



Department
of Health

Government Response to the
House of Commons Health
Select Committee Report on
End of Life Care
(Fifth Report of Session 2014-15)



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(Fifth Report of Session 2014-15)

Presented to Parliament
by the Secretary of State for Health
by Command of Her Majesty

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Introduction

The Government welcomes this considered inquiry into the ways in which end of life and palliative care is delivered in England. We also welcome the acknowledgement of the Health Select Committee ('the Committee') of the good practice in this area which is taking place across the health and social care system. We also recognise the force in the Committee's conclusions and its recommendations on the potential for improvement.

The Government echoes the Committee's recognition of the dedication of family carers, voluntary organisations and health and care professionals who provide care for people who are at the end of their lives with great diligence and skill.

In recent years, there has been a much greater focus on improving the quality and people's experience of end of life care. The End of Life Care Strategy in 2008 set this agenda, and this led to advancements such as the establishment of the Dying Matters Coalition, which has worked to change attitudes to death and dying in society, the National End of Life Care Intelligence Network, which has provided data to drive forward quality improvements and the annual VOICES-SF Survey of Bereaved People, which for the first time offers a systematic account of people's experience of end of life care, as reported by their bereaved relatives.

Since 2010, there has been considerable progress in two specific areas of end of life care – funding and choice. Following the Independent Review of Palliative Care

Funding in 2011, NHS England has worked on developing a set of currencies for specialist palliative care to support service planning and the commissioning of vital specialist palliative care services.

In terms of choice, the Government commissioned the independently-led Review of Choice in End of Life Care in July 2014. The Review published its advice to Government, *What's important to me: A Review of Choice in End of Life Care*, in February this year. We welcomed the vision of care centred around people's choices and preferences set out in the report, and we will respond in full later this year.

Perhaps the most significant recent advance in relation to the quality of end of life care has come in the form of the Five Priorities for Care of the Dying Person. These priorities were the central focus of *One Chance to Get it Right*, the report of the Leadership Alliance for the Care of Dying People developed in response to the Independent Review of the Liverpool Care Pathway.

The Five Priorities for Care offer a clear basis for the delivery of high quality, person centred care in the last days and hours of life, with a strong emphasis on recognising that a person is close to death, planning for their needs and clear and sensitive communication with the person and those important to them. These priorities offer solid foundations for the creation of high quality end of life care services in all settings and areas.

The Five Priorities also underpin the publication in September of the *Ambitions for Palliative and End of Life Care*, a national framework for local action produced by the National Palliative and End of Life Care Partnership, an alliance of statutory and third sector organisations across health and social care. This framework demonstrates how health and social care commissioners, service providers, clinicians, voluntary sector organisations and community leaders can deliver high quality end of life care services for everyone.

Government response to the Committee's conclusions and recommendations

Beyond the Liverpool Care Pathway

Every care provider should have a model in place based on the Five Priorities for Care that will deliver personal, bespoke care to people at the end of life. There should be no reason for any health or care organisation not to have introduced an appropriate alternative to the Liverpool Care Pathway. (Paragraph 34)

1. The Government's intentions on this matter have been clear since July 2014. The power of the Five Priorities of Care, developed by the Leadership Alliance for the Care of Dying People, is derived from the fact that they were developed by the entire spectrum of bodies and organisations involved in the commissioning, delivery, oversight and support of end of life care, and who made specific commitments with regard to their respective roles and responsibilities.

2. The Priorities make clear that care in the last few days of life should put patients and families at the centre of decisions about their treatment and care, involve sensitive communication and include detailed care plans tailored to individuals' needs. We would expect that all staff involved in the delivery of end of life care should base patient care on these priorities, which are aligned with best clinical practice.

3. To provide the necessary assurance good care is being delivered, the Care Quality Commission's end of life care inspection

regime for acute trusts looks to ensure that care based on the Five Priorities of Care is being delivered, as this is one of the criteria on which Trusts are rated.

We recommend that a senior named person in each NHS Trust and care provider is given responsibility for monitoring how end of life care is being delivered within their organisation. (Paragraph 35)

4. Although it is for individual Trusts to ensure that good quality end of life care is delivered, the Government has been clear that senior leadership is vital to the delivery of good end of life care.

5. Following the publication of the Independent Review into the Liverpool Care Pathway in July 2013, the then Minister of State for Care Services wrote to all NHS Trusts responsible for the delivery of end of life care, requesting that there be a nominated board member in each organisation with responsibility for end of life care.

6. The Care Quality Commission (CQC) inspection regime also highlights the importance of leadership in end of life care, as one of its five key lines of inquiry in end of life care is ensuring that services are well-led. This includes questions relating to whether the organisation has a named responsible clinical lead for end of life care, and a Board member with overall responsibility.

We welcome the focus on end of life care by the Care Quality Commission and recommend that they monitor both acute

and community health care providers' move to the new approach in their inspections and as part of their thematic review. (Paragraph 36)

7. The CQC is examining end of life care as one of the key services in its new acute hospital and community services inspection models. It has published its new inspection approach in provider handbooks for each sector of health and care. The Handbooks outline what the CQC's definition of end of life care services is and what it will do when it inspects them. This is supported by detailed guidance for inspection teams, with specific supporting questions to help inspectors assess whether a service is safe, effective, caring responsive and well-led. CQC has published information on its website about end of life care, the GP practice's role and how they will look at this important issue during its inspections.

8. The CQC continues to undertake a thematic review of inequalities and variation in end of life care. This is looking across sectors at variations in people's experience of end of life care, including geographical variations as well as the experience of people from particular groups, including people with the most complex conditions and those who are vulnerable because of their circumstances, who may experience end of life care which is of poorer quality and does not always meet their needs. The thematic work will also look at whether end of life care is effectively coordinated at local level. The thematic work will make recommendations at national and local level and will describe examples of good practice. The CQC will undertake fieldwork in local areas as part of the review, and plans to publish a report in 2016.

Generalist staff in acute settings must be competent in identifying people who are likely to be at the end of life, irrespective of their medical condition, so that they

can offer specialist care where it will be beneficial. We recommend that NHS Trusts ensure that generalist staff are provided with opportunities to learn from specialist palliative care teams. (Paragraph 51)

9. The Government agrees that generalist staff would benefit from greater interaction with specialist palliative care colleagues, and encourages all providers of end of life care services to do this. Since publication of *One Chance to Get it Right*, Health Education England (HEE) has focused on delivering the actions to which it committed in the response document. HEE has developed a workplan for its Local Education and Training Boards (LETBs) to ensure that it joins up all its work to support the workforce with other professional bodies and agencies to avoid "reinventing the wheel" in commissioning education and training or producing materials which are already available.

10. This workplan has been informed by a HEE commissioned independent review into the efficacy of existing education and training resources, practice and programmes on end of life care. This national work will assist local NHS Trusts on the ground to help support their staff in terms of upskilling and training for end of life care.

Access to Palliative and End of Life Care

Round-the-clock access to specialist palliative care will greatly improve the way that people with life-limiting conditions and their families and carers are treated. This would also help to address the variation in the quality of end of life care within hospital and community settings. We also recognise the value of specialist outreach services. We recommend that the Government and NHS England set

out how universal, seven-day access to palliative care could become available to all patients, including those with non-cancer diagnoses. (Paragraph 52)

11. The Government is committed to ensuring everyone can get the care they need, seven days a week. We know that this is particularly important in end of life care as people nearing the end of life are sometimes admitted to hospital at weekends merely because primary and community health services that could otherwise support them at home are either unavailable or unable to access specialist palliative care.

12. We know from evidence gathered by the Royal College of Physicians and Marie Curie in their clinical audit of deaths in acute hospitals which happened in May 2013 that, although only 21% of acute trusts offer a face to face specialist palliative care service seven days a week, 91% of all trusts surveyed offered 24/7 specialist palliative care telephone advice.

13. The importance of around the clock access to generalist and specialist palliative care was also highlighted by the recent Review of Choice in End of Life Care, which recommended that people being cared for outside of hospital should have access to 24/7 end of life care. Implementing this would require access to, and availability of, both generalist (GPs, community nurses) and specialist services to improve, and the Department and NHS England are looking into the best ways of achieving this.

14. NHS England is working with the CQC to build on the findings of their thematic review of inequalities in end of life care, which will identify groups of patients who do not have equitable access to specialist palliative care. NHS England will use this to develop a service specification for specialist palliative care, which will help commissioners in their

task of commissioning specialist palliative care services for their population.

People with dementia should have equal access to end of life care as those dying as a result of other conditions. Particular attention should be paid to discussing and documenting their wishes as early as possible following diagnosis. (Paragraph 53)

15. Throughout 2015/16 NHS England will encourage the use of care planning, including advance care planning for people with dementia, and has supported this with appropriate financial incentives. NHS England is working in collaboration with the Department of Health to support the delivery of improved post diagnostic care and support for people with dementia, their families and carers, by 2020. This work will span the whole of the life course of dementia from prevention and diagnosis to support for people at the end of their lives, and those important to them.

16. Ensuring that people with dementia experience high quality, advance planning which is delivered in a sensitive and patient centred way requires staff to be highly trained, for example, in initiating and holding difficult conversations with people with dementia and those important to them, and in assessment and management of common symptoms.

17. To support this, the Government's 2015/16 Mandate to HEE, published in March 2015, states that HEE will continue to roll out Tier 1 training on dementia across the NHS workforce, with Tier 1 tools and training opportunities being made available to all NHS staff by the end of 2018. Tier 1 training is being backed up with more in-depth training (Tiers 2 and 3) of expert leaders and staff working with people with dementia.

18. At the end of March 2015, 515,967 NHS staff had received Tier 1 training on dementia, exceeding the ambition in the 2014/15 HEE Mandate for 350,000 NHS staff to receive the training by March 2015. Over 100,000 social care workers have received dementia awareness training.

19. From 1 April 2015, newly appointed healthcare assistants and social care support workers, including those providing care and support to people with dementia and their carers, are expected to undertake the Care Certificate within their first 12 weeks of employment, by undertaking learning and demonstrating their competence in 15 Care Certificate Standards.

Commissioners should explicitly set out how they will provide specialist palliative care services for people from all backgrounds in their locality, including children and adolescents, people from ethnic minority backgrounds and those living in isolated or deprived communities and how they will ensure that those with a non-cancer diagnosis can also access specialist palliative care. (Paragraph 54)

20. Under the provisions of the NHS Act 2006 (as amended by the Health and Social Care Act 2012), Clinical Commissioning Groups (CCGs) must have regard to the need to reduce inequalities in health service access and outcomes, exercise their functions with a view to securing that health services are provided in an integrated way, where they consider that this would improve quality and reduce inequalities, and include in both their annual commissioning plan and their annual report an explanation of how they propose to and subsequently did discharge their duty to have regard to the need to reduce inequalities.

21. We also recognise that more can and should be done to ensure that access to care is opened up for people who have

difficulty in accessing care at present. NHS England has committed in *Actions for End of Life Care* to work to tackle these issues, with the assistance of the National End of Life Care Intelligence Network, and to work with the CQC in addressing the findings of its thematic review on inequalities in end of life care. The aim of this is to identify groups of people, across all age groups, who do not have equitable access to high quality end of life care.

22. For example, there is inequity of access related to a number of factors such as diagnosis, with only 20% of people diagnosed with organ failure (heart, lung, liver or kidney) or dementia either requesting or being identified for palliative care before dying, compared to 75% of cancer patients (source: Zheng et al, European Journal of Palliative Care, 2013). These issues were highlighted in the Review of Choice in End of Life Care, and we will address these concerns in the forthcoming response.

23. The Government also would wish to draw attention to, and welcome, the work of the CQC in this regard. As noted above, the CQC continues to undertake a thematic review of inequalities and variation in end of life care, looking across sectors at variations in people's experience of end of life care. This work includes geographical variations, people from specific groups, and people with the most complex conditions and those who are vulnerable because of their circumstances, who may experience end of life care which does not always meet their needs.

24. NHS England is developing a service specification for specialist palliative care, which will help commissioners in their task of commissioning specialist palliative care services for their population. There are already published a sample service specification for end of life care and a service specification for tertiary paediatric

palliative care services (under specialised commissioning), and a commissioning toolkit for end of life care is soon to be published by NHS Improving Quality (NHS IQ).

Competence of the workforce

We heard that too often staff lack confidence and training in raising end of life issues with their patients or delivering the right care. Training should be provided for all health and social care staff who are likely to provide care to people at the end of life, including training in communication skills. We recommend that NHS England works with care providers to identify and roll out tailored end of life care training. (Paragraph 75)

25. Since April 2013, HEE has been responsible for workforce planning, and the commissioning and provision of education. HEE is taking a system wide approach by promoting, supporting, embedding and implementing the Five Priorities for Care across Local Education and Training Boards (LETBs) and its stakeholder networks. It is also part of the NHS England steering group on end of life care and Public Health England's National End of Life Care Intelligence Network to ensure an integrated, consistent and coherent approach across the healthcare system in providing high quality end of life care.

26. During 2014/15, HEE identified a wealth of relevant education and training resources relating to end of life care that were available to the NHS workforce but found a lack of evidence into which types of education and training approaches delivered high quality care for the dying. To this end, HEE commissioned an independent review of the efficacy of existing education and training resources in March 2015, with the support of its stakeholders, to determine

the effectiveness of education and training resources in upskilling the NHS workforce to deliver high quality end of life care. The Review reported its findings to HEE in August 2015 and HEE has now developed a LETB workplan to take forward the findings of the review and continued implementation of the OCTGIR actions.

27. HEE will work in partnership with NHS England, the National Council for Palliative Care (NCPC) and other key stakeholders to showcase the outcomes from the Review, with a focus on best practice and effective education and training resources which deliver excellence in end of life care across the NHS workforce.

Advance Care Planning

We believe there is a role for the Government and NHS England to provide clarity and leadership with regards to the policy on advance care planning and its implementation. We recommend that the Government considers how it can further raise awareness of the mechanisms available to patients and carers under the Mental Capacity Act 2005 to make their wishes clear about end of life care. This should also include information about Advance Decisions to Refuse Treatment. The Department should provide an update to our successor Committee on the actions it has taken since publication of its response to the House of Lords Select Committee Report. (Paragraph 88)

28. Since the House of Lords Select Committee report on the Mental Capacity Act (MCA) in March 2014, the Government and its partners have been progressing a programme of work designed to raise awareness and understanding of the MCA among professionals, service users and their families. Achievements to date include:

- The production and distribution of an MCA “Rights Card” detailing key aspects of the Act;
- The incorporation on the MCA as a “key line of enquiry” in the CQC’s inspections of health and social care providers;
- The creation of a new on-line “MCA Directory” that acts as a repository of best practice materials on the MCA;
- The insertion of an MCA element into the NHS Standard Contract;
- The placing of a requirement in the foundation curriculum for doctors for training on the MCA.

29. There remains significant work to be done, particularly at the local level where implementation will ultimately be driven. To facilitate local partnership working the Government has agreed to launch a new National Mental Capacity Forum with an independent chair to drive efforts further.

30. Advance care planning is a process of discussion between the person and those who care for them (including families, those important to them and professionals) which enables the person to express their views, preferences and wishes about future care. An advance care plan itself is not legally binding but components of it may be, for example if it contains Advance Decisions to Refuse Treatment. It is important that this process is seen as voluntary and dynamic, and that the person understands that their contemporaneous views will always override any previous preferences they have expressed. It must also be recognised that not everybody will want to engage in advance care planning discussions, and that preference must also be respected.

31. Through the Transforming End of Life Care in Acute Hospitals programme led by NHS IQ, we are supporting acute

hospital service providers and professionals to improve end of life care using a set of enablers, including EPaCCS, advance care planning, rapid discharge pathway. Furthermore, the following publications have been published on the dedicated end of life care pages on the NHS IQ website to support clinician with advance care planning:

- Capacity, care planning and advance care planning;
- A guide to capacity, care planning and advance care planning, executive summary.

We recommend that all staff who provide palliative and end of life care to people with life limiting conditions should receive training in advance care planning, including the different models and forms that are available and the legal status of different options. Training should be developed in partnership with the National Council for Palliative Care and other non-government bodies with relevant expertise. (Paragraph 89)

32. HEE’s review into the efficacy of education and training resources on end of life care has provided a comprehensive overview of effective education and training resources for the healthcare workforce, particularly nurses, carers and medical professionals. HEE wants to fulfil its national leadership role by building on what already exists by providing a coherent framework to guide and support professionals and employers to deliver the best possible care for the dying through promoting the most effective education and training resources identified by the review.

33. HEE has engaged the NCPD, as one of a number of national and local providers of training on end of life care, through its review and plans to work with them on how the findings of the review can be embedded

across the third sector provider network in order to support development of a coherent consistent cross sector health and social care culture in the delivery of end of life care.

We recommend that the Government engage with Age UK to understand the outcome of their awareness raising pilots, learning lessons that can be applied to supporting other groups as well as older people to understand the options, and developing a strategy to promote advance care planning to patients in different settings. (Paragraph 91)

34. The Government value the support and challenge that Age UK has provided and we will continue to engage with Age UK and the valuable work that it has done in this and other areas. NHS England and Age UK worked together to produce a Practical Guide for Healthy Aging in January 2015, which is designed to support people with mild frailty based on the 11 principal risk factors associated with functional decline in older people living at home. More broadly, as part of the work it is doing to improve the delivery of care for people with long term conditions, NHS England recently published (in response to requests from commissioners) three 'service components' or 'handbooks' to provide practical support for good long-term conditions management. These draw on the latest research, best practice and case studies to show how this can be done in reality in, arguably, the three most important areas for long term conditions management:

- Case finding and risk stratification;
- Multi-disciplinary team working; and
- Personalised care support and planning.

35. The handbook on personalised care support and planning includes advance care planning with those who are in the last year(s) of life. Furthermore, Age UK has recently

published a guide to support this important agenda (*Before you go: Planning and support for the end of life*) which aims to inform people about planning for the end of life and help people to consider all of the options.

We recommend that the Government carry out a review of the cost of making a Lasting Power of Attorney (LPA), including the impact on take up by people from different socioeconomic groups, with a view to identifying any financial barriers for those who have been unable to take out LPAs, and what support is available to those who cannot afford to use a legal route. (Paragraph 93)

36. The Office of the Public Guardian (OPG), the body responsible for registering LPAs, has informed us that its fees are currently under review and that it will be consulting on proposed changes in 2016.

37. In terms of financial barriers and support, there are a number of existing options available for those on low incomes. Where a person making an LPA (referred to as 'the donor') receives certain means tested benefits when it is registered, the individual is not required to pay anything (an exemption); alternatively if their income before tax is less than £12,000 a year, they only have to pay half of the fee (a remission).

38. It is not essential to use a solicitor to make an LPA and the OPG launched revised versions of its forms and guidance on 1st July to simplify the application process. The OPG also works closely with organisations such as the Citizens Advice Bureau and the Alzheimer's Society who can offer support. In addition, there is the option of applying for an LPA using an online version of the form through GOV.uk with an assisted digital service to guide users through the process. There is no charge for using this service.

39. The OPG will shortly be carrying out research to enable it to better understand all of the barriers to uptake of the LPA, as this is a strategic priority for the organisation.

At present, should a person completing the LPA application form make any error, they are obliged to complete a new form and start the application process again, including paying a second time. We recommend that the Government review the LPA application process, with a view to making it simpler and cutting costs for applicants. (Paragraph 94)

40. On the issue of restarting the form in the instance of error, when the OPG receives an LPA for registration, it has to scrutinise each individual instrument to determine if there are any errors which would render it inoperable. Where there has been an error in execution the OPG has to determine whether it is material or immaterial. This determines whether the Public Guardian (PG) or the Court of Protection (CoP) has discretion in the matter.

41. Under Schedule 1 paragraph 3 of the Mental Capacity Act;

- 1) If an instrument differs in an immaterial respect in form or mode of expression from the prescribed form, it is to be treated by the Public Guardian as sufficient in point of form and expression.
- 2) The court may declare that an instrument which is not in the prescribed form is to be treated as if it were, if it is satisfied that the persons executing the instrument intended it to create a lasting power of attorney.

42. If the PG considers the defect to be material, meaning that the error in execution of the instrument is fundamental, then it cannot register the instrument unless directed to do so by the CoP. However, if the defect is fundamental then even the CoP cannot

exercise its discretion and the donor will have to execute a new instrument.

43. In other cases where a donor includes 'ineffective' provisions in an LPA which contradict how the attorneys have been chosen to act or which go beyond the scope of the limits set within the Mental Capacity Act and will prevent the instrument from operating, the Public Guardian applies to the CoP to determine the matter and if necessary they will sever the ineffective provision. This avoids the need for a donor to start the application process again and they are not charged for the application made by the Public Guardian. In the last financial year, 1081 applications for severance of ineffective provisions were made by the Public Guardian.

We recommend that the Government encourage and monitor the take up of electronic care planning and Electronic Palliative Care Coordination Systems (EPaCCS), to facilitate information sharing between providers, and that they review the best mechanisms to facilitate the understanding and take up of these plans. We also recommend that the Government explore options for a universal system for recording and filing advance care plans, with a standard template for use across England and a website dedicated to explaining the issues. (Paragraph 98)

44. The Government notes that NHS England and NHS IQ are already working with local health economies to facilitate the roll out of EPaCCS across England. A National Information Standard for End of Life Care Co-ordination (ISB 1580) has been developed to promote consistency of sharing of information. It supports consistent, accurate recording of a person's preferences for end of life care by defining and specifying the core record content required and providing additional guidance on implementation. The data set includes the person's preferences

and choices for end of life care, such as: their preferred place of death, the details of people they wished to be involved in decisions about their care, any decisions made about resuscitation, details of people appointed with lasting power of attorney, and contact details for key health and social care staff.

45. This national standard has been developed so that localities can maintain the highest level of quality, while initiating their own local solutions for sharing this critical and sensitive information. It evolved from a series of pilot sites across England, which tested the development and implementation of different approaches to EPaCCS (initially known as locality registers).

46. In addition, as part of the work of the National Information Board (NIB), a proof of concept exercise is underway (starting with end of life and maternity care) to assist in the development of mobile care records which patients and the public can control to ensure that their care preferences are respected. Both NHS England and NHS IQ are actively working with NIB partners to ensure that respective pieces of work are aligned.

47. The Government notes the Committee's suggestion of development of a standard template for care plans. The aforementioned NHS England handbook on personalised care support and planning offers guidance on the types of information and content that good care plans should offer.

48. Furthermore, NHS England is working with NHS Choices to update and improve the range and quality of information about palliative and end of life care on their website. The update will include a refresh on the information about care, treatment, support options and advance care planning.

The Department of Health has notified the Committee that NHS England is working with Health Education England

to develop a single accredited curriculum for paramedic training that will ensure that paramedics have the skills they need to resolve more calls on the phone (hear and treat) and at the scene (see and treat). We expect end of life care to feature in the new curriculum when the details are issued later in 2015. (Paragraph 99)

49. NHS England has been working with HEE and the College of Paramedics to develop this new curriculum. It is inclusive of the requirements arising out of the urgent and emergency care review and supports the delivery of the Ambulance Service Clinical Priorities in the areas of emergency care, urgent care, mental health, frail elderly people and falls, long term conditions, care for patients at the end of life and in public health and prevention.

Do Not Attempt Cardiopulmonary Resuscitation (DNACPR) Orders

We recommend that the Government review the use of DNACPR orders in acute care settings, including whether resuscitation decisions should be considered in the context of overall treatment plans. This Committee believes there is a case for standardising the recording mechanisms for the NHS in England. (Paragraph 108)

50. The potential value of standardising the recording mechanisms for anticipatory decisions about cardiopulmonary resuscitation (CPR) in the context of overall treatment plans has been recognised by healthcare professionals. A Working Group, co-chaired by the President of the Resuscitation Council (UK) and the Head of Nursing Practice at the Royal College of Nursing has been established to look into this issue. A small sub-group will make proposals to the Group for a form for recording an

emergency care and treatment plan, including decisions about CPR. The aim is to develop a national form that records decisions about CPR and other life-sustaining treatment in the context of a broader plan.

51. The Group believes that the form should:

- be underpinned by a robust decision-making process;
- support good decision-making;
- be person-centred;
- be used and accepted across all boundaries;
- be relevant in the entire range of healthcare settings including people's homes and acute hospitals; and,
- have the support of a broad range of stakeholder organisations.

52. Once this part of the project has been completed, use of the resulting form will be piloted prior to more widespread implementation.

53. The CQC are examining end of life care as one of the key services in their new acute hospital and community services inspection models. Initial findings from these inspections identified some concerns with Do Not Attempt Cardiopulmonary Resuscitation orders, particularly highlighting completion of forms, communication with patients and relatives, and that better metrics are needed, especially for those not under specialist care. The CQC continues to undertake a thematic review of inequalities and variation in end of life care which will also look at whether end of life care is effectively coordinated at local level, and the documentation and sharing of DNACPR decisions are likely to be part of this.

Community resourcing

We recommend that Health Education England and NHS England set out how they plan to address the shortfalls in the staffing of community care services. The Committee sees this as essential to enabling people to die at home and in other community settings including care homes and nursing homes, where that is their preference rather than in hospital. This should involve their plans for the recruitment and training of district nurses. (Paragraph 113)

54. The HEE national workforce plan reflects demand in both the acute and community sectors of nursing. In response to concerns from community employers that rising demand for nurses in the acute hospitals may be reducing supply into community posts, HEE has established a Transforming Primary and Community Nursing programme with NHS England to identify what further actions can be taken to ensure sufficient jobs are created in the community and that individuals are incentivised and supported to choose them. Specifically, the programme aims to ensure an adequate supply of highly skilled, competent nursing staff to improve individual outcomes and support the move to care closer or in the patient's home, including for people in the last stages of their life.

55. HEE is also working with NHS England and the wider system through its Workforce Advisory Board to better understand the wider primary care workforce needs arising from the NHS Five Year Forward View, to ensure that the community and district based nursing workforce is growing sufficiently to keep pace with the growth of GPs and to deliver the new models of care.

Free social care at end of life

We recommend that the Government clarify the eligibility criteria for the NHS Continuing Healthcare Fast Track Pathway and phase out the social care means test (financial assessment) for people at the end of life. (Paragraph 134)

This Committee strongly recommends that the Government provide free social care at the end of life to ensure that no one dies in hospital for want of a social care package of support. (Paragraph 135)

56. NHS Continuing Healthcare is a package of ongoing care that is arranged and funded solely by the NHS where the individual has been found to have a 'primary health need' as set out in the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care. Such care is provided to an individual aged 18 or over, to meet needs that have arisen as a result of disability, accident or illness.

57. If an individual has a rapidly deteriorating condition that may be entering a terminal phase, they may need NHS Continuing Healthcare funding to enable their needs to be met urgently. In all cases where an individual has such needs, consideration should be given to use of the Fast Track Pathway Tool for NHS Continuing Healthcare. Under such circumstances, an appropriate clinician considers that a person should be fast-tracked for NHS Continuing Healthcare and this in itself constitutes determination of a primary health need and therefore eligibility for 'fast-tracked' arrangements.

58. It is our intention to update the National Framework for NHS Continuing Healthcare and NHS-funded Nursing Care in the light of the Care Act 2014 and other developments in health and social care. This may include clarifying and strengthening areas, such as

arrangements for Fast Track cases, which might benefit from this within the Framework.

59. On the issue of access to social care and the social care means test, the Government recognises the vital role that social care support plays for many people nearing the end of life, in particular its role in increasing the likelihood of an individual dying in their choice of setting at the end of their life.

60. The Department of Health is considering options to ensure that more people are able to access the support they require and receive an appropriate health and social care package in a timely manner. As a first step, we have worked on identifying the barriers in the current social care system that may prevent someone from being cared for and dying in their preferred setting:

- The time taken to complete financial assessments;
- The price differentials between NHS and social care resulting in a preference for NHS treatment; and
- Insufficient capacity in the social care system to meet needs.

61. The next step is to better understand these problems so that options to tackle these can be further developed. Free social care at the end of life, that is care which is delivered to people who would normally pay for this care following the social care means test, is one of the possible solutions alongside many others that attempt to increase capacity in services and improve choice. Greater evidence is required on the costs and benefits of each of these options and we will continue to gather this.

62. These options will need to be considered against the wider context of adult social care, such as financial pressures, funding reform and the integration agenda, as well as the wider context of end of life

care such as the quality and availability of community health and social care services and the ability to share information across professional boundaries.

Funding

We recommend that the Government set out what it intends to do to ensure sustainable, long term funding for the hospice sector as part of their response to the Palliative Care Funding Review. (Paragraph 136)

We recommend that the Government ensure that their proposals for the future funding of palliative care fully recognises the importance of the voluntary sector. (Paragraph 137)

63. The recent publication by NHS England of the 2015/16 palliative care development currency represents an initial attempt to group specialist palliative care into packages of care. The currency is not mandatory and will be further tested and refined during 2015/16. The aim is that it will provide a meaningful tool to support service planning and commissioning of services. The currency was developed following a significant piloting exercise which actively involved the voluntary sector.

64. The currency will be further tested during 2015/16. This testing will involve a detailed data collection from providers of care and a qualitative study of commissioners and providers beginning to use the currency as part of the commissioning process. Organisations in the voluntary sector are taking part in this testing work, and the sector is also represented on the project's advisory board.

Bereavement support

Bereavement support provision is currently fragmented, with services not consistently provided around the country. Family members and carers are too often left inadequately supported. We recommend that the Government and NHS England raise awareness amongst health and social care staff of the impact of bereavement and provide for universal access to bereavement services in its funding plans for palliative care. (Paragraph 144)

65. Following the recommendations set out in the Independent Palliative Care Funding Review (2011), bereavement services have not been included in the scope of the 2015/16 development currency at per-patient funding level. The Government notes that this was an issue of concern raised in the engagement process which supported the development of the 2015/16 currency.

66. In general it is for commissioners (CCGs or NHS England as the case may be) to decide which services they should commission to meet the needs of the populations for whom they are responsible, taking into account relevant NICE guidance. However, as part of testing the development currency during 2015/16, information on how bereavement services are delivered and funded will be collected. This information will be used to consider how the currency interacts with funding streams for bereavement services and whether it is appropriate to include bereavement services in future iterations of the currency.

67. HEE is also working with the Social Care Institute for End of Life, which has developed a care hub to share knowledge, provide advice and disseminate guidance for those working in social care to improve the quality of care they give to people who are

dying in care homes, nursing homes and at home. Better awareness and understanding by care staff will also benefit the family and friends of people who are dying; evidence identifies bereavement outcomes are improved when individuals and families who have lost a loved one are well supported.

68. NHS England is also working in partnership with NHS IQ and the NCPC to support the 'Dying Matters' web portal. This provides a host of resources to patients, carers, their families, and NHS staff and organisations to help people talk more openly about dying, death and bereavement, and to make plans for the end of life.

Measuring quality of care

We recommend the development of outcome measures for palliative care. These must be properly evaluated and funded in order to improve the quality of care for people at the end of life. (Paragraph 150)

69. The Government welcomes the launch of Public Health England's (PHE) consultation in March 2015 on proposals to introduce a national individual-level data collection from specialist palliative care services. PHE is working closely on these proposals with NHS England, the Health and Social Care Information Centre (HSCIC), the NCPC, Help the Hospices and the Cicely Saunders Institute. PHE aims to start testing data collection this financial year and, if successful, will work with NHS England to consider implementation of a national system. To avoid duplication, this data set would be fully aligned with the data collection requirements of the new palliative care funding system. NHS England is also continuing to work on the development of outcome and experience measures for end of life care more broadly.

Research into Palliative and End of Life Care

We recommend that the Government pursue the research priorities that matter most to people with terminal illnesses, their families and carers and the staff providing care professionally to them, and set out what funding will be provided to ensure that future policy on palliative and end of life care is informed by a robust evidence base. (Paragraph 155)

70. The National Institute for Health Research (NIHR) Health Technology Assessment programme launched an open call in March 2015. The programme welcomed proposals for the evaluation of interventions for the management of end of life care in people with non-cancer and cancer related conditions, in particular interventions for the last 30 days of life. Development of the call was informed by the work of the Palliative and End of Life Care Priority Setting Partnership, which the NIHR jointly funded. Five applications have been shortlisted and full proposals will be considered in February 2016.

71. In addition, several research applications relating to end of life care have recently been awarded funding under other NIHR programmes including the Research for Patient Benefit programme. Total funding provided by the NIHR in this area will depend on the number, scale and duration of successful proposals.

72. The Cochrane Pain, Palliative and Supportive Care Group, supported by the NIHR, has completed a 'mapping review' of the requirements in *One Chance to Get it Right* for research evidence. The result is a Library of published palliative care and end of life research outputs, which became available in March 2015 as a searchable on-line research database. The database

summarises the evidence available. It contains over 1800 entries, including systematic reviews, randomised controlled trials, quasi-experimental studies, descriptive studies, and expert opinion.

Leadership

The Five Year Forward View sets out a direction of travel for the NHS in England, covering all the major statutory bodies. The Department of Health and NHS England should ensure that end of life care is prioritised and embedded in future planning at all levels. They should identify named individuals who will be responsible for ensuring that the new approach to end of life care, based on the Five Priorities, is delivered nationally. (Paragraph 159)

73. The Government fully supports the vision for the NHS set out in the Five Year Forward View. Ensuring that end of life care continues to improve so that everyone receives the good quality care they deserve as they approach the end of life is a key challenge for the health and care system in the coming years, and we want to improve services to meet that challenge.

74. The work that has been undertaken over the past few years, such as establishing the Five Priorities of Care, advancing the development of a funding system for specialist palliative care, commissioning the development of the narrative *Every Moment Counts* by National Voices and other key stakeholders, supporting the Palliative and End of Life Care Networks across England and NHS England's *Actions for End of Life Care* have led to improvements. We hope to drive more improvements through the system-wide *Ambitions for Palliative and End of Life Care*, published in September 2015 and the full Government response to *What's important to me: A Review of Choice in End*

of Life Care, which we intend to publish before the end of the year.

75. To achieve this, we need everyone who is responsible for end of life care to show leadership and responsibility. For the Department of Health, this means the Secretary of State and Parliamentary Under-Secretary of State for Care Quality. For NHS England this means the Chief Executive, National Medical and Nursing Directors, and the National Clinical Director for End of Life Care. On the front line, this means everyone involved in delivering end of life care in hospitals, hospices and community settings, up to the responsible board member in each organisation, supported by commissioners in CCGs. We are all committed to improving end of life care to ensure that people receive the best care possible.

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