

Recognised, valued and supported:

Next steps for the Carers Strategy

DH INFORMATION READER BOX	
Policy	Estates
HR / Workforce	Commissioning
Management	IM & T
Planning /	Finance
Clinical	Social Care / Partnership Working
Document Purpose	Policy
Gateway Reference	15179
Title	Recognised, valued and supported: next steps for the Carers Strategy
Author	Cross-Government publication
Publication Date	25 Nov 2010
Target Audience	PCT CEs, Care Trust CEs, Directors of PH, Local Authority CEs, Directors of Adult SSs, GPs, Directors of Children's SSs
Circulation List	NHS Trust CEs, SHA CEs, Foundation Trust CEs , Medical Directors, Directors of Nursing, PCT PEC Chairs, PCT Chairs, NHS Trust Board Chairs, Allied Health Professionals, Emergency Care Leads, Voluntary Organisations/NDPBs
Description	A cross-Government document which sets out how the Government will prioritise actions over the next four years to ensure the best possible outcomes for carers and those they support.
Cross Ref	Carers and personalisation: improving outcomes
Superseded Docs	Carers at the heart of 21st century families and communities
Action Required	N/A
Timing	N/A
Contact Details	Elaine Edgar Carers Policy Team Room 116, Wellington House, 133-155 Waterloo Road London SE1 8UG
For Recipient's Use	

(c) Crown Copyright 2010

First published 25 November 2010

Published to DH website, in electronic PDF format only

www.dh.gov.uk/publications

Contents

Contents	2
Foreword.....	3
Introduction.....	5
1. Identification and recognition	8
2. Realising and releasing potential	13
3. A life outside of caring	19
4. Supporting carers to stay healthy	26
5. Developing the evidence base on supporting carers	32
6. Supporting local delivery, transparency and local accountability	35
Annex A: Response to the call for views on priorities	36
Annex B: The evidence base for supporting carers in work	42
Annex C: A summary of key activities in the priority areas.....	49
References.....	53



Foreword

Many of us will be carers at some stage in our lives. It is a role that can come unexpectedly out of a crisis; it is a role that can creep up on you. Being a carer provokes a complex mix of emotions. It can be both rewarding and frustrating. It can be costly in life chances, financial security and health.

The Government recognises and values the contribution of carers. By caring for people in their own time and supporting other people's independence, carers embody the spirit of the Big Society.

Supporting carers' well-being is therefore in all our interests. There are key issues – employment, support, respite – that carers are likely to face in their caring role. But the circumstances of every carer are unique, and that is why there is an overriding need to personalise support to fit around individual and family preferences.

Recognised, valued and supported: next steps for the Carers Strategy sets out how the Coalition Government will work with carers and carers' organisations. Government – local and national – should reciprocate the support carers show with measures that ease the responsibility of caring. The additional £400 million via the NHS over the next four years to provide carers, including young carers, with breaks from their caring responsibilities is recognition of the vital role they play.

But that is only the start. The devolution of power from Whitehall to town halls does not end with the town hall. Citizens and communities should have more choice and control. Carers should be supported as individuals and in their families and communities to help shape, develop and run local services, if they wish to be involved. A first step is for all councils to give more control to carers, with personal budgets provided for everyone eligible by April 2013.

Our Big Society reforms will see public services opened to challenge, and local commissioners and care providers held to account. The knowledge, expertise and experience of carers will be vital. Just as the Big Society is about encouraging people from all walks of life to take a more active part in society, fostering a society that is more responsive and accessible to the needs of carers is a key strand. This will become more important as the population ages, and advances in clinical technology result in more children with very complex disabilities living longer, and more people – estimated at up to 3.4 million by 2037 – having caring roles.

Despite the growth in the number of carers, we do not assume that they can contribute to the Big Society unsupported. Government and business support for carers is vital.

Carers will only be able to access the right support if they are adequately informed about the options that are open to them, including options for employment. Employers, via their own Employers for Carers forum, have produced the evidence base that shows why supporting employees with caring responsibilities makes sense for the individual and for the employer (set out in more detail in Annex B). Employers for

Carers and all the business interests they represent are to be congratulated for showing leadership in supporting carers and contributing to expanding the amount of care provided by ordinary people across England.

In the light of *Universal Credit: Welfare that works*,¹ the Government is carefully considering whether changes to Carer's Allowance will be necessary to take account of the introduction of Universal Credit and provide clearer, more effective support for carers.

The recent Spending Review settlement protected the NHS and provided a solid basis for reform of social care, alongside the need for efficiency savings. The vision for adult social care focused on developing a more personalised, preventative service, delivered in partnership with the NHS and voluntary and user-led groups. The role of carers, and government's support for carers, in developing these kinds of services is therefore more vital than ever. This strategy explains what we will do to ensure that their vital caring role is recognised and supported over the next four years.



Rt Hon Andrew Lansley CBE MP
Secretary of State for Health



Paul Burstow MP
Minister of State for Care Services

On behalf of:

Department for Business, Innovation and Skills

Department for Communities and Local Government

Department for Education

Department of Health

Department for Work and Pensions

The Government Equalities Office

Introduction

This Carers Strategy sets an ambitious agenda of change over the coming decade. Building on a vision which values carers, the agenda to make this happen is substantial and challenging. The Government wishes to prioritise future actions to ensure the best possible outcomes for carers and those they support.

Carers at the heart of 21st-century families and communities² set out the following strategic vision and outcomes for carers:

Vision:

Carers will be universally recognised and valued as being fundamental to strong families and stable communities. Support will be tailored to meet individuals' needs, enabling carers to maintain a balance between their caring responsibilities and a life outside caring, while enabling the person they support to be a full and equal citizen.

Outcomes:

Carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role.

Carers will be able to have a life of their own alongside their caring role.

Carers will be supported so that they are not forced into financial hardship by their caring role.

Carers will be supported to stay mentally and physically well and treated with dignity.

Children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.

Over the summer, the Department of Health sought views on what the priorities over the next four-year period should be. Over 750 responses were received, representing the views of over 4,000 carers. A summary of these views is at Annex A, and quotes from respondents are included in this strategy. The Department of Health also asked the Standing Commission on Carers, the Government's expert advisory group chaired by Dame Philippa Russell, for its views on priorities.

Key messages from the responses are:

- carers need better and timely access to information – on the illness or condition of the person they are caring for; on appropriate caring; on accessing benefits and other support; and on financial and employment issues;
- carers can often feel excluded by clinicians – both health and social care professionals should respect, inform and involve carers more as expert partners in care;
- carers find accessing assessments overly bureaucratic and slow, and are often disappointed about the paucity of the services that follow;
- carers often feel forced to give up work to care;
- carers often neglect their own health and need advice to maintain their well-being;
- carers need breaks from caring in order to sustain their role as a carer;
- carers feel that the value of Carer's Allowance is inadequate, the rules around overlapping benefits are unfair and the earnings limit is a disincentive to work; and
- more should be done to identify and support young carers – in particular, schools should be more carer aware and the memorandum of understanding *Working together to support young carers* should be embedded.³

Drawing on the Standing Commission's advice and the responses, we have identified four priority areas:

Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages.

Enabling those with caring responsibilities to fulfil their educational and employment potential.

Personalised support both for carers and those they support, enabling them to have a family and community life.

Supporting carers to remain mentally and physically well.

These priority areas are both important in themselves and overlapping. Addressing any one of them adequately will require attention to all of them. Getting support for

carers right will help to build the mutually supportive and capable communities that the Big Society aspires to.

This strategy shows how government intends to support carers and will inform the outcomes and plans of health, social care, education and other services across government. In the next four sections we have set out why these areas are important and how focusing on them in local communities can make a positive difference for carers. We also identify the actions that government will take through this Parliament to support these priorities. These are summarised at Annex C.

The Carers Strategy covers health, education, social care and employment matters.

Health, education and social care are devolved matters and therefore references to those services in this document apply to England only. Employment matters in this strategy apply to England, Scotland and Wales. Further information about what the devolved administrations are doing to support carers can be found as follows:

- The Scottish Government's Carers and Young Carers Strategy at: www.scotland.gov.uk/Publications/2010/07/23153304/0
- The Northern Ireland Carers Strategy at: www.dhsspsni.gov.uk/index/hss/ec-community-care/ec-carers.htm
- The Welsh Assembly Government's Carers Strategy will shortly be revised. The current Welsh Carers Strategy action plan is at: <http://wales.gov.uk/topics/health/socialcare/carers/?lang=en>

1. Identification and recognition

Priority area 1: Supporting those with caring responsibilities to identify themselves as carers at an early stage, recognising the value of their contribution and involving them from the outset both in designing local care provision and in planning individual care packages

Supporting those with caring responsibilities to identify themselves as carers at an early stage

- 1.1 A significant number of people with caring responsibilities do not readily identify themselves as carers. They understandably see themselves primarily as a parent, spouse, son, daughter, partner, friend or neighbour. The concept of caring is assumed but not recognised in some families in ethnic minority communities.

“I’m not recognised as a carer. In China you wouldn’t say I’m a carer, you automatically care ‘because you should’ ... It’s the Chinese family way, our culture.” (quote from a carer)

- 1.2 Many carers do not identify themselves as such until they have been caring for a number of years. This is understandable when the caring role develops gradually, for example with the onset of dementia. And when a family member or friend is suddenly in need of support, such as after a stroke, it can be difficult to find the time and energy to think through what the future may hold in terms of a caring role.
- 1.3 The onset of mental health problems and the process of seeking help can be particularly traumatic for families. Those supporting people with mental health, personality disorder or substance misuse problems can be wary of seeking help outside the family because of the stigma, discrimination and bullying that are still too often associated with these conditions. Many young carers remain ‘hidden’ from health, social care and education services – partly as a result of those services needing to do more to identify them but also because of family fears that they will be taken into care or because the young people themselves are concerned about the reactions of others and bullying by their peers. Parents of children with long-term conditions or a disability often feel ‘invisible’ and that they are just seen as parents.
- 1.4 The consequences are that many carers are not offered or do not seek early access to information and advice on the specific illness or condition of the person they are supporting to help them care effectively and safely. They may also find it hard to know how to access information and advice on how to balance a caring role with other responsibilities and opportunities in their lives. Decisions about education and employment, support from the welfare and benefits system, and their own health and well-being may be overlooked. Many older carers can be

socially isolated, especially if they are looking after someone with dementia, have health problems themselves or find it difficult to access public transport.

“My parents would not have accessed financial support ... if their children were not aware of the system and applied on their behalf...” (quote from a carer)

- 1.5 Access to relevant and timely information and advice is also vital throughout the caring role, particularly at times of significant change, for example, to help parent carers negotiate the transition from children’s services to adult health and social care services, and at the end of life.
- 1.6 Both national and voluntary organisations play a key role in providing information, advice and support to carers every day of the year. In addition, Carers UK organises Carers’ Rights Day every December⁴ and a consortium of seven national voluntary organisations organises Carers Week every June. Over 12,000 events were organised in Carers Week in 2010.⁵
- 1.7 The Government wants to build on the excellent work that the voluntary sector undertakes. In November 2010, the Department of Health awarded almost £2 million in grants to Carers UK, Crossroads Care, The Princess Royal Trust for Carers, Partners in Policymaking, The Afiya Trust and The Children’s Society to support their work with carers. In addition, it has launched the Reaching out to Carers innovation fund to encourage patient-led and condition-specific voluntary organisations to focus more on how they can support carers, as often they are the first port of call for information when someone takes on caring responsibilities.

Recognising the value of the carers’ contribution and involving them from the outset both in designing local care provision and in planning individual care packages

- 1.8 One of the strongest messages that came through in the call for views on priorities over the summer is the frustration and anger that so many carers feel about the way they are treated by health professionals. Carers often do not feel valued or recognised as expert and equal partners in care.

“I do everything to care for my husband at home yet when he goes into hospital, I am just the wife!” (quote from a carer)

“I am not allowed to give my point of view, my concerns are sidelined or ignored and quite naturally I now feel useless, frustrated and angry at the lack of help, support and dare I say common sense. Most appear to have a ‘tick-box’ mentality. I belong in the tick-box titled: ‘carer’. My husband however is the ‘client’ so he has to ask for what he wants.” (quote from a carer)

“I have heard it suggested that professionals sometimes underestimate the skills and abilities of carers from ethnic

minority communities, simply because their English language skills are weak.” (quote from a care worker)

“There must be a balance between information and confidentiality. Confidentiality must not be used as an excuse for withholding information.” (quote from a carer)

- 1.9 Yet so many carers of all ages have developed an expert knowledge of the condition of the person they are supporting and have a close understanding of that person’s own aspirations and needs. Involving carers in planning and designing hospital discharge arrangements and individual care packages is common sense as they are key partners in ensuring effective delivery of care at home. The breakdown of hospital discharge arrangements can lead to readmissions that are both costly in terms of resources and stressful for the individual, carers and families concerned.
- 1.10 The increase in resources for reablement services announced in the Spending Review, together with hospitals taking responsibility for all care needs for 30 days after hospital discharge from 2011, is intended to reduce unnecessary readmissions. The NHS and councils should ensure that carers’ organisations are included in local discussions about how these new resources are used.
- 1.11 The Association of Directors of Adult Social Services has recently produced a review *Carers as partners in hospital discharge*⁶ which brings together key policy and good practice materials to inform hospital discharge processes. The Department of Health’s guidance on effective hospital discharge – *Ready to go?*⁷ – highlights that information sharing is a major issue for carers, particularly in mental health services. It is important that information about risks is shared with carers where appropriate. Guidance on *Information sharing and mental health*⁸ can help carers in potentially very difficult circumstances.

“Carers are not to be feared by staff; where they are well informed and supported about patients’ needs, they can continue to ensure that the hard work undertaken in hospital doesn’t unravel when a patient is sent home.” (quote from Carers Link, Accrington)

“From my own experience as carer for my mother ... doctors have taken on board my observations with regard to medication side-effects and, as a result, she is now on a regime that suits her, and her condition is vastly stabilised with more quality of life for all.” (quote from a carer)

“By working jointly with carers, linking our expertise with theirs, we have found better reported outcomes in terms of carers feeling better able to deal with the progressive nature of dementia.” (quote from a psychologist)

“Having carers involved in drug and alcohol treatment has been shown to increase the chances of the person they support staying in treatment and improved recovery outcomes. Treating carers as people with expertise and skills is also likely to lead to them feeling fulfilled, empowered and dedicated in their work caring for family members. This therefore offers cost efficiencies.”

(quote from Adfam)

- 1.12 Assumptions should not be made about who will provide care and to what extent. A whole family approach in assessment, enabling both the individuals who need support and those who will support them to identify their own needs and desired outcomes, is much more likely to result in individual care packages that can be sustained effectively. A whole family approach will also minimise the risk of young carers feeling forced into undertaking inappropriate caring roles. Many carers will be supporting more than one person, i.e. inter-generational or multi-generational caring, or providing a lifetime of care, for example when supporting someone with learning disabilities. With changing family structures and more mobile communities, many families will be ‘distance carers’, unable to provide regular day-to-day care although providing significant support to their relative.

Engaging carers in developing strong local communities

- 1.13 The knowledge and experience of carers will be invaluable in terms of designing local care provision. There have been many innovative developments initiated by carers themselves in partnership with the voluntary sector and local communities. A programme of grants and adviser support has enabled every local area in the last two years to support parent carer groups to become more involved in shaping local services. The National Network of Parent Carer Forums has been launched by the Department for Education, as a pilot arrangement, to help to cascade information and best practice and champion parent carer participation.
- 1.14 Councils and their strategic partners should routinely involve carers in their Joint Strategic Needs Assessment and development of local carers strategies to ensure that the needs of carers of all ages within the local population, including carers within ethnic minority communities, are adequately reflected.

“I don’t want ‘access’ to integrated services ... I want to help create them. I want more than consultation. I want co-production, to work on the challenges as an equal partner.”

(quote from a carer)

- 1.15 Carers and carers’ organisations can put their experience and knowledge to good use in developing a range of social enterprises providing personalised solutions that will deliver improved outcomes for both carers and the people they support. The combination of direct payments and growth in local delivery models could create a local ‘care economy’ whereby carer-led services enable fellow carers to retain employment and independence. Many former carers or those currently

caring with the capacity to do so would like the opportunity to put their expertise to good use, particularly if it can help current carers. They are natural contributors to the Big Society and it is important to build on the diversity of support that carers can offer.

- 1.16 It is important therefore that health and social care services, schools, voluntary organisations, faith and community organisations and employers are alert to and act to secure the benefits that can be gained by supporting carers of all ages. These local organisations can play a crucial role in helping people identify themselves as having a caring role and signpost them to relevant sources of information and advice as early as possible. Carers already contribute to the Big Society by supporting people to remain living in their local community. It is important that local organisations provide reciprocal support to carers and ensure that they do not feel isolated as a result of their role.

Next steps

- The Department of Health will make £1 million available in 2010/11 to patient-led and condition-specific voluntary organisations to enable them to focus on supporting carers through a Reaching out to Carers innovation fund.
- The Department of Health will provide additional resources for GP training, to increase GPs' awareness and understanding of carers' needs for support and the availability of appropriate services such as psychological therapies, building on successful pilot schemes undertaken by the Royal College of General Practitioners.
- Following the current consultation on *Liberating the NHS: An information revolution*,⁹ the Department of Health will publish an information strategy and plans for its implementation, working closely with carers and carers' organisations.
- In 2011, Skills for Care and Skills for Health will publish a learning and training framework on supporting carers, a guide for employers and commissioners of training, together with a wide range of tools to support development. The framework will be made widely available to enable commissioners to devise bespoke training for their local health and social care workforce.
- The Department of Health has included emerging evidence on effective early intervention in identifying, involving and supporting carers in *Carers and personalisation: improving outcomes*¹⁰ and the Social Care Institute for Excellence will gather further examples for inclusion in their Good Practice Framework.¹¹
- Revised guidance on undertaking Joint Strategic Needs Assessments will be published during 2011/12, recognising the importance of identifying the needs of carers in the local population.

2. Realising and releasing potential

Priority area 2: Enabling those with caring responsibilities to fulfil their educational and employment potential

Enabling young and adult carers to fulfil their educational potential

- 2.1 Inappropriate caring roles or long hours of caring are likely to have a detrimental impact on young carers' lives, including their health and educational achievement. Young carers should be supported to achieve their potential and to have the same opportunities that other young people enjoy. Adult carers should also be supported to pursue education, training, work or leisure activities if they wish and these aspirations should be taken into account when assessing a carer's need for support.
- 2.2 Awareness about the needs of young carers has increased in the last few years and is welcome. The Department for Education is supporting Young Carer Pathfinders to develop ways of supporting young carers.¹² However, it is still the case that some health and adult social care services and schools are failing to recognise the impact on the child of parental disability, mental ill health or substance misuse. This can lead to services making assumptions about families' ability to cope and to young people taking on inappropriate caring roles. Particularly, in relation to those young people caring for parents with a substance misuse or mental health problem, services should work closely with the family and children's services to identify any safeguarding concerns.

"... children grow up in all sorts of families, many of whom have a parent with a health issue but this does not mean that those parents cannot be and are not good parents, but it does mean that we need to enable, empower and expect parents and families to take responsibility for being the best they can be."
(quote from Bolton Barnardo's)

"There are too many children picking up the pieces by caring for their parents, and this is a scandal. Children need extra support when they are living with a sick parent, and should not have to carry extra burdens on top of the stress of worrying about their parent's condition and not being able to do normal family things." (quote from person with multiple sclerosis)

- 2.3 Young carers want their school and teachers and other school staff to be more supportive of their caring role, recognising that they are balancing a demanding home life with education. Young carers can be bullied and/or socially isolated and this can have an adverse impact on their education and social development.

Young carers are often strongly attached to their caring role and in some cases it is only with assertive support from teachers, personal tutors, young carers' services or family members that they can be encouraged to accept help to reduce the impact of their caring role.

- 2.4 To address these issues, last year the Association of Directors of Adult Social Services and the Association of Directors of Children's Services published *Working together to support young carers*,¹³ a model local memorandum of understanding. It sets out a practical framework for effective partnership working between health and social services and the voluntary sector and is unequivocal in stating that no care package should rely on a young person taking on an inappropriate caring role that may damage their health or put their education at risk. Through this strategy, Government is promoting the memorandum and encouraging councils to consider its adoption.
- 2.5 There is a wealth of other activity under way:
- The Princess Royal Trust for Carers and the Children's Society have produced a pack¹⁴ to help schools develop young carer policies and an increasing numbers of schools have included young carers as a theme within their Healthy Schools programmes. Examples are included in the guide on emerging evidence, *Carers and personalisation: improving outcomes*.
 - The Department for Education and Department of Health are working with the National Young Carers Coalition to develop an e-learning module to enable schools to identify and support young carers.
 - Local young carer services are broadening the support they offer to meet the needs of young adult carers (between 16 and 24 years of age) including helping to develop CVs and complete application forms, and making them aware of entitlements and adult support services.
- 2.6 Adult and community learning courses are available in every community to help adult carers to develop and update their existing skills, prepare for new careers or become community volunteers. Informal learning courses can also improve health and well-being by fostering regular social contact and civic participation and reaching out to those most in need.
- 2.7 As well as the initiatives already detailed, the Government is delivering a package of fully-funded learning entitlements, with an expectation that colleges and other training organisations will identify priority learners in their community and prioritise support for them to participate in learning activities. In addition, further education providers will have greater autonomy to deliver training flexibly, which will be of particular benefit in enabling carers to participate.
- 2.8 The Government has announced that part-time students starting their higher education courses in 2012/13 will, for the first time, be able to apply for up-front loans towards their tuition charges. Further details of the student support package for part-time students will be released in due course.

Enabling those with caring responsibilities to fulfil their employment potential

- 2.9 It is crucial that we place a much higher priority on supporting people of working age with caring responsibilities to remain in work, if they wish to do so. The Government wants to empower carers to fulfil their work potential, to protect their own and their family's current and future financial position and to enjoy the health benefits and self-esteem that paid employment or self-employment can bring. Yet many carers currently feel forced to give up work because they feel they have no other options available to them.

“It has been indicated by Social Services that I need to find a way Peter will be cared for while I go to work. In other words, I am being asked to give up my job as a nurse and care for Peter. I find this very unfair and not right.” (quote from a carer)

- 2.10 The fluctuating nature of some conditions such as mental health problems and personality disorder can mean that caring responsibilities can also fluctuate, often unpredictably. Understanding and flexibility in employers and work colleagues can help carers of people with these conditions to remain in work.
- 2.11 Carers cite flexible working as one of the most important factors in allowing them to juggle paid work, their caring responsibilities and family life. Those carers who are looking to return to paid work cite flexible working, as the most important component in their job search. While opportunities for flexible working have grown, this has not happened consistently across types of flexible working, and availability varies across different types of organisations, sectors and job levels. The availability of flexible work is particularly low for those looking for work, compared with existing employees. For people who have growing caring responsibilities, or have those responsibilities suddenly thrust upon them, the ability to change their working patterns is particularly important, and where it does not exist this may compel them to leave their job.

“We meet many carers who have to give up work due to the lack of flexibility and support by work and employers. They all want to continue working, but without the support and understanding by their workplaces and adequate input from social and health services to ensure their family member with dementia is safe and being well cared for, this is often not possible.” (quote from psychologist)

- 2.12 The link to the first priority area is therefore crucial. Paid workers who take on caring responsibilities will benefit from access to information and advice on balancing their caring role with paid work, for example through seeking flexible working arrangements and replacement care.

“As employers we have learned from our employees’ experiences that, where caring responsibilities have happened – or increased – suddenly, there is often a critical period of

around 6 weeks where the carer will need time and support to deal with the immediate situation. This may involve flexibility around leave in order to access information and establish caring arrangements and flexibility about working patterns in order to continue to work and care.” (quote from Employers for Carers)

- 2.13 It is clear that employer culture needs to change if the availability of flexible working is to grow. Although the Government can help to develop the debate about flexible working, it also needs to work closely with employer organisations to meet employers’ practical needs for information and advice.
- 2.14 Earlier this year the six government departments responsible for delivering the Carers Strategy signed a memorandum of understanding with Employers for Carers setting out how departments and Employers for Carers will work together to ensure that all parties make a positive contribution to supporting carers in the workplace and to further develop and promote good practice in supporting working carers.
- 2.15 In the light of the current economic climate and demographic changes it is vitally important that we place a priority on retaining the skills and experience of valued employees within the workforce so that both businesses and the wider economy can benefit from them. There is great potential for both telehealth and telecare to enable people to balance their caring responsibilities more easily with paid employment, for example by reducing the number of hospital appointments for routine monitoring and by making home environments safer and more secure. The Department of Health has been actively running what is believed to be the largest randomised control trial of telehealth and telecare anywhere in the world (involving over 6,000 people including 470 carers) which will provide an evaluated evidence base of the effects of using this technology in the care of people with long-term conditions. The results will be available in 2011.
- 2.16 In May 2010, the Social Care Institute for Excellence produced reports^{15 16} and a film on the ethical use of telecare and a further film about how telecare can support more personalised care .¹⁷
- 2.17 The Equality Act 2010, recognising the vital role that carers play and the disadvantage this role can bring with it, has strengthened carers’ protection against discrimination both in the workplace and when accessing services. The Government Equalities Office and Citizens Advice have published a quick-start guide on how the new law can help carers.¹⁸ The Equality and Human Rights Commission has also published wide-ranging guidance on the new law .¹⁹
- 2.18 *A vision for adult social care: Capable communities and active citizens*²⁰ identifies the importance of developing a plural market that matches a variety of needs, including those of carers who need high quality, reliable and affordable replacement care to enable them to continue to work. Councils have a key role to play in stimulating and shaping this market within their local communities.

“The development of public services needs to widen choice, recognising that if people have the funds, they will want to arrange and find the right solution for their family. Local and national Government have a role to play in helping to shape and develop these markets.” (quote from Carers UK)

- 2.19 Many carers of working age stress the importance of continuing in employment both for their own personal satisfaction and for their family’s economic well-being. There are also opportunities for economic gain in supporting carers of working age back into employment. People who have taken time out of work to care should be encouraged and supported to pursue what they would like to do, which might include returning to the same work they were doing before they assumed caring responsibilities or making use of the caring skills they have developed to help others in their local communities. Others may wish to access training to refresh their skills, to make a career change or develop other interests.

“To make a difference I have been working with local universities for the past 8 years, supporting the education of social work students...” (quote from a carer)

- 2.20 Welfare reform should also support carers’ independence. The introduction of new Jobcentre Plus support in 2009 to those people seeking to combine caring and working responsibilities has been well received by carers and carers’ organisations and is popular with Jobcentre Plus staff. Jobcentre Plus will continue to build on these useful beginnings.
- 2.21 The recently published White Paper, *Universal Credit: Welfare that works*, recognises the invaluable service carers provide to people in some of the most vulnerable circumstances in our society and that it is important that they get the support they need. It also recognises that the current earnings limit may act to trap some people on benefit, as they lose all entitlement to Carer’s Allowance once this limit is reached. People receiving Universal Credit who have caring responsibilities will have improved opportunities to maintain links with the world of work by being able to keep more of their income from part-time work than under the current system. In addition, the benefit rules which govern taking paid employment will be adjusted to recognise the caring that people do.
- 2.22 Recognising that some carers will find it easier to return to work if the person they care for is supported to work, the Department for Work and Pensions’ Work Choice programme will support significantly disabled people to find and stay in work or self-employment.

Next steps

- The Department for Education will make a new Early Intervention Grant available to local government from April 2011, bringing together a range of funding streams for early intervention services for young people and families, including young carers.

- Building on the best work of Connexions and Next Steps, the Department for Education and the Department for Business, Innovation and Skills will work with careers advice professionals, schools, colleges and universities to develop the first all-age careers service. This will be in place by September 2011 ahead of a fully operational service by April 2012 and will for the first time provide continuity of careers advice from childhood to adulthood through a revitalised careers service.
- The Government will issue a consultation document next year to consult with business on how best to take forward the Coalition commitment to extend to all employees the right to request flexible working. Legislative changes will then be introduced as necessary.
- Alongside legislative measures, the Government will explore a number of non-legislative proposals to build on the recommendations from the Family Friendly Working Hours Taskforce published earlier this year.²¹ This will, for example, include working with the Recruitment and Employment Confederation, business schools and recruitment agencies to encourage 'designing in' flexible working arrangements in job design and recruitment.
- The Department for Business, Innovation and Skills and the Department of Health will work together to examine how to reduce barriers to market entry for small local flexible enterprises to maximise growth opportunities and support more carers to stay in employment.
- The Department of Health and the Department for Business, Innovation and Skills will also work with industry and statutory and voluntary sector stakeholders to identify the barriers to and enablers of market growth in assisted living technologies, and to support further uptake and boost innovation.
- Skills for Care will set out plans for developing a skilled and competent social care workforce in a workforce development strategy to help employers support greater personalisation and improved quality of care that families can have confidence in. A personal assistant strategy will also be published next year, which will address the needs of both employers and personal assistants.
- The Department for Work and Pensions will continue to invest in supporting carers to return to work through Jobcentre Plus. The experience already gained will allow Jobcentre Plus offices to be more flexible in adapting services to meet local needs and to allow them to work in partnership with employers, training providers and the voluntary sector to meet these needs.

3. A life outside of caring

Priority area 3: Personalised support both for carers and those they support, enabling them to have a family and community life

The benefits of a personalised approach

- 3.1 Personalisation means that all services and support available to carers should be tailored to their specific needs as far as possible: for example, that advice and information should be inclusive of all, including disabled carers, young and older carers, inter-generational carers and carers from ethnic minority groups, and that universally available services should be flexible in their approaches in order to respond to the variety of ways in which those with caring responsibilities can best be supported.
- 3.2 Personalisation can provide individuals, carers and families with more choice, more control and more flexibility in the way that care and support are provided. Personalisation and a whole-family approach are complementary – it is important to look at a family’s needs as a whole but also to make sure that individual carers’ and users’ views are sought and cultural expectations are clarified when considering how best to support a family. No assumptions should be made about a carer’s ability and willingness to care. A whole-family approach is particularly relevant where young carers and inter-generational carers are involved but service users and carers of all ages can benefit from an integrated and holistic approach to providing personalised care and support.
- 3.3 Carers and those they care for will feel more confident and better able to access appropriate support if they have real and demonstrable choice and control over the resources used to secure the services they need. Personalisation also offers the opportunity to think more creatively about the use of a wider range of community services (including mainstream housing, leisure, transport and other provision) and for carers to become the ‘expert partners in care’.

“Rural carers can face particular issues around social exclusion and a life outside the caring role. It is vital that key services are able to demonstrate coverage around rural areas and meaningful services to carers in those localities.” (quote from Northamptonshire Carers)

- 3.4 There is increasing evidence of improved outcomes for carers through the use of personal budgets and the increased choice and control they offer. Personal budgets can contribute to greater independence for both carers and the people they support, enabling carers to have a life of their own. *A Vision for adult social care: Capable communities and active citizens*²² makes clear that councils should provide everyone who is eligible with a personal budget, preferably as a direct payment, by April 2013.

“Since my daughter started receiving direct payments life has been a lot better for both of us. She is a lot happier and has more interests as she now has paid carers to take her out, which in turn gives me a life of some sort.” (quote from a carer)

Assessments

- 3.5 In the call for views on priorities this summer, carers said that priority should be accorded to reducing the time for assessments both for the people they support and themselves.

“The system is completely oblivious to the impact the slow referral and assessment systems have on the lives of those it is set up to help and their carers. The system appears to create dependency, as carers are forced to give up work due to lack of support and take on the full-time carer’s role.” (quote from a carer)

“Another problem for carers is the person they care for being assessed as needing a service and then being put on an indefinite waiting list.” (quote from a carer)

- 3.6 Some councils have developed a system for training people in the voluntary sector as trusted assessors for carers to speed up response times and enable access to a wide range of support. Further details are provided in *Carers and personalisation: improving outcomes*.
- 3.7 The Association of Directors of Adult Social Services and The Princess Royal Trust for Carers have developed a carers support pathway that sets out the spectrum of support that carers might need and a self-assessment audit tool.²³ The Common Assessment Framework for Adults Demonstrator Programme is working with 12 council-led partnerships to increase the ease with which assessment and care planning information can be shared with carers. They are also looking at ways of sharing information that both service users and carers feel comfortable with, on paper or through the development of ‘Citizen Portals’, giving web-based access to information.²⁴
- 3.8 Young carers have said that often services focus on the adult in front of them without thinking through the implications of the disability, mental illness or substance misuse problem on the children of the family. This can lead to a child taking on a harmful caring role. An Ofsted report in 2009 found evidence of good practice but also barriers to young carers accessing the support they needed.²⁵
- 3.9 The Department of Health recognises that the legal framework surrounding adult social care, including arrangements for assessments, is complex and fragmented. It is keen to see greater flexibility and portability of assessments, and will consider how to pursue this in the light of the work of the Law Commission²⁶ and the Commission on the Funding of Care and Support.²⁷

Personalising support for carers and the people they support

- 3.10 Personalising support includes a number of ways in which carers can be more effectively supported as individuals to maintain their caring role and have a life of their own, maximising the opportunities for them to direct their own support. Equally, it includes the ability to have their own needs considered together with those of the people they support in order that, wherever this is required, families and other networks can develop their own mutually agreed solutions.
- 3.11 Personalisation and personal budgets can take many forms. It is important that carers do not have to manage the financial arrangements, nor indeed do they need to identify and procure their own services, unless they so wish. They can use intermediaries such as a voluntary organisation or use other models such as individual service funds or trusts. There is still anxiety among carers, particularly older carers, about money management and concern that there may be no services to buy. Advocacy and brokerage services, provided by carers' centres and user-led organisations, can serve to eliminate the anxiety that some carers hold about personalisation and personal budgets. Guidance has been produced for councils and their partners to help them make personal budgets work well for older people and their families.²⁸
- 3.12 Many carers' centres also tailor particular advice to older people, for example on welfare benefits, pensions and setting up trust funds.

“I do not know what I would do without our carers' centre to help us as we did not have a clue where to start with the forms.”
(quote from a carer)

- 3.13 The Office for Disability Issues has launched the Right to Control pilot scheme which aims to provide disabled people with greater choice and control over how public money is spent to meet their individual needs and ambitions.²⁹ The importance of involving carers in planning the support required for disabled people is well understood in the scheme. During the development of a disabled person's support plan and at any future review of that plan, anyone engaged in caring for that disabled person will be consulted and their views taken into account. The Right to Control will be delivered across seven pilot areas, known as Trailblazers, in England for an initial period of two years, commencing from December 2010.
- 3.14 The NHS White Paper, *Equity and excellence: Liberating the NHS*³⁰, commits to continuing and developing the personal health budget pilot programme and to exploring the creation of a right to a personal health budget in discrete areas: for example, for people who receive NHS continuing healthcare. Personal health budgets are based on an individual knowing how much NHS money is available to meet specific health needs and allow individuals and their carers more choice and control over the way this money is spent. One pilot is specifically looking at the use of budgets to support carers' needs. An independent evaluation will look at evidence across all the pilot sites of the impact of personal health budgets on

carers and families. The report of the pilots will be published in autumn 2012. The Government will then consider the roll-out of personal health budgets and how they can be combined with personal budgets in social care.³¹

Quality, Innovation, Productivity and Prevention (QIPP)

- 3.15 Over the next four years, the NHS needs to realise up to £20 billion of efficiency savings, to be reinvested in front-line clinical services, while also simultaneously improving quality. This is a significant challenge, but there are many examples of where the NHS can, and has, redesigned care to put patients and carers at its centre to deliver better outcomes and save money which can then be reinvested in new services. There are already a range of levers for commissioners of NHS services to use locally to focus on improving support for carers, including quality improvement goals relating to carers in local CQUIN (Commissioning for Quality and Innovation) schemes and quality accounts, published annually by each NHS healthcare provider on the quality of the services that they provide.
- 3.16 Each strategic health authority is developing a local QIPP and Reform Plan, setting out how it will meet the quality and productivity challenge and implement the *Liberating the NHS* White Paper reforms. In a number of areas, the NHS has asked for additional support to meet these challenges and a QIPP national work programme has been set up. A number of aspects of QIPP work are particularly relevant for supporting carers as well as the people they support.
- 3.17 The QIPP work on long-term conditions emphasises personalised care planning and supportive self-care in order to maximise independence and minimise unnecessary stays in hospital. Personalised care planning involves people in decisions about their care and engages them in discussions about their goals and aims for the way they want to live their lives. They agree a plan of how their healthcare will be managed, addressing an individual's full range of needs, and ensuring that services are designed around their needs. It recognises that there are other issues in addition to medical needs that can impact on the person's total health and well-being – for example, provision of appropriate aids and equipment, advice on lifting and moving or management of medication for carers. It is therefore a holistic process, with a strong focus on helping people, together with their carers, to achieve the outcomes they want for themselves, for example to live independently or return to work.
- 3.18 The QIPP work on end of life care has focused on improving the identification of people who are approaching the end of life, as well as care planning and advance care planning. This will help to ensure that discussions about people's preferences for end of life care take place, and that the right packages of care and support are made available to those at the end of life, and their carers, to make their choices about care a reality.
- 3.19 Successful delivery on the QIPP work on end of life care and long-term conditions requires the full engagement and support of carers and, as such, the

needs of carers will be fully considered in the development and implementation plans.

- 3.20 Many local and regional QIPP plans also include work on mental health because it is such a significant area of spending. The Department of Health is responding to this by providing some support nationally to QIPP and mental health.

“As a carer I have clear understanding of what works and does not work for the care of my son who has schizophrenia. By working in partnership with me as a carer, mental health services have been able to reduce the cost of his care from something over £100,000 per year to £20,000. Ignoring carers is not only bad practice but it will always cost more in the long term.” (quote from a carer from Rethink)

Assistive technology

- 3.21 The Department of Health is currently running what we believe is the largest randomised control trial of assistive technology anywhere in the world. There are over 6,000 participants in the trial over three sites which includes 470 carers. This Whole Systems Demonstrator Programme aims to provide fully evaluated evidence of how telecare and telehealth can support people with long-term conditions to maintain or regain independence, to improve confidence and to reduce their dependence on carers and family members. One of the principal themes of the evaluation will be to show how the technology can help carers by providing reassurance that the person they are caring for is being effectively supported. The reality of this kind of support is that it can lead to more independence for carers and in some cases provide some respite in their lives. The trial will help to demonstrate just what can be achieved. Videos showing how both carers and the people they support can benefit from telehealth and telecare are available at:

www.newhamwsdtrial.org/case-studies/telecare/
www.newhamwsdtrial.org/case-studies/telehealth/

Opportunities for growth in local models of care and support

- 3.22 The shift to personalised care provides opportunities for small businesses and social enterprises to tailor services to support individual, family and carers’ needs – whether funded by the State or self-funded.
- 3.23 In the future, consortia of GPs and other health professionals will have responsibility for commissioning services for their patients, including carers. Councils will take a leading role in integrating health, social care and public health services and ensuring that they meet the needs of local people and communities. They will need to work together to ensure that the right services are available to meet the care needs of people with personal health budgets and personal budgets for social care and self-funders. Subject to the response to the

Local democratic legitimacy in health consultation,³² due to be published in December, health and well-being boards will provide the vehicle for local partners to come together to achieve this.

- 3.24 *A vision for adult social care: Capable communities and active citizens*,³³ together with *Think local, act personal: Next steps for transforming adult social care*³⁴ – the partnership agreement with the social care sector – and best practice guidance, *Practical approaches to improving the lives of disabled and older people through building stronger communities*³⁵ set out a range of supporting materials to assist councils to develop their local community capacity to provide a personalised approach. In addition, the forthcoming mental health strategy will address the specific issues facing carers of people with mental health problems.
- 3.25 There are also many opportunities for volunteering and using social capital, although quality, continuity and reliability of support will be key to their success with carers. The voluntary sector frequently plays an important strategic role in developing new approaches to community engagement and the active involvement of a wide range of trained and supported volunteers in working with carers. There are already some excellent examples across the country of how complementary currencies schemes such as time banking are enabling communities to help each other. Schemes such as time banking enable carers to use their skills – for example in cooking, accounting or information technology – to help someone else in exchange for another time bank member providing, for example, a sitting service for the person they care for. There is also potential for other family members not directly involved in the caring relationship who live in another area of the country to give their time locally to a time bank, allowing their time credits to be ‘cashed in’ by their relative providing the main caring role.
- 3.26 Local government can be a catalyst for such social action, stimulating a community response and developing community capacity to provide innovative and creative ways of supporting carers and the people they care for.

Next steps

- *A vision for adult social care: Capable communities and active citizens* sets out the Government’s ambition for personalisation. Councils should provide all those who are eligible, including carers, with a personal budget, preferably as a direct payment, by April 2013. The Department of Health’s guide *Carers and personalisation: improving outcomes* will assist councils’ delivery of this commitment.
- The results of the Whole Systems Demonstrator Programme on telehealth and telecare will be published in 2011 and they will inform the adoption and spread of these technologies in the coming years. The Department of Health and the Department for Business, Innovation and Skills, with stakeholders, will ensure that the needs of carers are taken into account in influencing any future technological development.

- The Government is keen to see greater flexibility and portability of assessments, and will consider how to pursue this in the light of the work of the Law Commission and the Commission on the Funding of Care and Support.
- A new national campaign to help turn around the lives of families with multiple problems will be developed. The campaign will be underpinned by local Community Budgets – focused on family interventions – enabling a more flexible and integrated approach to delivering the help these families need. Community Budgets will be available in 16 councils in 2011/12 before national roll-out in 2013/14.
- In its response to the consultations which accompanied *Liberating the NHS*, the Government will publish more details on the relationship between GP consortia and councils allowing more and better joining up of services that meets people's and communities' needs.
- NHS organisations will continue to develop and implement their local plans for improvement. Increasing numbers of QIPP products are now being made available to support organisations to make large-scale change. Complementing this will be a significant engagement programme to mobilise NHS staff, patients, carers and the voluntary sector, enabling them to contribute to improving quality and productivity in the services they provide and use.
- In addition, we will ask the Standing Commission on Carers to prepare advice that could be used by the NHS to inform improved support for carers as part of improving outcomes for patients.

4. Supporting carers to stay healthy

Priority area 4: Supporting carers to remain mentally and physically well

- 4.1 Caring can be very rewarding and fulfilling but it can also be emotionally and physically draining without recognition and practical and emotional support.

“Older carers see it as their duty to devote their lives to caring for their partner and are willing to sacrifice their life to fulfil this responsibility. Lack of mobility and being housebound in their caring duty affects their mental and physical health.” (quote from a carer)

- 4.2 There is a clear relationship between poor health and caring that increases with the duration and intensity of the caring role. Those providing high levels of care are twice as likely to have poor health compared with those without caring responsibilities.³⁶ Young working age adults, for example those caring for a child with either physical or mental health problems, are more likely to have ill health than non-carers of the same age. Carers can also experience significant strain from a lack of knowledge about the nature of the problem, stigma, relationship problems and financial hardship. Carers who feel forced to give up work to care are also at particular risk of ill health. Caring for people with dementia can exact a heavy toll on the care providers, many of whom will be older people, over the course of the illness.³⁷

“I am supposed to be having my cataracts done but I just can’t because who will care for Mum?” (quote from a carer)

“Mum didn’t need to go into a home, we were managing in her own home, but you can only go on for so long doing everything and getting no sleep.” (quote from a carer)

- 4.3 Carers can neglect their own health because they are so busy supporting someone else. But other health problems can arise that are directly associated with the caring role. Stress and anxiety can be related to concerns about the person who is being cared for, frustration about a lack of information and advice and ‘battling’ with systems and organisations to obtain help and services. Depression can be related to financial worries and social isolation, and loss of self-esteem and confidence. Poor physical health, for example high blood pressure and heart problems, can be attributed to the anxiety associated with caring, and musculoskeletal problems can be attributed to inappropriate lifting and moving. And bereavement can be associated with poorer mental and physical health and increased use of health services.

- 4.4 Much of this ill health is avoidable or can be minimised. Supporting carers to remain physically and mentally well is therefore a key part of the prevention and public health agenda. Employers, health and social services, voluntary organisations, families, neighbours and friends can contribute in many different ways to support carers' health and well-being and this is particularly important for older carers and carers of children with complex, long-term disabilities.

“I had never heard of the Carers Centre but saw a leaflet in my GP surgery – it was a life saver. I now have somewhere to go that’s just for me. My son’s health continues to be poor with regular bouts of hospitalisation but I feel I can cope better. I receive regular free holistic therapy treatments along with practical information and support...” (quote from a carer)

Prevention and early interventions for carers

- 4.5 Access to relevant information – at the right time – is crucially important for all carers. Information and focused support at key stages along the care pathway, for example when a diagnosis is made, at the time of hospital discharge or at the end of the life of the person they have cared for, can improve health outcomes and experience for carers and be cost-effective.

“Many carers are confused by the apparently uncoordinated support they receive from various organisations. There also tends to be a lack of a personal touch. A more local front line support at GP practices would offer a more personalised, cost-effective and focused service.” (quote from a carer)

- 4.6 In the early stages of caring, relevant interventions might include advice and equipment to assist with lifting and moving, or assistive technology which supports service users to maximise their independence as well as enabling carers to continue to work and to engage in social and leisure activities. Emerging evidence shows that timely, flexible and quality support can help those with caring responsibilities to look after their own physical and mental health at the same time as supporting others. In addition, any carer who is experiencing depression or anxiety disorder – whether as a result of their caring or not – can access National Institute for Health and Clinical Excellence (NICE) approved treatment from local services set up under the Improving Access to Psychological Therapies (IAPT) programme. We will seek to expand access to IAPT for carers.

“The mental and emotional support I received saved my sanity and the use of direct payments gave me a little ‘me time’. My GP has been very supportive and treats me as an ‘expert’ in my wife’s care.” (quote from a carer)

- 4.7 Over half the respondents to the call for views on priorities highlighted the importance of regular breaks from caring responsibilities to help carers look after their own health and well-being and to sustain them in their caring role.

However, they raised concerns about the availability of breaks and how they are often still offered on a ‘one-size-fits-all’ basis, for example a sitting service. The majority of carers who had experienced a good break had organised them themselves using direct payments.

Supporting carers – learning from research

- 4.8 The 25 carers demonstrator sites established last year by the Department of Health are exploring ways in which the NHS can offer better support to carers and various ways of supporting breaks from caring, and are testing the effectiveness of health and well-being checks, specifically focusing on carers. The Centre for International Research on Care, Labour and Equalities (CIRCLE) at the University of Leeds is conducting an independent evaluation of the demonstrator sites. Its interim findings are on its website³⁸ and its final report will be available next year.
- 4.9 Direct payments to support a break have been much appreciated by participants in the demonstrator sites and used for a wide range of activities and interests, for example developing computer skills, gym membership, swimming lessons and a family holiday.

“I have taken advantage of the Give Us A Break pilot project in Bath and North East Somerset. This has been a real treat as it acknowledges the role of the family carer, provides time away, prioritises the carer and may be something the carer and ‘caree’ can do together.” (quote from a carer)

“Respite does not always mean somewhere to send the cared for person or for respite carers to come to the home. Different people use different ways of finding respite from their caring role and this needs to be recognised and funded.” (quote from a carer)

- 4.10 ‘Stress busting’ therapy sessions for carers offering massage and reflexology have also been popular. A Book Your Own Breaks online service where carers can book a preferred care support worker to provide alternative care at a time of their choice or care at short notice has enabled easy access to a range of support.

“I like the idea that I don’t have to have the same day every week and the fact that the care support worker has a good relationship with my husband means that we both look forward to the day. I can go out with the extra peace of mind he is happy.” (quote from a carer using the Book Your Own Breaks service in Hertfordshire)

- 4.11 The Government is committed to the future of the national NHS Health Check programme. As part of the programme, 40 to 74 year olds will be offered a free NHS Health Check that will help carers, among others, stay well for longer. Everyone receiving an NHS Health Check will receive a personal assessment

and individually tailored advice and support to help them manage their risk of heart disease, stroke and diabetes. The assessment can be carried out locally and in a variety of settings, including pharmacy and community settings, to help to ensure that the service is accessible to all those eligible, including carers who may find it more difficult to access some health services. Carers should be encouraged to take up their offers of a free NHS Health Check when they receive them.

“I had really good support from my GP service once I kept mentioning that I was a family carer – they opened up more convenient appointment times, and made sure I was receiving the health screening and checks that I should. However, I had to know that I was flagged as a carer, and had to remind the staff – gently.” (quote from a carer)

- 4.12 The carers demonstrator sites focusing on health and well-being checks are testing different ways of reaching out to carers, including those in ethnic minority communities, and offering structured consultations to discuss their own health and well-being. The final report from the independent evaluation of the demonstrator sites, particularly around accessibility for carers, will be fed into the ongoing policy considerations for the NHS Health Check programme.

“Time out to talk and evaluate my position as a carer. The health check gave me confidence in my own health.” (quote from a carer)

- 4.13 The carers demonstrator sites that are exploring better ways in which the NHS can support carers are also testing a number of approaches, including carer assessment support workers based in GP practices who help to identify carers and signpost them to support services, carer liaison teams, carers’ leads in clinical teams and a range of support materials.

“I love the How do I feel today? and Time to think about you documents. Even the word ‘assessment’ can put carers off. These help them think about their own needs in a way that’s acceptable and non-threatening.”

“After two and a half years getting absolutely nowhere, the Carers Liaison Worker listened and went on to find help and thanks to her, I now get the much needed break I wanted.”
(quotes from carers participating in demonstrator sites on better NHS support)

- 4.14 The Department of Health is also running a demonstrator site programme for the dementia adviser role and peer support networks, as detailed in the National Dementia Strategy.³⁹ The development of the dementia adviser role followed feedback from carers during consultation on the draft dementia strategy, as they expressed the wish to have someone with them on the journey who could provide information and advice as the needs of the person with dementia change. Similarly, people with dementia described the value of peer support networks in

building their confidence and providing emotional and psychological support. The programme is testing out different models of providing these services and the full evaluation will be available in the autumn of 2012.

Supporting parent carers of disabled children

- 4.15 The Government places importance on the provision of short breaks for parent carers of disabled children. The Department for Education has already announced that additional funding recycled from the Child Trust Fund will be used to support short breaks services. The legislative process to place a duty on councils to commission short breaks services should be completed in the New Year. The Department of Health has also made available up to £30 million this year for improvements to the children's palliative care sector, which plays a key role in supporting both ill and disabled children and their carers. This funding will enable both national and local organisations to increase and enhance the provision of care available.

Supporting carers in military families

- 4.16 The Ministry of Defence recognises that a growing number of military family members are becoming carers supporting Service personnel who have been injured in military operations overseas. The Ministry of Defence provides both emotional and practical support to carers as well as the people they support for as long as they need it through their welfare and medical staff. Service charities also offer a wide range of support to families whose relatives have been injured while serving in the Armed Forces.

Promoting health and well-being in local communities

- 4.17 Councils can play a vital role in leading change and stimulating action in their communities. Their broader role in promoting health and well-being will be enhanced by new public health functions to be outlined in the forthcoming White Paper on public health. Carers, alongside people who are using or come into contact with services, could well be key contributors to the new leadership role that councils will have in joining up services across the NHS, social care and public health. Subject to the Government's response to *Local democratic legitimacy in health*, this will be through local HealthWatch (replacing Local Involvement Networks (LINKs)) and the proposed health and well-being boards.
- 4.18 In addition, HealthWatch will be one of the key means of engaging with local communities to agree priorities for health improvement, encouraging more involvement of local voluntary and community organisations, and helping local people, including carers, to hold providers and commissioners to account.

Next steps

- The Government will make available to the NHS an additional £400 million to support carers to take breaks from their caring responsibilities over the next 4 years.
- The Department of Health will publish the independent evaluations of the carers demonstrator sites and the dementia demonstrator site programmes in autumn 2011 and autumn 2012 respectively.
- The Government will publish a new mental health strategy, early in the New Year, which will set out the outcomes that we expect all users of mental health services to benefit from, wherever they live and whatever their circumstances, including caring responsibilities. The strategy will include more details on the development of talking therapy services following the recent announcement that this will be expanded over the next four years.
- The Social Care Institute for Excellence will review the evidence and produce information for the sector about the preventative potential of telecare and telehealth as part of its broader work programme on prevention. Improving outcomes for carers will be addressed as part of that work.

5. Developing the evidence base on supporting carers

The evidence base for carers' interventions

- 5.1 There is a good evidence base on the problems that may be associated with caring responsibilities including mental and physical health problems, social isolation and lowered social functioning, and increased mortality as a result of mental or emotional distress, especially in more elderly carers.⁴⁰
- 5.2 There is some evidence of financial savings in supporting carers. A whole systems study tracked a sample of people over 75 years old who entered the health and social care system and found that for 20% of those needing care – often costly hospital care – this was due to the breakdown of a single carer on whom the older person was mainly dependent.⁴¹
- 5.3 However, there are difficulties in focusing on evidence of improved outcomes for carers from single carer-specific ‘interventions’. Rather the evidence from research^{42 43} shows that effective support to carers usually goes beyond a single intervention and encompasses good quality mainstream services, and sensitive and carer-aware professional practice (across health, social care, education and all local services). As importantly, evidence shows that a joint strategic approach by health, local government and voluntary organisations is needed for a local population to develop and commission a range of local services suited to the local needs of carers and people using services.
- 5.4 In terms of effective carer-specific services and interventions, quality standards were developed as part of the first national strategy for carers in 1999.⁴⁴ These were based on research evidence of what works and what is important to carers.⁴⁵
- 5.5 The standards relate to five outcomes that carers identified as key to their well-being – being informed, having a break, accessing emotional support, maintaining their own health and having a voice. These standards, each with detailed criteria, provide an evidence-based benchmark for carer support. The recent call for views on priorities has confirmed that these are the health and social care outcomes that carers are still seeking.
- 5.6 Through the QIPP Programme, the Department of Health will encourage further collection of evidence and offer solutions around evaluating services and outcome measures that local areas can embrace.

Young carer pathfinders

- 5.7 Seventeen councils are funded until March 2011 to help to develop innovative ways of identifying, assessing and supporting young carers and their families. Key to the approach is children's and adult services working effectively together alongside the voluntary sector and schools.
- 5.8 An early assessment of the impact of these projects shows that where intensive support, co-ordinated by a key worker, is focused on the whole family, this resulted in (between entry to and exit from the project) a 35% reduction in the number of young carers. The project was also effective in reducing by 33% the number for whom caring was having a negative impact.⁴⁶ The full evaluation will be published in March 2011.

The evidence base for supporting carers in work

- 5.9 Employers for Carers identify and promote the business case and benefits of supporting carers in the workplace and offering employers practical support to develop and benchmark good practice. They aim to create a culture that supports carers in and into work. They have developed an evidence base on supporting carers in work which is at Annex B.

Overview of carers' experiences

- 5.10 The Government will consider how to maintain a national overview of carers' experience. In 2009, GfK NOP Social Research was commissioned by the NHS Information Centre to conduct a face-to face survey of adult carers in England, and 2,400 carers were interviewed. Provisional results are available in the *Survey of carers in households in England 2009/10*⁴⁷ and full results should be published in December 2010. The question in the 2001 Census about caring will be repeated in the 2011 Census.
- 5.11 The Department for Business, Innovation and Skills already identifies carers in its work/life balance survey that focuses on the current workplace and extending the right to request flexible working.⁴⁸
- 5.12 The Department of Health is currently seeking views on repeating the Carers' Experience Survey⁴⁹ as part of its consultation *Transparency, quality and outcomes in adult social care*.⁵⁰
- 5.13 The Department of Health is also currently piloting a survey of bereaved relatives, as a means of measuring the quality of care provided to people at the end of life and their carers.⁵¹ The pilot will inform the development (subject to available funding) of regular national surveys of bereaved people.

Outcomes frameworks

- 5.14 The consultation document *Transparency in outcomes: A framework for adult social care* sets out proposals for building the evidence base, supporting transparency and demonstrating progress in social care. The response to the consultation on the NHS Outcomes Framework for 2011/12 will be published shortly.

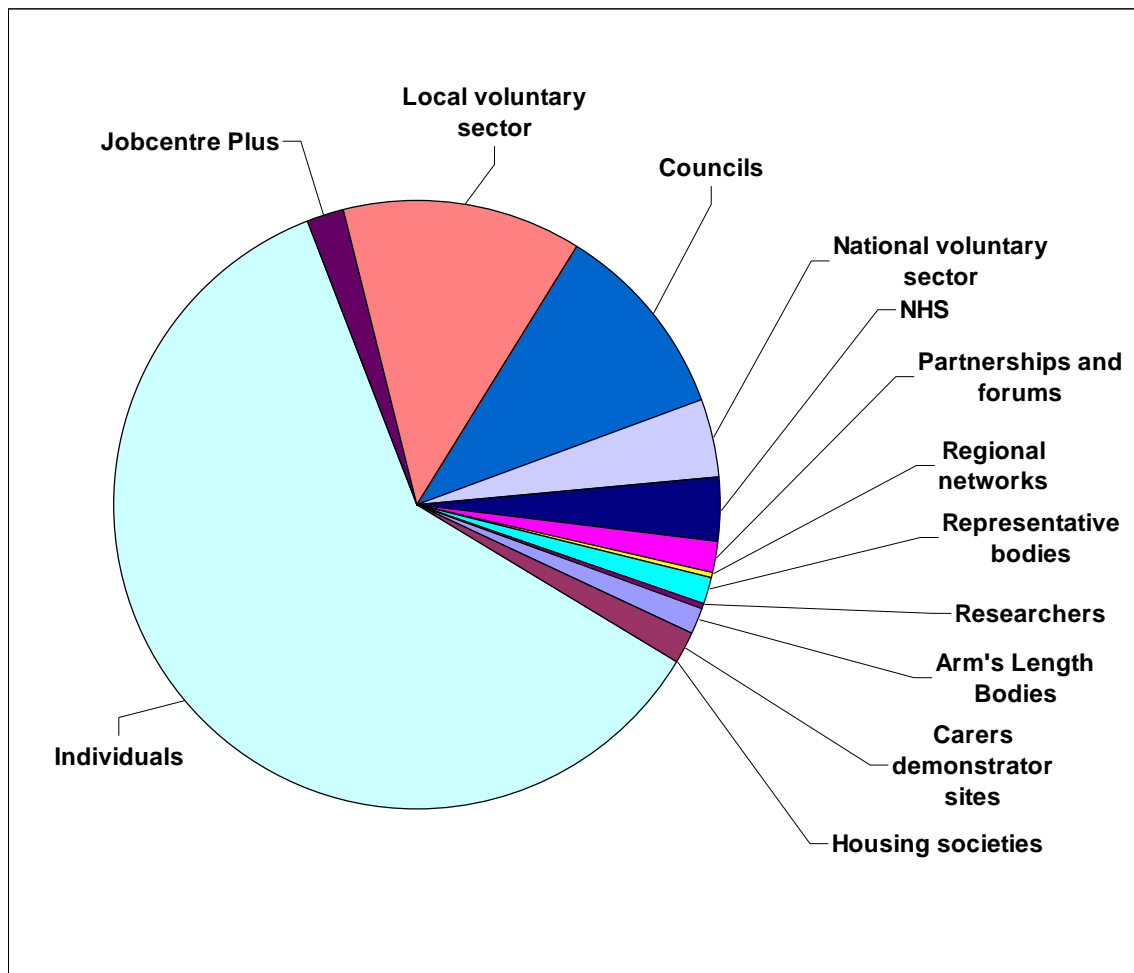
6. Supporting local delivery, transparency and local accountability

- 6.1 The Government is committed to shifting power away from Whitehall to those who know what will work best in their local communities – and carers are key players in their local communities in terms of their knowledge and experience and are very resourceful in finding practical solutions.
- 6.2 It is envisaged that local government will have an enhanced role in health with responsibility for leading Joint Strategic Needs Assessments along with GP consortia, developing shared priorities and strategies across social care, the NHS and public health, and addressing cross-cutting issues such as support for carers. They may wish to involve carers and draw on their knowledge and expertise.
- 6.3 The Government will shortly publish its response to the *Liberating the NHS* White Paper consultations, including *Local democratic legitimacy in health*, which will set out how we propose to formalise the new leadership role for local government in joining up services across the NHS, social care and public health in the Health and Social Care Bill. We will also outline plans for implementation, including through working with early implementers – local areas who are keen to push ahead with putting the new integrated arrangements into practice will be free to participate.
- 6.4 The shift to an outcomes-based approach to commissioning and procurement should ensure that carers and those they support have the information and advice they need to make confident decisions about their own care and support. Carers and the people they support should have the opportunity to play active roles in the design, development, delivery and review of innovative and personalised care and support arrangements in order to maximise choice and independence and to utilise the widest range of resources. Co-production with carers should be integral to the delivery of all care services.
- 6.5 Change of this kind will be challenging and will also require a wide range of organisations and communities to play a bigger role in shaping local services and exploring innovative and cost-effective options for care and support. Carers and families already make a huge contribution to the well-being of those they support. They now have a real opportunity to participate as equal and expert partners in the design and co-production of a new generation of care services and of more inclusive and mutually supportive communities.

Annex A: Response to the call for views on priorities

Overview

1. In July 2010, the Government called for views on the key priorities, supported wherever possible by evidence of good practice, that will have the greatest impact on improving carers' lives in the next four years.
2. In total, 764 responses were received. The following chart illustrates the breakdown of individual and organisational responses.

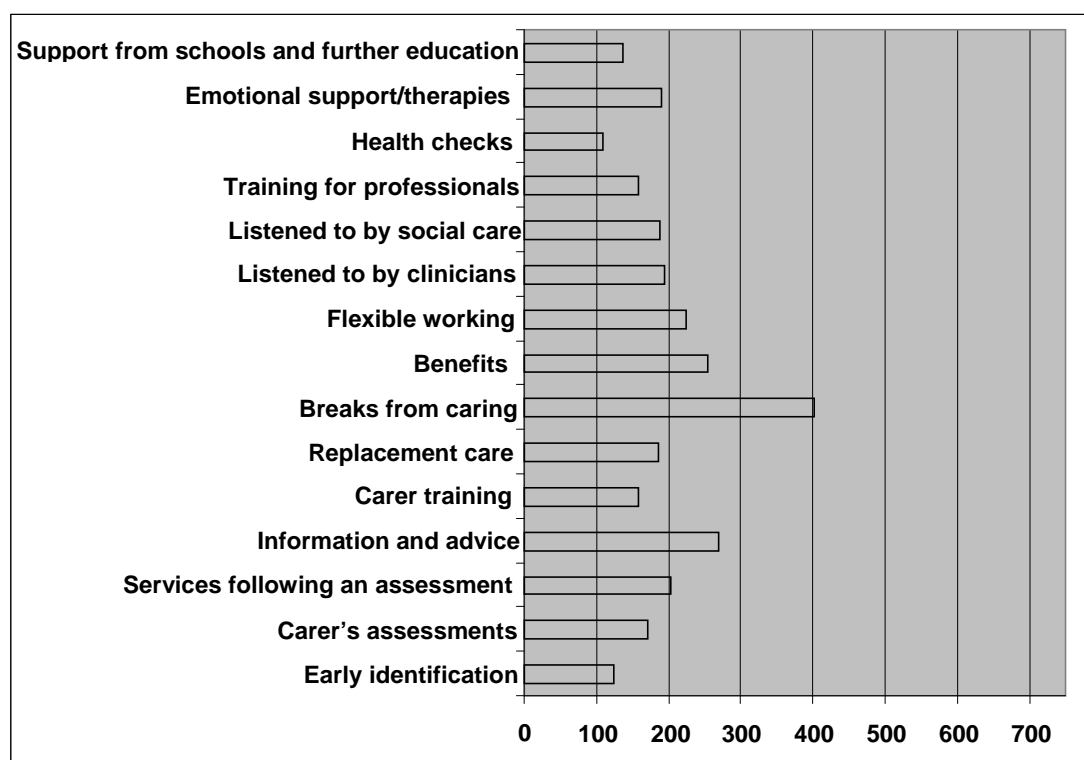


Type of respondent	Number of responses
Arm's length bodies	10
Carers demonstrator sites	13
Councils	81
Housing societies	1
Individuals	462
Jobcentre Plus	15
Local voluntary sector	97
National voluntary sector	31
NHS	26
Partnerships and forums	13
Regional networks	3
Representative bodies	9
Researchers/academics	3
	764

The call for views

3. Respondents were asked to outline their views under the five outcomes for carers contained in the strategic vision in the 2008 Carers Strategy:
 - *carers will be respected as expert care partners and will have access to the integrated and personalised services they need to support them in their caring role;*
 - *carers will be able to have a life of their own alongside their caring role;*
 - *carers will be supported so that they are not forced into financial hardship by their caring role;*
 - *carers will be supported to stay mentally and physically well and treated with dignity; and*
 - *children and young people will be protected from inappropriate caring and have the support they need to learn, develop and thrive and to enjoy positive childhoods.*
4. The issue of benefits and flexible working for carers did not form part of the call for evidence as they are already being considered as part of the Government's wider work on welfare reform and improving flexible working arrangements.

Key themes raised



Breaks from caring responsibilities

5. The theme raised most often, by over half of the respondents, is the need for breaks from caring in order to sustain carers in their role. While the majority of responses focused on the availability of breaks, a number focused on the type of breaks on offer. In order to be beneficial, breaks need to be personalised to meet the specific needs of the carer - many felt that breaks are currently offered on a 'one-size-fits-all' basis.
6. A number of responses, particularly those about young carers, stressed the need for breaks to involve the whole family, including the person being cared for.
7. Many felt that the provision of a break was not enough and that carers may need to be given additional support to help them to make the most of their break. For some this might be transportation, particularly for those living in rural communities. For others, socially isolated as a result of their caring role, this might be the establishment of networking events for carers.
8. The majority of those who had experienced a good break from caring responsibilities said that they had arranged these themselves with a direct payment.

Replacement care

9. Connected to breaks, 185 respondents raised concerns about the availability and quality of replacement care. Many stated that this impacts upon their ability to

have a meaningful break, as replacement carers often turned up late, if at all, and plans had to be rearranged or cancelled. In particular, those looking after a person with challenging behaviours feel unable to take a break as paid care workers are unwilling or unable to deal with episodes of challenging behaviour and will call the carer as soon as they feel unable to manage.

10. A number of carers pointed out that the availability of reliable replacement care also impacts upon their health and their ability to work, train and carry out their caring role, as without it they are unable to attend medical appointments or do something as simple as go shopping. A number of carers raised concerns about councils refusing to provide replacement care when they found employment.

Information and advice

11. Over a third of respondents felt that there is still a lack of information, advice and advocacy available to carers. Health and social care professionals do not proactively provide carers with information on their rights or the services available to them – carers have to seek out information themselves. A number of respondents thought that social services should proactively offer a carer's assessment and did not understand why they still had to request one despite being known to social services as a carer.
12. A number of carers also raised concerns about the lack of information that they receive from clinicians on the treatment or care of the person that they support, confidentiality being the usual reason for withholding such information. This issue is closely connected to carers feeling that they are not respected as expert partners in care.

Benefits

13. Despite this being outside of the scope of the call for views, 255 respondents felt that benefits could not be ignored. In particular, a large number of respondents were unhappy about the rules preventing individuals in receipt of State Pension from receiving Carer's Allowance, as caring responsibilities do not stop at retirement. In addition to this, there was a general dissatisfaction with the value of Carer's Allowance and the inflexible earnings limit. A number of respondents said that the £100 earnings limit is a disincentive to work and wanted to see the reduction in Carer's Allowance, as a result of employment, tapered.

Flexible working

14. Similarly, a number of respondents felt that they could not ignore flexible working, despite this also being outside of the scope of the call for views – 225 respondents raised this issue. While the majority welcomed the Government's efforts to encourage flexible working, many felt that there should be a legal duty on employers to provide this. A number of carers felt that they had been forced to give up work and said that they would not have done so had the support and information been available to them when they took on their caring responsibilities.

Services for carers and the people they care for

15. Some 204 respondents raised concerns about the services that are available to carers following an assessment. Issues were raised about the paucity of such services and the length of time that it takes to access them following an assessment. While there was overall support for personal budgets, and direct payments in particular, a number of respondents were concerned about the level of contribution that carers are expected to make and the fact that the payments that they receive fall short of the cost of services. A number of concerns were also raised about the additional responsibilities that come with the employment of personal assistants.
16. Respondents felt that the use of equipment or assistive technology (telehealth and telecare) could not only make the carer's job easier and safer, but also prove good value for money in allowing carers to have a life outside of caring without the need for replacement care.

Carers' assessments

17. Connected to carer services, 170 respondents also raised concerns about the process of conducting a carer's assessment, feeling that the process is too long and overly bureaucratic. A number thought that a carer's assessment should be offered and carers should not have to request one. Others felt that the assessments currently on offer are too narrow and should be broadened to cover advice on benefits and employment.
18. Concerns were also raised about the disjunction between multiple assessments, both in respect of separate assessments for the carer and the person being supported, and when there is more than one disabled person in the family. A mother of two disabled children described how she was assessed twice, once for each of her children.

Recognition by health and social care

19. Some 194 of those who responded did not feel that clinicians listen to them, and 188 respondents did not feel listened to by social care professionals. Carers felt frustrated that their contribution is not valued but also that care could be improved by the knowledge and experience the carer has gained in their caring role. In particular, many felt that their exclusion from clinical discussions made discharge from hospital more likely to fail. Of those who felt excluded from clinical and social care discussions, the majority felt that health and social care professionals needed additional training to make them 'carer aware'.

Carers' health and well-being

20. A quarter of those who responded were concerned about the additional stress put on carers as a result of their caring responsibilities and called for emotional support and other therapies to be made available.

21. A number of responses cited evidence of carers suffering disproportionate levels of poor health and felt that health checks should also be available to them.

Carers' training

22. A total of 158 respondents wanted better access to training; for many, this is training to assist them in carrying out their caring role effectively and safely. Other responses, however, highlighted other training needs, particularly around helping them to return to work and developing skills with training being a way of taking a break.

Early identification

23. The early identification of carers was raised by 123 respondents, with many feeling that this is a responsibility wider than just health and social care. In relation to young carers, a number of respondents felt that schools should both identify and support young carers. A number also felt that more needed to be done to reach out to individuals in particular communities, including ethnic minority communities, where caring is seen as part of their family responsibilities.

Next steps

24. This annex provides a brief overview of the responses received. A more detailed analysis will be published on the Department of Health website shortly (www.dh.gov.uk).

Annex B:

The evidence base for supporting carers in work

Prepared by Employers for Carers, a forum focused on ensuring that employers have the support to retain employees with caring responsibilities

The demographic drivers

1. Currently 3 million people in the UK juggle paid work with unpaid caring responsibilities – one in seven people in any workforce – and this number is set to increase by half as much again in the next 25 years due to:
 - an ageing population and more people living longer with disability as a result of advances in medical technology;
 - an ageing workforce, with fewer young people entering the job market and later retirement ages (including later State Pension ages);
 - tighter public sector budgets for care and support services which will increase the pressure on families and friends to care; and
 - more people therefore needing to work and care longer – three in five people will become carers at some stage in their lives, the majority during their working lives.
2. By 2017, we will reach the tipping point for care when the numbers of older people needing care will outstrip the numbers of working age family members currently available to meet that demand.⁵²

The business case for employers

3. Forward looking employers now recognise caring as an issue which will have an increasing impact on their employees and on themselves as businesses. Already 90% of working carers are aged 30 plus – employees in their prime employment years. The peak age for caring is also 45–64 when many employees will have gained valuable skills and experience. The Triennial Review published by the Equality and Human Rights Commission in October 2010⁵³ also highlighted that one in four women in their fifties, and nearly one in five men in this age group, are carers. Recent research⁵⁴ published by the Department for Work and Pensions and Carers UK indicated that as many as 1 million people (one in six carers) give up or cut back work to care, which is a real loss for employers as well as for families.

4. Far from compromising business objectives, research⁵⁵ shows that using a flexible and carer-friendly approach achieves impressive business benefits in:
 - increased **retention** of staff ;
 - reduced recruitment and retention costs;
 - increased **productivity** and performance;
 - reduced sick leave and absenteeism;
 - improved **service delivery**; and
 - improved **cost savings**.

Employers for Carers forum

“We have come together as employers who believe that supporting carers is good business. By working smarter, and offering real opportunities for people to transform the way they work, our members have seen how they can reduce costs and improve productivity as well as help to retain their most skilled staff at a time they can least afford to lose them.

“Accommodating carers isn’t difficult, disruptive or expensive, it’s just plain business sense – a small change in working hours or flexible arrangements can make all the difference both to the workforce and to the business.”

Caroline Waters OBE, Chair of Employers for Carers and Director, People and Policy for BT Group

Key issues

Staff retention and engagement

5. During recent years, and especially during the recent recession, more and more employers have been recognising the value of retaining – and where necessary re-hiring – skilled workers rather than incurring the costs of recruiting and retraining new staff.

Productivity and performance

6. Analysis of the 2001 Census shows that working – and working age – carers pay a heavy penalty in terms of their own health if they are not adequately supported to work and care. Those with heavy caring responsibilities are two to three times more likely than workers without caring responsibilities to be in poor health.⁵⁶ Research⁵⁷ has also shown that caring for 20 hours a week or more starts to have a substantial effect on employment, particularly for women. Supportive employers can play a key role in mitigating these impacts, and thereby increasing staff resilience, productivity and performance in the workplace.

Case studies

Small/medium enterprise – Listawood

With a workforce of around 200 people, Listawood is a manufacturer of promotional giveaways such as ceramic mugs, fridge magnets and mouse pads. The recent recession has resulted in a greater level of scrutiny being placed on the discretionary budgets used by organisations for such items, and this, combined with increased competition from emerging low wage economies, has placed enormous strain on their sector.

As part of their performance management framework, Listawood regularly survey their employees to measure staff satisfaction. The company is aware that it does not offer the best salary levels in the area – indeed only 56% of staff surveyed felt their pay was competitive when compared with other employers locally. Their deep-rooted culture of flexibility is, on the other hand, well recognised by staff:

- 97% of staff felt the company offered better opportunities for work/life balance than other employers in the area.
- 96% agreed that any request for flexible working would be fairly considered.
- 97% said they would be able to get time off at short notice if they needed to.

Staff turnover at the company is remarkably low – only a fraction of one per cent per annum. Listawood argues that their culture of flexibility and support of those needing to balance their home and work lives, often at short notice, is a significant driver of staff retention:

“Losing highly trained staff is incredibly disruptive in any business. In the sales environment it fractures customer relationships which can result in reduced levels of business, and in the factory it compromises manufacturing efficiency. On top of this, you then have to bear the costs associated with recruitment and training for their replacement. We are in no doubt that our staff retention levels are driven by our attitude to work/life balance rather than the generosity of our remuneration packages. This makes it possible for us to remain competitive and profitable in a highly competitive market, even during these unusually difficult trading conditions.”

Alex, Managing Director

“My grown-up daughter has suffered from a heart condition since her late teens that at times can be seriously debilitating. The company has always allowed me to take time off at short notice to care for her – something I really appreciate. Of course I always give back to the company when I can.”

Gilly, Administrator

“For the last year my sister-in-law has been seriously ill with cancer. I have needed to take time off each week supporting her emotionally and accompanying her to meetings with medical specialists. She has a husband and young children but she does not feel she can burden them with this and needs my support. I’ve been able to take this time off, often at short notice, with the support of my senior management colleagues and other more junior members of staff.”

Jenny, Production Director

Large employer – Centrica/British Gas

Centrica/British Gas has led on innovative family friendly and flexible working practices and in 2004 was one of the first employers to set up a carers' network. It reported quantified business benefits from its innovative flexible working programme, 'work:wise', in 2004 and from a subsequent study in 2007 on the impact of flexible working on performance. It has had particular success in retaining engineers, who had been identified as leaving the workplace. Now 60% of staff work flexibly and over half of these are men, including a large number of engineering staff.

Example: An installation engineer for British Gas for 25 years cares for his six-year-old daughter, who has a learning disability. He also has two other young children. Her condition means that there are extra medical concerns requiring tests, for example her hearing and sight. Hospital appointments are always during working hours and often made at short notice.

His manager allows him to organise his work around the customers. Early starts, which suit many customers, allow him time off later on in the day to be with his daughter. Working in a two-man team means that they share the work between them. His colleague covers for him when he needs the time and they make it work between them. He can also take short notice holiday when required.

“British Gas was one of the first UK companies to develop flexible employment policies to support staff with caring responsibilities. This makes it easier for employees to combine work and care, so they don't feel forced to choose between one or the other. Recruiting and training new staff can be expensive and unnecessary when a more flexible employment approach should ensure that existing, experienced people are retained.”

Phil Bentley, Managing Director

In 2007 Centrica was involved in a study, by Cranfield University in conjunction with Working Families, to examine the impact of flexible working on performance. Key findings included that over 50% of flexible workers, managers and co-workers of flexible workers felt that flexible working had a positive effect on performance. Flexible workers also scored significantly higher on indirect performance-related aspects such as commitment, empowerment, job satisfaction, job fulfilment and work/life balance (75%).

Public sector employer – Metropolitan Police Service

The Metropolitan Police Service (MPS) has more than 32,500 officers together with about 14,200 police staff, 230 traffic wardens and 4,300 Police Community Support Officers (PCSOs). The MPS is also supported by more than 3,600 volunteer police officers in the Metropolitan Special Constabulary and its Employer Supported Policing programme.

- **All** employees of the MPS can request flexible working. This takes the potential stigma out of it being something only carers and parents can request thereby making it more acceptable to be a carer. The MPS supports all forms of flexible working including flexi-time (police staff only).
- The provision of carer's leave is separate from other types of emergency leave and paid leave is doubled if the individual has multiple caring responsibilities.
- The MPS provides support for and encouragement of an employee-run (voluntary) Carers Support Group (including their own website and support for awareness days).
- Each Operational Command Unit has a work/life balance representative to support and advise. The MPS currently has over 200 volunteers.
- The MPS has a clear policy and standard operating procedures that set out managers' responsibilities.
- Relevant practitioners are included at strategic meetings where appropriate, such as Olympics planning.

The business case for the wider economy

7. Supporting carers in the workplace also has business benefits for the wider economy. Research⁵⁸ published in February 2010 sets out for the first time the economic and social benefits of investing in social care, calculating the amount of additional earnings (between £750 million and £1.5 billion per annum) and related tax and national insurance revenue that would come into the economy if working age carers were better supported by care and support services. It also calculates the amount saved in welfare benefit payments.
8. As the national population and workforce age, there are also associated risks of loss to the economy if more people have to give up work or reduce their working hours because they cannot get the support they need from external services. This includes lost tax revenue and lost contributions to the pensions pot, and there are also additional costs in the form of welfare benefit payments.

9. The cost to carers in terms of lost earnings is around £11,000 a year,⁵⁹ and there are also significant costs to employers in terms of recruitment and lost productivity. This is a particular concern during times of recession when issues of retention and productivity are especially important in order to survive the downturn and to enable recovery.

The business case for society

10. Supporting people to combine work and care also has benefits for society as a whole and, as with the economy, there are heavy risks to UK society if people are not supported to do this. The contribution of unpaid carers has been calculated⁶⁰ to be worth an estimated £87 billion per year – nearly as much as total spending on the NHS. Carers (80% of whom are of working age) play a crucial role both in providing (unpaid) care and in helping their families or friends to stay out of hospital or residential care. They provide a very valuable contribution, therefore, not only for individuals and families but also for our wider economy and society. Employers, the economy and society all benefit from this contribution and should therefore all support carers to combine work and care healthily and productively. Services that support family life – from child care and home care to adult care – are essential for both economic productivity and social cohesion.

Flexible employers need to be supported by flexible services

11. We are juggling increasingly complex family lives with increasingly demanding working lives. Forward looking employers already help their workforce to access care through providing information, signposting and services such as care vouchers and help with emergency care cover. However, they cannot do this alone and are increasingly recognising that they need to be supported by flexible and accessible care and support services.
12. **Evidence:** The most comprehensive research⁶¹ that has been undertaken to date with working carers found that services have a critical role in carers' ability (or inability) to remain in work. Only a third of carers surveyed said that they had adequate services to enable them to work and 41% said "they would rather be in paid work, but services available do not make a job possible".
13. External care and support services – and the wider infrastructure including housing, transport and assistive technologies – must therefore be fit for 21st century families and workplaces. People need different levels of help at different stages. Simple, practical services such as window cleaning or befriending may be needed at one level while quality, affordable, local care may be needed at another level, including residential care where appropriate. The availability of local care is particularly important to avoid isolation and loss of connectivity with family, friends and place.

Case study – building capacity in local communities

Practical support such as gardening or shopping can often make a real difference for people alongside the provision of care services. Further work needs to be done to identify and disseminate examples of good practice at local level such as ‘Southwark Circle’. This membership organisation, supported by Southwark Council, “*provides on-demand help with life’s practical tasks through local reliable Neighbourhood Helpers and a social network for teaching, learning and sharing*” (www.southwarkcircle.org.uk). There is also a significant role here for volunteering, with employers able to make a difference by contributing employee hours for these activities.

14. Caring is everybody’s business – the UK economy and society cannot afford **not** to support people to combine work and care.

Employers for Carers
20 Great Dover Street, London SE1 4LX
email: employers@carersuk.org
tel: 020 7378 4956
web: www.employersforcarers.org

Annex C: A summary of key activities in the priority areas

Priority area	Key activities
1. Identification and recognition	<ul style="list-style-type: none"> • The Department of Health will make £1 million available to patient-led and condition-specific voluntary organisations to enable them to focus on supporting carers through a Reaching out to Carers innovation fund. • The Department of Health will provide additional resources for GP training, to increase GPs' awareness and understanding of carers' needs for support. • Following the current consultation on <i>Liberating the NHS: An information revolution</i>, the Department of Health will publish an information strategy and plans for its implementation, working closely with carers and carers' organisations. • Skills for Care and Skills for Health will publish a learning and training framework on supporting carers, a guide for employers and commissioners of training, together with a wide range of support tools. • The Department of Health has published a guide on emerging evidence – <i>Carers and personalisation: improving outcomes</i> – and the Social Care Institute for Excellence will gather further examples of good practice for inclusion in their Good Practice Framework. • Revised guidance on undertaking Joint Strategic Needs Assessments will be published during 2011/12, recognising the importance of identifying the needs of carers in the local population.
2. Realising and releasing potential	<ul style="list-style-type: none"> • The Department for Education will make a new Early Intervention Grant available to local government, bringing together a range of funding streams for early intervention services for young people and families,

Priority area	Key activities
	<p>including young carers.</p> <ul style="list-style-type: none"> • The Department for Education and the Department for Business, Innovation and Skills will work with careers advice professionals, schools, colleges and universities to develop the first all-age careers service. This will provide young adults (including young carers) with continuity of careers advice. • The Government will issue a consultation document next year to consult with business on how best to take forward the Coalition commitment to extend to all employees the right to request flexible working. • The Government will explore a number of non-legislative proposals to build on the recommendations from the Family Friendly Working Hours Taskforce published earlier this year. This will include ‘designing in’ flexible working arrangements in job design and recruitment that will benefit carers. • The Department for Business, Innovation and Skills and the Department of Health will examine how to reduce barriers to market entry for small local flexible enterprises, to maximise growth opportunities. • The Department of Health and the Department for Business, Innovation and Skills will work with industry and statutory and voluntary sector stakeholders to identify the barriers to and enablers of market growth in assisted living technologies to benefit both carers and the people they support. • Skills for Care will set out plans for developing a skilled and competent social care workforce in a workforce development strategy to help employers support greater personalisation and improved quality of care. • The Department for Work and Pensions will continue to invest in supporting carers to return to work through Jobcentre Plus.
3. A life outside of caring	<ul style="list-style-type: none"> • <i>A vision for adult social care: Capable communities and active citizens</i> makes clear that councils should provide all those who are eligible with a personal

Priority area	Key activities
	<p data-bbox="746 237 1366 304">budget, preferably as a direct payment, by April 2013.</p> <ul style="list-style-type: none"> <li data-bbox="699 349 1422 528">• The Department of Health and the Department for Business, Innovation and Skills, working with stakeholders, will ensure that the needs of carers are taken into account in influencing any future technological development. <li data-bbox="699 573 1437 752">• The Government is keen to see greater flexibility and portability of assessments, and will consider how to pursue this in the light of the work of the Law Commission and the Commission on the Funding of Care and Support. <li data-bbox="699 797 1437 1010">• A new national campaign to help turn around the lives of families with multiple problems will be developed. The campaign will be underpinned by local Community Budgets focused on family interventions, enabling a more flexible and integrated approach. <li data-bbox="699 1055 1430 1234">• In its response to the consultations which accompanied <i>Liberating the NHS</i>, the Government will publish more details on the relationship between GP consortia and councils allowing more and better joining up of services. <li data-bbox="699 1279 1422 1491">• NHS organisations will continue to develop and implement their local plans for improvement as part of the quality and improvement challenge. This will be complemented by a significant engagement programme to mobilise NHS staff, patients, carers and the voluntary sector. <li data-bbox="699 1536 1382 1682">• The Standing Commission on Carers will prepare advice that could be used by the NHS to inform improved support for carers as part of improving outcomes for patients.

<p>4. Supporting carers to stay healthy</p>	<ul style="list-style-type: none">• The Government will make available to the NHS an additional £400 million to support carers to take breaks from their caring responsibilities over the next four years.• The Department of Health will publish the independent evaluations of the carers' demonstrator sites and the dementia demonstrator sites programmes.• The Government will publish a new mental health strategy, which will set out the outcomes that all users of mental health services can benefit from, including those with caring responsibilities.• The Social Care Institute for Excellence will produce information about the preventative potential of telecare and telehealth as part of its broader work programme on prevention.
---	--

References

-
- ¹ Department for Work and Pensions (2010) *Universal Credit: Welfare that works*
<http://tinyurl.com/universalcredit-whitepaper>
- ² HM Government (2008) *Carers at the heart of 21st-century families and communities: A caring system on your side, a life of your own*
<http://tinyurl.com/carers-heart-21C-families>
- ³ Association of Directors of Adult Social Services and Association of Directors of Children's Services (2009) *Working together to support young carers: A model memorandum of understanding between Statutory Directors for Children's Services and Adult Social Services*
<http://tinyurl.com/supporting-young-carers>
- ⁴ Carer's Rights Day
www.carersuk.org/Newsandcampaigns/CarersRightsDay
- ⁵ Carers Week
www.carersweek.org/
- ⁶ Association of Directors of Adult Social Services (2010) *Carers as partners in hospital discharge: Improving carer recognition, support and outcomes within timely and supported discharge processes*
<http://tinyurl.com/carers-partners-hospdischarge>
- ⁷ Department of Health (2010) *Ready to go? Planning the discharge and the transfer of patients from hospital and intermediate care*
<http://tinyurl.com/readytogo-discharge>
- ⁸ Department of Health (2009) *Information sharing and mental health: Guidance to support information sharing by mental health services*
<http://tinyurl.com/infosharing-mentalhealth>
- ⁹ Department of Health (2010) *Liberating the NHS: An information revolution*
<http://tinyurl.com/liberatingnhs-infoev>
- ¹⁰ Department of Health (2010) *Carers and personalisation: improving outcomes*
<http://tinyurl.com/carers-personalisation>
- ¹¹ Social Care Institute for Excellence, Social Care Good Practice Framework
www.scie.org.uk/goodpractice/browse/default.aspx
- ¹² Young Carer Pathfinders
<http://tinyurl.com/youngcarer-pathfinder>
- ¹³ Ibid ref 3
- ¹⁴ The Princess Royal Trust for Carers and The Children's Society (2010) *Do you care? Supporting young carers: A resource for schools*
<http://tinyurl.com/supporting-young-carers-prtc>
- ¹⁵ Social Care Institute for Excellence, Ethical issues on the use of telecare
<http://tinyurl.com/telecare-ethicalissues>
- ¹⁶ Social Care Institute for Excellence, Ethical issues on the use of telecare
<http://tinyurl.com/telecare-ethicalissues30>

¹⁷ Social Care Institute for Excellence reports and film on telecare
<http://tinyurl.com/SCIE-telecare>

¹⁸ Government Equalities Office and Citizens Advice (2010) *Equality Act 2010: What do I need to know as a carer?*
<http://tinyurl.com/equalitiesact2010>

¹⁹ Equality Act 2010 guidance
<http://tinyurl.com/equalityact-guidance>

²⁰ Department of Health (2010) *A vision for adult social care: Capable communities and active citizens*
www.dh.gov.uk/en/Aboutus/Features/DH_121664

²¹ HM Government (2010) *Flexibility for the future: The Government's response to the recommendations of the Family Friendly Working Hours Taskforce*
<http://tinyurl.com/family-friendly-taskforce-resp>

²² Ibid ref 20

²³ Princess Royal Trust for Carers and Association of Directors of Adult Social Services (2010) *Commissioning better outcomes for carers – and knowing if you have*
<http://tinyurl.com/commissioning-better-outcomes>

²⁴ Common Assessment Framework for Adults Network
www.dhcarenetworks.org.uk/caf/

²⁵ Ofsted (2009) *Supporting young carers: Identifying, assessing and meeting the needs of young carers and their families*
<http://tinyurl.com/supporting-young-carers-ofsted>

²⁶ Law Commission, Reform of adult social care law
www.lawcom.gov.uk/adult_social_care_consultation.htm

²⁷ Commission on the Funding of Care and Support
<http://carecommission.dh.gov.uk/>

²⁸ Department of Health (2010) *Putting People First: Personal budgets for older people – making it happen*
<http://tinyurl.com/personal-budgets>

²⁹ Right to Control Trailblazers
<http://tinyurl.com/right-to-control-trailblazers>

³⁰ Department of Health (2010) *Equity and excellence: Liberating the NHS*
<http://tinyurl.com/liberatingnhs>

³¹ Department of Health, Personal health budgets
www.personalhealthbudgets.dh.gov.uk/

³² Department of Health and Department for Communities and Local Government (2010) *Liberating the NHS: Local democratic legitimacy in health*
http://www.dh.gov.uk/en/Consultations/Liveconsultations/DH_117586

³³ Ibid ref 20

³⁴ Putting People First Consortium (2010) *Think local, act personal: Next steps for transforming adult social care*
<http://tinyurl.com/thinklocal-actpersonal>

³⁵ Department of Health (2010) *Practical approaches to improving the lives of disabled and older people through building stronger communities*
<http://tinyurl.com/approaches-improvinglives>

³⁶ Carers UK (2004) *In poor health: The impact of caring on health*
<http://tinyurl.com/in-poor-health>

³⁷ Census 2001
<http://tinyurl.com/census2001-carers>

³⁸ Evaluation of the National Carers' Strategy Demonstrator Sites Programme
<http://tinyurl.com/carers-strategy-demonstrators>

³⁹ Department of Health (2009) *Living well: National dementia strategy*
<http://tinyurl.com/national-dementia-strategy>

⁴⁰ Hirst, M., (2004) *Health Inequalities and Informal Care* Social Policy Research Unit: University of York
<http://www.york.ac.uk/inst/spru/pubs/pdf/healthinequalities.pdf>

⁴¹ (1998) *Developing a whole system approach to the analysis and improvement of health and social care services for older people – a pilot study in West Byfleet, Surrey*

⁴² Kings Fund (2006) *Informal Care in England*
<http://tinyurl.com/informalcare>

⁴³ Audit Commission (2004) *The effectiveness and cost effectiveness of support and services to informal carers of older people*
<http://tinyurl.com/effectiveness-supportforcarers>

⁴⁴ HM Government (1999) *Caring about carers: A national strategy for carers*
<http://tinyurl.com/caringaboutcarers>

⁴⁵ Blunden, R. (2002) *How good is your service to carers: Guide to checking quality standards*

⁴⁶ Ibid ref 12

⁴⁷ NHS Information Centre for Health and Social Care (2010) *Survey of carers in households in England 2009/10*
<http://tinyurl.com/carers-in-households>

⁴⁸ Department for Business, Innovation and Skills (2007) *The Third Work-life Balance Employee Survey: Main findings*
www.bis.gov.uk/files/file38388.pdf

⁴⁹ NHS Information Centre for Health and Social Care (2010) *Personal social services survey of adult carers in the UK 2009/10*
<http://tinyurl.com/psssurvey-adultcarers>

⁵⁰ Department of Health (2010) *Transparency in outcomes: A framework for adult social care*
www.dh.gov.uk/en/Consultations/Liveconsultations/DH_121509

⁵¹ Voices
www.southampton.ac.uk/voices/

⁵² Pickard, L. (2008) *Informal care for older people provided by their adult children: Projections of supply and demand to 2041 in England*. Report to the Strategy Unit and Department of Health
<http://tinyurl.com/informalcare-olderpeople>

⁵³ Equality and Human Rights Commission, *How fair in Britain? The first triennial review*
www.equalityhumanrights.com/key-projects/triennial-review/

⁵⁴ Carers UK and Ipsos MORI (2009) *One million people give up work to care – Carers Rights Day*

⁵⁵ Carers UK and University of Leeds (2007) *Carers, employment and services report series*
<http://tinyurl.com/more-than-a-job>

⁵⁶ Buckner, L. and Yeandle, S. (2006) *More than a job: Working carers – Evidence from the 2001 Census*. London: Carers UK

⁵⁷ Carers UK and University of Leeds (2007) *Carers, employment and services report series*
<http://tinyurl.com/carers-employment-services>

⁵⁸ Glasby, J., Ham, C., Littlechild, R. and McKay, S. (2010) *The case for social care reform – The wider economic and social benefits*. Birmingham: University of Birmingham
<http://tinyurl.com/screform>

⁵⁹ Carers UK (2008) *Real change, not short change: Carers' financial experiences*
<http://tinyurl.com/realchange-not-shortchange>

⁶⁰ Carers UK (2007) *Valuing carers – Calculating the value of unpaid care*
<http://tinyurl.com/valuing-carers>

⁶¹ Carers UK and University of Leeds (2007) *Carers, employment and services report series*. The research involved a survey and in-depth interviews with nearly 900 working age carers.

