professionals in the National Health Service, independent and voluntary sectors.'

'You are expected to work co-operatively within teams and to respect the skills, expertise and contributions of your colleagues. You must treat them fairly and without discrimination.'

'You must communicate effectively and share your knowledge, skill and expertise with other members of the team as required for the benefit of patients and clients.'

'Health care records are a tool of communication within the team. You must ensure that the health care record for the patient or client is an accurate account of treatment, care planning and delivery.'

Complaint handling

Council complaint handling

126 The *NHS and Community Care Act 1990* imposes on Social Services authorities a statutory duty to provide a complaints procedure. Statutory guidance has been issued by the Department of Health and authorities must have regard to it when managing complaints about their service. The statutory complaints process applicable to this complaint was that contained within the *Complaints Procedure Directions 1990* (these have now been superseded by *The Council Social Services Complaints (England) Regulations 2006* and associated guidance, for complaints made after August 2006).

127 The 1990 Directions established a three-part process consisting of a first, informal, stage aimed at resolving the complaint at a local level, but which progressed to the formal second stage if the complainant remained dissatisfied.

The matter was considered at the second stage by the designated complaints officer and an investigator might be appointed. If the complainant remained dissatisfied at the end of this stage of the process, he or she had the right to request an independent review by a panel set up by the council to review the stage 2 investigation. The panel did not carry out a fresh investigation, nor could it consider any aspect of the complaint that had not already been considered at an earlier stage. The panel had no power to make binding findings, but could make recommendations to the council to resolve the complaint. If the council rejected the findings it had to provide reasons for doing so.

NHS complaint handling

¹²⁸ Prior to 2004 complaint handling in the NHS was subject to various Directions which required NHS trusts to have written procedures for dealing with complaints within their organisation (known as local resolution) and to operate the second element of the complaints procedure (independent review). Complaints against primary care providers were dealt with at the local level under practice-based complaints procedures required under the provider's terms of service.

¹²⁹ However, on 30 July 2004 the *NHS (Complaints) Regulations 2004* (the Regulations) came into force, and created the procedure applicable to this complaint. These Regulations made detailed provision for the handling of complaints at local level by NHS bodies complained about and, if the complainant was dissatisfied with this local resolution, for the complaint to be given further consideration by the Healthcare Commission. Complaints against primary care providers continue to be dealt with at the local level by practice-based complaints procedures, but likewise move to the Healthcare Commission for the second stage of the process.

Complaints against NHS bodies

¹³⁰ The Regulations (Regulation 3(2)) emphasise that complaint handling arrangements by NHS bodies at the local level must ensure that complaints are dealt with speedily and efficiently and that complainants are treated courteously and sympathetically and, as far as possible, involved in decisions about how their complaints are handled. The guidance issued by the Department of Health to support the Regulations emphasises that the procedures should be open, fair, flexible and conciliatory and encourage communication on all sides, with the primary objective being to resolve the complaint satisfactorily while being fair to all parties.

¹³¹ *Part II* of the Regulations (Regulations 3 to 13) sets out the statutory requirements for NHS bodies managing complaints at the local level and deals with such matters as who may make complaints, when they may be made and the matters which may be complained about. A dedicated complaints manager must be identified along with a senior person in the organisation to take responsibility for the local complaints process and for complying with the Regulations. Regulation 13 states that the response to the complaint, which must be signed by the Chief Executive where possible, must be sent to the complainant within 20 working days from when the complaint was made, unless the complainant agrees to a longer period. That response must also inform complainants of their right to refer the complaint to the Healthcare Commission.

Complaints against GPs

- ¹³² Guidance to GPs is found in the 1996 *Practice-based Complaints Procedures. Guidance for general practices*. This is intended to be a good practice guide and sets out a model for a practice-based complaint procedure with sample resource leaflets and suggested forms. It is not intended to be prescriptive, so the only mandatory part of the guidance is that relating to the national criteria. These criteria, found in paragraph 3.1, are:
- Practice-based procedures should be managed by the practice.
 - One person should be nominated to administer the procedure.
 - The procedure must be in writing and must be publicised (and should include details of how to complain further).
 - Complaints should normally be acknowledged within two working days and an explanation normally provided within ten working days.
- ¹³³ The aim of the practice-based complaints procedure is to make the process more accessible, speedier and fairer to everyone and to try to resolve most complaints at practice level. Detailed procedures are expected to be workable, flexible and ‘user-friendly’ for patients and practices alike.

Complaint handling by the Healthcare Commission

- ¹³⁴ Complainants who are dissatisfied with the outcome of their complaint may ask the Healthcare Commission to consider the complaint, and *Part III* of the Regulations (Regulations 14 to 19) sets out the statutory requirements on the Healthcare Commission when considering complaints at this second level.

- ¹³⁵ Regulation 16 states that the Healthcare Commission must assess the nature and substance of the complaint and decide as soon as it is reasonably practicable how it should be dealt with ‘*having regard to*’ a number of matters including the views of the complainant and the body or person complained against and any other relevant circumstances. There is a wide range of options available to the Healthcare Commission for dealing with the complaint, apart from investigating it, including taking no further action, referring the matter back to the body or person complained about with recommendations as to action to resolve the complaint, and referring the matter to a health regulatory body.
- ¹³⁶ If the Healthcare Commission does decide to investigate, it must send the proposed terms of reference to the complainant and the body or person complained about (and any other body with an interest in the complaint) for comment. Once the investigation begins, the Healthcare Commission has a wide discretion in deciding how it will conduct the investigation (Regulation 17) and this may include taking such advice as seems to it to be required, and requesting (not demanding) the production of such information and documents as it considers necessary to enable it properly to consider the complaint. The Healthcare Commission has established its own internal standards for the handling of complaints and although, for example, the Regulations do not specify the type of advice to be taken the Healthcare Commission has acknowledged the need to seek appropriate guidance from a clinical adviser with relevant experience and expertise. Likewise, although the Regulations set no specific timescales for it to complete the investigatory process (Regulation 19 merely requires it to prepare a written report of its investigation ‘*as soon as is reasonably practicable*’), the

Healthcare Commission has said that it aims in the majority of cases to take no longer than six months to complete the process.

- 137 The report produced by the Healthcare Commission at the end of its investigation must summarise the nature and substance of the complaint, describe its investigations and summarise its conclusions, including any findings of fact, its opinion on the findings and the reasons for its opinion, and recommend what action should be taken and by whom to resolve the complaint or otherwise.

Section 3: the investigation

Background

¹³⁸ We have outlined the background to the complaint in Section 1 of this report. We say more about the key events associated with each aspect of the complaint in the relevant sections which follow.

The Health Service Ombudsman's investigation of the complaint against the Surgery

Complaint (a): care and treatment

¹³⁹ Tom's parents complain about the care and treatment provided for their son by the Surgery. In particular, they consider the Surgery failed to deal adequately with his pain and weight loss and failed to act upon advice to refer him for an endoscopy which they say was made by a consultant at the Hospice. They believe that if their son's weight and pain had been better managed, and the endoscopy had been performed, the course of events might have been different.

Key events

¹⁴⁰ Penhurst School's healthcare record dated February 2003 says that Tom's bouts of agitation had become more frequent since the beginning of that year and on 5 March 2003, following Mr and Mrs Wakefield's request, the GP wrote to the Hospice about the management of his pain.

¹⁴¹ On 10 March 2003 the Hospice's Medical Director wrote to Tom's parents (with a copy to the GP) saying that their son was probably experiencing background pain from several different sources. He thought that the most likely source was

musculoskeletal and that the secondary source was probably his bowels but his gastro-oesophageal reflux was not considered a significant problem at that point. The letter described a stepwise process for testing out different strategies for managing the pain.

¹⁴² On 14 July 2003 the Hospice's Medical Director agreed with Tom's parents that clonazepam (a drug used to control muscle spasms and seizures) should be added to the existing prescription of benzodiazepines (drugs used to help relieve muscle spasms). A follow-up letter to Mr and Mrs Wakefield noted that oral morphine had been tried, without success.

¹⁴³ On 8 August 2003 the Manager of the Vicarage (a respite placement used during school holidays) wrote to Tom's social worker after he had stayed there from 27 July to 4 August 2003. He noted that there had been:

'... a marked deterioration since Tom's last stay with us in October 2002. He had lost a considerable amount of weight, was having suppositories or enemas to manage his constipation, and was prescribed more medication for pain relief and muscle spasms.'

¹⁴⁴ He went on to note:

'It was obvious from the outset that Tom's needs were more complex e.g. pressure care treatment needed more frequently, methods to be found which would ease/reduce Tom's muscle spasms and aches.'

¹⁴⁵ On 12 August 2003 Tom's social worker noted there was a disagreement between Mrs Wakefield and Penhurst School regarding the prescription for clonazepam. Mrs Wakefield wanted the drug to be used and gradually increased in line with

the Hospice's Medical Director's advice, but the school was reluctant to agree to this because they felt that Tom's behaviour reflected his frustration about being at school rather than his pain. Later the GP said that he had discussed Tom's medication with the Hospice's Medical Director and it had been agreed to increase the dosage of diazepam (another benzodiazepine) instead.

- 146 In August 2003 the GP decided to ask the Community Learning Disability Team to become involved in Tom's case because he thought this might be helpful in obtaining adult accommodation for him. He wrote a detailed report to the Community Learning Disability Team which referred to Tom's medical history, behavioural problems, gastrointestinal problems and the difficulty of obtaining psychological support. He also described the problem of managing Tom's pain saying:

'It is very difficult to accurately assess Tom's pain and in addition to this he is extremely sensitive to pain killers. When we increased the dose of pain killers he went into severe constipation and required admission to hospital for bowel clearance. We are therefore not in a position to use Morphine or strong pain killers for this reason.'

- 147 In the report the GP said:

'I can predict that Tom will need significantly more medical input in his care in the future than he has required up until now. I would be most grateful if we could strongly consider his medical needs when considering a suitable placement in the near future.'

- 148 In September 2003 the GP referred Tom to a newly opened part of the Hospice, so his pain could be assessed while he was an in-patient. The Hospice notes include the following entry:

'Phoned [Tom's GP] who will arrange upper GI Ix [gastrointestinal investigation].'

- 149 On 26 September 2003 the Deputy Medical Director of the Hospice wrote to the GP following the assessment. She noted that Tom had had a couple of significant episodes of more severe pain, both of which occurred shortly after meals. She said:

'These observations suggest an upper gastrointestinal cause for some of Tom's pain, possibly oesophagitis, oesophageal stenosis or peptic ulcer. We note his past history of pyloric stenosis. As the Hospice's Medical Director discussed, we have initially increased his Omeprazole to 40mg daily, and added in Domperidone 10mg tds [three times a day] as a trial [these are both drugs for controlling acid reflux]. I gather you are going to consider referral for possible endoscopy to clarify diagnosis.'

- 150 An unsigned file note in Tom's health record, dated 17 October 2003 (which the GP thought was made by the school nurse) and titled 'review with [doctor at the Hospice]', says, 'endoscopy ruled out as thought to be impractical'.

- 151 A note for this date in the Hospice health record says:

*'Tom came in for appointment
Pain still a problem.*

Discussed options

*– GI = would not consider surgery for
upper GI problem. Already on maximum
drug Px [prescription]. Therefore no point
in proceeding.'*

152 Tom started receiving morphine in October 2003 when he was in respite care. On 14 November 2003 Mr and Mrs Wakefield contacted the GP about a prescription of morphine by the Hospice's Medical Director. Subsequently, morphine was administered either by the nurses from Penhurst School or, if they were unavailable, by nurses from the Surgery.

153 On 19 November 2003 a speech and language therapist noted that Tom's eating and drinking skills were being compromised by deteriorating health and posture, and were causing concern. The therapist noted that although his swallow was strong he got some 'pooling' and often had to swallow repeatedly to clear any debris. She also noted that he was becoming distressed during meals, possibly due to pain associated with the movement of food through his digestive system.

154 On 20 November 2003 Tom was admitted to the Windrush Unit.

Mrs Wakefield's recollections and views

155 Mrs Wakefield said that from 2001 her son's self-harming behaviour had increased. She could understand that his strong personality and his history of self-harming might have led the school to believe that the deterioration in his behaviour was not a response to pain. She said the school staff had strongly indicated to her that he was displaying bad temper because

he was bored at school. However, from 2002 his behaviour was much more extreme and it went on for too long for it to be explained as an expression of frustration about still being at school. She said he would wake up from sleep screaming and could only be calmed by being moved to his chair. With hindsight she thought the change in position was reducing the extent of the acid reflux he had been experiencing. She said there were other signs that indicated that he was in pain – he would be tense, sweating and pale. She explained that her son was showing signs of experiencing pain in his sleep and the pain appeared to come in spasms and would wake him up. She described the state of his scalp as 'mute testimony' to his distress.

156 Mrs Wakefield said she had spoken to her son's GP about pain and the need to investigate its cause on many occasions on the telephone and during the GP's regular visits to Penhurst School. She had raised her concern with staff at the school and the GP that the pain was caused by acid reflux, and was told that this could not be the case because he was on medication. She was concerned that the GP might not have seen her son unless staff had indicated that he should be seen. Mrs Wakefield explained that, in 2003 because of her concerns about her son's pain, she decided to contact the GP direct, as it was clear to her that something was very wrong with him. She said that initially the GP had dismissed her request that her son should be assessed at the Hospice. She said the GP had not thought it appropriate because he was not terminally ill. Mrs Wakefield thought that the GP's view was coloured by the school's view. However, the GP had agreed to the referral.

157 Mrs Wakefield recalled that the doctors at the Hospice had no difficulty in communicating with her son. The consultant there had informed her that his joints were on the point of dislocating which no one had mentioned to her before. Mrs Wakefield recalled that the consultant was also clear that her son was experiencing bouts of severe gastric pain and that this needed to be investigated. She said he had recommended an endoscopy and had indicated that he was surprised that one had not been carried out before. He also recommended morphine for pain relief.

158 Mrs Wakefield said the GP had been reluctant to prescribe morphine. She believed that this was partly because of his concern about the constipating effects of the drug, which she could understand, but she thought that it also stemmed to some extent from personally held views about prescribing controlled drugs.

159 Mrs Wakefield said that in the months before he left school her son's appetite had declined and he had lost a lot of weight. Mrs Wakefield recalled that significant weight loss had been identified while he was in a respite placement, but this observation did not appear to have been acted on. Mrs Wakefield said she discussed her concerns about this with the GP. She had been told that there would be no point in 'tube feeding' because he would have pulled the tube out. Mrs Wakefield explained that because she thought that the GP was referring to nasogastric feeding she had not disagreed with him. She did not realise at the time that the GP was referring to feeding via a percutaneous endoscopic gastrostomy (PEG), which would allow a feeding tube to be passed directly into Tom's stomach or, indeed, that this had been an option.

160 Mrs Wakefield recalled that it had been suggested to her that if her son was receiving morphine, it would have been harder to place him in permanent adult accommodation, although she had subsequently found out that this was not the case. She had concluded that his medical care was being compromised by the Council's need to keep her son at the school as long as possible.

The Surgery's position

161 The Surgery's position is set out in the GP's letter of 6 January 2003 in which he responded to Mr and Mrs Wakefield's complaint. In that letter the GP described the actions he had taken and the rationale for those actions. He explained his reluctance to prescribe morphine because of its potential side-effects and problems of storing controlled drugs at the school. He also explained the risks for Tom of undergoing an endoscopy.

The Surgery's response to the Health Service Ombudsman's enquiries

162 My investigator made enquiries of the Surgery and the GP provided further detailed information about Tom's care and treatment. He said he had no special training in the field of learning disabilities although he provided a full GP service to all the children at Penhurst School. He saw every child several times a year for formal review and he had a low threshold for seeing them.

163 The GP recalled that Tom had been very badly afflicted with constipation and that he had spent a lot of time trying to address this condition. He said that in 2003 the symptoms of indigestion were '*fairly well under control*'.

164 The GP said:

'At no time did I discount the possibility of arranging an endoscopy but in view of the profound behavioural and physical disabilities suffered by Thomas, I felt it was imperative that the potential benefits of carrying out this procedure significantly outweighed the very considerable possible risks. It is important also to note that Tom's feeding problems were intermittent and often related to those who were involved in the feeding and that the problems experienced whilst he was an inpatient at [the Hospice] may well have been because he was in an unfamiliar environment and being fed by people he was not used to.'

'As the situation stood in September 2003, Thomas had an established diagnosis of longstanding oesophageal reflux, which had been well controlled on standard medication. He had in the past had exacerbations but these had usually settled quickly on conservative treatment.'

165 The GP said that at the time he was not aware that Mr and Mrs Wakefield were unhappy with the treatment decisions regarding Tom's gastrointestinal problems. He described how he prescribed different drugs to control Tom's symptoms and episodes of indigestion and this treatment was in accordance with assessments and recommendations from the Hospice. He also noted that Tom's parents had remained concerned about the management of their son's pain after the assessment and therefore he had arranged for further spinal X-rays which showed that there had been no specific deterioration since the previous X-ray.

166 With regard to Tom's weight, the GP said that there had been a weight chart in the nursing records at Penhurst School and that it was standard nursing procedure to regularly record the weights of all children at the school. He was confident that had there been any significant ongoing weight concerns, these would have been drawn to his attention. He also said Tom's oral intake had been variable and often had a major behavioural component to it. Although there were periods when his intake had been poor, in general he had a good appetite and was able to take things orally most of the time.

167 The GP said that he had never discounted the possibility that at some stage Tom would need a PEG feeding tube, but this was an option to be considered when oral intake definitely became insufficient. Given Tom's very significant behavioural problems, he felt that had a PEG feeding tube been fitted it was very likely that he would have pulled it out and this would have had significant adverse consequences. He did not recall a prolonged period when Tom's oral intake or weight loss would have merited the insertion of a PEG feeding tube. Therefore, he had not referred him to a specialist.

168 With regard to communication, the GP recalled that he had communicated a great deal with Tom's parents in the weeks between 26 September and 20 November 2003 about issues including pain relief.

169 The GP said that the report from the speech and language therapist would have arrived on the day before Tom was transferred to the Windrush Unit. Therefore, he would not have been in a position to take action in response to its findings.

The Hospice's Medical Director's response to the Health Service Ombudsman's enquiries

170 My investigator contacted the Hospice's Medical Director – the medical consultant who was the Medical Director of the Hospice at the time of the events complained about. He said he remembered Tom and his family and he had a clear memory of Mr and Mrs Wakefield as loving and dedicated parents. However, given five years have passed since he saw Tom, he said he only had a 'very sketchy' memory about details of discussions with Tom's GP and his parents about his care and treatment, and prognosis.

171 The Hospice's Medical Director said it was 'quite possible' that he had suggested the GP prescribe morphine but he did not recall what he had discussed with the GP on this point. He also said he may have discussed whether Tom should have had an endoscopy with the GP, but he was clear that he would not have made an explicit recommendation to this effect. He said if he had suggested an endoscopy it would have been as a way of having some certainty about the diagnosis of oesophagitis. However, he also said Tom would have been a high risk for surgery and whatever might have been found during the examination may not have changed the treatment Tom was receiving. He said he doubted whether Tom would have suffered because he had not undergone an endoscopy.

172 My investigator told the Hospice's Medical Director that Mr and Mrs Wakefield had said he had repeatedly told them Tom was not dying. The Hospice's Medical Director said he doubted whether he would have said this as he was seeing Tom at the Hospice which was a facility which focused specifically on caring for people with life-limiting illnesses. He said he remembered that treating Tom was a matter of achieving a

balance to give him the best quality of life. He also said it was inevitable that Tom would die.

The advice of the Health Service Ombudsman's Professional Advisers

Pain control

173 My GP Adviser said that the GP seemed very concerned about Tom's complex problems and had liaised well with the team working at Penhurst School. He said Tom had been admitted to hospital with severe abdominal pain due to constipation on more than one occasion and the GP's concerns about the constipating effects of opioids were reasonable. He noted that it must have been very difficult to establish whether Tom's pain was from his scoliosis, his gut spasms or his oesophagitis. My GP Adviser said that the GP had tried to look at the problem of pain in a holistic way rather than simply increasing the strength of medication to control pain. He also noted that the GP had tried to get psychological advice to help him understand Tom's behaviour and its relationship to pain. My GP Adviser noted that Hospice records for May 2003 stated that the GP 'seems very clued up ... and is very actively involved'.

174 My Pharmacy Adviser said records showed the GP had taken a reasonable approach to controlling a range of symptoms and this may have reduced Tom's pain. He said:

'Clinically, a decision to prescribe opioid analgesia such as MST [morphine sulphate – a drug to treat severe pain] for Tom would need to have been taken with great care. Most analgesics ... can have a tendency to cause or to exacerbate constipation. Opioids are particularly renowned for this and Tom was said to have been "sensitive" to the constipating effects of analgesics.'

175 My Pharmacy Adviser added that it appeared that Mr and Mrs Wakefield were keen for a prescription for an opioid analgesic for Tom and that the GP appeared reluctant to prescribe this because he was concerned about unwanted side-effects which are commonly associated with treatment by opioids. He also noted that when the Hospice had written suggesting opioid analgesia they had cautioned that constipation could be a problem. My Pharmacy Adviser also said there is some evidence that there were difficulties in keeping opioids at Penhurst School. He said this may have been related to a lack of suitable secure storage or of suitable staff to guarantee that doses could be given on time by those legally and appropriately qualified to do so. However, my Pharmacy Adviser noted that by 27 October 2003, a scheme had been devised in which a rota was put in place for doses of MST to be given to Tom by his parents, by a Penhurst School nurse, or by the Surgery.

176 My Pharmacy Adviser said that records show that in April 2003 Tom was tried with an oral opioid but that this was not successful in managing his pain over ensuing months and that clinicians were concerned about exacerbating Tom's constipation. He said that Tom started receiving MST sometime in October 2003, before he was transferred to the Windrush Unit. My Pharmacy Adviser said further adjustments were made to Tom's medication and records from the Hospice suggested his background pain was better controlled at this time.

177 In summary, my Pharmacy Adviser said:

'... the GP can be said to have shown reluctance and may have been somewhat slow to respond to suggestions about prescribing opioid analgesics for Tom. However, the evidence, such as it is,

points to the fact that he did respond to such suggestions in his own time. Opioid analgesics, when tried, did not always prove to be the panacea that the Wakefields had hoped for and they may have overlooked the comments from the hospice that oral morphine had not been successful when prescribed in the first half of 2003. However, during the period from the end of October to December 2003, MST was being used to good effect.'

Tom's weight

178 With regard to Tom's weight and nutrition, my GP Adviser said people with Tom's type of problems should be weighed at least every two months. He said that he had not found any information in the records to show that Tom had been regularly weighed. He noted that Tom had lost 3.7kg between November 2003 and February 2004 and that photographs showed morphological evidence of weight loss over an 18-month period.

179 My GP Adviser explained that Tom would have been at risk of weight loss, but typically his weight problems would fluctuate. He also explained that monitoring Tom's weight loss was not necessarily the GP's responsibility and it was likely this would have been part of the basic care provided by Penhurst School. My GP Adviser noted that no mention of weight loss had been made at a multidisciplinary case conference held on 13 August 2003, which the GP attended.

180 My First Gastroenterology Adviser noted that a speech and language therapy report dated 19 November 2003, which the GP had not seen, recorded that Tom's eating and drinking skills had deteriorated and had been affected by his worsening general health and posture. He said this indicated that, by this time, Tom's nutritional status had already started to decline.

Endoscopy

- 181 My First Gastroenterology Adviser said Tom had gastric surgery as a young child, and explained that these complex procedures may have resulted in long-term reflux problems, a consequence recognised by the prescription of acid suppressants throughout Tom's life. He explained that oesophagitis and oesophageal ulceration may be intractable due to the difficulty of maintaining an upright posture after meals.
- 182 My First Gastroenterology Adviser said that, although Tom's general health had been declining during 2003, earlier intervention and diagnosis of his severe oesophageal ulceration may have improved Tom's chances of survival and would have allowed steps to be taken to reduce his upper abdominal pain.
- 183 My GP Adviser said that a decision on whether or not Tom should be referred for endoscopy was not straightforward. He said the GP had been very conscious of Tom's history and appeared to have felt that endoscopy would not provide any new information. My GP Adviser considered that the GP's explanation about not referring Tom for endoscopy was not unreasonable. He said other clinicians might well have come to a similar view because the risks of carrying out an endoscopy under a general anaesthetic, especially given Tom's spinal problems, potentially outweighed any health gain.
- 184 However, my GP Adviser said that had he received the letter from the Hospice asking him to consider a referral for endoscopy, although his instinct as GP might have been first to try a slightly more powerful acid suppressing drug, he would have discussed such a decision with his local gastroenterology specialist, before deciding whether to refer or not.

- 185 My GP Adviser said he could not establish whether the GP had discussed his decision not to refer Tom for endoscopy with Mr and Mrs Wakefield.

The Health Service Ombudsman's findings

- 186 Mr and Mrs Wakefield are dissatisfied about the care and treatment provided for their son by the Surgery, particularly in terms of management of pain, monitoring his weight loss and the decision regarding an endoscopy.

Management of pain

- 187 My Professional Advisers have said that the GP's attempts to treat Tom's pain were reasonable. In particular, they drew attention to the GP's holistic approach to managing Tom's pain. This is illustrated by his attempt to get advice from a psychologist to help him understand Tom's distress, his unwillingness to simply increase doses of painkillers and his appropriate concern about side-effects of pain control. My Professional Advisers also noted that the GP referred Tom to the Hospice for assessment of his pain and the Hospice records show that the GP seemed aware of the relevant issues and was actively involved in his care. I also note that the Hospice's Medical Director said he may have suggested the GP prescribe morphine, but that this would have been a suggestion and not an explicit recommendation. I recognise the difficulties faced by the GP and acknowledge the efforts he made to accommodate the views of Mr and Mrs Wakefield and of other doctors, bearing in mind Tom's complex needs and the risks associated with different courses of action.

188 Having studied the available evidence and taken account of the advice provided by my Professional Advisers I am satisfied that the GP's clinical judgments about the management of Tom's pain did not fall below a reasonable standard in the circumstances. Therefore, I find there was **no service failure** in this regard.

Monitoring Tom's weight

189 The GP said he was not aware that there were any worries regarding Tom's nutrition and weight and that if the other professionals had concerns they would have brought these to his or Penhurst School's attention. The GP did not think Tom had a prolonged period of weight loss and he had not, therefore, thought it necessary to refer him for a PEG feeding tube.

190 My GP Adviser explained that although patients such as Tom should have their weight monitored regularly because they are at risk of fluctuations in their weight, it was not necessarily the GP's responsibility to ensure weights were recorded. It would have been his responsibility to investigate weight loss had it been brought to his attention. However, I have found no evidence that this was the case. In particular, weight loss was not mentioned at a multidisciplinary meeting about Tom which was attended by the GP. Also, it is unlikely that the GP had seen the speech and language therapy report which raises concerns about Tom's eating and drinking skills because the report is dated on the day before he was transferred to the Windrush Unit.

191 That said, it seems to me it would have been apparent that Tom was losing weight before he left Penhurst School. A photograph of Tom taken when he was 17 years old does not show someone who looked noticeably thin. However, in August 2003 the manager of Tom's respite placement noted he had lost considerable weight

over the nine months since October 2002. Also, when Tom was admitted to the Windrush Unit he was described as being 'very slim'.

192 It is only with the benefit of hindsight that a clear distinction between a fluctuation and a continual downward trend in weight can be identified. Given the risk that Tom would lose weight I can see that the GP could have been more proactive in matters relating to Tom's weight and nutritional status as part of his assessment of his health. However, monitoring Tom's weight was not necessarily the GP's responsibility and there is no record that concerns about weight or nutrition were brought to his attention.

193 On balance, having studied available evidence and taken account of the advice provided by my Professional Advisers, I find there is no evidence that the GP's clinical judgments about the management of Tom's weight and nutrition fell below a reasonable standard in the circumstances. Therefore, I find there was **no service failure** in this regard.

The decision not to refer Tom for an endoscopy

194 I have seen no record of any explicit recommendation from the Hospice that Tom should undergo an endoscopy. The Hospice's Medical Director could not recall the precise details of discussions with the GP, but he was clear that it would not have been his practice to make an explicit recommendation that Tom should undergo this procedure. Indeed, he said the purpose of any such investigation would only have been to confirm a diagnosis and that the risks and benefits to Tom would have had to be weighed carefully.

195 The GP has said that he did not refer Tom for an endoscopy because, in his view, the letter from the Hospice had not recommended immediate referral, but had suggested that medication changes should be tried first. The GP informed me that if Tom's indigestion problems had persisted or worsened, he would have discussed the merits of a non-urgent referral for endoscopy with a gastroenterologist. I have no reason to doubt this statement.

196 My GP and Gastroenterology Advisers said, as the Hospice staff had mentioned a referral for an endoscopy, it would have been better if the GP had discussed the matter with a specialist before reaching a decision. My GP Adviser said this is what he himself would have done. However, my GP Adviser also said the GP's reasoning about the risk that endoscopy would pose for Tom was reasonable.

197 Having considered the evidence I cannot see a compelling argument that the GP should have referred Tom for an endoscopy before his move from Penhurst School. There is evidence that the GP considered the options and made an assessment of the risks of the procedure. It seems likely to me that this would have been the approach which, after their discussion and correspondence between clinicians involved in Tom's care, the Hospice's Medical Director expected him to take. Furthermore, I note that the Hospice's Medical Director has said that he did not think Tom would have been disadvantaged because he had not undergone an endoscopy.

198 I am satisfied that the GP's decision not to refer Tom for an endoscopy did not fall below a reasonable standard in the circumstances. Therefore, I find **no service failure** in this regard.

Complaint (b): complaint handling by the Surgery

199 Mr and Mrs Wakefield remain dissatisfied with the way the Surgery handled their complaint.

Key events

200 On 27 July 2004 Mr and Mrs Wakefield complained to Oxfordshire PCT that the GP had failed to:

- react appropriately to the signs of Tom's medical condition;
- act on the advice of the Hospice consultant; and
- make urgent referrals for further investigation which meant the causes of Tom's problems were not identified.

201 They said that had these issues been dealt with properly Tom would not have been in pain and the sequence of events would have been different.

202 Oxfordshire PCT passed the complaint to the GP for local resolution and the GP twice (in August and October 2004) offered to meet with Mr and Mrs Wakefield in a conciliation meeting. However, they declined these offers because they said they had not been listened to on previous occasions.

203 On 6 January 2005 the GP responded to the complaint. He gave background information relating to Tom's challenging behaviour, his scoliosis and his gastrointestinal and feeding problems. He also explained the reasons why he was reluctant to prescribe opioid painkillers or refer Tom for an endoscopy. He described how he had taken action in response to Mr and Mrs Wakefield's concerns about Tom's pain, for example organising a spinal X-ray, and how he had responded to the assessments and recommendations from the Hospice, for example by adjusting Tom's medication. He also described how he had responded to Mr and Mrs Wakefield's concerns about provision of adult facilities for Tom by raising the issue in a detailed report to the Adult Learning Disabilities Team in August 2003.

The Health Service Ombudsman's findings

204 In Section 2 I have described the standards governing the way in which NHS bodies should have handled complaints at the time of Mr and Mrs Wakefield's complaint. I have compared the Surgery's actions with those Regulations.

205 I find the Surgery acted appropriately in offering to try and resolve the complaint at a conciliation meeting. Mr and Mrs Wakefield had known the GP for some years and a face-to-face meeting would have been an appropriate way to try and resolve their concerns.

206 I find the GP's response addressed all the key issues in the complaint and provided an appropriate level of detail and explanation.

207 It seems the GP received the complaint via Oxfordshire PCT some time in August 2004 but did not respond in writing until 6 January 2005. Generally, I would consider this delay was unreasonable. However, I note that in this case the GP had twice offered to meet with Mr and Mrs Wakefield to discuss and resolve their concerns. When they declined these offers he responded in writing.

Complaint handling by the Surgery: the Health Service Ombudsman's conclusion

208 In terms of complaint handling, I find the Surgery acted in line with the Regulations and demonstrated reasonable practice as set out in my *Principles of Good Administration*. Despite the delayed response I conclude, on balance, any shortcomings in the way in which the Surgery responded to Mr and Mrs Wakefield's complaint **do not amount to maladministration**.

The complaint against the Surgery: the Health Service Ombudsman's conclusions

209 I find that the care and treatment provided by the Surgery, including the management of Tom's pain and weight loss, and the decision not to refer him for an endoscopy did not fall below a reasonable standard in the circumstances. I find **no evidence of service failure** by the Surgery. I have considered the way in which the Surgery responded to Mr and Mrs Wakefield's complaint and I find **no evidence of maladministration**.

210 Therefore, I **do not uphold** Mr and Mrs Wakefield's complaint against the Surgery.

The Local Government Ombudsman's investigation of the complaint against the Council

Complaint (c): the actions of the Council

211 Mr and Mrs Wakefield complain that the Council failed to plan for, or commission, new provision for Tom, or to deal appropriately with his transition into adult accommodation. They said Tom's social worker had failed to pass on information regarding the offer (in October 2003) of a suitable permanent placement for Tom. They also complain about the way the Council responded to their complaints about Tom's transition to adult care. Although their complaint was investigated at Stage 2 of the Council's complaints procedure, Mr and Mrs Wakefield consider that they still lack an adequate response and remain uncertain of the actions taken by the Council in the light of its investigation.

Mrs Wakefield's recollections and views

212 Mrs Wakefield said it had been her understanding that a referral to Adult Social Services could not be made until Tom reached 17½ years old. Tom's previous social worker had done a lot. However, the new social worker who took over in February 2003 had not met with Tom until he had been in charge of his case for some considerable time. Mrs Wakefield said she could not see how he could possibly assess Tom's needs, or work effectively on his case, without meeting Tom. She said she had had great difficulty getting hold of the social worker as he never appeared to be on the end of a telephone.

213 Mrs Wakefield said she and Mr Wakefield had set out 'a hierarchy' of what they considered Tom's needs to be. They knew that it was unlikely that they would find somewhere that would meet all his needs; they had therefore indicated that they were prepared to be flexible. Despite this, they felt the social worker had made assumptions about the kind of accommodation they would accept.

214 Mrs Wakefield said it was untrue for Social Services to say that the family had turned down suitable placements for Tom. One placement had been offered in a Huntington's Chorea unit (an inherited disorder that leads to loss of control of movement and changes in personality). They felt there was a risk that Tom might be physically harmed by one of the patients there, all of whom were considerably older than Tom. The second place was too far away.

215 Mr and Mrs Wakefield were very angry that Social Services had not informed them about a suitable placement which had become available in October 2003. Mrs Wakefield had only learnt about the offer when the organisation concerned had written to her in January 2004. They also told her that Social Services had been notified of an offer in October 2003. She was certain that if Tom had been taken out of the environment he was in at this time, the course of events would have been different.

216 She thought it odd that Tom was judged to need a medical assessment 21 days into the notice period that the school had given. She said that if a medical assessment was genuinely required, this should surely have been identified earlier.

- 217 Mrs Wakefield said that, in her opinion, it was well known that Social Services in Gloucestershire were operating on a crisis management basis. It had been in Social Services' interests for Tom to remain at the school as long as possible because this delayed the need to find a placement for him.
- 218 Mrs Wakefield was unhappy that the Social Services Stage 2 investigation had not upheld the complaint that Tom had been 'placed' at the Windrush Unit. She considered that the matter had been glossed over on a technicality. She did not consider that the recommendations went far enough to prevent a recurrence.
- 219 Mrs Wakefield did not think that the other recommendations made in the Social Services' report had been implemented. The Council was still purchasing places and not actively trying to resource vacancies. Only two part-time transition workers had been appointed despite the commitments set out in the report. Mrs Wakefield wanted the people concerned to acknowledge and apologise for their failures, and the part they had played in contributing to the course of events.
- 221 A new social worker was appointed for Tom in February 2003.
- 222 It is unclear when exactly the search for appropriate accommodation for Tom started. Mr and Mrs Wakefield informed the investigator who conducted the Stage 2 investigation that Tom's social worker was looking for permanent accommodation some time before March 2002. Information made available by the Council to the Stage 2 investigation clarifies that during 2002 suitable establishments as opposed to actual placements were being sought. The records indicate that there was no specific activity between 21 December 2002 and the new social worker's visit to Mr and Mrs Wakefield on 27 February 2003, when their hierarchy of needs regarding a suitable placement for Tom was discussed.
- 223 Tom's social worker noted a discussion with Mrs Wakefield on 8 August 2003 in which she said she had been very impressed with an independent provider that might be able to offer accommodation to Tom in October, and that she would consider the placement should it arise.

Evidence from the Council's records

- 220 In April 2002, when Tom became 18, his case was transferred from the Council's Children and Families Service to its Adult Learning Disabilities Team. Tom was allocated a specialist social worker but he left the service in December 2002. In his transfer summary he recorded that he had been working on two objectives: to identify appropriate respite placements for when the school was closed and to identify appropriate accommodation for Tom when he was due to leave the school. Other than this it seems that no specific plan of care had been drawn up.
- 224 On 3 October 2003 Penhurst School informed the Community Learning Disability Team that it was giving six weeks' notice to terminate Tom's placement, because Tom was not tolerating school.
- 225 On 23 October 2003 Tom's social worker was contacted about the offer of a residential place to Tom, by Voyage, an organisation that Mrs Wakefield had said she would consider. Mrs Wakefield did not become aware of this until January 2004, when the organisation concerned wrote to her, following her enquiries about vacancies. Voyage said:

'I spoke to [Tom's social worker] on 23 October 2003 to apprise him of the situation at our small home in [Somerset] making [him] aware that we had a vacancy at this property which had the potential to provide for your son with relative immediacy. [The social worker] informed me during this conversation that Tom's needs had deteriorated and that he would need nursing care, that he was using morphine and [a placement in Warwickshire] was being considered.'

226 In July 2003 it was noted that all of Tom's needs could be met by carers with the exception of pain relief and gut function, which needed to be carried out or monitored by a Registered Nurse. By the time of the assessment carried out in October 2003, there was a much higher need for nursing input into Tom's care. The difference of opinion between Penhurst School and Mrs Wakefield about the cause of Tom's self-harming behaviour was noted.

227 In summary, the social worker's records noted that from October 2002 Tom's scoliosis was worsening and pain medication was being administered. The community nurse from the Community Learning Disability Team had carried out an assessment of care needs in July 2003, and had noted that *'Tom's major need is for pain relief which is constantly being reassessed ... This is due to scoliosis'*.

228 On 13 November 2003 an urgent email was sent from the Community Learning Disability Team's manager to the Consultant in Charge at the Windrush Unit. It noted that a meeting had been held with the Consultant in Charge on 10 November 2003, to discuss the possibility of Tom *'coming in to Windrush on a short term basis for further assessment with a view to moving on to a longer term home'*. The email

acknowledged that this would not be easy for the Windrush Unit given that their current brief was to vacate beds. The Windrush Unit would need reassurance that Tom would not become a 'bed blocker'. The email reiterated that the Windrush Unit appeared to be the only short-term option left. It said that Social Services would fund supplementary staff to cater for Tom's social care needs and that:

'Strenuous efforts would be made to find placements to relocate some of your other Windrush patients and it would be very helpful if you can identify one or two that we could realistically focus on as a start – ones who would be easiest to move on, so we can practically make a start ASAP.'

It was also noted that the Council had been trying hard to find long-term solutions for Tom and would continue to do so. It was proposed that a meeting be set up (to include Mr and Mrs Wakefield) to clarify how Social Services commissioning staff would work with health staff.

229 The email concluded:

'We will continue to be jointly committed to looking at the long term solution for Tom and will be active in this, bearing in mind that it is understood that a Windrush admission would be temporary and for assessment and treatment only.'

230 Tom was admitted to the Windrush Unit on 20 November 2003.

231 On 23 December 2003 the Social Services Joint Commissioning Manager (the Joint Commissioning Manager) responded to Mr and Mrs Wakefield's concerns about the failure to provide suitable permanent accommodation

for Tom. He noted Tom was in an appropriate placement and it had been agreed at the meeting held on 18 November 2003 that his stay at the Windrush Unit would allow for an assessment of his pain which, it had been agreed, was a top priority.

232 He said that in planning for people with disabilities, Social Services duties and obligations were discharged in a number of ways depending on individual circumstances, and that there was little direct provision of residential services:

'We purchase the services that we need, at the time that we need them, from the private, voluntary and independent sector. Our long term planning tends to be for sections of population rather than on an individual basis.'

233 He noted that Mr and Mrs Wakefield's letter had alluded to the creation of a project team to create a facility for people with profound and multiple learning disabilities. The Joint Commissioning Manager said Social Services had a number of successful projects providing housing and services to people with profound and multiple learning disabilities, including working with housing and health authorities in the creation of such places. However, he said such projects took a long time to set up and that the last one had taken five years to complete.

234 He went on to note that Social Services now needed to create a new strategy for people with learning disabilities, taking into account the direction outlined in Valuing People. The approval of the Joint Commissioning Strategy Group would be needed before any new projects could be set up.

The Council's investigation

235 In January 2004 Mrs Wakefield complained about the Council's planning of Tom's transition to adult care. The complaint was initially investigated by a customer relations officer. Subsequently, the complaint was investigated by an independent investigator (the Independent Investigator) at Stage 2 of the Social Services complaints procedure. The Independent Investigator met with Mr and Mrs Wakefield in March 2004 and then again in July and September 2004.

236 In July 2004 Mr and Mrs Wakefield informed the Independent Investigator that they wanted the investigation to consider the following:

- A failure to plan or commission provision.
- A failure to deal with transition.
- Significant Social Services failings in the handling of Tom's case.
- An inappropriate placement (the Windrush Unit).
- A failure to investigate Tom's physical problems.
- A failure to provide a specialised NHS assessment for profound and multiple learning disabilities.

They said they considered the authority had acted in a way that was contrary and damaging to the best interests, rights and life chances of a person with profound and multiple learning disabilities and his family.

237 The Independent Investigator interviewed Social Services staff, independent providers, another service user, and Mr and Mrs Wakefield. He examined the Social Services files for Tom, correspondence from Mr and Mrs Wakefield and the national guidance and standards, including Valuing People, Social Services Inspectorate inspection criteria, the Government's (2003) *Care Homes for Adults (18-65)*, the 2004 report of the Learning Disability Taskforce, which was set up after the publication of Valuing People, and the Council's Transitions Protocol (June 2002) for the transfer of young people with disabilities from children and families to adult care.

238 The report was issued in October 2004.

239 The Independent Investigator noted the standards set out by the Social Services Inspectorate in 1998 in *Moving into the Mainstream*. These said that Social Services departments should:

- regularly collect and distribute aggregate information about the numbers and needs of people with learning disabilities as well as information on resources, budgets and expenditure on services for people with learning disabilities;
- collaborate with other Council departments and organisations in preparing plans for services for people with learning disabilities;
- plan to address the needs of people in transition; and
- adopt a proactive approach to managing the market in relation to local services for young people with learning disabilities.

240 The Independent Investigator noted the Social Services Inspectorate standards that prevailed at that time also specified that:

- an effective commissioning strategy should be in operation which was responsive to changing and diverse population needs;
- the range of services available should be sufficiently broad and varied to meet service user and carer needs, take account of their preferences and achieve a balance of quality and coverage;
- arrangements for referral, assessment, care planning and monitoring and review should be convenient, timely and responsive to individual needs, preferences and ethnic diversity; and
- councils should work with partners to commission and deliver services that were responsive to individuals, safe and reliable, and offer a good range of choices.

241 The Independent Investigator said that he had been informed by the Council's interim Joint Commissioning Manager that:

- the Council did not have a commissioning strategy but was developing one;
- there were particular gaps for people with profound and multiple learning disabilities and challenging behaviour. The market was currently being mapped to assess the need for specialist services. Among the actions under consideration was to seek first refusal on placements arising in the county; and
- transition arrangements had been poor with information not being shared.

- 242 The Independent Investigator noted that in June 2002 the Council had adopted a new Transitions Protocol. However, Tom had already reached 18 and the new protocol could not be applied retrospectively. The Stage 2 report set out information about assessments of Tom's needs during 2002-03. The Independent Investigator noted that he could not investigate the medical treatment or the actions of health professionals as this lay outside the jurisdiction of the Social Services complaints procedure; he had therefore focused on whether Social Services had identified Tom's needs appropriately.
- 243 The Independent Investigator noted that Tom's worsening health had been reflected in four joint assessments of care needs completed by health staff between November 2002 and November 2003. The files also contained a series of reports on Tom's other care needs completed by school staff and others, which indicated an increasing need for medical input into Tom's care.
- 244 The Independent Investigator noted Tom's social worker had started looking for suitable establishments for Tom some time before March 2002. He left and a new social worker was allocated to Tom in February 2003. The new social worker informed the Independent Investigator that the Council did not have a list of providers that might be able to meet Tom's complex needs and that initially he had restricted his search to homes which offered nursing care. In June 2003 Mrs Wakefield had expressed her unhappiness with this approach, so he widened his search to include establishments that only provided residential care. The social worker had said it was good practice to anticipate future needs and in his opinion Tom's needs would be likely to require nursing care in the near future.
- 245 The social worker informed the Independent Investigator that he had looked at trade magazines, the internet and the National Care Standards Commission's website for a list of establishments able to offer care for people with learning and physical disabilities. He had also contacted two home-finding agencies and an association of care home providers as well as speaking to colleagues. He estimated that he had made approximately 95 telephone calls to try to find a placement for Tom.
- 246 The social worker had identified two potential placements, both of which Mr and Mrs Wakefield considered unsuitable because of their distance from the family home. Additionally, Mr and Mrs Wakefield said the vacant accommodation in the first placement was on the second floor, which meant it would have been difficult and time consuming for staff to take Tom out. Regarding the second placement Tom would have been the youngest resident by 25 years.
- 247 Mr and Mrs Wakefield had themselves identified two potential placements. The first declined to offer a place to Tom because of his self-harming behaviour. Mr and Mrs Wakefield were impressed by the second establishment and, on being informed that another vacancy might arise in the autumn of 2003, they informed Tom's social worker that they were happy in principle for Tom to move in should the place become available for him.
- The Council's Stage 2 investigation findings*
- 248 The Independent Investigator did not comment on the heads of complaint that involved clinical issues as these fell outside his remit.

- 249 The Independent Investigator found that no plans had been made for Tom's future accommodation other than to purchase such accommodation as it became available. Consequently, it had taken nearly two years to find Tom accommodation. He upheld the complaints that there had been a failure to plan for or commission new provision, and failure to deal with Tom's transition.
- 250 He did not uphold the complaint that there had been a failure to fully assess Tom's needs, as there were a number of thorough assessments, including joint assessments, on file.
- 251 The complaint that there had been significant Social Services failings in the handling of Tom's individual case was upheld. The Independent Investigator found that the Council's search for accommodation had been ineffective because there was no specific commissioning plan for Tom that took account of the way the market worked. The Independent Investigator found that neither the social worker nor the manager of the Community Learning Disability Team had notified the assistant team manager who was actively involved with Tom's case, or Mr and Mrs Wakefield, about the vacancy that became available in October 2003.
- 252 The Independent Investigator said that although it was clear that the Windrush Unit had been regarded as somewhere to 'place' Tom, it was in fact an NHS assessment unit and Tom had finally been admitted for medical assessment. He could not make any findings about this as he could not consider medical issues. Also, he noted that the Council had not technically made a placement as it had not funded care for Tom. However, the Independent Investigator recognised that the correspondence between the Council's staff and Mr and Mrs Wakefield did not acknowledge that there had been two reasons for Tom's admission: assessment and the fact that he was facing homelessness. In his view, therefore, the correspondence could be interpreted as being '*a less than accurate statement of the circumstances*'. The Independent Investigator said it was hard to criticise Social Services for Tom's admission to the Windrush Unit, given that there was no other place for Tom to go, and that extra effort had been made to try and meet Tom's needs while he was there.
- 253 The Independent Investigator said the PCT and Social Services had failed to plan for Tom's transition and had not been able to meet his needs in a reasonable time. However, he did not think that the Council had acted in a way that was contrary to the best interests, rights and life chances of a person with profound and multiple learning disabilities and his family. The Independent Investigator considered the lack of accommodation for Tom and uncertainty about his future added to the distress caused by his worsening condition.
- 254 The Independent Investigator went on to note that '*the Council appears to be planning in earnest to improve the situation*' and that he understood that '*transitions workers are to be appointed to work specifically with young people with disabilities*'.
- 255 He made the following specific recommendations:
- ' ...
- i. While the authority's efforts remain focussed on purchasing for young people like Tom it should ensure that it receives vacancy bulletins from those local providers who produce them.*

ii. To correct any misunderstanding resulting from the Joint Commissioning Manager's correspondence, the authority should acknowledge that Tom's admission to Windrush was a way to accommodate him, not simply as a period of assessment.

iii. The authority should acknowledge that it had been unable to meet the needs and reasonable expectations of Tom and his family in the provision of accommodation.

iv. The authority should apologise for the failure to pass on details of the Voyage placement.'

256 The Independent Investigator concluded:

'I have attempted to fairly decide these complaints assessing each on its own merits and I have not upheld all of them. The danger of this approach is that it may detract from my overall view on this complaint. I believe that Tom Wakefield and his family were entitled to expect that accommodation would be available within a reasonable time to meet Tom's needs and reasonable aspirations and without prolonged uncertainty. I believe that the authority failed to deliver this.'

and

'Clearly, the family have been through a harrowing time. I have been taken aback by the descriptions of Tom's condition when he was admitted to Windrush and his condition at the end. As a Social Work professional Mr B told me he was shocked by Tom's appearance and injuries when he saw him at Windrush. I can only imagine the distress caused to the family.'

The Council's response to the Stage 2 investigation report

- 257 The Head of Adult Care Services wrote to Mr and Mrs Wakefield on 29 October 2004, enclosing a copy of the Stage 2 investigation report. She said it was clear that Mr and Mrs Wakefield had been through a very distressing time and that *'our failure in our ability to support you in, both finding a suitable placement for Tom, and in managing his transition from the Children and Families Service into Adult Services, has clearly contributed to your distress. I would like to extend my deepest apology for this'*.
- 258 She also said she agreed with the conclusion that both Tom and his family were entitled to expect that accommodation would be provided in a reasonable time and the Council had failed to deliver this. She went on to reassure Mr and Mrs Wakefield that the Council was committed to developing a commissioning strategy for people with learning disabilities, and that it was currently completing a mapping exercise to determine the need for specialised services.
- 259 She concluded by confirming that she was happy to accept all of the recommendations and apologised for the failure to pass on details of the placement that became available in October 2003.
- 260 Mr and Mrs Wakefield were exhausted and therefore decided not to pursue their complaint to Stage 3 of the Social Services complaints procedure. Following a second complaint to Social Services, which is not part of this investigation, Social Services staff met with Mr and Mrs Wakefield and asked if they wished to be involved in the development of the Joint Commissioning Strategy and to attend the Learning Disability Partnership Board. They declined.

261 The Council informed the Local Government Ombudsman that the following action has been taken as a consequence of Mr and Mrs Wakefield's complaint:

- A Learning Disability Joint Commissioning Strategy has been completed and signed off. A copy has been made available to the Local Government Ombudsman.
- The transitions policy is currently being revised, in the light of an initial pilot which had shown that the link to education services was not robust enough; a copy of the project plan has been forwarded to the Local Government Ombudsman and the Council confirmed that all milestones have been met.
- A transitions worker post had been established in the Children with Disabilities Team.
- Updates from providers with vacancies are faxed through to the team on a regular basis.
- A joint commissioner/provider group has been established and meets regularly.
- The block contract for the provision of residential care has been re-let to a new provider who was working with the Council to develop a wider range of provision for adults with learning disabilities.
- Independent sector providers are now standing members of the Learning Disability Partnership Board.
- The Council has increased the contracted service provision for people with profound and multiple learning disabilities.

- Commissioners are working with other regional commissioners to build more robust relationships with residential colleges and the Learning and Skills Council to improve transitional arrangements.
- Clear guidance has been given to all staff about the right of individuals and their nominated representatives to have access to information held about them.

262 The Local Government Ombudsman was also informed that the Children and Young Persons Department has a new field team structure with two teams, managed separately. One team is responsible for core assessments and section 17 (children in need) activity. The second team is responsible for transitions, looked-after children and short-term breaks. There is a part-time deputy manager for the transitions function, supported by two full-time transitions social workers and one family support assessor.

263 The Council said that to date it had secured 20 additional residential beds for people with profound and multiple learning disabilities, with more coming on line in 2008.

The Local Government Ombudsman's findings

264 There is extensive legislation and guidance setting out the responsibilities of councils for assessing and arranging appropriate care for those who require community care.

265 Government policy guidance emphasises the importance of collaboration between agencies and the need for care plans to be person-centred. Valuing People emphasises the need for an anticipatory and person-centred approach to care planning in the provision of services for learning-disabled people. Valuing People also requires councils to establish Learning

Disability Partnership Boards and to take the lead role within these boards for ensuring that appropriate plans are drawn up and provision made for people with learning disabilities to whom councils had a duty of care.

266 I consider the Independent Investigator conducted a thorough Stage 2 investigation and quite properly did not consider matters about healthcare which lay outside the Council's remit.

267 In the course of the Stage 2 investigation the Council acknowledged that there was no commissioning strategy in place, there were gaps in its plans for people with profound and multiple learning disabilities and challenging behaviour and that transition arrangements had been poor, with information not being shared. It is clear that the Council had not met the relevant Social Services Inspectorate criteria. That was **maladministration**.

268 The offer of a place for Tom, in a home that Mrs Wakefield had indicated she would probably accept, came at around the time when Tom was given notice to leave by the school. Like the Stage 2 Independent Investigator I do not understand how such an opportunity was missed to pursue the suitability and availability of such an offer, given Social Services were well aware that there was an urgent need to find appropriate accommodation for Tom, and that Mr and Mrs Wakefield would be happy with the placement. I note that no record exists of this offer in Social Services' files. I conclude that there was a serious failure on the part of Social Services to manage Tom's transition in this respect, and that was **maladministration**. I conclude that to some extent the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons, in that transition planning to meet his needs was inadequate.

269 Mrs Wakefield informed the Local Government Ombudsman that Social Services were operating on a crisis management basis and that the school's agreement that Tom could stay until he was 20 meant finding provision for him ceased to be an immediate priority. It is clear that the school's decision to ask Tom to leave caught Social Services unprepared, as indicated in the email of 13 November 2003. This finding is supported by the fact that the apparent need for medical assessment arose only just before he was due to have to leave the school. The email went on to note that Social Services understood Tom's admission would pose difficulties for the Windrush Unit and reassurance would be wanted that Tom would not become a 'bed blocker'. I consider this email clearly indicates that the Partnership Trust did not regard the Windrush Unit as a provider of accommodation for clients such as Tom. Therefore, the Windrush Unit had not been considered for either a placement or assessment prior to the school giving notice. I consider the email also indicates that people's placements, including Tom's, were determined by what was available, and not on a person-centred basis. That was **maladministration**.

270 I therefore consider the Stage 2 Independent Investigator's decision to uphold the complaints that there had been a failure by Social Services to plan for or commission new provision to deal with Tom's transition and that there had been significant failings in the handling of Tom's individual case was reasonable.

271 In light of the fact that several joint assessments by Social Services had been carried out during the period from November 2002 to November 2004, I agree with the Stage 2 Independent Investigator's decision not to uphold the complaint about lack of appropriate assessments.

272 Because of his imminent homelessness and because admission to the Windrush Unit would allow for a comprehensive assessment of his health and social care needs, the Stage 2 Independent Investigator did not uphold the complaint that it was inappropriate to have placed Tom at the Windrush Unit. However, he concluded that the admission to the Windrush Unit had served a dual purpose and that this had not been fully acknowledged in the correspondence with Mr and Mrs Wakefield. The email of 13 November 2003 supports this view. It is clear that the Windrush Unit was being considered when Tom's notice to leave was about to expire. Due to Social Services' failure to properly deal with the offer of a suitable place made in October 2003, Tom had no other place to go. I am concerned to note therefore that the Council's letter of apology following the Stage 2 investigation report did not specifically acknowledge the Independent Investigator's view on this matter.

273 The Stage 2 Independent Investigator did not uphold the complaint that the PCT and Social Services had acted in a way that was contrary and damaging to the best interests, rights and life chances of an individual with profound and multiple learning disabilities and his family because this aspect of the complaint was about the consequences of a deficiency in planning for Tom. His view was that Social Services had not acted contrary to Tom's best interests but had not been able to meet his needs in a reasonable time because of a failure to plan properly for his future. I have been unable to find any evidence that there was any intention on the part of Social Services to act in a way that was contrary to Tom's and his family's interests. Assessments were carried out and some efforts were made to find accommodation for him, albeit in an unplanned and unstructured way with poor liaison and communication with other relevant

organisations. Therefore, I consider the Stage 2 Independent Investigator's decision on this matter to be reasonable as far as it went.

Injustice

274 I am pleased to see that Social Services agreed to implement the Independent Investigator's recommendations. The action that the Council has taken has been carefully examined and has been found to be robust. In view of this, there is nothing further I can suggest that would add any more value to the action already taken.

275 I am also pleased to see that the Council subsequently offered Mr and Mrs Wakefield the opportunity to be part of the development of the Joint Commissioning Strategy and to attend the Learning Disability Partnership Board. I regard this as appropriate.

276 However, I find that further consideration needed to be given to the consequences for Tom of Social Services' failure to plan effectively and make provision for his transition to Adult Services, including their failure to act on the offer of a suitable placement which was made in October 2003. It is not possible to establish what might have happened to Tom had he moved to this placement. I cannot know whether staff there would have taken different action to identify and manage the cause of his pain and declining health. Tom's family will never know if his prospects and his life would have been improved if Social Services had planned efficiently for his transition to Adult Services, had made proper provision for him and had pursued the placement offer made in October 2003. I consider this unanswerable question will remain a source of distress for Mr and Mrs Wakefield and I **uphold** this complaint to this extent and recognise that there is **unremedied injustice** for Mr and Mrs Wakefield.

277 We say more about injustice in Section 4 of this report.

The Local Government Ombudsman's recommendations

278 I **recommend** that the Chief Executive of the Council apologise to Mr and Mrs Wakefield for the failings I have set out in this report.

279 I also **recommend** that the Council offer compensation of £5,000 to Mr and Mrs Wakefield in recognition of the injustice they have suffered in consequence of the maladministration I have identified.

The Council's response

280 The Chief Executive of the Council acknowledged the failings identified in this report and unconditionally expressed his sincere apologies to Tom's family. I have outlined above some of the actions taken by the Council in respect of its failings in this case. In particular, I note the commitment to implement the recommendations made by the Council's Independent Investigator and the offer to involve Mr and Mrs Wakefield in commissioning and planning activity. I have already commented that I find these actions are appropriate and I am reassured that lessons have been learnt from this case. The Chief Executive told me about further recent actions by the Council. He also accepted my recommendation regarding a compensation payment.

The Health Service Ombudsman's investigation of the complaint against the PCT

Complaint (d): the actions of the PCT

281 Mr and Mrs Wakefield complain that the PCT failed to liaise appropriately with the Council in planning for Tom's transition into adult accommodation.

282 National legislation, policy and guidance make clear that the PCT had its own responsibilities both as a commissioner and as a provider of health services, including for people with learning disabilities.

The PCT's position

- 283 In correspondence the PCT acknowledged that at the time of the events described in this complaint:
- it did not have a joint commissioning strategy for services for people with learning disabilities;
 - there were weaknesses in clinical governance arrangements;
 - it did not have arrangements in place in line with all the relevant guidance;
 - there were weaknesses in staff training; and
 - health facilitators were not in place.

The actions of the PCT: the Health Service Ombudsman's findings and conclusion

284 The lead responsibility for planning and making provision for Tom's transition to appropriate adult care lay with the Council. However, the extensive legislation and national guidance show that the PCT had its own responsibilities both as a commissioner and as a provider of health services. In particular, the PCT had a duty to commission health services that met nationally expected standards for all its population, including people with learning disabilities.

285 The PCT has confirmed that at the time of the events complained about, there were shortcomings in its planning for the needs of people with learning disabilities and it did not have arrangements in line with all the relevant guidance and responsibilities at the time. Although there was some input from the Community Learning Disability Team, health facilitators were not available.

286 Had the PCT fulfilled its own responsibilities in accordance with its legal obligations and in line with national policy and administrative guidance, there can be no guarantee that appropriate adult accommodation for Tom would have been found which addressed his complex health needs at the time he needed it. Nevertheless, the PCT's failure to fulfil its responsibilities in relation to people with profound and multiple learning disabilities meant the chances of Tom making an effective transition to adult accommodation were significantly diminished. Without the systems and structure in place, any attempt by the PCT to liaise appropriately with the Council in planning Tom's transition into adult accommodation was virtually bound to fail. Tom had complex needs related to his learning disability and the PCT failed to provide

a service which met those needs. Therefore, I conclude there was **service failure** by the PCT and that this failure was for disability related reasons.

Complaint (e): complaint handling by the PCT

287 Mr and Mrs Wakefield remain dissatisfied with the way the PCT handled their complaint.

Key events

288 On 21 January 2004 Mr and Mrs Wakefield complained to the PCT that it had failed to liaise appropriately with Social Services regarding the need to properly plan for and provide an adult placement for Tom.

289 On 29 January 2004 the PCT acknowledged Mr and Mrs Wakefield's complaint but it did not formally respond to the complaint until prompted to do so by the Healthcare Commission. The PCT has explained that it knew the Partnership Trust and Social Services would be responding to similar complaints from Mr and Mrs Wakefield and, therefore, it felt it could add little to the responses produced by them.

290 On 12 June 2006, in response to the Healthcare Commission's recommendation, the PCT wrote to Mr and Mrs Wakefield and apologised for its failings. It said that as a result of events complained about lessons had been learnt and protocols had been amended.

Complaint handling by the PCT: the Health Service Ombudsman's findings and conclusion

291 In Section 2 I have summarised the Regulations relating to the way in which NHS bodies should handle complaints. I have compared the PCT's actions with those Regulations.

292 Although I can understand why the PCT considered it could add little to responses which it knew were to be provided by the Partnership Trust and Social Services, this did not absolve it of the responsibility to respond to the complaint itself. It was not acceptable that Mr and Mrs Wakefield had to wait over two years for a response from the PCT. This was **maladministration**.

Complaint against the PCT: the Health Service Ombudsman's conclusion

293 On the basis of evidence available to me and in the light of additional information provided by the PCT, I conclude that for disability related reasons the PCT's actions in relation to arranging an adult placement for Tom amounted to **service failure**. Furthermore, there was **maladministration** in the way it handled Mr and Mrs Wakefield's complaint.

Recent action by the PCT

294 The PCT informed me of action it has taken to address the service failings in this case. It said it had taken action:

- to give patients and their carers a 'stronger voice' by, for example, improving advocacy services and involving users in the Learning Disability Partnership Board;

- to develop a joint commissioning strategy and change action plan which included review of services and wide consultation with locality groups and the Learning Disability Partnership Board; and
- to improve operational and management processes by, for example, agreeing a multi-agency transition pathway and setting up an exceptional needs panel focusing on joint decision making for funding and placements.

Injustice

295 I have taken into account these recent actions by the PCT to improve services. However, the fact remains that at the time Tom needed help from the PCT he did not receive a reasonable standard of service. Although the Council had lead responsibility for planning for transition to adult care, we cannot know what difference it would have made to Tom and his family in terms of securing appropriate accommodation if the PCT at the time had fulfilled its responsibilities to people with profound and multiple learning disabilities. This unanswered question remains a cause of distress for Mr and Mrs Wakefield which has yet to be acknowledged and is, therefore, an **unremedied injustice**.

296 Therefore, I **uphold** Mr and Mrs Wakefield's complaint against the PCT.

297 We say more about injustice in Section 4 of this report.

The Health Service Ombudsman's recommendations

298 I **recommend** that the Chief Executive of the PCT apologise to Mr and Mrs Wakefield for the failings I have set out in this report.

299 I also **recommend** that the PCT offer compensation of £5,000 to Mr and Mrs Wakefield in recognition of the injustice they have suffered in consequence of service failure and maladministration I have identified.

The PCT's response

300 The Chief Executive of the PCT has asked me to place on record his sincere regret and unqualified apology to Mr and Mrs Wakefield for their suffering and distress. He told me the PCT unreservedly recognises its failures in this case and is committed to treating my report as a learning opportunity. I have outlined above some of the actions already taken by the PCT to address its service failings. The Chief Executive also accepted my recommendation regarding a compensation payment.

The Health Service Ombudsman's investigation of the complaint against the Partnership Trust

Complaint (f): care and treatment at the Windrush Unit

301 Mr and Mrs Wakefield complain that Tom's admission to the Windrush Unit was inappropriate and that while there he received inadequate care and treatment. They complain specifically that the Partnership Trust did not investigate an injury to Tom's ear, that he was generally at risk and he was in a poor physical environment. They also complain that Tom's discharge from the Windrush Unit was badly managed.

Key events

302 The Windrush Unit was a ward-based facility providing physical and mental assessment for adults with learning disabilities. People would usually be admitted for about 12 weeks. During that time an assessment would be made of all the factors thought to be affecting an individual's mental or physical state. By the point of discharge a patient should have had an established plan to inform their continued care and treatment.

303 On 20 November 2003, following a short assessment to determine his suitability, Tom was admitted to the Windrush Unit.

304 On admission the Consultant in Charge noted that Tom:

'... had shown a change in his presentation over the preceding 18 months ... thought to be related to increased pain, that set off a chain of deteriorating events with increasing self-injurious behaviour and increasing medication which may itself have been contributing to rather than improving the problems.'

305 She set out a detailed plan for the assessment of Tom's needs, as follows:

'Physical assessment including full phlebotomy (blood testing).

'Baseline monitoring to be carried out by nursing staff including:

- *weigh weekly;*
- *twice daily pulse, temperature and blood pressure;*

- *chart sleep, bowels, bladder and diet.*

'Referral to multi-disciplinary team including:

- *Psychology team;*
- *SALT (Speech and Language Therapist), (for communication and swallowing);*
- *Dietician, diet and bowel function;*
- *OT (Occupational Therapy) for skills and activity;*
- *Physiotherapy ROM exercise recommendations, manual handling, postural management;*
- *Nursing risk assessments, care plans, baseline monitoring, pain assessment.*

'Onward referrals to:

- *Gastroenterology – regarding upper GI pain associated with eating and possibly relating to an ulcer or oesophagitis;*
- *Orthopaedics – review of scoliosis and right femoral head;*
- *Incontinence Nurse advice re: bowels;*
- *Pain clinic for assessment and advice re medication;*
- *Optician;*
- *Dentistry.'*

306 On 12 December 2003 Tom was reviewed by staff at the Hospice. A file note for this date said his background pain was better controlled since the introduction of MST (morphine sulphate) and noted his *'pain now? more clearly GI related'*.

307 On either 17 or 18 January 2004 Tom sustained an injury to his ear. The nursing records for 18 January 2004 note that his ear looked swollen, that the cause was to be queried and Tom was to see a doctor. The Consultant in Charge reviewed Tom's injury the next day. However, Tom developed a 'cauliflower ear' (when an ear becomes thickened or deformed due to physical contact) and was taken to A&E at the Acute Trust on 20 January 2004. The injury became infected and Tom required in-patient admission for wound drainage under general anaesthetic.

308 On 29 January 2004 a possible permanent placement was identified for Tom at Prospect Place, a permanent residential care home for adults with learning and physical disabilities.

309 On 13 February 2004 the Consultant in Charge at the Windrush Unit wrote to the manager of Prospect Place, to inform her that Tom did not intrinsically require nursing care, and that his healthcare needs could be met through the Community Learning Disability Team and generic services. She said a discharge summary would be sent with Tom on the day of his discharge, which would only contain information on his medication. She said a fuller summary would follow later.

310 On 23 February 2004 Tom moved into permanent accommodation, his new home at Prospect Place. His medical notes did not accompany him.

311 The discharge summary was sent nine days after Tom left the Windrush Unit. It noted details of his mental and physical condition and included information about treatment given, for example changes to his drug prescription. The summary noted that Tom had sustained an ear injury that could have resulted from sheering his upper ear whilst pulling his hand across the top of his head or could have resulted from contact with the head rest in his chair, or during transfer in the hoist. It was also noted that Tom had indicated, in a yes/no answer session some five days after the event, that the injury had occurred during hoisting and had been an accident. It had left him with some deformity in the cartilage of the ear.

312 In the discharge summary the Consultant in Charge said:

'As a forward placement was found in a community home for Tom ... agreement was made to move towards discharge rather earlier than I would ideally have anticipated as I still feel there are a lot of changes to be made to Tom's regime which will be difficult to do in the community in a stepwise controlled fashion.'

and

'The ongoing use of morphine based pain killers is obviously problematic in a young man both in terms of the compromise to his respiratory system, the constipating side effects and the increased tolerance that he is likely to show if using this medication over the much longer term that we would anticipate his life continuing for.'

313 The Consultant in Charge went on to note that Tom continued to have bowel difficulties and gastro-oesophageal reflux, which she said would warrant review by a gastroenterologist.

Mrs Wakefield's recollections and views

314 Mrs Wakefield told my investigator she thought the Windrush Unit had been an inappropriate and unsafe place for Tom because it was a psychiatric unit and not, therefore, geared to assessing physiological needs. She felt his admission reflected the continuing assumption that Tom's behaviour did not have a physical cause.

315 Mrs Wakefield said she and her husband had at first been reluctant for Tom to transfer to the Windrush Unit. They felt that it was unlikely to be able to provide the social stimulation and therapeutic environment he required. However, they said that following discussion with a number of health and social care staff, they were persuaded that the Windrush Unit might offer the opportunity for all of Tom's needs – physical and behavioural – to be assessed, and were told that Social Services would provide additional support for Tom. Therefore, although Tom's referral to the Windrush Unit had come about as a result of a series of unfortunate events, rather than a coherent plan, Mr and Mrs Wakefield hoped it might actually turn out to be an opportunity to get to the bottom of Tom's pain and weight loss and result in a plan which would relieve their son's distress.

316 Mrs Wakefield said she and her husband thought the Windrush Unit was unsafe because they often found pills in Tom's bed, his bed clothes were often left unchanged, and he would sometimes be covered in blood. Often he would not be out of bed and would be left screaming in pain. She said there was nothing to stimulate patients. She felt that the Windrush Unit was 'a dumping ground'. She said bathrooms were dirty and rubbish was left lying around and the environment was noisy and this disturbed Tom.

- 317 Mrs Wakefield said she was worried that Tom's weight was not regularly monitored while he was in the Windrush Unit and that no one had noticed how much weight he was losing. She said a PEG feeding tube had not been suggested. However, Tom had been referred for non-urgent endoscopy.
- 318 Mrs Wakefield said she had been told the ear injury was self-inflicted, but she did not think Tom could have done this. She said her son had later indicated that the injury had been caused accidentally. She was sure the injury had occurred in connection with the hoist system.
- 319 Mrs Wakefield understood that Social Services had agreed to fund social care staff to support Tom at the Windrush Unit and in this respect Tom had been '*a first*'. However, she said there had been no communication between Windrush Unit staff and the Social Services staff, who essentially had been left by Windrush Unit staff '*to get on with it*'. Consequently, Tom did not appear to have received basic nursing care or to have had the benefit of social care. Mrs Wakefield said that at times Tom had been left on his own for long periods. She said Tom never went out on trips, so she arranged transport for him.
- 320 Mrs Wakefield said when Tom was discharged into permanent accommodation at Prospect Place, she had arranged transport because she wanted to make sure he got there. She recalled that Prospect Place had not been given any information about him and the discharge process had been a shambles. Although staff at Prospect Place had been very good with Tom and were able to communicate with him, they had not been given relevant medical information and this had influenced the events that had followed.

The Partnership Trust's position

- 321 The Partnership Trust's position is set out in the then Chief Executive's responses to Mr and Mrs Wakefield's complaints.

Tom's admission to the Windrush Unit

- 322 In his response of 23 February 2004 the Chief Executive explained Tom had been admitted for a medical assessment (envisaged as taking 12 weeks) which had coincided with the date for transfer from school. He said Tom had been admitted with the agreement of Social Services who had funded additional support as Mr and Mrs Wakefield considered Tom should have plenty of activity to occupy him. Social Services had continued to seek places for Tom and had identified two, one being short term and another being more permanent. He also said that it was his understanding (from Social Services) that Mr and Mrs Wakefield had turned down a number of placements because they felt they were unsuitable.
- 323 In his letter of 27 August 2004 the Chief Executive explained that the Windrush Unit was not a place of last resort but had a defined clinical role for two groups of clients. Some clients had been there for some time and alternative longer-term care placements were being explored while others were admitted for medical assessment and treatment. He acknowledged that this dual role was not ideal and could lead to a misunderstanding about the Unit's medical assessment and treatment role. He also acknowledged that the environment had been poorly managed at the time Tom was there.

324 The Chief Executive also said the Partnership Trust's records indicated that Tom's admission had been urgent and related to complex physical and behavioural needs. Tom's physical problems were detailed by the Consultant in Charge on admission and this seemed to indicate that Tom's admission was appropriate.

The care and treatment provided to Tom

325 In his response of 27 August 2004 the Chief Executive said liaison arrangements between Windrush Unit staff and the agency staff funded by Social Services had not been consistently effective. Consequently, the Partnership Trust's standards of health and social care had not been met.

326 In his letter of 14 September 2004 the Chief Executive said Tom had undergone a series of assessments and investigations including admission to the Hospice. The Hospice assessment report had supported the care plan drawn up at the Windrush Unit and had not suggested that any other referrals or additional investigations should be undertaken. He also commented that the Consultant in Charge had been aware that Tom had seen a number of consultants in Oxfordshire. She did not want to repeat previous assessments and had, instead, sought details from Oxfordshire.

The injury to Tom's ear

327 In his letter of 23 February 2004 the Chief Executive said he had been unable to establish how Tom had injured his ear because no incident form had been completed. He said the Consultant in Charge had concluded that the injury had arisen because of some sort of impact and had arranged for Tom to be seen in A&E at the Trust. In a subsequent letter of 14 September 2004 the Chief Executive said further investigation had not revealed the cause of the injury but it was possible that the injury

was self-inflicted given Tom's history of self-harming.

Discharge arrangements

328 The Chief Executive addressed arrangements for Tom's discharge to Prospect Place in his letter of 14 September 2004. He explained that the Windrush Unit had only been informed by the Council on 5 February 2004 that Tom would move on 23 February 2004. He said the Consultant in Charge had provided Tom's new GP with a full discharge summary nine days after Tom's discharge which was in line with normal practice. He also said that after Tom's discharge the Consultant in Charge continued to have responsibility for some medical care for Tom, for example, she facilitated a clinical meeting about Tom which was held on 23 March 2004.

329 I also saw evidence of two reviews conducted by Partnership Trust staff about Tom's discharge. The report of the first review, which was undated, said:

- A review meeting had been set for 5 February 2004. Its purpose was changed to a discharge meeting at the start. Tom's named nurse had not been present nor had a representative from the Community Learning Disability Team. Information required for discharge had not been gathered prior to the meeting and no new GP had been identified. Tom's parents had been present and medical information was reviewed and discussed.
- No written referral had been made to the Community Learning Disability Team to alert them to Tom's discharge.
- A new GP for Tom had been identified on 12 February 2004 at a discharge meeting and the discharge summary had been dictated on 3 March 2004.

- The Clinical Nurse Manager at the Windrush Unit had not ensured that the discharge pack that normally accompanied people transferring for a new placement met the expected standard, nor had the Nurse Manager checked that transport was arranged.
- 330 The report of the first review said that it was unacceptable for the discharge process to be led by a relative or other non-professional and that the named nurse or designated deputy must be present to ensure that discharge took place in line with local policy. It stated that a checklist of documents that must be completed prior to discharge would be drawn up and adhered to in future.
- 331 The second review was held on 4 August 2004 and Community Learning Disability Team staff employed by the Partnership Trust attended. The report of the second review reiterated many of the points made in the earlier review and added the following:
- Tom had been transported to his new home in a taxi with an escort who staff at the home had said ‘*dumped and run*’. Tom had been left in a hallway and there was no handover discussion.
 - No paperwork or notes accompanied Tom although some paperwork had been sent later in a carrier bag with incomplete/incorrect material. There was no discharge summary and the new GP received no information or contact details.
 - Tom’s notes were still at the Windrush Unit on 2 March 2004, so a member of the Community Learning Disability Team called to pick them up.

The advice of the Health Service Ombudsman’s Professional Advisers

My Psychiatry Adviser

- 332 My Psychiatry Adviser considered that Tom’s admission to the Windrush Unit was appropriate and that Tom’s clinical presentation matched the admission criteria for the Unit. He also felt that the Consultant in Charge had made a good initial plan for Tom. He was, however, concerned about the apparent failure to observe and react to Tom’s weight loss during his stay at the Windrush Unit.

My Nursing Adviser and my Learning Disability Nursing Adviser

The nursing care provided to Tom at the Windrush Unit

- 333 My Nursing Adviser noted the instructions set out in the comprehensive management plan drawn up by the Consultant in Charge on Tom’s admission. She said these would need to be carried out by nursing staff to help inform treatment plans for Tom. She said it was difficult to find any correlation between the Consultant in Charge’s clinical requests and the reports in the available nursing notes. For example:
- Although the consultant had requested twice weekly weight measurement, weight was only charted 4 times in 96 days; 4 entries were made from 26 November 2003 to 12 February 2004 showing a decrease in weight from 34.2kg to 30.5kg. The adviser could find no plan of action addressing Tom’s weight loss, or any indication that this information was passed to medical staff.
 - There is no evidence in the records of input from a dietician or nutritionist, even though Tom continued to lose weight. Although the nursing notes for the Windrush Unit

frequently express comments such as 'refused all food' and 'very little diet taken', 'taking little diet' there was no evidence in the nursing notes that staff were concerned with, or about, Tom's intake of food. There were few fluid and food recording charts.

- 'Recording of sleep pattern' charts were available for six days in January 2004 and then for ten days before discharge in February 2004.
- Recording of bowel movements started in January 2004, and there were few entries regarding urine output.
- Medication charts had not been filled in.

334 My Nursing Adviser noted that no assessments had been made of pain and that pain assessment charts had been left blank. She said:

'... the few prescription charts available do not indicate that drugs have been given. Nursing records are not well written and do not give the reader confidence that the nursing staff were capable of caring for a patient with acute physical pain. Most entries made relate to subjective views from staff when Tom was screaming in pain or attempting to self-harm. Considering the amount of analgesia that was being administered over a prolonged period of time, and particularly when Tom was having increasingly higher dosages of opiates, it is surprising that monitoring of his respirations were not carried out more frequently. A lot of assumptions were made as to the cause of his pain possibly being abdominal, musculoskeletal, or both.'

335 Five incident forms were started while Tom was in the Windrush Unit regarding:

- an injury to his nose
- bruising/swelling to his finger
- bruising to his arm
- further injury to his face
- pills found in bed.

336 My Nursing Adviser found that none of the incident forms had been fully completed, nor did they give any indication that action would be taken to prevent a recurrence. She could not establish from the nursing records if Tom's parents had been informed of all of these incidents. The Nursing Adviser was concerned that few risk assessments had been completed with regard to maintaining a safe environment for Tom.

337 In summary, my Nursing Adviser said Tom's weight fell quite dramatically during his stay at the Windrush Unit but was not monitored, his pain levels did not appear to have been well monitored or managed, and his nutritional needs were not assessed. She was critical of the nursing care delivered to Tom, including a failure to act sooner in delivering care for his physical needs. She considered the nurses in the Unit had not had the appropriate skills and knowledge to care for a patient such as Tom with his deteriorating physical condition. My Learning Disability Nursing Adviser concurred with my Nursing Adviser's views.

338 My Nursing Adviser said she had:

'... serious concerns relating to the nurses' professionalism in delivering patient care and their adherence to their professional body the Nursing and Midwifery Council's Code of Professional Conduct, which clearly set out the standards and guidelines to which all registered nurses must adhere.'

The injury to Tom's ear

339 My Nursing Adviser noted that Tom had been asked questions by staff who often worked in the Unit as to how the injury had occurred. His parents were not present. His responses to the questions indicated that it had been an accident caused by the hoist. An incident form had not been completed at that time and the Nursing Adviser could find no evidence in the nursing notes that this was considered a serious injury to Tom, or that staff had been alerted to the severity of the incident to prevent it happening again. She concluded that it was too late now to establish how the injury had occurred.

Discharge arrangements

340 My Nursing Adviser said the discharge meeting had been poorly organised. There had been a lack of preparation for the meeting and this had resulted in no professional handover to the new placement. Tom had been transferred without key carers escorting him.

341 My Nursing Adviser noted that the discharge letter stated there had been assessments from speech and language therapy, occupational therapy and nursing therapy. However, the assessment reports that she had seen related to February 2003 from Penhurst School, and not to the care received in the Windrush Unit between November 2003 and February 2004.

My Learning Disability Nursing Adviser also said no referral had been made to a dietician and that no psychology input had been obtained.

Care and treatment at the Windrush Unit: the Health Service Ombudsman's findings

342 As there were distinct aspects to Mr and Mrs Wakefield's complaints against the Partnership Trust I will deal with each in turn.

Tom's admission to the Windrush Unit

343 Mr and Mrs Wakefield were concerned that Tom was inappropriately admitted to the Windrush Unit. I can see that in the context of Tom having received notice to leave Penhurst School Mr and Mrs Wakefield had concerns about the possibility of the Windrush Unit becoming a de facto placement for Tom by the Council, in the absence of the offer of adult accommodation. Nevertheless, in making a finding about the Partnership Trust I have to consider whether the decision to admit Tom to the Windrush Unit was reasonable. My Psychiatry Adviser said that, based on information from Tom's GP, Tom's behaviour had changed and his medication might need review, and taking account of an initial assessment by a nurse from the Unit, the Consultant in Charge had made an appropriate decision to accept Tom for assessment. Therefore, in terms of the Partnership Trust's actions in admitting Tom to the Windrush Unit, I find **no evidence of service failure**.

Tom's care and treatment

344 My Professional Adviser told me the Consultant in Charge at the Windrush Unit drew up a sound plan of action and social care staff were provided to ensure that Tom's social needs continued to be met while he was being assessed. However, the rest of Tom's stay at the Windrush Unit did not live up to this standard.

- 345 During the three months that Tom was a patient at the Windrush Unit, the Consultant in Charge did enact some of her plan. She completed the eradication of Tom's *Helicobacter pylori* (stomach bacteria) and treated his anaemia, but her plans for involving other professionals did not materialise. Despite her referrals, Tom was not seen by a gastroenterologist or by an orthopaedic surgeon. The arrangements for enabling the social care staff to work as part of Tom's team were not effective.
- 346 The failure to report the injury to Tom's ear and to report fully on other incidents meant Tom was placed at unnecessary risk of further injury or harm.
- 347 The Windrush Unit tried to serve two client groups with different needs. It was being closed down when Tom was a patient there and the physical environment was not well managed. I can understand that the Partnership Trust was in something of a dilemma because substantial investment to bring the Windrush Unit to modern standards would not have represented good use of public money. Nevertheless, it is not acceptable for patients to experience such a poor environment. These were matters that could have been addressed.
- 348 The General Medical Council's Good Medical Practice says that a consultant is responsible for ensuring the care provided for patients is co-ordinated and managed, and for ensuring that those to whom he or she delegates care are competent to provide the care involved. The Consultant in Charge said Tom had been discharged early and that she would have liked him to have stayed longer at the Windrush Unit. However, Tom spent over three months at the Windrush Unit – the normal length of stay for an assessment. Therefore, I find it hard to understand why there was not more progress during that time in implementing the Consultant's well designed plan.
- 349 I am also concerned that my Nursing Adviser considers nurses at the Windrush Unit lacked the skills necessary to care for Tom's considerable physical needs.
- 350 Turning specifically to the nursing care provided to Tom, my Nursing Advisers have found many examples of very poor nursing care. Tom's weight, food and liquid intake were not monitored. Bowel and bladder observations were few. Pain charts were left blank. Medication charts were not completed and Tom's respirations were not monitored while he was taking morphine. I note my Nursing Adviser has serious concerns about the nurses' professionalism and about their adherence to professional guidance. In view of the fact that the purpose of the Windrush Unit was to provide physical as well as psychiatric assessment for people with learning disabilities, I am particularly concerned that my Nursing Adviser considers nursing staff appeared to lack the skills to provide care to a patient such as Tom.
- 351 Tom was in the Windrush Unit for almost 14 weeks. At first there was a comprehensive plan for Tom and he did receive treatment and care. However, taken in the round and considering the evidence I have seen, including the advice of my Professional Advisers, I conclude that the overall care and treatment which Tom experienced while in the Windrush Unit fell significantly below a reasonable standard in the circumstances. I conclude that many of the failings in the Partnership Trust's care and treatment of Tom were for disability related reasons. This was **service failure**.

The management of Tom's discharge to Prospect Place

352 In Section 2 I refer to the Department of Health's good practice guidance Discharge from Hospital. The advice I have received and the evidence of reviews conducted by the Partnership Trust and the Community Learning Disability Team indicate that arrangements for Tom's discharge, and the discharge itself, fell well below the standards set out by the Department of Health. On discharge, he was put in a taxi and left at his new home. No proper handover of care and records took place. This was **service failure**.

Care and treatment at the Windrush Unit: the Health Service Ombudsman's conclusion

353 Having considered the evidence about Tom's stay at the Windrush Unit, including the advice I have received and Mrs Wakefield's recollections and views, I conclude that there was **service failure** in the care and treatment provided for Tom and that this failure was in part for reasons related to his disability.

Complaint (g): complaint handling by the Partnership Trust

354 Mr and Mrs Wakefield remain dissatisfied with the way the Partnership Trust handled their complaint.

Key events

355 On 25 January 2004 Mr and Mrs Wakefield complained to the Partnership Trust about the injury to Tom's ear. Their main points of concern were:

- there was no contemporaneous incident report about the injury;
- there was no note of the incident in the communication book used by agency staff; and
- Windrush Unit staff had attributed the injury to Tom self-harming, but other medical opinion had indicated that he could not have inflicted such injury on himself.

They also said Tom was inappropriately placed at the Windrush Unit and had been placed there against their wishes because of a failure to plan and make provision for him.

356 On 23 February 2004 the Chief Executive responded with an explanation of the reason why Tom was placed at the Windrush Unit. He also described what Partnership Trust records showed staff had done on discovering Tom's ear injury. He said he had been unable to establish how the injury had occurred. He acknowledged that staff had been wrong to suggest Tom had injured himself and he apologised for this. However, later in the response he again said self-harm was a possible cause of the injury. The response also included a report of actions the Partnership Trust had taken to prevent recurrence of such an event, including improved incident reporting and record keeping.

357 Mr and Mrs Wakefield were not satisfied with this response and on 8 July 2004 they raised further concerns. Their main concerns were:

- the Windrush Unit had been an unsuitable placement for Tom, he had been placed there against their wishes (they had not refused other placements) and the environment was inadequate;

- the response about Tom's ear injury was inadequate, especially the investigation into how the injury had occurred and the suggestion that it had been self-inflicted;
- medical and social care were inadequate; and
- there had been no proper discharge arrangements for Tom's transfer to Prospect Place.

358 On 27 August 2004 the Chief Executive responded with further explanation about Tom's placement at the Windrush Unit and information about its function, facilities and arrangements for providing care. He acknowledged that the Windrush Unit did not provide the best environment for its two groups of clients and reported on the development of new facilities for clients with learning disabilities. He also acknowledged that the environment had been poorly managed and apologised for this. Furthermore, he acknowledged that liaison between Windrush Unit staff and agency staff had not been consistently effective which meant the aspirations for the standard of health and social care had not been met. He apologised for these shortcomings, but did not detail action taken to improve services. He also apologised for not being able to explain how Tom had injured his ear and enclosed copies of documents relating to the Partnership Trust's investigation of the cause of the injury.

359 On 14 September 2004 the Chief Executive responded to Mr and Mrs Wakefield's complaint about medical care. He explained about assessments which had taken place and plans which had been drawn up for Tom's care. He also said staff had been concerned that they did not repeat assessment unnecessarily.

360 With regard to the complaint about discharge arrangements, the Chief Executive said there had been some communication between professionals but the timescale had been short and there had been some uncertainty about ongoing responsibilities for Tom's care. He said a discharge summary had been sent nine days after Tom's discharge and this was in line with normal practice. He also described how meetings and discussions had taken place involving Windrush Unit staff after Tom had been discharged.

Complaint handling by the Partnership Trust: the Health Service Ombudsman's findings and conclusions

361 In Section 2 I have summarised the Regulations relating to the way in which NHS bodies should handle complaints. I have compared the Partnership Trust's actions with those Regulations.

362 On the whole the Partnership Trust responded to Mr and Mrs Wakefield's complaint within a reasonable timescale, although the Chief Executive's third letter was sent more than two months after the second complaint was received. I accept that it was not unreasonable to split the response to the second complaint into two letters, although an integrated approach would have been better.

363 Each of the three responses from the Chief Executive addressed the key issues complained about, gave details about Tom's care and treatment and explored some of the rationale behind treatment decisions. However, it is clear from the Chief Executive's responses that investigation of some matters, especially discharge arrangements, was inadequate. On this matter the Chief Executive was defensive and provided excuses

rather than explanations. I was not convinced that the Partnership Trust had recognised and acknowledged its failings on this important issue. In contrast, my investigation has revealed significant failings in discharge arrangements.

364 That said, the Chief Executive did acknowledge and apologise for some failings, such as poor incident reporting, and did inform Mr and Mrs Wakefield about some changes which had taken place to address those failings. But there was no information about improvements in discharge planning.

365 I find that repeatedly suggesting that Tom had injured his own ear was inappropriate and insensitive, especially given the circumstances of the events complained about.

366 I conclude that the failings in the way the Partnership Trust handled Mr and Mrs Wakefield's complaint amount to **maladministration**.

Complaints against the Partnership Trust: the Health Service Ombudsman's conclusions

367 Having studied the evidence available in the light of the advice of my Professional Advisers and considered Mrs Wakefield's recollections and views, I conclude that there was **service failure** in the Partnership Trust's management of arrangements for Tom's care and treatment, specifically:

- i. failure to implement the plan of care drawn up on admission;
- ii. failure to properly report the injury to Tom's ear;

iii. failure to provide a suitable physical environment;

iv. failure to provide a reasonable standard of nursing care; and

v. failure to make appropriate arrangements for Tom's transfer to Prospect Place.

368 I also conclude there was **maladministration** in the way the Partnership Trust handled Mr and Mrs Wakefield's complaint.

Further information provided by the Partnership Trust

369 In response to the draft report the Partnership Trust provided me with a wide range of information to demonstrate action taken to address shortcomings identified in my investigation. These measures were detailed in an action plan and included:

- measures to improve care environments;
- additional skills training for professional staff, including incident reporting and emergency response training;
- introduction of new care pathways, benchmarking and other care quality improvement measures;
- improved liaison between professionals, for example using a Care Programme Approach for multidisciplinary discharge planning and documentation;
- improved multi-agency working, for example link posts with the Acute Trust; and

- improved risk management procedures and heightened focus on protection of vulnerable adults.

Injustice

370 I have taken into account these recent actions by the Partnership Trust to improve services for people with learning disabilities. However, the fact remains that at the time Tom needed help from the Partnership Trust he did not receive a reasonable standard of service. Mr and Mrs Wakefield consider that Tom suffered unnecessarily while at the Windrush Unit. We cannot know whether the outcome for Tom would have been different had the Consultant's plan been pursued more effectively by the Windrush Unit's staff and if Tom had been provided with better treatment and care. However, it is clear that while Tom was in the Windrush Unit care and treatment were inadequate and, in particular, his weight continued to decline. Furthermore, he lacked social support. Failures to appropriately pursue referrals may have disadvantaged Tom.

371 Although there was no service failure by the Partnership Trust in Tom's admission to the Windrush Unit, there was service failure while he was there and, notably, in the management of his discharge. This service failure contributed to the injustice of unnecessary distress and suffering for Tom and his family. Moreover, partly due to failings in the Partnership Trust's complaint handling, Mr and Mrs Wakefield have had to wait four years to learn the truth about Tom's care and treatment in the Windrush Unit. This will undoubtedly have contributed to their distress which remains an **unremedied injustice**.

372 Therefore, I **uphold** Mr and Mrs Wakefield's complaint against the Partnership Trust.

373 We say more about injustice in Section 4 of this report.

The Health Service Ombudsman's recommendations

374 I **recommend** that the Chief Executive of the Partnership Trust apologise to Mr and Mrs Wakefield for the failings I have set out in this report.

375 I also **recommend** that the Partnership Trust offer compensation of £10,000 to Mr and Mrs Wakefield in recognition of the injustice they have suffered in consequence of the service failure and maladministration I have identified.

The Partnership Trust's response

376 The Chief Executive of the Partnership Trust has asked me to place on record his apology to Mr and Mrs Wakefield. He also offered to meet Mr and Mrs Wakefield to offer them his personal apologies. He told me the Partnership Trust is committed to learning from my report and outlined key learning points and actions the Partnership Trust has taken to address its service failings. The Chief Executive told me that in response to this case the Partnership Trust has produced an action plan which has been shared with Monitor (the government body which regulates NHS foundation trusts). That plan has also been reported to the Practice Standards Committee and progress is being monitored by the Partnership Trust Board. Furthermore, in 2009 the Chief Executive intends to commission an independent review of progress against the action plan and he will make this available to Mr and Mrs Wakefield and the wider public. He confirmed that the Partnership Trust is willing to work openly and collaboratively

with local and central bodies regarding the matters raised in this case. The Chief Executive also accepted my recommendation regarding a compensation payment.

The Health Service Ombudsman's investigation of complaints against the Acute Trust

Complaint (h): care and treatment at the Acute Trust

377 Mr and Mrs Wakefield complain about the care and treatment provided for Tom by the Acute Trust, particularly with regard to pain management, hydration and nutrition from his admission on 6 April 2004 until his death on 25 May 2004.

Key events

378 Tom experienced considerable distress almost as soon as he moved to Prospect Place and was admitted to an acute hospital (not the subject of a complaint) on 2 March 2004, where he was found to be suffering from severe constipation. He was discharged back to his residential home on 5 March 2004.

379 On 6 April 2004 Tom was admitted to the Acute Trust. Events at the Trust between his admission and death on 25 May 2004 are summarised at Annex B.

Mrs Wakefield's recollections and views

380 Mrs Wakefield said that although she and her husband had concerns about some of the care provided by the Acute Trust, they had not complained at the time because they had

already made several complaints about the care and treatment provided to Tom by other organisations and felt that they could not cope with any more. Mrs Wakefield said when Tom had been admitted to hospital she and her husband had been concerned by a consultant's attitude. She recalled that the consultant had said: *'there is not much that we can do here'*. The consultant concerned had not spoken to Tom. Afterwards they had placed a note by Tom's bedside informing staff that he could understand what was said and had the same feelings and sensitivities as everyone else.

381 Mrs Wakefield had been under the impression that Tom would be provided with palliative care when he had been admitted because she had been informed that the palliative care team at the Hospice would be contacted. However, she had subsequently found out that the palliative care team were not involved until 24 hours before his death.

382 Mrs Wakefield said she had asked about Tom's nutrition and had been told that he would be alright for a few days because he was being given fluids. She said that, however, Tom had been nil by mouth for a week before a PEG feeding tube was inserted. She said that everyone apart from her appeared to be aware that Tom's condition had deteriorated too much for him to survive. No one had told her what his chances of survival were.

The Acute Trust's position

383 In response to my enquiries the Acute Trust said Mr and Mrs Wakefield had not complained directly to the Acute Trust so it had not been able to respond to their concerns. When my investigative staff met staff from the Acute Trust they said they were very surprised that

Mr and Mrs Wakefield had complained about the care and treatment Tom had received because they believed they had developed a close and caring relationship with the family. Staff said they felt they had made reasonable adjustments to meet Tom's needs, for example, additional involvement of consultants and the former Deputy Director of Nursing. They said the adjustments they had made, including sensitive support for the family, were not always recorded.

384 Nonetheless, the Acute Trust said it intended to conduct an internal inquiry after the Ombudsmen had reported.

385 The Acute Trust provided details of policies and procedures, for example, about assessment, planning and delivery of care and administration of medicines. It also provided details about the Gloucestershire Patient Profile which is used for recording care and confirmed it provided training to all nursing staff on the use, completion and interpretation of this documentation. When my investigative staff visited the Acute Trust they were given a more detailed explanation about this method of documenting nursing care.

386 The Acute Trust said it had implemented the Essence of Care benchmarking standards of care, including benchmarking for nutrition. It also provided details about its Acute Pain Service.

387 The Trust said policies for reporting and recording of incidents had first been introduced in 2002 and had been revised subsequently. Learning from incidents was fed back to staff and used in training sessions to demonstrate the importance of reporting to improve practice and the safety of patients and staff. The Acute Trust acknowledged that learning from incidents and

complaints needed to improve and had been identified as a key measure in relation to the Patient Safety Objective adopted by the Trust in 2007.

388 The Acute Trust said it recognised the needs of people with learning disabilities, and in line with the guidance set out in Valuing People it had collaborated with the Partnership Trust in developing a resource and training pack for staff which was available on all wards. Link nurses had been identified in areas where patients with learning disabilities were most likely to be admitted. A carers' group had been set up and a self-assessment proforma had been introduced.

The advice of the Health Service Ombudsman's Professional Advisers

My Gastroenterology Advisers

389 My First Gastroenterology Adviser said by the time Tom was admitted to the Acute Trust his health had deteriorated too far for there to be a realistic prospect of recovery.

390 My Second Gastroenterology Adviser said:

'Tom suffered life-threatening episodes of respiratory failure that appear to be due to chaotic prescriptions of a mixture of interacting sedatives, analgesics and other medications. This was unacceptable. In the case of some opioids the prescriptions did not conform to legal requirements for controlled drugs. The ultimate responsibility for this lies with the prescribing doctor, but it is equally surprising that the prescriptions were not queried by pharmacy or nursing staff. It would appear that the situation may have been influenced by the perception of a pressing need to alleviate Tom's obvious distress and by the involvement

of a surprising number of junior doctors in the prescribing process. It seems clear from the record that some of the junior doctors involved “out of hours” in Tom’s care were new to his clinical problems. This raises questions about the continuity of care, which hinges on the quality of the handover between doctors on consecutive periods of duty, assuming that such formal handover occurred (none are recorded in the clinical notes). I note that on one occasion (2 May 2004) both the house officer and the registrar on call were temporary locum appointments. There also appeared to be instances of inconsistencies or misunderstandings within the clinical team: for example, with regard to the purpose of PEG placement, the need to refrain from oral fluids or medications following PEG placement, and the required calorie content of gastric feeds. Such inconsistencies are suggestive of incomplete communications within the clinical team.

‘...’

‘Having said this, there can be no doubt that Tom’s medical problem was extraordinarily difficult to manage. As indicated by the acute pain consultant it is crucial to diagnose the cause of Tom’s pain in order to treat effectively. However, despite reasonable efforts the cause of Tom’s distress was never diagnosed – indeed, it could not be ascertained with certainty whether his behaviour indicated pain since pain, discomfort, displeasure and distress appeared to be indicated by the same behavioural mannerism.

‘...’

‘While Tom was in the Acute Trust, there is remarkably little comment in the medical notes concerning Tom’s weight loss and an extreme paucity of objective measurements of his weight. It is not clear from the record whether the tardiness in replacing a proper PEG tube, ... , contributed to his poor nutritional state. However, despite receiving appropriately calculated calorie feed through the larger of the temporary tubes, Tom failed to gain weight.

‘...’

‘Very sadly, I feel that Tom’s mode of death was consistent with the natural history of such a degree of disability. With the exception of the prescription issues referred to above, I do not think that the standard of care fell to an unreasonable level.

‘...’

‘On balance, I have to conclude that there were issues, outlined above, regarding the prescription of Tom’s medications that were not acceptable. I also feel that the very difficult management of Tom’s pain should have been supervised by a specialist in pain management and not (apparently) left largely in the hands of some very junior doctors.’

³⁹¹ In their response to our draft report Mr and Mrs Wakefield asked that my Second Gastroenterology Adviser provide more detailed explanations about the advice he gave me. This further advice is at Annex C.

392 Mr and Mrs Wakefield also asked for information about re-feeding syndrome. My First Gastroenterology Adviser provided this information which is at Annex D.

My Nursing Adviser

The management of Tom's pain

393 My Nursing Adviser said the acute pain nurse contributed to assessment of Tom's pain when he was admitted and proposed a useful treatment plan. Pain care plans commenced on admission but appeared to stop on 13 May 2004. She said whilst the nursing staff used care plans to evaluate Tom's daily medication there were no regular assessments of his pain. She considered the plans did not give an indication of the effects of analgesia or why breakthrough pain drugs were administered. There was no separate monitoring of Tom's pain once a syringe driver was in place.

Monitoring of vital signs

394 My Nursing Adviser said Early Warning Scoring System charts were used to monitor temperature, pulse and respirations and had been reasonably well filled in at some points during admission. She said recording of respirations is vital when opioids such as morphine are being used fairly regularly, especially in patients who are taking a 'cocktail' of drugs. Although Tom was receiving opioids regularly there was no record of his respirations during the first few days of his admission. Between 24 and 29 April 2004 Tom was receiving his opioids through a syringe driver and observations should have been recorded on a half-hourly basis to ensure no deterioration in his condition, but there is no indication that this happened.

395 My Nursing Adviser could see from Tom's medical records that on 22 April 2004 Tom became unresponsive with a respiratory

rate of 6/7 breaths per minute. Naloxone was administered with good effect and, appropriately, an Acute Life Threatening Events-Recognition and Treatment (ALERT) Care Plan was commenced on 23 April 2004. She said a similar incident occurred on 24 May 2004 and naloxone was administered. Minimal observations were carried out for a short period. Oxygen was administered to Tom but not written up as a proper prescription.

396 My Nursing Adviser said:

'... for a patient as compromised as Tom was with aspiration pneumonia and recurrent chest infections, there should be serious consideration given as to whether an opioid overdose may have been a cause or contributing factor in the two serious events.'

She said there was no evidence that Tom's parents had been told about these two serious episodes.

397 My Nursing Adviser said there were patient profiles in the nursing notes but they had been only partially completed. She explained that if patient profiles were not fully completed they could not contribute to the management of risk in caring for a patient with such complex needs. My Nursing Adviser reviewed the evidence about nursing records in the light of the Trust's additional explanation about documentation, but she found no reason to change her advice.

Monitoring of nutrition and fluid intake and gastrostomy care plan

398 My Nursing Adviser said Tom's nutrition and fluid intake were not monitored well. No nutritional nursing care plan was commenced on admission. Fluid balance charts (including intravenous fluid charts) were poorly completed

often giving no indication for days whether Tom had passed any urine. My Nursing Adviser said there seemed to be no plan for managing Tom's hydration on the occasions when his feeding tube or drip 'fell out'.

399 However, my Nursing Adviser found evidence in speech and language therapy and dietician records that Tom was reviewed regularly. She said these records showed consideration had been given to appropriate timing and duration of feeding and there was evidence of discussion with nurses and carers, for example about the most appropriate position for Tom when he was receiving nutrition via his PEG feeding tube. She also said there was evidence of multidisciplinary discussions and engagement of carers regarding management of the feeding tube, for example regarding caring for the feeding tube insertion site and monitoring for infection. My Nursing Adviser said the therapy records showed a reasonable level of assessment and care planning for management of the PEG feeding system.

400 My Nursing Adviser found no record of Tom's weight until 10 May 2004. There are further records of his weight on 17 and 21 May 2004. My Nursing Adviser considered this to be an extremely serious omission on the part of nursing staff.

Bowel management

401 Tom had a history of severe constipation over a long period of time and required laxatives, a good diet, and enemas to aid his bowel movements. My Nursing Adviser noted that Tom's parents frequently commented to the nursing staff that they were concerned about Tom's bowels. My Nursing Adviser said that in circumstances such as these she would have expected, as a minimum, a care plan outlining how Tom's bowels could be managed. However, there was no care

plan; instead, notes were written sporadically in the communication sheets. These range from 'severely constipated' to 'loose bowel movements' and 'smelly green stools'. She was concerned to see that nothing was recorded in the notes to suggest there might have been a problem with his bowels.

Privacy and dignity

402 My Nursing Adviser said:

'The nursing records available do not give the impression that this young and severely disabled man was afforded the best possible care available. There is no evidence to indicate that on a daily basis his hygiene needs such as bathing, mouth care, bowel management and social needs were met.'

403 My Nursing Adviser noted that carers from Prospect Place visited regularly and may have been involved in his care. However, she said Tom's care was the responsibility of the nursing staff at the Acute Trust and, as such, all of his needs should have been assessed, planned, evaluated and recorded as having been given by the nursing staff during his admission. The nursing records do not indicate this was the case.

Communication with Tom and his family

404 My Nursing Adviser said she could find no clear evidence in the nursing records that communicating with Tom or assisting his understanding of what was happening to him was discussed with his family.

405 In summary, my Nursing Adviser considered there was evidence of:

- poor assessment and planning to meet Tom's individual physical needs;

- poor monitoring of Tom's respiratory rate;
- failure to observe the deterioration in Tom's condition;
- poor record keeping, for example, in risk assessment, about tissue viability and on fluid charts;
- poor incident recording and reporting; and
- lack of concern over two serious events relating to his drug therapy.

406 My Nursing Adviser said many aspects of care in the Acute Trust fell below a reasonable standard of nursing care, which should have been provided by registered nurses to any patient in their care. She therefore had serious concerns relating to the nurses' adherence to the standards set out in key documents including the Nursing and Midwifery Council's Code of Conduct.

My Learning Disability Nursing Adviser

407 My Learning Disability Nursing Adviser said Tom's care had been planned and communicated via standardised care plans which did not take into account his disabilities and communication deficits. She commented that no member of nursing staff appeared to acknowledge that these care plans were unsuitable for Tom. My Learning Disability Nursing Adviser could find no evidence that communicating with Tom and/or those communicating on his behalf had been fully addressed by the Acute Trust.

My Pharmacy Adviser

408 My Pharmacy Adviser said calculating an appropriate dose of medicines for a patient as frail as Tom was difficult and would have been complicated by his ongoing weight loss. He noted there may have been a significant risk of unwanted side-effects emerging from a number of the medicines he was receiving and that, although Tom was an adult, given his frailty, the advice of a pharmacist with paediatric experience, or a paediatrician, could have been helpful in tailoring doses more appropriately to his individual requirements. He could find no evidence to indicate that this had been done while Tom was in hospital.

409 My Pharmacy Adviser said there were frequent occasions where correct procedures for writing prescriptions had been overlooked. For example, very few of the medicines written up for 'as required' administration included any additional directions for nursing staff to follow in order to assist them in deciding whether or not an 'as required' dose should be given. He noted that some of the 'as required' prescriptions did not state, as they should have done, the circumstances when a dose might need to be given, a maximum number of doses per day, and the minimum interval between doses or the maximum dose in a 24-hour period. He said the 'as required' prescription for morphine on 15 April 2004 was especially poor, lacked detail and was, therefore, potentially dangerous. He was also concerned to see that the prescription which was written to supply Tom with diamorphine via a syringe driver was incorrectly dated and contained no indication, as it should have done, of the amount of diamorphine to be delivered through the syringe driver within a specified time.

410 My Pharmacy Adviser said there were many potential side-effects from the individual drugs and combination of drugs which Tom was taking. He noted that opioids suppress respiration and taking baclofen at the same time can enhance this problem. Furthermore, he said the sedative effects of drugs like diazepam are increased in a patient taking opioids.

411 My Pharmacy Adviser explained that it was by no means certain that Tom would have experienced all, or indeed any, unwanted side-effects. However, he agreed with my Nursing Adviser's concern that Tom should have been monitored more closely, particularly in the early stages of his admission.

412 My Pharmacy Adviser expressed concern about the regime set up for administration of diamorphine to Tom via a syringe driver. He said the regime did not conform to the recommended method for the control of chronic pain. He said that he could understand and sympathise with the reasons behind choosing to load the syringe driver with a lower dose of diamorphine than was going to be needed, then relying upon additional bolus injections to control Tom's breakthrough pain. However, he said each injection was likely to have caused distress and to have run the risk of Tom suffering unnecessary pain. He said that with this method of pain control more effort and rigour should have been applied to monitoring his clinical response and vital signs, with emphasis on his respiratory rate.

413 My Pharmacy Adviser said the fact that small doses of naloxone were used to good effect pointed to opioid toxicity as the cause of Tom's respiratory depression.

Care and treatment at the Acute Trust: the Health Service Ombudsman's findings

414 Mr and Mrs Wakefield asked me to investigate the care and treatment which Tom received at the Acute Trust in the seven weeks leading up to his death.

415 It is clear to me that the combination of Tom's complex health needs, poor nutritional state and disabilities meant that reaching a diagnosis and finding appropriate clinical treatment presented a significant challenge. I do not think staff at the Acute Trust shied away from this challenge. I have not seen any evidence that the investigations carried out could be considered unreasonable and I have seen evidence of appropriate measures which were taken to address some of Tom's needs, such as inserting and managing a PEG feeding tube. However, there is also evidence of some failings in nursing care, particularly in assessment, planning and record keeping, relating to nutrition and hydration, and pain management.

416 Having considered all the evidence and taken account of prevailing standards and the advice of my Professional Advisers, I do not think that a list of all the specific failings in what was a complex and challenging situation would provide the most appropriate representation of Tom's experience in the last two months of his life or the nature of the failures of the Acute Trust. Rather, I have decided to consider his care and treatment in the round. From this perspective, I find there is compelling evidence that the Acute Trust failed to provide Tom with a reasonable standard of care and treatment in the circumstances.

417 I have identified aspects of the care and treatment provided by the Acute Trust where I consider the failings are particularly significant:

- The co-ordination and supervision of Tom's care fell well below prevailing standards. Junior doctors and locum staff appeared to lack support in caring for Tom. There was no clear evidence of the appropriate involvement of a pharmacist in the management of his medication. At times communication between the members of the clinical team appears to have been confused. The General Medical Council's booklet Good Medical Practice provides very clear guidance about consultant responsibility for ensuring care is co-ordinated across disciplines, for example, suitable arrangements should be in place when the consultant is not available and locum and junior staff should be properly supported. There is evidence that this did not happen in Tom's case.
- Record keeping was poor and there were gaps in Tom's health records. Both the General Medical Council and the Nursing and Midwifery Council regard good record keeping as an absolutely essential element of nursing and medical care.
- There is evidence of inadequate observations to maintain Tom's safety while he was receiving morphine.
- The arrangements for calculating and managing Tom's medication, particularly his morphine, were poor. Tom was frail, yet his weight seems not to have been factored into the calculation of the dosages of all his medicines. Tom was being given many drugs, yet there was no obvious plan for managing the potential for interaction between

them. Instructions for the delivery of Tom's medication were inadequate and created the potential for adverse effects. During the time that Tom was receiving infusions of diamorphine his respiratory rate fell on at least two occasions to a level that required naloxone to be administered. The ALERT arrangements instituted after the first event were not properly followed through and a similar incident occurred soon after.

- The incidents referred to above were not properly recorded, nor was the incident when the nurse allowed some intravenous feed to run through at one time. Vulnerable patients such as Tom rely on staff to demonstrate the highest levels of integrity and accountability. The failure to properly report and record these highly significant incidents put Tom at greater risk of recurrence.
- My Nursing Adviser has pointed to failings in the nursing care provided to Tom. She considered these failings meant the nursing care provided was below the levels expected by the Nursing and Midwifery Council and guidance such as Essence of Care. I have seen nothing which persuades me to question that advice. Rather, it leads me to question whether staff knew how to make appropriate adjustments for a person with learning disabilities.
- My Nursing Adviser and my Learning Disability Nursing Adviser said that the core care plans drawn up on admission did not take into account Tom's disabilities and communication problems. Again, this leads me to question whether staff knew how to make appropriate adjustments for a person with learning disabilities.

- There is no evidence that Tom’s parents were made aware of his prognosis and it seems to me that Mr and Mrs Wakefield were not properly involved in discussion about their son’s imminent death.

Care and treatment at the Acute Trust: the Health Service Ombudsman’s conclusion

418 I am left in no doubt that the Acute Trust failed to provide Tom with a reasonable level of care and treatment in the circumstances. I consider that many of the failings in the Acute Trust’s care and treatment of Tom were for disability related reasons. This was **service failure**.

Injustice

419 I note my Professional Advisers’ views that by the time Tom reached hospital his condition had deteriorated to a point where recovery was unlikely. Nevertheless, I have identified that there were significant failings in the standard of care provided to Tom. This service failure by the Acute Trust contributed to the injustice of unnecessary distress and suffering for Tom and his family and is an **unremedied injustice**.

420 Therefore I **uphold** Mr and Mrs Wakefield’s complaint against the Acute Trust.

421 We say more about injustice in Section 4 of this report.

The Health Service Ombudsman’s recommendations

422 I **recommend** that the Chief Executive of the Acute Trust apologise to Mr and Mrs Wakefield for the failings I have set out in this report.

423 I also **recommend** that the Acute Trust offer compensation of £10,000 to Mr and Mrs Wakefield in recognition of the injustice they have suffered in consequence of the service failure I have identified.

The Acute Trust’s response

424 The Chief Executive of the Acute Trust asked to place on record his apology to Mr and Mrs Wakefield. He also offered to meet them to express his personal apologies. He said the Acute Trust is committed to learning from this case and is developing an action plan to address the issues highlighted by my investigation. He explained that this plan will be notified to Monitor and progress would be reported to the Acute Trust Board. Furthermore, the Chief Executive said he would be happy to share the action plan with Mr and Mrs Wakefield. He accepted my recommendation regarding a compensation payment.

The Health Service Ombudsman’s investigation of the complaint against the Healthcare Commission

Complaint (i): the Healthcare Commission’s review of Mr and Mrs Wakefield’s complaints

425 Mr and Mrs Wakefield are dissatisfied with the way the Healthcare Commission (the Commission) handled their complaint. They say the Commission’s review has not addressed all of their complaints, the Commission has not considered all the relevant information, and the Commission did not take appropriate advice.

The basis for the Health Service Ombudsman's determination of the complaints

426 The regulations and standards which apply to the Commission's handling of complaints are set out in Section 2 of this report. When assessing the way in which the Commission handled Mr and Mrs Wakefield's complaints I have regard to those regulations and standards and to my own *Principles of Good Administration* and *Principles for Remedy*.

The Health Service Ombudsman's jurisdiction and role

427 Section 1 above sets out the basis of my jurisdiction in relation to complaints made to me that a person (or body) has sustained injustice or hardship in consequence of maladministration by the Commission in the exercise of its complaint handling function.

428 When complaints have already been reviewed by the Commission, I do not normally carry out an investigation of the original complaint, but investigate the way in which the Commission has conducted its review. Specifically, I consider whether:

- i. there were any flaws in the Commission's review process which make the decision unsafe;
- ii. the Commission's decision at the end of the review process was reasonable; and
- iii. the service the Commission provided was reasonable and in line with its own service standards.

429 When I uphold a complaint about the Commission's complaint handling, because I find that the review process was flawed, or the decision unreasonable, I normally refer the complaint back to the Commission for it to remedy the failure by conducting a further review.

The Health Service Ombudsman's decision

430 For the reasons given below, I **uphold** Mr and Mrs Wakefield's complaint about the Commission's complaint handling. However, I did not consider it appropriate to recommend a further review by the Commission and I therefore decided to investigate the complaint myself.

The Commission's reviews

Key events

431 Mr and Mrs Wakefield first complained to the Commission in February 2005. Their complaints were that:

- the GP failed to search for the causes of Tom's pain, or to act on the advice of the Hospice doctor;
- the Partnership Trust failed to investigate the impact injury to Tom's ear, failed to carry out appropriate medical investigations, and failed to discharge Tom properly;
- the environment at the Partnership Trust had been unsatisfactory; and
- the PCT had failed to plan properly for Tom's transition into permanent adult accommodation.

432 Mr and Mrs Wakefield said they considered that Tom's death was preventable and had occurred as a result of a combination of failures that had been raised on numerous occasions. Mr and

Mrs Wakefield also said that, although they had not previously complained about the Acute Trust, they wanted the Commission to consider the care and treatment Tom received while he was a patient there because it formed an integral part of his care and would better inform the Commission's overall understanding of their complaint.

433 The Commission's Case Manager wrote to the GP, the Partnership Trust and the PCT in May 2005 to ask for records and files. There was then a gap of five months until Mencap met with the Commission on 25 October 2005 to find out what was happening. They were told that a decision was expected by the end of November 2005.

434 The Commission wrote to Mr and Mrs Wakefield six months later in April 2006 to apologise for the further delay and to update them with the progress of its review. Mr and Mrs Wakefield were informed that, as three different health providers had been complained about, separate case numbers had been allocated to the respective complaints.

The Commission's first decision

435 The Commission issued its first decision on 28 April 2006. In its letter, the Commission only addressed Mr and Mrs Wakefield's complaint against the PCT. The Commission found that, although Mr and Mrs Wakefield's complaint had been acknowledged by the PCT, the PCT had held back from issuing a full response because of the proximity of the anniversary of Tom's death. When it learned that the Commission would be investigating the complaint, the PCT decided not to respond until the Commission had finished its investigation. The Commission decided to refer the complaint back to the PCT recommending that the PCT apologise and explain its reasons for not responding, and address Mr and Mrs Wakefield's complaint, albeit belatedly.

The PCT's response

436 The PCT wrote to Mr and Mrs Wakefield on 12 June 2006. The PCT said there was little it could add to the responses that Mr and Mrs Wakefield had received from the Partnership Trust and Social Services, except to say that as a service commissioner it would be looking at how the identified shortcomings had been addressed, particularly with regard to communication issues between different clinical teams and professionals, and in improving the quality and speed of communication. The PCT apologised for its failings and said that it had learnt from this complaint and had amended its protocols to reflect this.

The Commission's second decision

437 On 12 May 2006 the Commission issued its second decision about Mr and Mrs Wakefield's complaint. This addressed the complaint against the GP. The GP had informed the Commission that he no longer held Tom's clinical records; however, he sent the Commission a copy of the computerised GP patient summary notes and a prescribing history for Tom. There is no evidence to indicate that the Commission asked for medical records from any other source.

438 The Commission sought clinical advice from a GP (the Commission's First GP Adviser) who, on the basis of the information provided by the GP, concluded that he '*had acted entirely appropriately in looking after Tom*'. He said that the GP's explanations for his clinical decisions were accurate and appropriate and were supported by the clinical records.

439 In the light of the clinical advice which the Commission had obtained, the Commission decided not to take any further action on the complaint against the GP.

The Commission's final decision

440 On 10 May 2006, two days before the second decision was issued, Mencap contacted the Commission to raise their concerns about the Commission's first decision. They said Mr and Mrs Wakefield were dissatisfied that, after 15 months, the Commission had decided to refer their complaint about the PCT back to the PCT – and that their other complaints had not been addressed at all.

441 On 21 June 2006 the Commission informed Mr and Mrs Wakefield that, although decisions on the complaints against the PCT and the GP had already been issued on 28 April and 12 May 2006, in the light of Mencap's letter, these complaints would now be reconsidered together with the complaint against the Partnership Trust which appeared not to have been considered at all up to that point. No mention was made of Mr and Mrs Wakefield's complaint about the Acute Trust.

442 In October 2006 the Case Manager informed Mr and Mrs Wakefield that their case was being reallocated to another case manager. The new Case Manager spoke to Mrs Wakefield in November 2006 to clarify the heads of complaint; she wrote to her on 21 November 2006 to confirm that she would be reviewing the complaint in its entirety.

443 The Commission split Mr and Mrs Wakefield's complaint against their GP into six issues which included their concerns that the GP failed to search for the causes of Tom's pain, act on the advice of the Hospice doctor or manage Tom's nutritional needs adequately. As part of its review, the Commission obtained advice from a different GP (the Commission's Second GP Adviser). In her report the Commission's Second GP Adviser referred to the General Medical

Council's 2006 version of Good Medical Practice, to information contained on an American website concerned with gastrointestinal endoscopy, and to National Institute for Clinical Excellence guidance on dyspepsia issued in August 2004. She concluded that:

- it was unclear whether Tom's parents were present when the decision not to refer Tom for endoscopy was discussed on 17 October 2003. However, the GP's grounds for not referring Tom for endoscopy were reasonable;
- it was unlikely that vomiting or feeding difficulties were major problems for Tom during the time in question;
- there was no evidence to suggest that a PEG feeding tube had been considered; however, the Adviser did not consider that the conditions for the insertion of a PEG feeding tube had been met up to November 2003;
- there was no evidence of a formal diagnosis of hip dislocation and she thought the GP's management of Tom's pain had been reasonable; and
- communication between the healthcare professionals and Tom's parents could have been improved. She recommended that a clear indication be given as to who is expected to make a referral for specialist advice. She recommended that the GP review his practice and protocols against the National Institute for Clinical Excellence guidance CG17 on dyspepsia.

444 The Commission divided Mr and Mrs Wakefield's complaint against the Partnership Trust into five issues which included their concerns that staff

failed to investigate the impact injury to Tom's ear, failed to carry out appropriate medical investigations and failed to discharge Tom properly. As part of its review, the Commission sought professional advice from a learning disability nurse (the Commission's Learning Disability Adviser) and a consultant psychiatrist (the Commission's Psychiatric Adviser).

445 The Commission's Learning Disability Adviser made some general comments about the way in which transition should have been handled. However, she focused on the injury that Tom sustained while a patient at the Partnership Trust. She was critical of the Partnership Trust's investigation into Tom's injury and did not consider that the Trust's response went far enough. The only record of this advice is a note of her discussion with the Commission's Case Manager. It is unclear whether this adviser reviewed Tom's nursing records.

446 The Commission's Psychiatric Adviser said:

- in view of Tom's deteriorating health, his admission to the Partnership Trust was not inappropriate. He noted that a carefully considered clinical plan had been drawn up and some progress had been made. He felt that urgent referral had not been required;
- the Partnership Trust had acknowledged that Tom's discharge had not been handled well, and that action had been taken to ensure that there would not be a recurrence. Further, the Partnership Trust appeared to have been quite open about shortcomings and had initiated action to produce system changes and there was nothing more that he could add; and

- he had been struck by the meticulous efforts of the Consultant in Charge. Tom had received a relatively good standard of care at the Partnership Trust and much of the remaining unresolved complaint stemmed from differing views on the optimum approach to Tom's clinical management.

447 The Commission's Psychiatric Adviser did, however, make some recommendations. These included that the Partnership Trust:

- consider whether it required input from a dedicated GP to look after the patients' physical health needs and a specialist liaison nursing team to facilitate access to mainstream secondary medical care;
- consider more consultation with key stakeholders regarding care; and
- embrace the latest guidance on consent which, if it had been used fully, would have evidenced consultation with partners in Tom's care.

448 The Commission issued its final decision on 31 January 2007. In respect of Mr and Mrs Wakefield's complaint about the PCT, the Commission said that, in its response of 12 June 2006, the PCT had explained why it had not responded initially to Mr and Mrs Wakefield's complaints, offered an apology for that, and had subsequently reviewed the responses which Social Services and the Partnership Trust had provided. The Commission concluded that this was an appropriate response from the PCT as a service commissioner, and that no further action on the part of the PCT was warranted.

449 The Commission did not uphold any of Mr and Mrs Wakefield's complaints about the GP.

450 The Commission did not uphold Mr and Mrs Wakefield's complaints about the appropriateness of Tom's admission to the Partnership Trust or the failure of staff there to carry out medical tests. The Commission concluded that the Partnership Trust had been open about the failures in the discharge process and was satisfied that changes had been put in place to ensure that discharge arrangements were more effective in the future. The Commission did, however, uphold Mr and Mrs Wakefield's complaint about the Partnership Trust's investigation into the injury which Tom sustained while in its care. The Commission recommended that the lessons from the incident be shared with staff and the Partnership Trust offer Mr and Mrs Wakefield an unreserved apology for the way in which this incident was handled.

451 The Commission made no reference to Mr and Mrs Wakefield's complaint about the Acute Trust.

The advice of the Health Service Ombudsman's Professional Advisers

452 I asked my Professional Advisers for their views about the Commission's clinical advice. They considered that the advice from the GP and consultant psychiatrist was appropriate. However, they were concerned that the Commission did not seek appropriate professional advice about Tom's general medical and nursing needs while he was at the Partnership Trust. Such advice has been critical to my investigation of the Partnership Trust's actions.

The Health Service Ombudsman's findings

453 I have explained that I assess the way in which the Commission conducted its review by considering the review process, the decision and whether the service provided was reasonable.

454 I find that the Commission's process was flawed. It is clear that Mr and Mrs Wakefield wanted the Commission to bring all four aspects of their complaint together and investigate them in the round. The Commission did not do this, deciding instead to split Mr and Mrs Wakefield's complaint into discrete elements.

455 The Commission then failed to address significant aspects of Mr and Mrs Wakefield's complaint. Initially, the Commission only provided decisions about two of the four bodies that Mr and Mrs Wakefield had complained about (the PCT and the GP). Mr and Mrs Wakefield's complaint about the Partnership Trust and Acute Trust were not addressed. Following Mencap's intervention, the Commission decided to re-review their complaints. This was the Commission's opportunity to get its handling of Mr and Mrs Wakefield's complaint right. The Commission's final report, issued on completion of the reconsideration process, did address Mr and Mrs Wakefield's complaints about the GP, PCT and Partnership Trust as a whole. That said, I can understand their disappointment that the Commission's report contained no synthesis of its findings – and still no mention was made about their complaint against the Acute Trust.

456 I also have concerns about the Commission's clinical advice. First, the Commission did not obtain Tom's full health records to inform its assessment of the care provided by the GP. I am not persuaded that either of the Commission's

GP Advisers could reach a properly informed view about Tom's care and treatment without this information.

457 Secondly, my Professional Advisers have raised concerns that the Commission did not seek appropriate professional advice about Tom's general medical and nursing needs while he was a patient at the Partnership Trust. I would expect that when the Commission reviews complaints which involve clinical care, it would obtain appropriate advice from professional advisers with relevant experience and expertise. Clearly, in order to properly and comprehensively address Mr and Mrs Wakefield's complaint about the standard of care and treatment their son received at the Partnership Trust, the Commission should have obtained appropriate medical and nursing advice. Whilst the Commission appears to have taken advice from a specialist learning disability nurse, the only record of that advice is a note of a discussion between that adviser and the Commission's Case Manager, and it is unclear whether the Commission's Learning Disability Adviser had reviewed Tom's nursing records. My findings from my own investigation have raised serious concerns about the nursing care provided to Tom and underline the extent to which the absence of appropriate general nursing advice impacted on the quality of the Commission's response.

458 I find that the clinical advice which the Commission obtained was inappropriate and inadequate. This renders its decisions unreliable and unsafe.

459 Finally, I find that some of the Commission's decisions were not adequately explained. The Commission did not uphold Mr and Mrs Wakefield's complaint about the GP, but did not explain why its Clinical Adviser had

reached the view that the GP had acted entirely appropriately in looking after Tom. I note also that, in respect of the Commission's final decision, the Commission's Psychiatric Adviser found that the care and treatment provided by the Partnership Trust had been reasonable, yet he made a number of significant recommendations for improvement. The Commission appears to have accepted this view and reflected it in its final decision letter without questioning the contradictory messages that such a response conveyed to Mr and Mrs Wakefield.

460 I also find that the Commission provided a poor service. It took the Commission 15 and 17 months to complete the reviews of Mr and Mrs Wakefield's complaints about the PCT and the GP respectively, and 8 months to complete the re-review. Its service standard at the time was that, in the majority of cases, the review process should take no longer than six months. Whilst I do not consider that the length of time it took the Commission to complete the reviews would necessarily, in itself, amount to a poor service, I was concerned to note that there were long gaps during its first and second reviews when the Commission did not keep in touch with Mr and Mrs Wakefield. In particular, there appear to have been two occasions where the Commission did not contact Mr and Mrs Wakefield for approximately five months. One of the six *Principles of Good Administration* (referred to in Section 2 of this report) is that public bodies should be customer focused, and specifically that they should tell people if things are going to take longer than they had said they would. Failing to do this, and failing to have made contact with the complainants for such lengthy periods of time does not, in my view, reflect good administrative practice or customer service.

461 I conclude that the failings I have identified in the Commission's handling of Mr and Mrs Wakefield's complaint amount to **maladministration**.

Injustice

462 The injustice arising from the Commission's maladministration is that Mr and Mrs Wakefield did not get the joined-up, comprehensive review of their complaints to which they were entitled. The Commission's review fell far short of a reasonable standard and, in particular, did not provide them with the explanations they sought.

463 Therefore, I **uphold** Mr and Mrs Wakefield's complaint against the Commission.

The Health Service Ombudsman's recommendation

464 I **recommend** that the Commission apologise to Mr and Mrs Wakefield for failing to carry out a proper review of their complaint.

The Commission's response

465 The Chief Executive has accepted my recommendation and she will write to Mr and Mrs Wakefield to express her apologies once this report has been issued.

Section 4: the Ombudsmen's final comments

Introduction

⁴⁶⁶ Mr and Mrs Wakefield's overarching complaint is that Tom's death was avoidable, that he suffered unnecessarily and received less favourable treatment for reasons related to his learning disabilities. In this the final section of our report we address Mr and Mrs Wakefield's overarching complaint.

⁴⁶⁷ In assessing the actions of the Surgery, the PCT, the Partnership Trust, the Council and the Acute Trust we have taken account of relevant legislation and related policy and administrative guidance as described in Section 2 of this report. We have taken account of available evidence and considered the advice of our Professional Advisers.

Was Tom treated less favourably for reasons related to his learning disabilities? The Ombudsmen's conclusions

⁴⁶⁸ Mr and Mrs Wakefield believe their son was treated less favourably for reasons related to his learning disabilities.

⁴⁶⁹ The Local Government Ombudsman concluded that some of the Council's maladministration in its arrangements for Tom's transition to adult accommodation was for disability related reasons.

⁴⁷⁰ The Health Service Ombudsman found that there were shortcomings in the PCT's fulfilment of its responsibilities with regard to the planning for the health needs of people with profound and multiple learning disabilities and concluded that this service failure by the PCT was for disability related reasons.

⁴⁷¹ The Health Service Ombudsman also found service failures by the Partnership Trust and concluded that some of these service failures, in terms of managing Tom's discharge and Tom's care and treatment, were for disability related reasons.

⁴⁷² The Health Service Ombudsman also found service failure in relation to the nursing and medical care provided by the Acute Trust and concluded that some of these service failures were for disability related reasons.

⁴⁷³ In Section 2 we set out our approach to human rights. On that basis, we also conclude that the service failure and maladministration at the Council, the Partnership Trust, the PCT and the Acute Trust constituted a failure to live up to human rights principles, especially those of dignity and equality.

⁴⁷⁴ There is no evidence of any positive intention to humiliate or debase Tom. Nevertheless, the standard of service does raise the question whether the actions of the Council, the Partnership Trust, the PCT and the Acute Trust constitute a failure to respect Tom's dignity.

⁴⁷⁵ In these respects we conclude that the maladministration and service failures we have found showed inadequate respect for Tom Wakefield's status as a person.

Did Tom suffer unnecessarily?

⁴⁷⁶ The Health Service Ombudsman concludes that service failure by the Partnership Trust and the Acute Trust resulted in unnecessary suffering for Tom in the final months of his life.

Was Tom's death avoidable?

- 477 Mr and Mrs Wakefield believe that had their son received appropriate and reasonable service from the bodies they complained about his death would have been avoided. They have said they accepted that Tom had a life-limiting illness, but not that his condition was life-threatening. They have said that doctors did not give them any indication that their son was likely to die.
- 478 In considering whether to make a finding about avoidable death we assessed whether the injustice or hardship complained about (in this case Tom's death) arose in consequence of the service failure or maladministration we have identified.
- 479 We have concluded that there was public service failure by the Council, the PCT, the Partnership Trust and the Acute Trust and that those combined failings resulted in significant unremedied injustice for Tom and his parents. Mr and Mrs Wakefield will never know if, had appropriate arrangements been in place – as they should have been – for Tom's transition to adult care, his life would have been longer or if he could have had some extra enjoyment in his last year of life.
- 480 However, on balance, we cannot say that Tom's death was in consequence of the service failure or maladministration we identified. Rather, we have seen that Tom's condition was declining for many years and that this decline began before the events complained about. Therefore, we cannot conclude that Tom's death was avoidable.

Mr and Mrs Wakefield's response to the Ombudsmen's draft report

- 481 Mr and Mrs Wakefield were dissatisfied with the outcome of some aspects of our investigation. Their response to our report contained many detailed points which we have addressed separately in liaison with Mencap. However, Mr and Mrs Wakefield's dissatisfaction focused primarily on the Health Service Ombudsman's decision not to uphold their complaint against the Surgery. They continue to believe that the '*actions of the GP were pivotal*' to what happened to Tom. They also strongly disagree with the decision of both Ombudsmen where we did not conclude that Tom's death was avoidable. In particular, Mr and Mrs Wakefield do not accept that their son was '*in an inevitable decline*'. They asked for a more detailed explanation of the advice provided by the Second Gastroenterology Adviser. They also said that essential evidence in support of their position could be provided by the Hospice's Medical Director and they asked for him to be interviewed.
- 482 In response to Mr and Mrs Wakefield's concerns the Health Service Ombudsman asked for further, more detailed advice from the Second Gastroenterology Adviser (now included at Annex C of this report) and she arranged for the Hospice's Medical Director to be interviewed (now included in the section of this report relating to the Surgery).

483 The Health Service Ombudsman carefully considered the additional information provided by the Second Gastroenterology Adviser and the interview evidence of the Hospice's Medical Director. However, she found no evidence that would cast doubt on her findings and decisions about the Surgery. Furthermore, after careful deliberation, neither Ombudsman found any grounds in the new evidence which would cast doubt on their conclusion about whether Tom's death was avoidable.

Our concluding remarks

484 In earlier sections of this, our joint report, we have set out our investigation and findings with regard to the care, treatment and service Tom Wakefield and his parents received from the Council, the NHS and the Healthcare Commission. We are acutely aware that our findings will undoubtedly cause further distress to Mr and Mrs Wakefield and that they do not agree with all our conclusions. However, we can assure them that their complaints have been thoroughly and impartially investigated and that our conclusions have been drawn from careful consideration of detailed evidence, including the opinion of independent professional advisers.

485 We hope our report will provide Tom's family with the explanations they seek and reassure them that lessons have been learnt and learning shared as a result of their complaint, so that others are now less likely to suffer the same experiences as they and their son did. We also hope that our report will draw what has been a long and complex complaints process to a close.



Ann Abraham
Parliamentary and Health Service Ombudsman



Jerry White
Local Government Ombudsman

March 2009

ANNEX A

Good Medical Practice, 2001: Relevant sections

The duties of a doctor

'Patients must be able to trust doctors with their lives and well-being. To justify that trust, we as a profession have a duty to maintain a good standard of practice and care and to show respect for human life. In particular as a doctor you must:

- *make the care of your patient your first concern;*
- *treat every patient politely and considerately;*
- *respect patients' dignity and privacy;*
- *listen to patients and respect their views;*
- *give patients information in a way they can understand;*
- *respect the rights of patients to be fully involved in decisions about their care;*
- *keep your professional knowledge and skills up to date;*
- *recognise the limits of your professional competence;*
- *be honest and trustworthy;*
- *respect and protect confidential information;*
- *make sure that your personal beliefs do not prejudice your patients' care;*

- *act quickly to protect patients from risk if you have good reason to believe that you or a colleague may not be fit to practise;*
- *avoid abusing your position as a doctor; and*
- *work with colleagues in the ways that best serve patients' interests.*

In all these matters you must never discriminate unfairly against your patients or colleagues. And you must always be prepared to justify your actions to them.'

Providing a good standard of practice and care (sections 2 and 3)

'Good clinical care must include:

- *an adequate assessment of the patient's conditions, based on the history and symptoms and, if necessary, an appropriate examination;*
- *providing or arranging investigations or treatment where necessary;*
- *taking suitable and prompt action when necessary;*
- *referring the patient to another practitioner, when indicated.*

'In providing care you must:

- *recognise and work within the limits of your professional competence;*
- *be willing to consult colleagues;*

- *be competent when making diagnoses and when giving or arranging treatment;*
- *keep clear, accurate, legible and contemporaneous patient records which report the relevant clinical findings, the decisions made, the information given to patients and any drugs or other treatment prescribed;*
- *keep colleagues well informed when sharing the care of patients;*
- *provide the necessary care to alleviate pain and distress whether or not curative treatment is possible;*
- *prescribe drugs or treatment, including repeat prescriptions, only where you have adequate knowledge of the patient's health and medical needs. You must not give or recommend to patients any investigation or treatment which you know is not in their best interests, nor withhold appropriate treatments or referral;*
- *report adverse drug reactions as required under the relevant reporting scheme, and co-operate with requests for information from organisations monitoring the public health;*
- *make efficient use of the resources available to you.'*

Working with colleagues (section 36)

'Healthcare is increasingly provided by multi-disciplinary teams. Working in a team does not change your personal accountability for your professional conduct and the care you provide. When working in a team, you must:

- *respect the skills and contributions of your colleagues;*
- *...*
- *communicate effectively with colleagues within and outside the team.'*

Arranging cover (section 39)

'You must be satisfied that, when you are off duty, suitable arrangements are made for your patients' medical care. These arrangements should include effective hand-over procedures and clear communication between doctors.'

Delegation and referral (section 46)

'Delegation involves asking a nurse, doctor, medical student or other health care worker to provide treatment or care on your behalf. When you delegate care or treatment you must be sure that the person to whom you delegate is competent to carry out the procedure or provide the therapy involved. You must always pass on enough information about the patient and the treatment needed. You will still be responsible for the overall management of the patient.'

ANNEX B

Summary of events at the Acute Trust

6 April 2004

Tom was admitted following a request from his GP for investigation and treatment of pain. He had opened his bowels that day and the abdominal X-ray performed on admission did not reveal anything diagnostic. Constipation was ruled out. The surgical team found it extremely difficult to assess Tom, but routine examinations and investigations for abdominal pain were performed. He was promptly transferred to the care of the gastroenterology clinical team. The consultant was on leave for the first week of Tom's admission. There was liaison with Tom's mother, his carers and the GP. Advice was sought from a consultant specialising in the management of acute pain who emphasised the importance of establishing an accurate diagnosis of the cause of the pain to enable a logical management plan.

The gastroenterology team discussed the various known causes of Tom's pain. Although it was clear that Tom had suffered with musculoskeletal pain for some time it was thought, on balance, that Tom also had abdominal pain – primarily because of his decreased appetite and *'spasms of the abdominal wall'*.

The initial management plan for Tom was to try to exclude a gastrointestinal cause for his symptoms by investigating Tom by endoscopy under sedation, by abdominal ultrasound and by treating him for constipation even though the X-ray taken on admission had not shown specific evidence of this.

13 April 2004

The Community Learning Disability Team notes indicate they offered support to ward staff at the Acute Trust in managing Tom. The Community Learning Disability Team Speech and Language Therapist requested a referral for a swallow assessment, and ward staff reported that a referral

had been made. The Community Learning Disability Team Speech and Language Therapist noted that Tom was eating custard and breathing it into his upper respiratory passages before swallowing. Therefore, in her view, he was at risk of aspiration. She also noted that he appeared to have a chest infection and she suggested that Tom should be 'nil by mouth' (that is, he should be given no fluid or food orally).

15 April 2004

An endoscopy was performed. This revealed inflammation of the gullet with ulceration caused by gastric acid from the stomach through a wide opening between the stomach and the gullet. Tom was treated with strong doses of proton pump inhibitors – drugs to suppress acid production so that refluxed gastric products are less likely to damage the gullet and cause pain. This treatment did not seem to provide Tom with relief.

16 April 2004

The Acute Trust's Speech and Language Therapist assessed Tom and found his swallow to be unsafe, with risk of inhalation of swallowed food and liquid. She recommended that Tom should be nil by mouth and a PEG feeding tube should be fitted. Tom was hydrated intravenously.

17 April 2004

Tom's health records show his white blood cell count was raised, implying continued infection despite intravenous antibiotic treatment.

20 April 2004

An abdominal ultrasound was performed but revealed nothing abnormal.

21 April 2004

A CT scan showed no evidence of a source of pain in the biliary tract, pancreas or abdomen, but did reveal extensive pneumonia in the lower half of Tom's left lung. This was treated with intravenous antibiotics.

22 April 2004

Tom suffered an episode of severe respiratory failure which did not appear to be related to his pneumonia, but resulted from a loss of respiratory drive (a failure to breathe). His respirations fell to 7 per minute. He responded rapidly to an injection of naloxone, an antidote to drugs of the morphine group.

The Community Learning Disability Team nurse noted her concern about the standard of nursing care provided to Tom, and about the uncertainty regarding Tom's future. She noted there was a difference of view between health professionals, for example, with regard to insertion of a PEG feeding tube. She noted it had been agreed that there should be a meeting to discuss these concerns and agree a way forward.

27 April 2004

A PEG feeding tube was inserted and feeding was initially successful, but Tom's pain was still not well controlled.

3 May 2004

A further respiratory crisis occurred when Tom's pulse rate became markedly elevated and his blood oxygen saturation level fell well below normal. It was thought that this was caused by further inhalation of refluxed feed from the stomach. It was therefore decided that all PEG feeding should occur during the day while Tom was sitting up, rather than at night while he was lying down.

5 May 2004

PEG feeding was stopped when a carer accidentally pulled out the PEG feeding tube. Nutrition was provided intravenously.

A nurse allowed 300ml of intravenous feeding through in a short time.

7 May 2004

A substitute PEG feeding tube of paediatric size was inserted, to allow administration of drugs.

11 May 2004

The small tube was replaced by a larger one.

12 May 2004

The Community Learning Disability Team notes record that although the PEG feeding tube had been refitted little feed was going in. The Speech and Language Therapist expressed concern regarding Tom's weight, which she noted as being approximately 4 stone.

19 May 2004

The Community Learning Disability Team's Speech and Language Therapist noted that when she had visited Tom, although she had found him to be better, he was still very thin and was losing weight although the PEG feed was being increased.

20 May 2004

The PEG feeding tube fell out while Tom was being bathed and a new tube was inserted.

23 May 2004

During the night Tom suffered a further respiratory crisis with reduced respiratory rate associated with hypothermia. He was reviewed by an Intensive Therapy Unit consultant.

24 May 2004

Tom suffered another episode of severe respiratory failure which did not appear to be related to his pneumonia, but resulted from a loss of respiratory drive. Naloxone was administered.

25 May 2004

Tom died at 5.00pm.

ANNEX C

Further clinical advice provided by the Second Gastroenterology Adviser

The following detailed clinical advice was provided by Dr Ralph Barry in response to Mr and Mrs Wakefield's comments on the draft report.

Avoidable death

On this issue Dr Barry said:

'Mr and Mrs Wakefield challenge the finding in the draft report that Tom's death was not avoidable. This finding is based in part on the statement in my initial advice that, "I feel that Tom's mode of death was consistent with the natural history of such a degree of disability". I remain of this opinion.

'...

'It is important to understand, however, that the statement refers to the manner of Tom's sad death, not the timing. The clinical evidence indicates that Tom's death occurred as a result of the progressive physical consequences of the brain injuries sustained at birth, of which his learning disabilities were but one manifestation.'

Dr Barry described the neurological consequences of Tom's cerebral palsy (other than his learning disabilities) and the consequential vulnerability of his respiratory system. He said:

'The weakness, rigidity and inco-ordination of the muscles of the upper throat resulted in inhalation of swallowed liquids which causes collapse of the lung by blocking the airways. Infection of the collapsed lung will usually follow (pneumonia). In Tom, the risks of major inhalation were markedly increased

by the free reflux of stomach contents backwards into the oesophagus. The marked kyphoscoliosis (abnormal curvatures that result from abnormal muscle stresses on the spine) seriously decreases lung volumes and also considerably reduces movements of the ribs. As a result, ventilation of the lungs is seriously impaired (restrictive lung disease) as also is the ability to cough effectively. This impairment of the protective cough reflex further increases the risks of developing pneumonia and the reduced lung volumes exacerbate the consequences of such infections. It is for these reasons that I consider lung problems as the Achilles heel of this particular neurological damage. There is clear, objective evidence in the clinical record that Tom had episodes of serious inhalation and an established pneumonia in the period prior to his death.

'I believe Tom's death was entirely consistent with the pattern I have outlined above, but I am unable to say it was avoidable. Rather, it was a consequence of his difficulties in swallowing and gastro-oesophageal reflux. The impaired swallowing was a consequence of the neurological damage sustained at birth. The gastro-oesophageal reflux had also been a problem since infancy.'

The nature and time of Tom's decline

On this issue Dr Barry said:

'Much of the evidence for Tom's "decline" comes from the observations of his parents and various carers and antedates Tom's admission to the Acute Trust. On the basis of the documentation available to me, there seem to be three strands to Tom's deterioration in health namely progressive weight loss, pain and

(possibly) reflux oesophagitis (inflammation, ulceration or bleeding of the oesophagus caused by reflux of acid from the stomach).

'Progressive weight loss

'It would appear that visible weight loss became a concern to his carers some time in the autumn of 2003 as evidenced by: (i) documented 3.7kg weight loss between November 2003 and February 2004; (ii) Speech and Language Therapy assessment on 19 November 2003 recording a decline in nutritional status; (iii) photographic evidence of weight loss over a period of 18 months; and (iv) correspondence from the manager of the Respite Centre which refers to a considerable weight loss over nine months since October 2003. I also note that Tom was described as "very slim" on admission to the Windrush Unit. It is apparent that much of Tom's weight loss occurred before his admission to the Acute Trust. However, given the visible evidence of weight loss, it is surprising that there is such a paucity of objective measures of Tom's weight during his admission to the Acute Trust. By 17 and 21 May 2004, Tom's weight was recorded as 25 and 28.3kg respectively which is clearly abnormal for his age.

'Pain

'Pain was clearly a long-standing feature of Tom's condition. The date of onset is not clear. It was responsible for his admission to the Acute Trust in March and April 2004, but was also the apparent reason for his referral to the Hospice in March 2003. The correspondence from the Hospice indicates that the cause of pain was believed to be multifactorial, but that the dominant cause was probably musculoskeletal (meaning that it arose from

his muscular spasticity and skeletal deformity). At that time, pain from his bowel was also believed to be a factor, but pain from reflux oesophagitis was not considered significant.

'The impression from the records is that the pain contributed to Tom's "decline" because of increasing severity or frequency and the difficulty in controlling it.

'Reflux oesophagitis

'It is difficult to be certain that reflux oesophagitis was a true factor in Tom's "declining health", but I understand that it is an important factor in his parents' eyes. However, the timing of the onset of symptoms of oesophagitis is clear, because Tom required surgery in infancy for bleeding oesophagitis caused by gastro-oesophageal reflux. The clinical correspondence from Tom's carers prior to his admission to the Acute Trust indicates that Tom was treated with antacid medications throughout his life because of perceived reflux symptoms.

'In respect of these three factors, I would offer the following observations.

'The most obvious and visible component of Tom's decline is his weight loss. His nutritional deterioration was not inevitable and his parlous nutritional state should undoubtedly have received earlier and more aggressive attention. On admission to the Acute Trust, the medical notes do not convey a sense of urgency in his nutritional management, although the recognition of impaired swallowing on 16 April 2004 required the discontinuation of oral feeding before the insertion of a PEG feeding tube. However, notwithstanding Tom's obvious weight loss, he died of infection

(pneumonia) and not of starvation. The cause of the pneumonia was inhalation pneumonitis in the context of impaired lung function and gastro-oesophageal reflux that had been present from infancy. The presence of oesophagitis is symptomatic of the gastro-oesophageal reflux but is not directly relevant to inhalation – the cause of his death.

‘In their response ... Mr and Mrs Wakefield reasonably ask, “At what point do the clinical advisors think that it was reasonable to assume that Tom’s life was at risk ...”. My response would be, from the time at which it was recognised that Tom’s swallow was unsafe (19 November 2003, confirmed again on 16 April 2004). However, the risk of inhalation dated from infancy.

‘Tom’s pain was a very distressing component of his “decline” and I am very critical of the management of his pain. However, I have not said that at no point was Tom’s pain fully investigated. Tom underwent various blood tests and X-rays immediately on admission to the Acute Trust and was then appropriately referred to specialist gastroenterologists who investigated by further blood tests, upper gastrointestinal endoscopy, ultrasound scans, computed tomography (CT scans) and the further advice of a consultant specialist in pain was also obtained. Notwithstanding these investigations, the definitive cause of Tom’s pain was not specifically identified – as witnessed by several references in the clinical record to this uncertainty.

‘From Mr and Mrs Wakefield’s response to the draft report, it seems they are of the view that his pain was caused by reflux oesophagitis and would have been relieved by early diagnosis at endoscopy. I am obliged to regard this

(very understandable) belief as an unsafe assumption for the following reasons. In reflux oesophagitis, pain does not correlate well with the severity of the visible changes in the oesophagus. Severe, bleeding oesophagitis may be completely painless. Pain can also be quite severe in the total absence of any visible inflammation. Of direct relevance, however, is the observation that Tom’s pain was not relieved or modified when his oesophagitis was treated with very powerful acid suppressants following endoscopy in the Acute Trust.’

Is there a point at which an opportunity to prevent or delay Tom’s decline was missed?

On this point Dr Barry said:

‘I am unable to identify any evidence of a specific point at which an opportunity existed to change the course of Tom’s decline. However, I remain of the view that after the Autumn of 2003, when Tom’s weight loss appears to have been identified, appropriate nutritional support should have been instigated. Arguably, this may have arrested his weight loss or even improved his resistance to infection. However, Tom’s death resulted from inhalation which was not specifically related to his declining weight.’

Conclusion

Dr Barry concluded by saying:

‘It is apparent that I had failed to make it explicitly clear in my initial advice that Tom’s very sad death was related to the progressive physical consequences of his brain injury (not his learning disabilities) and the functional

abnormalities of his lower oesophagus that had been present from infancy. I have tried to clarify these issues above.

'I remain critical of the issues highlighted in my original advice. I fully appreciate the concerns that Tom's parents have eloquently expressed and I am conscious of the distress they have suffered. From the moment of birth, death cannot be avoided, only postponed, and only very rarely is it possible to say when. In Tom, the volume of his gastro-oesophageal reflux was an ever-present danger. Once his ability to swallow became impaired, presumably a consequence of the neurological damage sustained at birth, episodes of inhalation and consequential pneumonias seem inevitable.'

ANNEX D

Re-feeding syndrome

Mrs Wakefield asked about 're-feeding syndrome'. She wondered whether Tom had suffered from this while he was at the Acute Trust and whether it was one of the factors leading to his deterioration and death.

The First Gastroenterology Adviser explained that 're-feeding syndrome' occurs when malnourished patients are fed too aggressively after a period of starvation. The body switches over to using glucose as an energy source with high levels of insulin released which drives essential minerals, such as phosphate, into cells and increases magnesium and potassium loss in the urine. These changes affect all body organs and are potentially very dangerous. The careful monitoring of the blood levels of these minerals is essential when feeding is restarted. He noted that because a post mortem was not carried out it was not possible to say whether Tom suffered from 're-feeding syndrome' in addition to his other conditions. We note that the Acute Trust has informed us that its retrospective review of records demonstrates that 're-feeding syndrome' did not occur in Tom's case.

We hope that this information is of some help to Mrs Wakefield.

PHSO-0006

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office

ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.

6 lives: the provision of public services to people with learning disabilities



Part 8: EasyRead overview and summary investigation reports

Six lives: the provision of public services to people with learning disabilities

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Second report

Session 2008-2009

Presented to Parliament pursuant to
Section 14(4) of the Health Service Commissioners Act 1993

Ordered by
The House of Commons
to be printed on
23 March 2009

HC 203-VIII
London: The Stationery Office
£64.15



We need to put this page here for Parliament.
The report begins on the next page.

6 lives: the provision of public services to people with learning disabilities

Overview and summary investigation reports

Written by the Health Service Ombudsman
and the Local Government Ombudsman



EasyRead Report

This is the EasyRead version of a report that looks at services given to 6 people with learning disabilities who died.

What is an Ombudsman?



The **Health Service Ombudsman** has the power to look into complaints people make about the NHS.

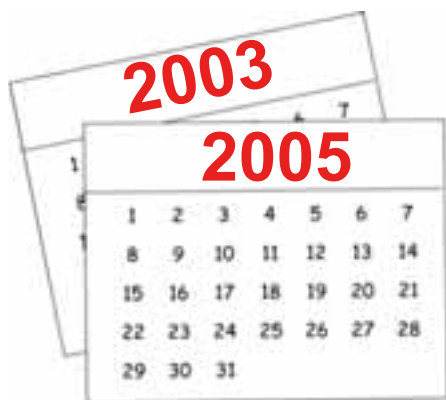


The **Local Government Ombudsman** has the power to look into complaints people make about local councils.



The Ombudsmen get involved if people are not happy with the way organisations deal with their complaints.

What this report is about



This report is about public services given to 6 people.

These 6 people died while they were in health or social care between 2003 and 2005.



Mencap wrote a report called 'Death by Indifference' in March 2007. The report said that these 6 people should not have died.



Mencap made complaints against 20 organisations for their families.



Mencap said the organisations involved had discriminated against these 6 people because they had learning disabilities.



Mencap asked the Health Service and Local Government Ombudsmen to look into the complaints of all 6 families.



The Health Service Ombudsman looked at 3 cases on her own. She looked at 3 with the Local Government Ombudsman.



The reports show what can go wrong when organisations are not able to meet each person's own needs or even offer a very simple level of service to everyone.



The families of 5 of the 6 people were unhappy about how their complaints were dealt with by each organisation and by the Healthcare Commission.



The Ombudsmen are keen to make sure that complaints are used to make services better in the future.



The Ombudsmen know they cannot put things right when people have died. But they can make services better when things go wrong.



It is clear in the reports that some of the organisations involved did not understand the laws about human rights and disability discrimination.



The Ombudsmen found that organisations need to make some really big changes to the way they see people with learning disabilities and the way they work.



The Ombudsmen did not agree with all of the complaints that the families made.



The Health Service Ombudsman has come up with some guidelines on how organisations can work well and deal with complaints properly.

The basic guidelines are:



- get it right



- focus on customers



- be open and honest



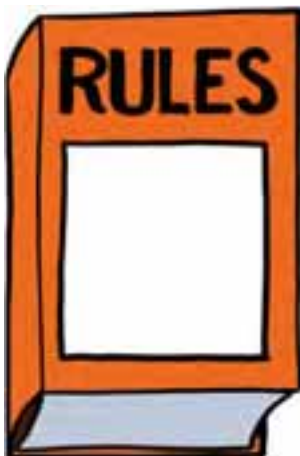
- put things right



- act fairly and do the right amount of work



- want to make changes for the better.

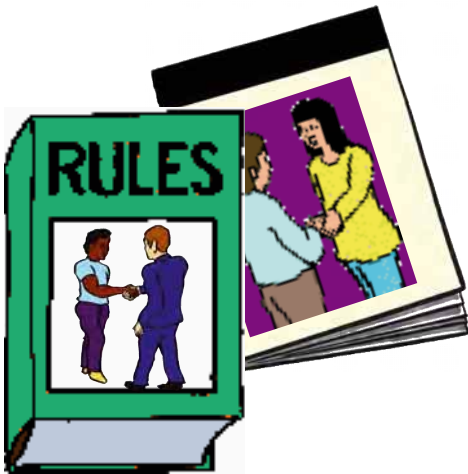


The rules for good ways of working are important to the cases the Ombudsmen look into.

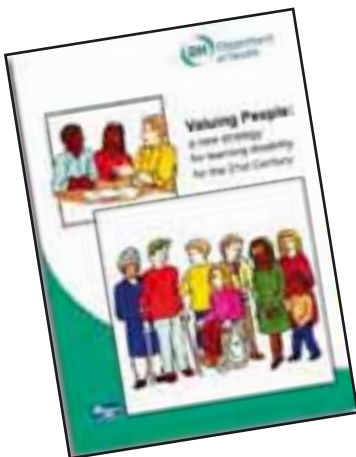


Important guidelines and good ways of working

The investigation reports explain what guidelines and information organisations should be using to work out how good their services are.

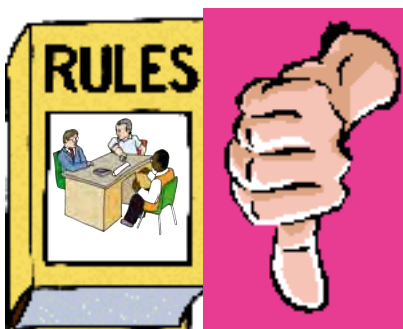


Lots of rules and information have been written to tell health and social care experts how to treat everybody equally and fairly.



Valuing People was written in 2001.

It says that public services must treat people with learning disabilities with respect and dignity.



The Ombudsmen were very upset to find out that these simple rules were not always followed.



Treating each person separately

It is against the law for services to treat people unfairly because they have a disability.



Equality for people with disabilities does not mean getting the same treatment as everyone else. People with disabilities may need different treatment.



Some of the organisations the Ombudsmen looked at did not know how to meet the needs of the people they were treating.



Some of the people who died were not treated fairly.





Doing simple things well

To give good care to adults services need to:

- talk together



- work together to get things done



- talk with families and carers



- follow rules



- have good management



- work with advocates.

Advocates are people who act for or speak for someone.



To make this work we need people in organisations who:

- can take control of situations.



Handling complaints

The families involved in this report said that nobody wanted to put things right or say sorry.



The Healthcare Commission is part of the complaints system, and looks at complaints against health services.

The families hoped they would get some answers. But sometimes they got the same treatment that they got from the other services.



The way health and social care complaints are dealt with will change in April 2009.



The Government said that we need to have 1 complaints system for health and social care.



The Ombudsmen think these changes will work really well.

What should be done to try and put things right



Not all health and social care experts treat people with learning disabilities unfairly.



But the same complaints show up again and again in different organisations.



This tells the Ombudsmen that some people do not understand how to care for people with learning disabilities.



The Ombudsmen think that when things have gone wrong:

- bosses in charge of the organisations involved should say sorry



- organisations should pay compensation



- everybody must know how to do things better next time.



The Ombudsmen really want to change things for the better, and to make these changes last.



The Ombudsmen know this will not be easy.



What the Ombudsmen think should happen now

1. All NHS and social care organisations in England must look at:



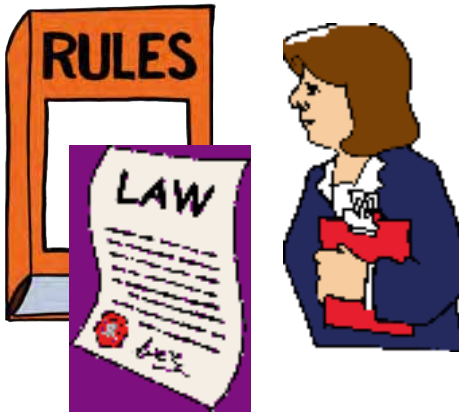
- how well they can meet the different needs of people with learning disabilities



- how they can give the right care to people with learning disabilities.

1 Year					
1	2	3	4	5	
6	7	8	9	10	11 12
13	14	15	16	17	18 19
20	21	22	23	24	25 26
27	28	29	30		

They must do this within 1 year.



2. Organisations which check health and social care services should take a look at how well their rules work for people with learning disabilities.



They must do this within 1 year.



3. The Department of Health should keep an eye on how well these ideas are working and help organisations to do these things.



The Department of Health should write their own report within 18 months after this report has come out.

The Ombudsmen's investigations into the 6 cases

How the Ombudsmen did their investigations

The Ombudsmen's investigators spoke to the families to make sure we heard their stories.

It was important to hear what the families remembered.

The Ombudsmen's investigators looked at documents that said what happened in each case and how complaints to NHS and Council services were dealt with.

The organisations involved also gave the Ombudsmen information.

The Ombudsmen had some medical experts to help them in their investigations.

The Ombudsmen did not want to show real people and their stories as drawings.

The case of Mark Cannon

The Health Service and Local Government Ombudsmen looked into Mark Cannon's case together.

Mark Cannon's parents complained about the treatment he got from **the NHS and social care organisations** in his area.

Mark Cannon was 30 years old and lived with his mother, stepfather and sister.

He went to a day centre 5 times a week, and sometimes stayed at a care home run by the Council.

Mark Cannon was staying at the care home in 2003, when he fell and broke a bone in his leg.

The Local Government Ombudsman found that the Council should have made sure that Mark Cannon was safe during his stay at the care home.

The Local Government Ombudsman agreed with the complaint against the Council.

Mark Cannon was then sent to hospital, where the bone in his leg was mended and he went home.

Mark Cannon got worse and went back to hospital. He was sent home a week later.

Mark Cannon's local doctor visited him at home.

Mark Cannon got worse and went back into hospital again.

He got worse and died in hospital a few weeks later.

The Health Service Ombudsman found that the local doctor gave Mark Cannon proper care and treatment.

The Health Service Ombudsman did not agree with the complaint against the local doctor.

The Health Service Ombudsman found that Mark Cannon did not get the proper care and treatment when he was in hospital.

The hospital dealt badly with Mark Cannon's parents' complaint against the hospital.

The Health Service Ombudsman agreed with the complaint against the hospital.

The Healthcare Commission dealt badly with Mark Cannon's parents' complaint against the hospital.

The Health Service Ombudsman agreed with the complaint against the Healthcare Commission.

What should the hospital, the Council and the Healthcare Commission do?

The Chief Executives should say sorry for what the organisations did wrong.

The hospital should pay £10,000 each to Mark Cannon's mother and to Mark Cannon's father. The hospital has agreed to do these things.

The Council should pay £10,000 each to Mark Cannon's mother and to Mark Cannon's father.

Was Mark Cannon treated unfairly because of his learning disabilities?

The Ombudsmen decided that Mark Cannon was treated unfairly partly because of his learning disabilities.

The Ombudsmen decided that Mark Cannon was not treated with dignity or equality. This was not done on purpose.

Was Mark Cannon's death avoidable?

Lots of different things let Mark Cannon down.

The Ombudsmen decided that Mark Cannon should not have died.

The case of Warren Cox

The Health Service Ombudsman looked into Warren Cox's case.

Warren Cox's parents complained about the treatment he got from the **NHS organisations** in his area.

Warren Cox was 30 years old and lived with his parents.

Warren Cox started to feel unwell in 2004. The local doctor told Warren Cox's parents on the telephone that Warren Cox had an infection.

Warren Cox's parents were very worried, because Warren Cox's stomach was swollen.

The Out of Hours doctor said Warren Cox should go to hospital for an X-ray.

The Out of Hours doctor is the doctor who works when the surgery is closed.

Warren Cox went to hospital. A little while later, Warren Cox's heart stopped, he stopped breathing and he died.

The Health Service Ombudsman found that the local doctor, the Out of Hours doctor and the hospital gave Warren Cox proper care and treatment.

The Health Service Ombudsman did not agree with the complaint against the local doctor, the Out of Hours doctor or the hospital.

Complaint handling

The Health Service Ombudsman found that the local doctor and the hospital dealt ok with Warren Cox's parents' complaint.

The Health Service Ombudsman found that the Healthcare Commission dealt badly with Warren Cox's parents' complaint.

The Health Service Ombudsman agreed with the complaint against the Healthcare Commission.

The Health Service Ombudsman said the Healthcare Commission should say sorry to Warren Cox's parents for not looking at their complaint properly.

The Healthcare Commission agreed to do this.

Was Warren Cox treated unfairly because of his learning disabilities?

The Health Service Ombudsman found nothing to show that Warren Cox was treated unfairly because of his learning disabilities.

Was Warren Cox's death avoidable?

The Health Service Ombudsman could not say that quicker treatment would have stopped Warren Cox from dying.

The case of Emma Kemp

The Health Service Ombudsman looked into Emma Kemp's case.

Emma Kemp's mother complained about the treatment she got from **NHS organisations** in her area.

Emma Kemp was 26 years old and lived in a care home.

Emma Kemp's doctor found a lump at the top of her leg in 2004. Emma Kemp had some tests done and the doctor said she had cancer.

Emma Kemp's mother was told by an expert that cancer treatment was unlikely to make her better. Another expert agreed.

Emma Kemp died later in 2004.

The Health Service Ombudsman found that the local doctors gave Emma Kemp proper care.

The Health Service Ombudsman did not agree with the complaint against the local doctors.

The Health Service Ombudsman decided hospital staff did the best they could at the time.

The Health Service Ombudsman did not agree with the complaint against the hospital.

Complaint handling

The Health Service Ombudsman found that the hospital handled Emma Kemp's mother's complaint badly.

The hospital said sorry.

The Healthcare Commission did not give Emma Kemp's mother the right advice first of all but looked at the complaint again fairly well.

The Health Service Ombudsman did not agree with the complaint against the Healthcare Commission.

Was Emma Kemp treated unfairly because of her learning disabilities?

The Health Service Ombudsman found that Emma Kemp was not treated unfairly because of her learning disabilities.

Was Emma Kemp's death avoidable?

The Health Service Ombudsman found that health experts did not let Emma Kemp down by not treating her cancer.

But we will never know if Emma Kemp would still be alive if she had gone through cancer treatment.

The case of Edward Hughes

The Health Service and Local Government Ombudsmen looked into Edward Hughes' case together.

Edward Hughes' sister complained about the treatment he got from the **NHS and social care organisations** in his area.

Edward Hughes was 61 years old and had lived in a care home for most of his adult life. Edward Hughes had an operation in 2004.

The Health Service Ombudsman found that some of the care and treatment the hospital gave to Edward Hughes was ok but some was not.

The Health Service Ombudsman agreed with the complaints against the hospital.

Edward Hughes spent nearly 2 weeks in hospital, and then he was sent home.

Workers at his care home were worried about him and they asked a local doctor to visit Edward Hughes the next day.

The local doctor said he did not need to go back into hospital. Edward Hughes collapsed and died later that day.

The Health Service Ombudsman decided that the local doctor had given Edward Hughes proper care.

The Health Service Ombudsman did not agree with the complaint against the local doctor.

The Local Government Ombudsman decided that the care home staff gave Edward Hughes proper care.

The Local Government Ombudsman did not agree with the complaint against the Council.

Complaint handling

The Health Service Ombudsman found that the local doctor dealt with Edward Hughes' sister's complaint ok.

The Health Service Ombudsman found that the hospital dealt badly with Edward Hughes' sister's complaint.

The Health Service Ombudsman found that the Healthcare Commission dealt with Edward Hughes' sister's complaint ok in parts and badly at other parts.

The Healthcare Commission agreed to say sorry.

Was Edward Hughes treated unfairly because of his learning disabilities?

The Health Service Ombudsman decided that the hospital did not give Edward Hughes proper care and treatment partly because of his learning disabilities.

Edward Hughes was not treated with dignity and equality.

This was not done on purpose.

Was Edward Hughes' death avoidable?

The Health Service Ombudsman said it was not possible to say for sure why Edward Hughes died.

The Health Service Ombudsman did not decide that Edward Hughes' death was avoidable.

What should the hospital do?

The hospital should say sorry to Edward Hughes' sister and pay her £10,000. The hospital agreed.

The case of Martin Ryan

The Health Service Ombudsman looked into Martin Ryan's case.

Martin Ryan's mother complained about the treatment he got from the hospital in his area.

Martin Ryan was 43 years old and lived in a care home.

He was living happily with his carers when he had a stroke in 2005. He went to hospital. Martin Ryan died when he was in hospital.

The Health Service Ombudsman found that the hospital did not give Martin Ryan proper care and treatment.

The Health Service Ombudsman found the hospital dealt with Martin Ryan's mother's complaint badly.

The Health Service Ombudsman agreed with the complaint against the hospital.

Was Martin Ryan treated unfairly because of his learning disabilities?

The Health Service Ombudsman decided that Martin Ryan was treated unfairly partly because of his learning disabilities.

The Health Service Ombudsman also decided that the hospital did not treat Martin Ryan with dignity and equality.

This was not done on purpose.

Was Martin Ryan's death avoidable?

The Health Service Ombudsman decided that if Martin Ryan's care and treatment had been better, it is likely he would still be alive.

What should the hospital do?

The hospital should say sorry to Martin Ryan's parents and pay his parents £40,000. The hospital agreed.

The case of Tom Wakefield

The Health Service and Local Government Ombudsmen looked into Tom Wakefield's case together.

Tom Wakefield's parents complained about the treatment he got from the **NHS and social care organisations** in his area.

Tom Wakefield was 20 years old and lived at school from the age of 6.

The Health Service Ombudsman found that the local doctor's care and treatment of Tom Wakefield was ok.

The Health Service Ombudsman did not agree with the complaint against the local doctor.

The Local Government Ombudsman found that the Council should have organised for Tom Wakefield to move to an adult care home when he turned 19.

The Council did not work well in finding Tom Wakefield a place.

The Local Government Ombudsman agreed with the complaint against the Council.

The Primary Care Trust (PCT) is the local NHS.

The Health Service Ombudsman found that the PCT did not plan properly for the health needs of people with serious learning disabilities.

The Health Service Ombudsman agreed with the complaint against the PCT.

Tom Wakefield spent 3 months in an Assessment Unit before he got a place in an adult care home.

An Assessment Unit looks at what a person needs and decides what care to give.

The Assessment Unit was run by the Partnership Trust.

The Partnership Trust runs special NHS hospital services.

The Health Service Ombudsman found that it was ok for the Assessment Unit to admit Tom Wakefield but that Tom Wakefield's needs were not met and he did not get proper care and treatment.

The Health Service Ombudsman agreed with the complaint against the Partnership Trust.

Tom Wakefield got worse. He soon became so ill that he was sent to the Acute Hospital.

An Acute Hospital Trust is a hospital just for special cases.

The Health Service Ombudsman found that the Acute Hospital did not give Tom Wakefield proper care and treatment.

The Health Service Ombudsman agreed with the complaint against the Acute Hospital.

Complaint Handling

The Health Service Ombudsman found that the local doctor dealt ok with Tom Wakefield's parents' complaint.

The Ombudsmen found that the Council, the PCT, the Partnership Trust and the Healthcare Commission dealt badly with Tom Wakefield's parents' complaint.

They agreed to say sorry.

Was Tom Wakefield treated unfairly because of his learning disabilities?

The Ombudsmen decided that Tom Wakefield was treated unfairly partly because of his learning disabilities.

The Ombudsmen decided that Tom Wakefield was not treated with dignity and equality. This was not done on purpose.

The Health Service Ombudsman decided that Tom Wakefield suffered more than he should have in the last few months of his life.

Was Tom Wakefield's death avoidable?

The Ombudsmen found that Tom Wakefield's condition had been getting worse for many years and that this had started before the things Tom Wakefield's parents complained about.

The Ombudsmen could not say that Tom Wakefield would still be alive if he had been given different treatment.

What should the organisations involved do?

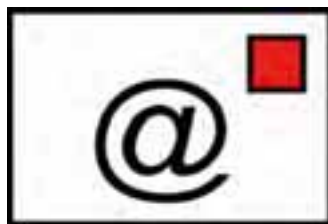
The Council, the PCT, the Partnership Trust and the Acute Hospital should say sorry to Tom Wakefield's parents and pay Tom Wakefield's parents a total of £30,000.

They agreed.



This is the end of the report.

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PHSO-0006

Printed in the UK by The Stationery Office Limited
on behalf of the Controller of Her Majesty's Stationery Office

ID5846104 03/09

Printed on Paper containing 75% recycled fibre content minimum.