



# Carers Strategy: Second National Action Plan 2014 - 2016

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# Carers Strategy: Second National Action Plan 2014 - 2016

**Prepared by the Department of Health**

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# Foreword by Rt. Hon Norman Lamb Minister of State for Care and Support on behalf of the Inter-Ministerial Group on Carers

Supporting carers to care effectively and safely; look after their own health and well-being; fulfil their education and employment potential; and have a life of their own alongside caring responsibilities are priorities across this Government.

Most people are likely to be affected by or have caring responsibilities at some stage in their lives.

We know that there are carers of all ages - young carers supporting their parents and siblings through to older couples providing mutual support to one another.

Since we published the Coalition Government's *Recognised, valued and supported: next steps for the Carers Strategy* in 2010, we have taken steps to improve awareness about the significant contribution that carers make and to improve support for carers in many spheres, including through Government legislation. Both the Care Act and Children and Families Act 2014 have set out significant improvements for assessing and supporting carers of all ages. The extension of the right to request flexible working to all employees introduced from 30 June 2014, will also help carers who wish to stay in paid employment alongside caring responsibilities.

In recognition of the growing demands for care and support in the last few years, the Government has put more money into social care, transferring funding from the NHS. Many LAs have protected expenditure on social care as a priority, but that has not always been the case. We recognise the social care system as well as the NHS is under significant pressure and also needs fundamental change. The Care Act and the introduction of the Better Care Fund provide for significant new opportunities to improve the integration of health and social care and provide more seamless support for individuals and their families. Our vision for improving primary health care *Transforming Primary Care: Safe, proactive, personalised care* recognises the importance of involving and supporting carers.

And we very much welcome NHS England's *Commitment for Carers* setting out its priorities for action to support carers in the next few years.

Over the coming months our focus shifts to implementing the reforms we have set out in legislation. We want to ensure good outcomes for carers of all ages both in terms of their own health and well-being and in terms of their own quality of life. We will explore the available evidence to assess the impact of caring roles on people's broader circumstances.

We will also continue to work in partnership with carers organisations and a wide range of other key stakeholders through specific initiatives to improve identification and support of carers in schools, colleges, universities, and in the workplace as well as in their own homes and communities.

Much progress has been made in recent years in raising awareness and understanding of the enormous contribution that carers make to society, the difference they make to the lives of those they care for but also the impact that caring itself can have on carers' own lives. Caring can be very rewarding but it can also limit opportunities to pursue education, employment and fulfilling friendships and relationships.

Put simply the country cannot do without the contribution of carers. We owe it to carers not to take them for granted but to recognise and value what they do, and to support them to have fulfilling lives of their own.

A handwritten signature in black ink, appearing to read 'Norman Lamb', with a horizontal line underneath.

**Norman Lamb**  
**Minister of State for Care and Support**

On behalf of the Inter-Ministerial Group on Carers:

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 Action Plan builds on the previous Government's national Carers Strategy of 2008<sup>1</sup> and the Coalition Government's update of 2010<sup>2</sup>. It retains the strategic vision for recognising, valuing and supporting carers from 2008, which has been the vision of successive Governments, and the four areas for priority action identified in 2010 by the Coalition Government.

This document therefore provides a brief overview of evidence gathered and the main achievements in recognising and supporting carers during the last few years and identifies key actions for the next two years.

Health, education, and social care are devolved issues and therefore references in this document to those areas relate to England only. Welfare reform and some of the employment initiatives mentioned in this document relate to England, Scotland and Wales.

***Carers at the heart of 21st-century families and communities (2008) 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.

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<sup>1</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136492/carers\\_at\\_the\\_heart\\_of\\_21\\_century\\_families.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/136492/carers_at_the_heart_of_21_century_families.pdf)

<sup>2</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213804/dh\\_122393.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213804/dh_122393.pdf)

**Recognised, valued and supported: Next steps for the Carers Strategy (2010) identified four priority areas as follows:**

- 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.

Most of us will have caring responsibilities at one or more stages in our lives. Much has been published in the last few years about demographic changes and the impact they are having and will have on all our lives. People are living longer both with lifelong disabilities and long term health conditions which they develop as they grow older. Over the next 20 years the number of people aged over 85 is expected to double<sup>3</sup>. There is also a continuing shift away from institutional care to care provided at home and in the community. The majority of people with dementia, for example, are now cared for at home by a relative or friend. While this shift is welcome, it is important to recognise that the pressure on families to care in their own homes, particularly for spouses and partners, is growing significantly and is predicted to double over the next 30 years<sup>4</sup>. There are currently 670,000 people with dementia in England. This number is also expected to double in the next 30 years. In addition, the Prime Minister's Challenge on Dementia<sup>5</sup> states that there are currently 550,000 people in England acting as primary carers for people with dementia.

Families and friends want to provide good care but we know that they can encounter significant challenges in their lives in doing so – for example, juggling caring roles with education or paid employment; endeavouring to provide care at a distance; managing a multiplicity of caring roles, including multi-generational caring and mutual caring. They also face challenges in looking after their own health while caring for someone else and having a life of their own alongside caring.

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<sup>3</sup> <http://www.ons.gov.uk/ons/rel/npp/national-population-projections/2012-based-projections/stb-2012-based-npp-principal-and-key-variants.html>

<sup>4</sup> <http://www.pssru.ac.uk/archive/pdf/dp2515.pdf>

<sup>5</sup> <http://dementiachallenge.dh.gov.uk/about-the-challenge/>

Since *Recognised, valued and supported: next steps for the carers strategy* was published in 2010, more data have become available about the extent and nature of caring responsibilities and the impact of caring on the lives of those who provide care. This can help to shape policies and practices to support families and carers to manage those challenges more effectively.

### **2011 Census**

While the 2011 Census<sup>6</sup> found that 5.4 million people in England were providing unpaid care (the same proportion of the population as reported in 2001), over a third were providing 20 or more hours care a week, an increase of 5% on 2001 figures.

The Census also found that there were over 166,000 young carers aged 5-17 in England – an increase of over 26,000 since 2001. The majority were providing 1 to 19 hours care but over 8% were providing 50 or more hours of care. Significantly, more women than men in the age group 50-64 were providing care<sup>7</sup>. But there has been a shift in the age group of 65 and above – more men were providing care than women in 2011.

It is clear from the 2011 Census that the general health of carers deteriorates incrementally with the increasing hours of care provided. 5.2% of carers reported their own health as ‘not good’ and this rose to almost 16% among those caring for more than 50 hours a week.

While 55% of female adult carers and 44.9% of male adult carers reported they were economically active, only 12.1% of women and 9.3% of men were working full-time alongside caring responsibilities and only 1.2% of women and 1% of men reported they were in full-time employment while providing 50 hours or more care a week.

### **Voluntary sector surveys**

The voluntary sector has continued to publish surveys which provide valuable insights into the experience and personal circumstances of carers of all ages. These include, for example, The Children Society’s report about young carers *Hidden from View: the experience of young carers in England*<sup>8</sup>, the Carers Trust’s Report *A Road Less Rocky – Supporting Carers of People with*

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<sup>6</sup> [http://www.ons.gov.uk/ons/dcp171778\\_290685.pdf](http://www.ons.gov.uk/ons/dcp171778_290685.pdf)

<sup>7</sup> [http://www.ons.gov.uk/ons/dcp171776\\_310295.pdf](http://www.ons.gov.uk/ons/dcp171776_310295.pdf)

<sup>8</sup> [http://www.childrensociety.org.uk/sites/default/files/tcs/report\\_hidden-from-view\\_young-carers\\_final.pdf](http://www.childrensociety.org.uk/sites/default/files/tcs/report_hidden-from-view_young-carers_final.pdf)

*Dementia*,<sup>9</sup> and Carers UK annual reports on *The State of Caring*<sup>10</sup> and its *Caring & Family Finances Inquiry*<sup>11</sup>.

The Children's Society report shows that around 1 in 20 of young carers miss school because of caring responsibilities and many have significantly lower educational attainment at GCSE level, the equivalent to nine grades lower overall (i.e. the difference between nine Bs and nine Cs) than their peers. Many young carers between the age of 16 and 19 are neither in education, employment or training.

It is evident from Carers UK's *The State of Caring* surveys and the *Caring & Family Finances Inquiry* that many carers of working age feel forced to give up work to care and after a period of absence many find it difficult to return to the labour market. The State of Caring survey in 2011 found that of carers who had given up work or reduced their working hours to care, a fifth were £10-15k a year worse off and a further fifth were losing £15-20k. Many older working carers aged 55-64 are likely to lose at least £30k a year.<sup>12</sup>

### ***Carers' experience of care and support***

The Personal Social Services Survey of Adult Carers in England 2012-13<sup>13</sup> has gathered extensive information from adults caring for someone aged over 18, in receipt of support wholly or partially funded by social services, to find out more about their experience of support from social services and about their quality of life. This is a valuable source of data for local councils in terms of informing Joint Strategic Needs Assessments, the development of local Carers Strategies and Better Care fund plans. It is now mandatory for councils to undertake this survey every two years.

The highest level of carers' needs were reported among carers with mental health problems of their own, among carers from Asian/British Asian Communities, carers under age 64 and among those caring for 15 -20 years.

The vast majority of carers in this country are not in touch with social care. It is important therefore that we also collect data that tells us about the lives of carers who may be providing

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<sup>9</sup>[http://www.carers.org/sites/default/files/dementia\\_executive\\_summary\\_english\\_only\\_final\\_use\\_this\\_one.pdf](http://www.carers.org/sites/default/files/dementia_executive_summary_english_only_final_use_this_one.pdf)

<sup>10</sup><http://www.carersuk.org/for-professionals/policy/policy-library/state-of-caring-2014>

<sup>11</sup><http://www.carersuk.org/36-for-professionals/report/138-caring-family-finances-inquiry>

<sup>12</sup><https://www.gov.uk/government/publications/supporting-working-carers-the-benefits-to-families-business-and-the-economy>

<sup>13</sup><http://www.hscic.gov.uk/catalogue/PUB12630>

lower levels of care or are self-funding support. The Survey of Carers in Households in 2009-10<sup>14</sup>, based on a randomised sample of households, collected data from 2,400 carers. Only 6% of the carers surveyed had been offered a carer's assessment and 4% had been assessed by a local authority.

Overall 62% of the carers surveyed felt their own health was good while 8% felt it was bad. 80% defined their quality of life as good. Among carers of working age, 26% felt their caring responsibilities had affected their ability to take up or remain in employment while 74% did not think this was the case. Flexibility in working hours was felt to be the most important thing that would help carers who wanted to work to return to or stay in paid employment.

Other important sources of information in the last few years about the experiences of families and carers include the review of Winterbourne View<sup>15</sup> and the reports of the Mid Staffordshire Inquiry<sup>16</sup>. Both highlighted the importance of clear and honest communications with families and the involvement of family carers and friends in order to maintain and improve the quality of care and support to vulnerable people.

### ***NIHR School for Social Care Research and Department of Health's Policy Research Programme***

A number of research projects have been commissioned to improve the evidence base about carers in England. These include projects on carers and employment; carers and personalisation; social care practice with carers; satisfaction with social care of older carers of people with long-term conditions from different ethnicities; home support for people with dementia and their carers: and carers resource allocation systems. Further details can be found at <http://sscr.nihr.ac.uk/projects.php>

### ***Progress since 2010***

Since the publication of *Recognised, valued and supported: next steps for the Carers Strategy* significant progress has been made in a number of the key areas identified for action, particularly the legal reforms that will enable the extension of the right to request flexible working arrangements to all employees, better integration between health and social care and improved entitlements to assessment for carers of all ages.

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<sup>14</sup> <http://www.hscic.gov.uk/pubs/carersurvey0910>

<sup>15</sup> <https://www.gov.uk/government/publications/winterbourne-view-hospital-department-of-health-review-and-response>

<sup>16</sup> <http://www.midstaffspublicinquiry.com/>

New initiatives and actions have also been identified and are being taken forward, including the recommendations of the Task & Finish Group that produced the report *Supporting Working Carers: The Benefits to Families, Business and the Economy*<sup>17</sup>; the Department for Work and Pension's *Fuller Working Lives: A Framework for Action*, published in June 2014<sup>18</sup> and the development of NHS England's *Commitment to Carers*<sup>19</sup>.

As the focus shifts from legislation to implementation of the reforms, the Government will ensure that the impact on carers of the changes is monitored and, where appropriate, future priorities for action to support carers are identified.

It is therefore vitally important that we continue to gather information about carers' experiences and to seek their views on how support can be improved for them and the people they care for. Earlier this year, the NHS and Social Care Information Centre launched a consultation about repeating the Survey of Carers in Households.<sup>20</sup>

We must seek to ensure carers of all ages are actively involved in developing strategies, policies and practice both at national and local level so that we can keep up the momentum of improving support for carers.

This document sets out some of the key issues for carers and their families, reports on progress to date, and outlines the next steps and forthcoming actions which will maintain and accelerate progress over the coming two years, as new legislation and other reforms are implemented at a local level.

The plan focuses on the four key priority areas which were highlighted in the Government's 2010 strategy to demonstrate activity against the areas set out. However, in reviewing progress

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<sup>17</sup> <https://www.gov.uk/government/publications/supporting-working-carers-the-benefits-to-families-business-and-the-economy>

<sup>18</sup>

[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/319872/fuller-working-lives.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/319872/fuller-working-lives.pdf)

<sup>19</sup> <http://www.england.nhs.uk/wp-content/uploads/2014/05/commitment-to-carers-may14.pdf>

<sup>20</sup> <http://www.hscic.gov.uk/article/4723/Survey-of-Carers-In-Households-England-2009-2010>

and setting out further actions in these areas, the plan considers other emerging and cross-cutting policy and practical issues which are relevant to more than one of the existing four priorities – including the issues of financial hardship for carers, and the development of the evidence base. These are not presented as separate chapters, but are referenced throughout the plan to show how they impact on the existing priorities.

# Priority Area 1: Identification and recognition

*“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 in designing local care provision and in planning individual care packages”*

## **Key issues**

- Supporting people with caring responsibilities to identify themselves as carers so they can access the information, advice and support that is available
- Carers feeling their knowledge and experience are valued by health and social care professionals
- Involving carers in planning individual care packages and in developing local strategies.

***Supporting people with caring responsibilities to identify themselves as carers so they can access the information, advice and support that is available***

1.1 Helping those with caring responsibilities to be aware of their legal entitlements and how to access relevant information, advice and support remain key priorities within the national carers’ strategy. Our understanding of the issues faced by carers has been increased by new studies in this area:

- The Children’s Society report *Hidden from view: the experiences of young carers in England*, draws on the Department for Education’s Longitudinal Study of Young People in England. It recognises that many young carers remain ‘under the radar’ and hidden from health, social care and education services, including children caring for family members with mental illness or a substance dependency.
- NHS Improving Quality’s document *Commitment for Carers: Report and findings*<sup>21</sup> captures the responses it received to an engagement exercise with carers and carers’ organisations last year. Key themes in the feedback included ‘recognising me as a carer’ and ‘recognising that I may need help’.
- Macmillan Cancer Care has produced evidence that three in five people providing unpaid care to people with cancer lacked awareness of carers’ entitlements. They

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<sup>21</sup>[http://www.nhs.uk/media/2447325/commitment-for-carers\\_new.pdf](http://www.nhs.uk/media/2447325/commitment-for-carers_new.pdf)

found that only one in three carers of people with cancer had heard of a local authority carer's' assessment and only one in twenty had received a carer's assessment.<sup>22</sup>

- 1.2 Information and advice is needed to address different aspects of caring at different times during a caring pathway, tailored to individual needs. Carers may want help to develop skills and knowledge to care effectively and they may want advice and support to look after their own health and well-being and that of their family while caring for someone else.
- 1.3 It is important that carers and families have time to think through their options and make informed decisions about their own lives alongside caring, including decisions about remaining in education or paid employment, claiming benefits and contributing to pensions. Early access to information and advice and, where appropriate, early intervention (rather than waiting until a crisis occurs), are key elements in supporting people to undertake caring roles effectively.
- 1.4 Out of a population of 5.4 million carers in England, it is estimated that up to 2 million people cease caring and another 2 million begin caring responsibilities every year<sup>23</sup> - so there is by no means a 'static' population of carers. Efforts to engage with those new to caring roles therefore need to be constantly renewed and sustained.
- 1.5 Many people with caring responsibilities are clear that they do not want to be 'labelled' as a carer – they see themselves primarily as a parent, spouse, son and daughter, partner or friend. We should respect such decisions. However, it is also important that those who come across people with caring responsibilities as part of their work – whether they are teachers, health and social care professionals, or employers - should proactively signpost them to sources of information, advice and support which are available to those who provide care, including information about improved legal entitlements for carers.

***Carers feeling that their knowledge and experience is valued by health and social care professionals***

- 1.6 Another clear theme that emerged in NHS Improving Quality's engagement exercise from carers was 'treat me as an expert in care, involve me'. In responding to Carers UK's *State of Caring* survey last year, over half of the 3,000 respondents said that they had not been consulted at all about the discharge from hospital of someone they cared for or had only been consulted at the last minute.

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<sup>22</sup><http://www.macmillan.org.uk/Documents/GetInvolved/Campaigns/MPs/MacmillangeneralCarersbriefingApril2014.pdf>

<sup>23</sup><http://www.carersuk.org/for-professionals/policy/policy-library/facts-about-carers-2014>

- 1.7 While 56% of respondents to the Personal Social Services Survey of Adult Carers in England said they always felt consulted or involved in discussions about support for the person they cared for, 21% felt they were never consulted. Those caring for someone with substance misuse problems felt least involved.
- 1.8 Health and social care professionals recognising and valuing the knowledge and expertise that carers of all ages may have, both about the individual for whom they care and the illness or disability, is crucial. Such insights can help health and social care professionals in planning and providing effective care - in terms of individual care packages and in developing local strategies, commissioning and operational plans.

### ***Involving carers in planning individual care packages and in developing local strategies***

- 1.9 Families and carers – including young carers - should be involved in care planning for the person they support at an early stage. This is particularly important in planning discharge from hospital, reablement and ongoing community support and can help to reduce the likelihood of unwanted, unnecessary and costly admissions and re-admissions to acute health care.
- 1.10 Carers of all ages should also be involved in local strategic planning, for example by health and wellbeing boards, clinical commissioning groups and local authorities. This is particularly important as we plan for implementation of provisions within the Care Act and the Children and Families Act.

### **Progress since 2010 and next steps**

#### *Developing the legislative framework to support identification of carers' needs for support*

- 1.11 The Department of Health has worked closely with local government, the Care and Support Alliance, carers' organisations and the Standing Commission on Carers among many others in developing the legislation on care and support, and supporting its passage through Parliament.
- 1.12 In addition, both the Department of Health and the Department for Education have worked closely with the National Young Carers Coalition and the Parent Carers Network in considering how the provisions of both the Care Act<sup>24</sup> and the Children and Families Act<sup>25</sup> can support young carers and parent carers of disabled children.

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<sup>24</sup> <http://www.legislation.gov.uk/ukpga/2014/23/contents/enacted>

<sup>25</sup> <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted>

- 1.13 This collaborative working has continued as we have prepared secondary legislation and statutory guidance for public consultation which ended in summer 2014, and in planning for implementation of new legislation.
  - 1.14 Both the Care Act and the Children and Families Act will introduce a number of changes from April 2015 that will improve the identification of unmet needs for support, including the needs of carers, within a local authority's population.
  - 1.15 The Care Act will place a duty on local authorities to identify carers with unmet needs within their local population as part of their wider responsibilities for making provision to prevent and delay the development of needs for support. In a similar way, the Children and Families Act will require local authorities to take steps to identify the extent to which there are young carers within their area who have unmet needs for support.
  - 1.16 The Care Act will also place a duty on NHS bodies (NHS England, Clinical Commissioning Groups, NHS Trusts and NHS Foundation Trusts) to co-operate with local authorities in delivering the Care Act functions, including the duty to identify carers' unmet needs for support.
  - 1.17 Through both the Children and Families Act and Care Act provisions, we will strengthen entitlements to a carer's assessment for young carers, parent carers of disabled children and adults caring for adults. Carers will no longer need to be providing 'a substantial amount of care on a regular basis' to be entitled to a carer's assessment. Instead local authorities will be required to undertake an assessment where it appears that a carer may have needs for support of any level.
  - 1.18 In addition, a 'whole family approach' to assessment was set out in the Care Act regulations and guidance, which were published on 23 October 2014. This will help to identify individuals within the family who are providing support, including young carers, and an understanding of the caring role they are undertaking. Where it appears there may be a need for support as a carer, a separate carer's assessment can be undertaken, including a young carer's assessment. A whole family approach to assessment in particular will help to identify children undertaking inappropriate or excessive caring roles, so that appropriate support can be put in place either for the carer, or the person receiving care, or both.
  - 1.19 Underpinning all these new or updated legal obligations are regulations and statutory guidance which support local authorities in carrying out their responsibilities. Draft regulations and guidance were produced in collaboration with stakeholders, following the model of co-production of the Bill and published in June for public consultation. The final
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versions and a consultation response were published on 23 October ahead of the new provisions coming into effect in April 2015.

- 1.20 Alongside these statutory documents a range of non-statutory products, including practice guidance, toolkits and other types of practical support, to help local authorities with implementation of the Care Act, are being produced. Over 2014-15, we have been working with the social care sector to understand what types of support would be most helpful, building on best practice where it exists, and have worked together to develop them. In addition to the other guides and products already in use, this will allow all authorities to access and make use of additional support to ensure the outcomes of the Care Act are achieved for carers and their families.

### ***Raising awareness to support early identification of people with caring responsibilities***

#### **Carers Week theme for 2014 – Quest for Carers**

The Carers Week Quest during Carers Week (9 -15 June 2014) has encouraged improved collaborative working in local communities to reach out to the many carers in the UK who are not receiving support.

Activities focussed on working together in local communities to reach as many carers as possible and with national voluntary organisations to embed identification of carers in their core activities. <http://www.carersweek.org/carers-week-quest>

- 1.21 The Government believes that raising awareness about the crucial role of carers and how they can be supported will lead to positive changes in attitudes and behaviours within organisations that are best placed to signpost people with caring responsibilities to information, advice and support, including employers, schools, colleges, local authorities and the NHS.

### ***Promoting awareness of carers amongst healthcare professionals***

- 1.22 In the last few years, the Department of Health has invested over £2 million in a programme of work by the Royal College of GPs, Royal College of Nursing, School and Public Health Nurses Association (SAPHNA), Queen's Nursing Institute, Carers UK, and Carers Trust to promote awareness and understanding of carers' needs for support among healthcare professionals and to encourage earlier identification of carers, so that they can be signposted to relevant information, advice and support.

- 1.23 GP carer champions, as well as voluntary sector carers' ambassadors, have been recruited who are increasing understanding locally about supporting carers at both strategic and practice levels.

### **Carers UK Carer Ambassadors**

Carers UK has recently uploaded the experiences of some of its Carer Ambassadors to its website. They describe the key priorities they have identified for raising awareness about carers locally and the challenges and opportunities they have encountered <http://www.carersuk.org/how-you-can-help/volunteer/your-experiences>

- 1.24 Initiatives developed by the professional nursing organisations include reaching out to schools and local communities to ensure that young carers' needs are recognised. District and General Practice nurses are working on projects to identify and support carers locally and address unmet needs.
- 1.25 The Department of Health has committed over £1 million in 2014-15 to enable these organisations to build on this earlier work and to develop new initiatives.
- 1.26 New projects from the Carers Trust include work with pharmacy organisations to identify carers in pharmacy settings; and with Public Health England and NHS Employers to identify more carers through the 2014 flu vaccination campaign<sup>26</sup>.
- 1.27 The RCGP is creating an information hub about identification and support for carers for all staff working within primary healthcare, particularly focusing on GPs, clinical commissioning groups and health and wellbeing boards. The hub will include links to national and local resources managed by carers' organisations. It will explore with NHS England using GP practice IT systems to support the identification and support of carers, for example by having automatic alerts on the records of patients who have caring responsibilities, and, with the carer's agreement, using an automated carer referral system in GP practices to local carers centres and other schemes.<sup>27</sup> The hub will be launched in December.
- 1.28 The College will also work with its Faculties to train Associates in Training and 'First 5 GPs' (GPs in their first five years of practice) on identifying and supporting carers.
- 1.29 Last year the Queen's Nursing Institute received funding from the Department of Health to develop an online resource to help nurses and healthcare assistants who visit patients within their homes to work more effectively with carers. The resource has been showcased to over 100 community nurses at a seminar at Liverpool John Moores University. They

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<sup>26</sup> <http://www.carers.org/press-release/professionals-asked-encourage-unpaid-carers-get-free-flu-jab>

<sup>27</sup> Further information on the RCGP work programme is available at <http://www.rcgp.org.uk/clinical-and-research/clinical-resources/carers-support.aspx>

received a comprehensive introduction to the importance of working effectively with carers, including young carers, a number of whom participated.

- 1.30 The young carers' pathway was launched in April 2014<sup>28</sup> and the Department of Health has held three champion training days for school nurses, in association with SAPHNA. Young carers have contributed to the training of approximately 100 school nursing champions.
- 1.31 Department of Health guidance to support district nurses and practice nurses to identify and support adult carers was launched in July 2014.<sup>29</sup>
- 1.32 The next phase of the project will focus on general practice nurses, community nurses and school nurses, and the role that they can play in supporting carers of all ages. The aims of the project include developing a network of community nurses dedicated to supporting the needs of carers; recruiting carers' nurse champions across all specialties; developing online resources and learning events and carrying out a national survey to identify areas of greatest need and potential for improvement<sup>30</sup>.
- 1.33 *Transforming Primary Care* set out the Department of Health and NHS England's vision for out-of-hospital care services to become more proactive, integrated and personalised<sup>31</sup>, and our plan for achieving this vision. This plan has two main components:
- The introduction of the Proactive Care Programme, which will provide over 800,000 people with the most complex needs a proactive and personalised programme of care and support, tailored to their needs and views.
  - The introduction of a named, accountable GP for all people aged 75 and over, who will have overall responsibility for and oversight of their care.
- 1.34 *Transforming Primary Care* also set out examples of good practice in the provision of high quality, person-centred care by GPs, and emphasised the importance of GPs identifying

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<sup>28</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299270/Young\\_Carers\\_pathway\\_Interactive\\_FINAL.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299270/Young_Carers_pathway_Interactive_FINAL.pdf)

<sup>29</sup> <https://www.gov.uk/government/publications/supporting-adult-carers-through-community-nursing>

<sup>30</sup> The online carers resource can be accessed at [http://www.qni.org.uk/for\\_nurses/supporting\\_carers](http://www.qni.org.uk/for_nurses/supporting_carers)

<sup>31</sup> <https://www.gov.uk/government/publications/plans-to-improve-primary-care>

carers, and supporting them to carry out their caring role, for example through signposting them to relevant information, advice and support.

1.35 In its *Commitment to Carers*, NHS England has committed to raise the profile of carers and how they can be supported effectively by healthcare staff. Key actions identified for next year include:

- working with relevant bodies, including Health Education England, to support the use of training packages for healthcare staff that increase awareness about carers and support staff to identify, involve and recognise carers as experts, and as individuals with their own needs, choices and aspirations
- working with the National Institute for Health and Care Excellence (NICE) and other partners to develop measurement and best practice guidance to increase awareness of carers among NHS staff and the identification of carers
- holding a young carers festival, in partnership with NHS Improving Quality, to explore how young people can be better supported and the well-being of young carers better promoted by the NHS.

#### **‘See me talk to me’ project Lincolnshire**

Young carers are provided with a card to identify themselves as carers and to set out the permissions they have been given by the person they support to discuss details of their medication and caring arrangements.

<https://www.lincolnshirecommunityhealthservices.nhs.uk/ed/content/young-carers-card>

#### **Identification of young carers**

1.36 Between 2011 and 2015, the Department for Education provided more than £2.7 million in funding to support work with local authorities and voluntary and community organisations on the identification and support of young carers. Work supported by that funding includes:

- The Children’s Society’s Prevention Through Partnership programme<sup>32</sup> which held 17 regional workshops across England for professionals, managers and commissioners between 2011 and 2013. The workshops helped children’s and adult services develop plans to work more closely together and adopt ‘whole family’ approaches to identifying and supporting young carers.

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<sup>32</sup> <http://www.youngcarer.com/resources/ptp>

- The Carers Trust’s Integrated Interventions programme that ran between 2011 and 2013 funded eight innovative local projects<sup>33</sup>. Each project was made up of a voluntary organisation partnered with a statutory organisation to test new ways to work together to embed family focused approaches. They specifically focussed on early identification, intervention and prevention of excessive or harmful caring and improving integrated interventions for young carers. Examples of good policy and practice from these projects and others across the country were identified and shared on the Trust’s website<sup>34</sup>.

1.37 The Next Steps programme runs from 2013 to 2015, delivered by Carers Trust and The Children’s Society. It includes: capacity building workshops for local statutory and voluntary services on whole family approaches and preparing for the new legislation that takes effect from April 2015; continued funding for four of the integrated intervention projects; and training events for practitioners on reaching out to young carers in ethnic minority communities and in families affected by substance misuse, parental mental illness, or HIV.

1.38 The Department for Education is also investing in the first ever national research project on young carers. The project started in September 2014 and will consist of both quantitative and qualitative research into young carers, to develop a more reliable and up to date estimate of the number of young carers in England, including those who are currently not known to local authorities and schools. It will also seek to identify the nature of the care and support that young carers provide; the impact of caring responsibilities on their own physical and mental health; education and development and the type and level of support they are receiving and whether this addresses the needs of the whole family.

1.39 The Government also welcomes the significant amount of support in recent years from the Big Lottery, the Co-operative, and the Queen’s Trust in funding initiatives to support the early identification of carers, particularly young carers and young adult carers.

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<sup>33</sup> <http://professionals.carers.org/young-carers/articles/integrated-interventions-partnership-sites,7141,PR.html>

<sup>34</sup> <http://professionals.carers.org/young-carers/articles/supporting-young-carers-and-their-families-examples-of-practice,7139,PR.html>

### **A social network for young carers**

Funded by a Youth in Focus grant from the Big Lottery a four year programme is establishing a national network of young carers and young adult carers up to the age of 25, developed by young carer champions to raise awareness of the issues that young carers face and inform policy and decision-makers about the changes they want to see at local and national level.

A central element of the programme is a safe social network for young carers on the Makewaves website which is widely used in schools, colleges and youth groups. This will help to identify young carers in different environments:

<https://www.makewav.es/YCiF>

### **'About time'**

In the last year the Co-operative's staff and members have been fundraising to support Carers Trust as its Charity of the Year. A comprehensive series of projects is being rolled out as part of the 'About Time' programme, identifying and supporting young adult carers between the ages of 14 to 25 in their local communities.

Fifty projects are being established across the UK to provide practical support to 4,500 young adult carers, including:

- increasing the awareness and profile of young adult carers with one or more agency e.g. job centres, schools, colleges, universities, pupil referral units, employers
- influencing and supporting health and social care providers to improve young adult carers access to medical information and support
- opportunities for young adult carers to improve and maintain their health and well-being.

Over 800 young adult carers that are at risk of not being in education, employment or training, or are socially disengaged, will receive targeted support which addresses their specific needs and provides them with a goal oriented action plan and the support mechanisms to realise their goals.

<http://www.carers.org/co-op-charity-year>

## ***Involving carers as partners in providing individual care***

### *Care and support*

- 1.40 From April 2015, the Care Act will require local authorities to involve carers when assessing an adult's need for care and support. Local authorities will also be required to provide a written record of the assessment to the carer as well as the person to whom the assessment relates.
- 1.41 When eligible needs for care and support are identified, local authorities will be required to prepare a care and support plan setting out the needs that the local authority will meet and how it is going to meet them. Local authorities will be required to involve carers in the preparation of such plans and to provide copies of the plan to carers as well as those for whom it has been prepared.

### *Health care*

- 1.42 The Mandate to NHS England<sup>35</sup> includes an objective 'to ensure that the NHS becomes dramatically better at involving patients and their carers, and empowering them to manage and make decisions about their own care and treatment'.
- 1.43 As part of its plans to deliver that objective, NHS England intends to bring together guidance, published evidence, and local case studies to support carers to be informed and engaged in health care. This will be embedded in its work programme on developing the House of Care toolkit<sup>36</sup>.
- 1.44 In addition, as part of the Patient Online Programme, NHS England will scope the potential for carers to access the GP medical records of the people they care for where the patient has given consent.

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<sup>35</sup>[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/256406/Mandate\\_14\\_15.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/256406/Mandate_14_15.pdf)

<sup>36</sup><http://www.england.nhs.uk/resources/resources-for-ccgs/out-frwrk/dom-2/house-care-mod/>

### **'The Triangle of Care'**

The Triangle of Care approach, initially developed by Carers Trust and the National Mental Health Development Unit, is intended to improve carers' and families' engagement in the care planning and treatment of people with mental ill-health, focusing on a three-way partnership between patients, carers and professionals. Funded by the Department of Health, Carers Trust has expanded the original project to all mental health services, including specialist services.

Regional groups have been established in all parts of England to share good practice and work towards implementing the Triangle of Care standards in mental health services.

Carers Trust has also worked with the Royal College of Nursing to adapt the Triangle of Care to meet the needs of carers of people with dementia, when that person is admitted to a general hospital.

<http://www.carers.org/news/mental-health-and-triangle-care>

[http://www.rcn.org.uk/newsevents/news/article/uk/the\\_triangle\\_of\\_care\\_a\\_new\\_guide\\_for\\_dementia](http://www.rcn.org.uk/newsevents/news/article/uk/the_triangle_of_care_a_new_guide_for_dementia)

### **Dementia Action Alliance The Carers' Call to Action (CC2A)**

In November 2013 the Alliance launched a call to action to support the needs and rights for family carers of people with dementia through the following shared vision. Carers of people with dementia:

- have recognition of their unique experience
- are recognised as essential partners in care
- have access to expertise to be effective carers for the person with dementia
- have assessments and support to maintain their own health and well-being
- have confidence that they are able to access good quality care, support and respite services. Organisations and individuals can sign up at: [www.dementiaaction.org.uk/carers](http://www.dementiaaction.org.uk/carers)

### ***Involving carers as strategic partners***

1.45 At a national level, both Carers Trust and Carers UK are members of the Health and Care Voluntary Sector Strategic Partner Programme, which is funded to work strategically with the Department of Health, NHS England and Public Health.

1.46 Key areas of their work in the last couple of years have included the development of legislation on care and support and associated regulations and statutory guidance. Their work programme in 2014-15 is focussed on preparing for the implementation of the Care Act, the *Carers Quest* initiative, bringing together the evidence base on health inequalities facing carers and developing local capacity for carer engagement in health and care. As

part of their work, they will develop toolkits and other resources to help carers understand local health and care structures and the new legislation. They will work with Healthwatch at a national level to help ensure that local Healthwatch engage with carers' issues and involve carers in their work. They will also explore how carers are being involved in work on integration of health and care, including integration pioneer sites.

- 1.47 At a local level health and wellbeing boards, clinical commissioning groups and local authorities have important roles to play in looking at the needs of the whole community through Joint Strategic Needs Assessment and joint health and wellbeing strategies.
- 1.48 Many areas have developed their own local carers' strategies involving carers as strategic partners and have begun to refresh them in anticipation of the changes that both the Care Act and the Children and Families Act will bring from 2015. Some areas are developing a 'local offer' for carers setting out what carers can expect from health and social care, Jobcentre Plus and the local voluntary sector.

### **Supporting Carers to Care in Hertfordshire**

Supporting carers to care is one of the priorities of Hertfordshire's Health and Wellbeing Strategy. The priority is measured by 3 local indicators and is underpinned by Hertfordshire's *Commitment to Carers*. Organisations are asked to sign up to the Commitment to ensure that the aspirations in the Health and Wellbeing Strategy result in real improvements for carers.

A range of partners have already signed up including clinical commissioning groups, Healthwatch, a borough council and voluntary and community sector partners. Their pledges mean that organisations are committed to reaching out to more carers and ensuring that they receive support, that carers have a voice and are involved at a strategic level and that carer employees of those organisations are recognised and supported. On a practical level, examples of support pledged include carer champions within GP surgeries and support to local carers groups.

Further information is available at:-

<http://www.hertsdirect.org/services/healthsoc/carersupport/hertscommitcare/>

## Summary of key actions

### 1.49 The Government will:

- work with local authorities and other partners to help them prepare for implementation of the Care Act and Children and Families Act, including developing practical guides and toolkits, assuring readiness and reviewing progress.
- work with the Health and Care Voluntary Sector Strategic Partner Programme to improve identification and involvement of carers.
- provide funding for the final year of the Department of Health programme to test approaches to identification of carers by healthcare professionals, and disseminate learning from the programme to support future work.
- invest in the Department for Education's research into the lives of young carers and their families.
- continue to fund the Next Steps programme until March 2015 to support local services in working with young carers.
- encourage local partners to develop or refresh carers' strategies that consider how the actions of different organisations can identify and support carers of all ages and to disseminate information about the 'local offer' to carers.
- with NHS England, encourage the identification of carers as part of work to implement the vision set out in *Transforming Primary Care*.
- support NHS England in delivering its plans to improve identification and recognition of carers of all ages through delivery of its *Commitment to Carers*.

# Priority Area 2: Realising and releasing potential

*“Enabling those with caring responsibilities to fulfil their education and employment potential”*

## **Key Issues**

- Support for young carers and young adult carers
- Support for carers of working age

### ***Support for young carers and young adult carers***

- 2.1 The 2011 Census identified 166,000 young people between the ages of 5 and 17 with caring responsibilities; however, other studies suggest it is likely that there are far more. The Carers Trust/Nottingham University report *Young Adult Carers at School: Experiences and Perceptions of Caring and Education*<sup>37</sup> includes the results of a survey of almost 300 young carers conducted in 2013. Two thirds were providing a high level of care. 42% said there was not a particular person at school who recognised them as a carer and helped them. Less than half (46%) thought they had received good careers advice and only 19% of the total sample thought that it took their caring role into account. A quarter, (26%) were bullied at school because of their caring role.
- 2.2 The Children’s Society report *Hidden from view: the experiences of young carers in England* found that excessive and inappropriate caring responsibilities can have a significant and long lasting effect on education and future prospects. For example, the young carers involved in the study had:
- significantly lower educational attainment at GCSE level than their peers. That’s the equivalent to nine grades lower overall, or the difference between nine B’s and nine C’s.
  - an average family annual income £5,000 lower than families who do not have a young carer.
  - a greater likelihood of being not in education, employment or training (NEET) between the ages of 16 and 19.

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<sup>37</sup> [http://www.carers.org/sites/default/files/young\\_adult\\_carers\\_at\\_school-8\\_11\\_13-1\\_proof\\_4\\_final.pdf](http://www.carers.org/sites/default/files/young_adult_carers_at_school-8_11_13-1_proof_4_final.pdf)

2.3 There has also been a 25% increase in the number of young adult carers up to age 24 between 2001 and 2011. The impact of caring upon a young adult's health and well-being can be significant and affect their confidence as learners and employees. Friendships and relationships in early adulthood are important but such interactions are often restricted for young adult carers, especially if they do not have the opportunities to develop relationships through learning and employment. This can lead to loneliness and isolation. Young adult carers not in paid employment can face significant financial hardship both in the short and longer term.

### ***Support for carers of working age***

- 2.4 The Carers in Employment Task and Finish Group which reported to Government last year, recognised that supporting carers to remain in work is a challenge but also an economic opportunity. Supporting carers to remain in work alongside their caring responsibilities can benefit carers themselves, employers and the economy. The public expenditure costs of carers unable to stay in employment have been estimated to be £1.3 billion a year<sup>38</sup>.
- 2.5 Employers are losing skilled and experienced staff between the ages of 45 and 64 who are in the 'peak age' of caring. Over half of the respondents to Carers UK *State of Caring Survey* in 2013 who gave up work to care, said they have spent over 5 years out of work. Of those who gave up work, retired early or reduced hours to care, 25% said they did so because the cost of replacement care was too high, 23% said services were not sufficiently flexible and 20% said services were not sufficiently reliable. 25% said that although their employer was sympathetic, they were not offered support.
- 2.6 Carers UK and Employers for Carers also recently carried out an employer and employee survey to find out the impact of working while caring for someone with dementia. This indicated a 'disconnect' between employers' policies and employee experience. 83% of employers said they offered flexible working arrangements but only 48% of carers reported this form of help was available in their workplace. 33% of employers mentioned they had a specific policy for carers, but this was reported by only 19% of employees.

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<sup>38</sup> [http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/Findings\\_10\\_carers-employment\\_web.pdf](http://www.lse.ac.uk/LSEHealthAndSocialCare/pdf/Findings_10_carers-employment_web.pdf)

2.7 Carers UK's *Caring and Family Finances Inquiry* highlighted the significant concerns among carers about 'the income shock' in reducing working hours or giving up paid work altogether at a time when the family is facing additional costs of ill health and disability, care services, adaptations and equipment, higher household and transport bills. It also identified carers' continuing concerns about the rate of Carer's Allowance and the associated earnings limit.

### **Progress since 2010 and next steps**

#### ***Equality Act 2010***

If someone is looking after a family member who is elderly or disabled, the Equality Act offers protection against direct discrimination because of their caring responsibilities. Free advice and support is available from the Equality Advisory Support Service (EASS). More information about the provisions of the Equalities Act is available in *Equality Act 2010: What do I need to know as a carer?*

<http://www.equalityadvisoryservice.com/ci/fattach/get/585/1354033248/redirect/1/filename/carers.pdf>

#### ***Fulfilling education potential of young carers and young adult carers***

##### *Young carers*

2.8 Statutory guidance related to the Children and Families Act 2014 will set out how assessments of young carers' needs should be carried out and will include consideration of the need to be able to participate in education or training. Young carers should be supported to meet their requirement to participate in training or education.

2.9 As already indicated in the previous section, the Department for Education has invested significantly in research and a programme of work delivered by the Carers Trust and The Children's Society to help local services identify and support young carers.

2.10 In September 2011 the Department for Education published *Turning around the lives of families with multiple problems - an evaluation of the Family and Young Carer Pathfinders Programme*<sup>39</sup>. The evidence suggests that intensive, family focused support resulted in a significant improvement in outcomes for the families supported by the Young Carer

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<sup>39</sup> <https://www.gov.uk/government/publications/evaluation-of-the-family-and-young-carer-pathfinders-programme>

Pathfinders. The research findings also revealed that the Pathfinders generated net programme benefits. A conservative assessment of the return on investment indicates that for every £1 spent, the Young Carer Pathfinders have generated a financial saving of £1.89.

2.11 The Department for Education has also secured support from the National Governors Association in raising awareness of young carers in schools and academies.

### **Working Together to Support Young Carers and their Families**

In 2012 the Association of Directors of Children's Services, Association of Directors of Adult Social Services and The Children's Society published a template of a local memorandum of understanding between Directors of Children's Services and Adult Social Services.

The intention is to promote working together between adult and children's social care and education services. The memorandum of understanding is not intended to be prescriptive - it suggests a comprehensive basis for local authorities working in partnership with health, education and voluntary sector partners

[http://www.youngcarer.com/sites/default/files/imce\\_user\\_files/PTP/mou\\_young\\_carers\\_2012.pdf](http://www.youngcarer.com/sites/default/files/imce_user_files/PTP/mou_young_carers_2012.pdf)

2.12 In 2011 the Department for Education and the National Young Carers Coalition launched an e-learning module to enable staff in schools and academies to identify and support young carers<sup>40</sup>. This will be updated in 2014-15 to reflect the new legislation.

2.13 Professional guidance to help school nurses to identify and support young carers has also recently been launched<sup>41</sup>. Guidance to support district nurses and practice nurses to identify and support adult carers was launched on 18 July 2014. The Department of Health has been working with the School and Public Health Nurses Association to train school nurses to be champions for young carers. They will help head teachers and governors decide how best to support young carers in schools. Over 150 have been trained to date and it is envisaged this number will be doubled in the next year. The programme will also be extended to include district nurses and general practice nurses.

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<sup>40</sup> <http://tinyurl.com/pfxgk4c>

<sup>41</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/299270/Young\\_Carers\\_pathway\\_Interactive\\_FINAL.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/299270/Young_Carers_pathway_Interactive_FINAL.pdf)

## Young Carers in Schools Award

As part of the Young Carers in Focus programme and funded by the Big Lottery and The Queen's Trust and several leading charities. The Children's Society and Carers Trust have recently launched the Young Carers in Schools Award. It is currently being piloted in Leeds.

To gain the Award schools must demonstrate they adhere to five simple standards:

- **Understand** - assigned members of staff with responsibility for understanding and addressing young carers' needs
- **Inform** – pupil awareness is raised by sharing knowledge about disability, illness and young carers throughout the school
- **Identify** – young carers are identified in the school
- **Listen** - young carers are listened to, consulted with and given time and space to talk
- **Support** – young carers are supported within the school, and signposted to whole family resources and services outside the school.

To qualify for the Award schools will supply evidence for each standard and awards will be made at three levels – bronze, silver and gold.

[www.youngcarer.com/ycinschools](http://www.youngcarer.com/ycinschools)

### *Young adult carers*

- 2.14 Where a young person, including a young adult carer, wishes to apply to attend a higher or further education institution, local authorities should help them identify the institution best suited to their academic ability and potential, and career aspirations as part of 'transition' planning. Once an offer has been accepted, local authorities should ensure the relevant institution is made aware as soon as possible of a carer's needs for personal support and discuss a plan for meeting them.
- 2.15 Wherever possible, this should be in the form of a conversation involving the carer, anyone else they wish to involve, the local authority, and the institution – as well as the local authority where the institution is located, where appropriate.
- 2.16 The 16-19 Bursary Fund, introduced in September 2011, targets financial support towards young people who most need help with the costs of staying on in post-16 further education. The most vulnerable young people receive yearly bursaries of £1,200. The rest of the fund is allocated on a discretionary basis by schools and colleges.
- 2.17 Young adult carers can claim the discretionary element of the bursary. However, lack of awareness among learning providers and young adult carers themselves can prevent

them from receiving this support. The 16-19 Bursary Guidance<sup>42</sup> has therefore been updated to mention young carers specifically as potential candidates for consideration for a discretionary award.

2.18 *Raising the Participation Age*<sup>43</sup> has meant that pupils who left year 11 in summer 2013 need to continue in education or training for at least a further year, and pupils who started year 11 or below in September 2013 will need to continue until at least their 18<sup>th</sup> birthday. Statutory guidance<sup>44</sup> has made clear that local authorities may consider full-time caring responsibilities as full-time work depending on individual circumstances, so part-time education or training alongside that work would count as full participation in education or training.

2.19 This provision is only intended for the small number of young adult carers aged 16 or 17 who are willing and able to undertake significant caring roles and balance them with their education or training without any adverse impact on their own health or welfare. The need to protect young people from inappropriate or excessive caring responsibilities remains.

2.20 From April 2014, the National Careers Service, working with the British Chambers of Commerce and the National Careers Council, started piloting different ways that schools, businesses and career development professionals can work together to help young people understand the careers options available to them. *Careers guidance and inspiration in schools: Statutory guidance for governing bodies, school leaders and school staff*<sup>45</sup> includes a section on targeted support for vulnerable and disadvantaged young people. This describes how schools should work with local authorities to identify young people who are in need of targeted support or who are at risk of not participating post-16. Schools and local authorities will need to agree how these young people can be referred for intensive support drawn from a range of education and training support services available locally.

2.21 The Department of Health has provided funding of over £120,000 to the National Institute of Adult Continuing Education for a project *WE Care – improving Work and Education for*

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<sup>42</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/329473/16\\_to\\_19\\_Bursary\\_Fund\\_Guide.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/329473/16_to_19_Bursary_Fund_Guide.pdf)

<sup>43</sup> <https://www.gov.uk/government/policies/increasing-opportunities-for-young-people-and-helping-them-to-achieve-their-potential/supporting-pages/raising-the-participation-age>

<sup>44</sup> <https://www.gov.uk/government/publications/participation-of-young-people-education-employment-and-training>

<sup>45</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/302422/Careers\\_Statutory\\_Guidance\\_-\\_9\\_April\\_2014.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/302422/Careers_Statutory_Guidance_-_9_April_2014.pdf)

*young adult carers*<sup>46</sup>. It is developing networks and resources to enable young adult carers to access targeted information, advice and support, engage and progress in learning, leading to sustainable employment and progress at work. All young adult carers can benefit from this project and there is a specific focus on young adult male carers and young adult carers from black and minority ethnic communities.

### **National Institute of Adult Continuing Education ( NIACE) WE Care project**

Through the WE Care project, NIACE has published a series of case studies demonstrating good practice in enabling young adult carers to engage and progress in learning. Two short summaries are shown below. The full case studies can be downloaded from NIACE's website - <http://www.niace.org.uk/current-work/young-adult-carers>

#### **York College**

York College is a Further Education College which currently supports around 100 young adult carers. The College's support system provides carers with the individualised support they need to succeed in their learning. When a carer is identified they are given a Young Carer's Card; they can then show this to their tutors and receive additional support without having to explain their personal circumstances. The teams within the College work closely together to create a comprehensive package of support for young adult carers, from finances and employment through to emotional and pastoral care. This holistic approach is crucial in enabling young adult carers to make effective transitions.

#### **Barnardo's**

Barnardo's CareFree Project provides a range of practical and emotional support to young adult carers and their families in Leicester and Leicestershire. This includes looking at parental ill health and its impact on the family, to one-to-one support with issues around anger, self-esteem and confidence. They also run young adult carers' groups which provide young adult carers with regular respite and a 'check-in' with the same support worker and peer group. To ensure long-term success in learning and work, the project provides focussed help to enable young adult carers to access sustainable support from their learning provider or from adult social services.

2.22 Funded through a grant from the Department for Business, Innovation and Skills, NIACE is also working with a wide range of organisations to support young adult carers to engage in training, including through its Young Adult Carers National Policy Forum.

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<sup>46</sup> <http://www.niace.org.uk/current-work/young-adult-carers>

- 2.23 The Government will set up a Task and Finish group involving the Department for Business, Innovation & Skills, Department of Health, Department for Work & Pensions, Department for Education and Government Equalities Office, to consider the factors that make it difficult for young people with caring responsibilities as they prepare for adulthood, particularly in terms of the transition from school to college, university or paid employment.
- 2.24 This group will be supported by the Young Adult Carers National Policy Forum in an advisory capacity. The Task and Finish Group will report to the Inter-Ministerial Group on Carers in summer 2015.
- 2.25 In implementing the Care Act provisions for an adult carer's assessment, local authorities will continue to be required to consider an adult carer's wishes in respect of education and employment. In addition, the Care Act includes new provisions to support young carers in preparing for adulthood. A local authority will be required to assess a young carer where it appears there are likely to be needs for support as a carer after becoming 18, for example in planning for further or higher education or paid employment, as long as it is satisfied that it would be of significant benefit to the young carer to do so.

### ***Supporting working carers to return to or remain in employment***

- 2.26 Many people with caring responsibilities can and do balance work and care, but the more intense the caring, the more difficult this becomes. In "Fuller Working Lives Framework for Action" published in June 2014, we identified some actions intended to support working carers as we recognise the need for specific interventions for this group.

### ***Universal credit***

- 2.27 We recognise that most carers of working age wish to stay in touch with the job market, not just for their financial well-being, but also to enhance their own lives and the lives of those for whom they care. Universal Credit will provide support for carers and improve their opportunities to maintain their links with work. Whilst Carer's Allowance stops when the claimant earns more than £102 a week net of allowable expenses, there will not be a similar 'cliff-edge' effect in Universal Credit as the award will reduce gradually, in line with the taper, as earnings increase. This will enable carers to keep more of their own money as they enter or move back into the labour market. The Government recently announced that from April 2015, the earnings threshold for Carer's Allowance will be raised to £110 a week.
- 2.28 Gloucestershire and West of England Jobcentre Plus District is also commencing work to identify and understand the particular barriers to employment for carers in Bristol and South Gloucestershire, with the aim of designing specific interventions to support carers into work.

## **Promoting Flexible Working**

- 2.29 Through provisions in the Children and Families Act, the Government has committed to extend the right to request flexible working to all employees after a 26 weeks qualifying period. This right came into effect from 30 June 2014.
- 2.30 The universal 'right to request' builds upon a previous entitlement that applied to certain categories of carers only. Part of the objective behind extending the right to request to all employees is to raise the profile of flexible working, and to de-stigmatise flexible working as *only* a carer's or mother's issue.
- 2.31 The Department for Work & Pensions explored non-legislative ways of stimulating the availability of flexible working opportunities through a working group of employment experts from the private sector and produced practical ideas and tools aimed at stimulating awareness of the business benefits of flexible working and its implementation.
- 2.32 The working group advised the Advisory, Conciliation and Arbitration Service which has developed the Code of Practice on flexible working arrangements<sup>47</sup> and has been closely involved in the development of the good practice guide<sup>48</sup> that will accompany the publication of the Code. The guide covers all aspects of flexible working and how it should work in practice.
- 2.33 In addition, the group has developed a strapline to be used in job advertisements which identify an employer who is open to discussions about flexible working arrangements. The strapline is currently being promoted and tested with a number of national employers to identify impact on recruitment practice.
- 2.34 Jobcentre Plus has looked at ways to stimulate the creation of flexible jobs by improving its job brokering and matching services and employer advisory services. In future, activity to align work with employers will include engagement to raise awareness of the needs of carers.
- 2.35 The Government recognises it needs to lead by example in promoting flexible working – over 80% of Government Departments currently offer some form of flexible working, including part-time working, home and remote working. The Cabinet Office is leading a project *The Way We Work*, which is looking at ways of increasing flexible working across the Civil Service.

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<sup>47</sup> Acas Code of Practice

<http://www.acas.org.uk/media/pdf/f/e/Code-of-Practice-on-handling-in-a-reasonable-manner-requests-to-work-flexibly.pdf>

<sup>48</sup> Acas Good Practice Guide

<http://www.acas.org.uk/media/pdf/1/a/The-right-to-request-flexible-working-the-Acas-guide.pdf>

*Following up the Task & Finish Group on supporting carers to remain in employment*

2.36 The Employers for Carers and Department of Health Task & Finish Group set up in 2012 explored a number of ways in which carers could be supported to combine paid work and care. The Government is implementing the Group's recommendations aimed at it and has encouraged other bodies to implement those recommendations directed at them. A complete list of the recommendations is at Annex A.

2.37 The Group's key recommendations to Government to initiate new activity include:

- developing a pledge in the Public Health Responsibility Deal Health at Work Network<sup>49</sup> on the promotion of the health and well-being of unpaid carers.
- championing membership of Employers for Carers among Government departments.
- working with key stakeholders in a number of local authority areas to explore ways in which people can be supported to combine work and care, and the market for care and support services can be stimulated to grow to encompass carers' needs.

2.38 Work has already begun to develop a pledge in the Public Health Responsibility Deal health at work network for employers to support their staff with caring responsibilities, building on the existing pledge for those with chronic health conditions<sup>50</sup>. The following pledge has been agreed:

*"We will support our workers with chronic conditions or those with caring responsibilities by doing one or both of the following:*

- *Embedding the principles of the chronic conditions guides (developed through the Responsibility Deal's health at work network) within human resource procedures to ensure that those with chronic conditions at work are managed in the best way possible with reasonable flexibilities and workplace adjustments.*
- *Supporting our employees in meeting their employment obligations and external caring responsibilities in a manner that seeks to protect and promote their own health and well-being. And seeking to promote a workplace culture which is understanding and supportive of carers in the workforce."*

2.39 The Department of Health has agreed to sign up to the pledge, once it is launched and a number of other members of the network are keen to do so. These principles are also reflected in the Workplace Well-being Charter, which was refreshed by Health@Work in conjunction with Public Health England earlier in the year. The Charter provides employers with an easy and clear guide on how to make workplaces a supportive and productive environment in which employees can flourish. The new set of Charter

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<sup>49</sup> <https://responsibilitydeal.dh.gov.uk/pledges/>

<sup>50</sup> <https://responsibilitydeal.dh.gov.uk/pledges/pledge/?pl=11>

standards were launched on 4 June 2014<sup>51</sup>. These will be followed by a series of topic guides – unpacking the content of the Standards<sup>52</sup> – including one on supporting carers in employment. In addition, both the Department of Health and NHS England have recently become members of Employers for Carers, joining the Department of Work & Pensions and the Foreign and Commonwealth Office.

2.40 The Department of Health, together with the Department for Work & Pensions and the Government Equalities Office, have commissioned the Social Care Institute for Excellence to set up pilots in a number of local communities to explore ways in which people can be supported to combine work and care. This will include exploring how increased use of assistive technology and the development of a diverse care market will help to cater for carers' needs in balancing caring responsibilities with paid employment. This work will be informed by the NIHR School for Social Care Research studies *Overcoming barriers: unpaid care and employment in England*. Expressions of interest have been sought from local authorities and details of the pilots project will be announced in autumn 2014.

In 2013 Carers UK launched 'Jointly' - an app to help families manage caring alongside other aspects of their lives. It offers a practical way to share information and co-ordinate responsibilities and tasks among an invited network of support.

<http://www.carersuk.org/help-and-advice/practical-help/equipment-and-technology/jointly-app>

## Summary of key actions

2.41 The Government will:

- Fund The Children's Society and Carers Trust to deliver the Next Steps programme, including a series of workshops for local managers and other professionals to deliver a "whole-family" approach to assessment and support for young carers.
- Update the e-learning for staff in schools and academies on identifying and supporting young carers.
- train 150 more school nurses to be champions for young carers.
- set up a Task & Finish group to consider issues of particular relevance to young adult carers, and what further actions could be taken by national and local government and other partners.

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<sup>51</sup> <http://www.wellbeingcharter.org.uk/index.php>

<sup>52</sup> [http://www.wellbeingcharter.org.uk/media/PDF/WWC\\_Self\\_Assessment\\_Standards\\_A4\\_Booklet\\_Liverpool\\_2\\_WEB.PDF](http://www.wellbeingcharter.org.uk/media/PDF/WWC_Self_Assessment_Standards_A4_Booklet_Liverpool_2_WEB.PDF)

- consult on draft regulations and guidance to support implementation of the Children and Families Act's provisions in relation to young carers' assessments.
- continue to explore ways of increasing flexible working opportunities following the introduction of the right for all employees to request flexible working arrangements from 30 June 2014
- initiate a pilot scheme to explore ways in which local authorities and other local partners can support carers to maintain paid employment.
- promote the new carer-specific pledge in the Public Health Responsibility Deal, to increase uptake amongst organisations in the scheme.

## Priority Area 3: A life alongside caring

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

### **Key Issues**

- Personalising support for carers and the people they support
- Availability of good quality information, advice and support

### ***Personalising support for carers and the people they support***

- 3.1 We know that the circumstances of individual carers vary enormously, and this means that a one-size-fits-all approach to support will not deliver the outcomes that matter most to carers and their families. Personalising support so that it fits around the lives, goals and needs of the carer is critical to supporting them personally both as part of their caring role, and in maintaining their own health and well-being.
- 3.2 The Health Survey for England 2012<sup>53</sup> provides useful insights into the nature and extent of caring responsibilities. The survey found:
- Care was most commonly provided to a parent (46% men and 47% women).
  - In the 45-64 age range most carers were supporting a parent (61% men and 60% women).
  - 22% men and 15% women reported caring for a spouse or partner.
  - In the 16-44 age range care for a grandparent was relatively common (22% men and 17% women).
  - Most of those providing care did so for one person (11% men and 14% women, while 3% and 4% respectively reported caring for two or more people).
  - Adults in the 45-64 age range were most likely to report caring for two or more people (5% men and 7% women).
  - The majority of care was provided to someone in a different household (60% men and 67% women).
  - Older men aged 65 and over were more likely to care for someone in the same household (52%) reflecting that many were caring for a spouse. This was less common for women in the same age group (39%).

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<sup>53</sup> <http://www.hscic.gov.uk/catalogue/PUB13218/HSE2012-Ch9-Social-care-provision.pdf>

- 3.3 Carers UK's report *Caring at a Distance: bridging the gap*<sup>54</sup> was based on a survey of almost 1,000 individuals in paid employment who were also caring for someone outside their own household. The majority were caring for an older relative. 82% were providing emotional support and regular practical help with managing care arrangements, shopping and housework; helping with paperwork and financial matters. Almost half were managing medication and around 40% were assisting with personal care and physical assistance. Three fifths were providing 1-19 hours of care a week: one fifth was providing 20-34 hours and one fifth was providing 35 and more hours of care.
- 3.4 The Carers UK report *Sandwich caring families under pressure*<sup>55</sup> and the Institute for Public Policy Research's report *The sandwich generation – older women balancing work and care*<sup>56</sup> both indicate that women, in particular, are faced with competing demands for care from both older and younger family members. In the UK, 28 per cent of grandparents with grandchildren under the age of 16 still have a parent who is alive. 60% of grandfathers and 36% of grandmothers who belong to this generation are still working full-time.
- 3.5 Mutual caring is also common in elderly couples, but can also occur if an elderly parent has a son or daughter with a disability.
- 3.6 We know that families and individuals are investing more of their own time and financial resources in caring, and are often providing complex and intensive levels of care. It is of crucial importance that we consistently keep in mind the potential impact of caring on the lives of carers, in particular the impact on their health and well-being; education and employment opportunities; social life and social inclusion; and both individual and family finances.

### ***Availability of good quality information, advice and support***

- 3.7 There is a wealth of information available to support people who have caring responsibilities but we know that many families are unaware that such information exists or

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<sup>54</sup> <http://www.employersforcarers.org/resources/research/item/246-caring-at-a-distance-bridging-the-gap>

<sup>55</sup> <http://www.carersuk.org/news-and-campaigns/press-releases/sandwich-caring-families-under-pressure>

<sup>56</sup> [http://www.ippr.org/assets/media/images/media/files/publication/2013/08/sandwich-generation-August2013\\_11168\\_11168.pdf](http://www.ippr.org/assets/media/images/media/files/publication/2013/08/sandwich-generation-August2013_11168_11168.pdf)

still struggle to find information and advice that is relevant to their particular needs for support, including financial support.

- 3.8 Those who are receiving support from social services may still experience difficulties in obtaining the information they need.
- 3.9 For those who have had little contact before with health and social care, finding the right information can cause much frustration and make stressful situations even more stressful, particularly when trying to arrange care and support quickly. Early interventions to guide families to information, advice and support as soon as they start to care can help people identify practical support, think through the options for remaining in paid employment or education and managing other family commitments alongside caring, and reduce the likelihood of falling into financial hardship.
- 3.10 Both health and social care can play a key role in providing and, where appropriate, signposting families to information, advice and support, so that they can make informed choices and decisions about the care they are able to provide. But we know that wrong assumptions are still often made about the extent and nature of care and support that individuals and families are able and willing to provide, and about the levels of knowledge and preparedness that families have, for example, when a relative is being discharged from hospital or at the end of a period of reablement.
- 3.11 We need to continue to prioritise supporting carers of all ages to manage their caring responsibilities alongside other aspects of their lives.
- 3.12 There are still many anxieties and misconceptions about the reforms that are being made in social care, welfare and education and the impact these will have on the lives of carers. As we implement reforms in all these areas, we must focus on communicating effectively to carers as well as the people they support about the changes that are being made and involve them in planning implementation. We must also monitor and evaluate the impact of reforms on carers' lives.

## **Progress since 2010 and next steps**

### ***Availability of information and advice***

- 3.13 *The Power of Information: putting all of us in control of the health and care information we need* was published in May 2012<sup>57</sup>. This makes clear what a carer should expect from health and social care, including:

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<sup>57</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/213689/dh\\_134205.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/213689/dh_134205.pdf)

- access to trusted information on health, care and support through a single portal, reducing the complexity and confusion of navigating the system. This includes information about the options available for providing care and on the quality and performance of local services and information on support available to carers, including breaks and financial assistance.
- access to services and health and care records online, when authorised by the person/people for whom they care, helping carers to carry out their responsibilities safely, conveniently and effectively.
- good information being available for professionals, making it easier and quicker for carers to explain to professionals what is going on and what other services are being provided.

Online provider quality profiles, which are published on NHS Choices, provide a comprehensive source of information about all care providers registered by the Care Quality Commission in England. The profiles allow comparisons of different adult social care providers, including care homes, home care, supported living and shared lives schemes and families can simply type in their post code to find providers in their local area.

<http://www.nhs.uk/Service-Search/Care-homes-and-care-at-home/LocationSearch/11>

3.14 Building on the NHS Choices services, an integrated Customer Service Information Platform is being developed and introduced. Since April 2013 this includes new social care information, improved links to information about services, improved information on online and mobile applications and tools, and the opportunity for public comment and feedback on providers of care services. This is increasingly improving links between social care, health and public health information provided at a national level. Many people with caring responsibilities who visit the NHS Choices site are initially looking for information on a specific health condition. Increasing links to information and advice to support carers from areas addressing dementia or stroke, for example, can guide them to helpful information about their caring role. Further improvements in the functional design of the service are planned which will personalise visits to the site and specifically recommend information that might be useful.

3.15 The Carers Direct service currently includes web-based information and advice for carers of all ages (through NHS Choices) as well as a telephone helpline service through which carers can be signposted to local sources of support<sup>58</sup>. This source of information is, of

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<sup>58</sup> <http://www.nhs.uk/carersdirect/carerslives/updates/pages/new-to-carers-direct.aspx>

course, complemented by the comprehensive information and advice services of the national carers' organisations and those organisations who advise on caring for people with specific conditions and of different ages<sup>59</sup>.

### **Alzheimer's Society Carer Information and Support Programme (CriSP)**

With support from Lloyds Banking Group the Alzheimer's Society is extending its Carer Information and Support Programme over the next 2 years to reach carers who have not been able to access the service before.

CriSP helps carers to build on their knowledge of dementia and access further support. It includes practical information so that carer can cope better on a day to day basis and plan for the future. Another important benefit is the support that people receive from other people on the programme through mutual understanding and sharing experiences.

In addition, the programme is being adapted specifically for South Asian Families.

<http://www.alzheimers.org.uk/crisp>

3.16 At a local level, local authorities will be required by the Care Act to establish and maintain a service to provide information and advice for its local population relating to care and support for adults, including support for carers. In particular, local authorities will be required to provide information and advice on how the care and support system works locally, the types of care and support and choice of providers in the area and how to access it. Statutory guidance will set out more detail of the expectations on local authority's information and advice services. This includes a more integrated approach to the service with health organisations especially GPs, and increased access to financial advice to support people to plan to meet future or immediate care costs. Joint work to provide support to local authorities, the voluntary and private sectors began in 2013. The Think Local Act Personal (TLAP) Partnership has published a range of practice guidance<sup>60</sup>. This work will continue over the next year.

3.17 The Children and Families Act requires that from 1 September 2014, local authorities must consult with families and publish a special educational needs and disability local offer, which includes information on services across education, health and care and from birth to 25; how to access specialist support; how decisions are made including eligibility criteria for accessing services where appropriate; and how to complain or appeal. The local offer will include information on support available for parent carers of disabled children.

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<sup>59</sup> <http://www.carersuk.org/> <http://www.carers.org/> <http://www.ageuk.org.uk/>  
<http://www.childrensociety.org.uk/>

<sup>60</sup> <http://www.thinklocalactpersonal.org.uk/Browse/Informationandadvice/>

- 3.18 The Care Act also introduces a new duty on local authorities from April 2015 to provide independent advocacy. This is aimed at adults who would have substantial difficulty in being fully involved in the care and support processes where there is no one appropriate available to support and represent that person's wishes. It will apply to all adults, as part of their own assessment and care planning and care reviews, as well as to carers. It will also apply to children and young people who are approaching the transition to adult care and support, when a child's needs assessment is carried out, and when a young carer's assessment is undertaken.

In August 2012, a **carers' hub service** was commissioned in the London Borough of Richmond.

This is led by Richmond Carers Centre in partnership with 8 other local organisations which support carers. Together they provide a universal information and advice service, emotional support, financial and debt advice, short breaks and leisure activities, a young carers service, a programme of workshops giving carers better skills to cope with life and caring and encourage carers to participate in national and local engagement exercises.

[http://www.richmond.gov.uk/carers\\_hub\\_service](http://www.richmond.gov.uk/carers_hub_service)

The Carers Hub Service also has a protocol for cross referrals to a Richmond Borough Mind project which supports carers of people with mental health difficulties.

<http://www.richmondchs.org/>

### ***Supporting adults caring for adults to have a life of their own alongside caring***

#### *Promoting well-being*

- 3.19 All of the provisions in Part 1 of the Care Act about care and support are underpinned by a general duty on local authorities to promote an individual's well-being, when they are exercising any of the Act's functions relating to care and support. This duty applies equally to carers as to people needing care and support.

#### **Promoting individual well-being**

Well-being relates to any of the following:

- personal dignity – including treating the individual with respect
- physical and mental health and emotional well-being
- protection from abuse and neglect
- control by the individual over day to day life
- participation in work, education, training and recreation
- social and economic well-being
- domestic, family and personal relationships
- suitability of living accommodation.

### *Carers' assessments*

- 3.20 There are specific provisions for a carer's assessment in the Care Act which make clear that a local authority will be required to explore whether a carer or potential carer is willing and able to care and continue to care.
- 3.21 A local authority will also be required to establish the outcomes that a carer wishes to achieve in day to day life and whether the provision of support to the carer could contribute to the achievement of those outcomes. Under current laws local authorities must have regard to whether the carer works or wishes to work and whether they are participating or wish to participate in education, training or recreation. This is reaffirmed in the Care Act.
- 3.22 Regulations and guidance have set out how a 'whole family approach' to assessment should be adopted in assessing carers as well as those needing care and support. This covers, for example, parenting and other caring responsibilities.

### *Meeting eligible needs for support*

- 3.23 For the first time, local authorities will be required through the Care Act to meet eligible needs for support for adult carers of adults. Eligibility criteria have been set out in regulations.
- 3.24 The Act makes clear that even when a carer's needs do not meet the eligibility criteria, a local authority will still be required to provide written information and advice about what could be done to meet or reduce those needs and to prevent and delay the development of needs in the future.

### *Personal budgets, direct payments and support plans for carers*

- 3.25 Increasing numbers of individuals and families have been taking charge of the way they are supported, through the use of personal budgets and direct payments. The number of carers receiving self-directed support, including direct payments, increased by 32% between 2011-12 and 2012-13<sup>61</sup>. The Care Act and Children and Families Act will place

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<sup>61</sup> <http://www.hscic.gov.uk/article/2021/Website-Search?productid=13822&q=Referrals%2c+Assessments+and+Packages+of+Care+Collection&sort=Relevance&size=10&page=1&area=both#top>

the provision of personal budgets and personal care and support planning for adult carers and those they care for on a clear statutory footing.

- 3.26 Care Act regulations and guidance published on 23 October 2014 set out in detail the requirements of local authorities for providing personal budgets, direct payments and support plans both for carers, in their own right, and the people they support. Guidance also includes the Government's expectations about reducing monitoring and reporting burdens on the use of personal budgets and direct payments, as well as minimising restrictions about how personal budgets and direct payments can be utilised or which care providers can be employed.

### **Achieving sustainable social care through personalisation**

Bristol Council has explored how personalisation can stimulate the market for more environmentally sustainable care and support services. Semi-structured discussions in focus groups probed issues of local importance spanning housing, transport as well as care and support. The rationale was that this would help develop a clearer understanding of needs across the life-course as opposed to a response to ill health or a care need at a particular time.

Local people exchanged experiences of where they live, the places and activities they enjoy, how they get around, what they like and what they would like to see changed. Creative discussions ensued about different ways in which care and support could be provided. The ideas generated were often simple and low-cost, promoted independent living and were of benefit to the community as a whole.

A guide for community engagement has been developed to help commissioners and providers of care and support, as well as community groups, to engage with citizens to develop responsive, personalised and environmentally sustainable services. The guide is available on SCIE's website as part of its Sustainable Social Care programme. This promotes care and support which is right for those who need it, their family and carers and at the same time brings social, economic and environmental benefits for all.

<http://www.scie.org.uk/adults/sustainablesocialcare/files/sustainablesocialcareandpersonalisation.pdf>

- 3.27 Previous regulations have excluded the payment from being used to pay for care from a close family member living in the same household, except where the local authority determined this to be necessary. The new Care and Support (Direct Payments) Regulations 2014<sup>62</sup> maintain this provision regarding paying a family member living in the same household for care, but they also provide a distinction between 'care' and 'administration / management' of the direct payment. This allows people to pay a close family member living in the same household to provide management and/or administrative support to the direct payment holder in cases where the local authority determines this to be necessary. This allows family members performing this task to be paid a proportion of the direct payment, similar to what many direct payment holders pay to third-party support organisations.
- 3.28 The new requirements of the Care Act amount to a significant step forward for the rights of carers, and, for the first time, an equivalence in law with the people for whom they care. The Government has already announced new funding to implement the extended assessment rights, as well as the duty to meet carers' eligible needs.
- 3.29 To further support local authorities with performing these responsibilities, as noted previously, we intend to develop a range of non-statutory products, including practice guidance, toolkits and other types of practical support, where a need for such materials is identified by the sector. This will include practice guidance about effective and efficient interventions for carers. This will support local authorities to implement the Care Act and achieve the best outcomes for carers and their families<sup>63</sup>.

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<sup>62</sup> <https://www.gov.uk/government/news/final-care-act-guidance-published>

<sup>63</sup> You will find more information here: [http://www.local.gov.uk/web/guest/care-support-reform/-/journal\\_content/56/10180/6522308/ARTICLE](http://www.local.gov.uk/web/guest/care-support-reform/-/journal_content/56/10180/6522308/ARTICLE)

### **Think Local Act Personal (TLAP) – Personalisation Action Plan**

Following a summit last year, chaired by the Minister for Care and Support, Think Local Act Personal, the sector-wide partnership for personalising care and support, has published a Personalisation Action Plan outlining key activity by the adult care and support sector ahead of implementation of the Care Act.

<http://www.thinklocalactpersonal.org.uk/library/PersonalisationActionPlanFINAL.pdf>

Key actions for TLAP include:

- gathering evidence of emerging good practice on personal budgets for older people
- sharing good practice on personal health budgets for people with learning disability including joint health and care budgets
- supporting further uptake and engagement with *Making it Real*, markers of progress for personalised care and support developed by service users, carers and families to demonstrate good care and support. TLAP wants all local authorities in England signed up to using Making it Real markers of progress by April 2015.

*Making it real:* <http://www.thinklocalactpersonal.org.uk/Browse/mir/aboutMIR/>

*Making it real for carers:*

[http://www.thinklocalactpersonal.org.uk/library/MIR\\_carers\\_FINAL.pdf](http://www.thinklocalactpersonal.org.uk/library/MIR_carers_FINAL.pdf)

*Making it real for young carers:*

<http://www.thinklocalactpersonal.org.uk/library/MIRyoungcarersFINAL.pdf>

*Making it real for people with dementia:*

[http://www.thinklocalactpersonal.org.uk/library/MIR\\_dementia\\_FINAL.pdf](http://www.thinklocalactpersonal.org.uk/library/MIR_dementia_FINAL.pdf)

### ***Supporting parent carers of disabled children and young carers to have a life of their own alongside caring***

3.30 Parent carers of disabled children have been closely engaged in plans to improve support for children and young people with special education needs and disability. These improvements have now been enshrined in the Children and Families Act 2014. Parents will have much more choice and control about the support they and their children receive. From September 2014, this included a clear and transparent 'local offer' of services for all children and young people with additional needs; a more streamlined assessment process; a new Education, Health and Care Plan for children and young people with more complex needs from birth up to 25 years of age produced in partnership with parents and young

people; and the offer of a personal budget for families and young people with an Education, Health and Care Plan.

- 3.31 The Children and Families Act 2014 consolidates existing legislation on assessments for parent carers of disabled children into the Children Act 1989. Putting all the relevant legislation into one place will help to ensure parent carers are better able to understand it and local practitioners are able to implement it effectively. The Government has also taken this opportunity to ensure a more consistent approach to the support for parent carers alongside other carers and therefore the new legislation removes the requirement that a parent carer must be providing, or intending to provide, a "substantial amount of care on a regular basis" in order to be assessed.
- 3.32 Armed Forces family and carer issues remain a priority for the Ministry of Defence and Department of Health. The Government has made available to the MoD money received from London Interbank Offered Rate (LIBOR) fines to support Armed Forces Covenant projects. These include over £200k to fund the service charity Soldiers, Sailors, Airmen and Families Association (SSAFA), who will offer holidays for children of Service personnel, who have additional needs and/ or a disability, allowing young people to develop their social skills and gain independence and providing breaks for Service families and carers.

### ***Integration of adult social care and health services***

- 3.33 The Care Act requires local authorities to promote the integration of care and support services with health services where this would promote the well-being of adults with care and support needs, and carers, prevent or delay needs for support developing or improve the quality of care and support.
- 3.34 The establishment of the £3.8 billion Better Care Fund (BCF), which was announced in last year's Spending Review, will enable health and social care services to work together more closely in local areas to bring about a much more integrated system of health and social care and enable a substantial shift of activity and resource to more preventative care. BCF plans have been agreed between the NHS and local authorities, and have been signed off by health and wellbeing boards before implementation begins in 2015/16. Areas chose to pool 39% more than the minimum £3.8 billion requirement, with around £5.3 billion of health and social care budgets pooled nationally.
- 3.35 The Better Care Fund will include £130 million NHS funding for carers' breaks for carers of all ages, as well as funding to support delivery of the extended rights to assessment and support for adult carers in 2015/16. Guidance<sup>64</sup> for developing the plans stipulates that the local plans should set out the level of resource that will be dedicated to carer-specific support, including carers' breaks, and identify how the chosen methods for supporting

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<sup>64</sup> <http://www.england.nhs.uk/wp-content/uploads/2013/12/bcf-plann-guid.pdf>

carers will help to meet key outcomes for the Fund, for example, reducing delayed transfers of care from hospital into the community because of a lack of social care support.

- 3.36 Fourteen Integration Pioneer sites<sup>65</sup> were identified to demonstrate innovative ways of delivering co-ordinated health and social care. The aim was to provide better support at home and earlier treatment in the community to prevent people needing emergency care in hospital or care homes.

*Cheshire Integration Pioneer Site*

Connecting Care across Cheshire will join up local health and social care services around the needs of local people and take away the organisational boundaries that can get in the way of good care. There will be a particular focus on older people with long-term conditions and families with complex needs.

Local people will only have to tell their story once – rather than facing repetition, duplication and confusion. The programme will also tackle issues at an earlier stage before they escalate to more costly crisis services.

<https://www.easterncheshireccg.nhs.uk/News/Connecting-Care-in-Cheshire---leading-the-way-for-joining-up-health-and-social-care.htm>

***Closing the Gap: Priorities for essential change in mental health***

- 3.37 People who use mental health services and those that care for them continue to report gaps in provision and long waits for services which can impact significantly on their lives.
- 3.38 *Closing the Gap: Priorities for essential change in mental health*<sup>66</sup>, sets out 25 challenges to improve the lives of people with mental health problems, and those who care for them. As well as measures to promote mental well-being, increase access to mental health services, and better integrate physical and mental health, it also identifies better support for carers and their closer involvement in decisions about mental health provision as priorities for action in the next two years.

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<sup>65</sup> <https://www.gov.uk/government/news/integration-pioneers-leading-the-way-for-health-and-care-reform--2>

<sup>66</sup> [https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/281250/Closing\\_the\\_gap\\_V2\\_-\\_17\\_Feb\\_2014.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/281250/Closing_the_gap_V2_-_17_Feb_2014.pdf)

3.39 The Standing Commission on Carers focussed its fact-finding visits for 2013-14 on how carers of those with mental health problems, including young carers, are involved and supported. They will report to the Minister for Care and Support.

*South Devon and Torbay Integration Pioneer Site*

South Devon and Torbay already has well co-ordinated or integrated health and social care but as a Pioneer site now plans to offer people joined up care across the whole spectrum of services, by including mental health and GP services. They are looking at ways to move towards seven day services so that care on a Sunday is as good as care on a Monday – and patients are always in the place that is best for them. The teams want to ensure that mental health services are every bit as good and easy to get as other health services and coordinate care so that people only have to tell their story once, whether they need health, social care, GP or mental health services.

<http://southdevonandtorbayccg.nhs.uk/index.php/2012-05-05-21-22-02/latest-news/215-pioneer-bid-news-release>

***Dementia care – the ambition***

3.40 In March 2012 the Prime Minister set a challenge to deliver major improvements in dementia care and research by 2015, including improvements in health and social care, creating dementia friendly communities and improving dementia research. On 28 February 2014 the Department of Health set out its ambition<sup>67</sup> for people with dementia and their carers to have:

- a timely assessment of their condition and diagnosis
- someone who can help and advise, such as a dementia adviser
- a tailored plan of care
- support to remain as independent as possible
- access to high-quality personalised information to help understand and manage their condition
- access to support services such as reminiscence and counselling
- co-ordinated care towards the end of life
- timely access to support for carers
- seamless care with health and social care professionals working together to provide the best care and support.

3.41 In its *Commitment to Carers* NHS England has confirmed it will support timely diagnosis of dementia and support for carers. For example, the revised Dementia Enhanced Service,

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<sup>67</sup> <http://dementiachallenge.dh.gov.uk/2014/02/28/improving-dementia-diagnosis/>

which will be introduced from March 2015, will include an offer of a health check for carers and signposting to relevant information, advice and support.

- 3.42 Commissioning for Quality and Innovation (CQUIN) is a way of linking payments to healthcare providers to improvements in outcomes. In 2013-14, the dementia CQUIN was extended to include support for carers of people with dementia. To qualify for the incentive payments (which amount to thirty per cent of the available funding for the dementia CQUIN) providers must undertake a monthly audit of carers of people with dementia and report the findings to their Board at least twice per year. The precise content of this audit is determined locally but must include a question on whether carers of people with dementia feel adequately supported. This element of the dementia CQUIN remains in place for 2014-15.
- 3.43 The Department of Health is supporting the Dementia Action Alliance's Carers' Call to Action, which is supporting the needs and rights of family carers of people with dementia through the development of the shared vision set out earlier in this document.

### ***Financial support for carers***

- 3.44 The rate of Carer's Allowance has risen to £61.35 a week from April 2014, an increase of 2.7% as its uprating is linked to the Consumer Price Index (CPI). The carer premiums in the income-related benefits and the additional amount for carers in pension credit are similarly protected and have risen to £34.20 in April 2014.
- 3.45 In addition, Universal Credit includes a carer element to support carers on a low income who provide care for at least 35 hours per week for a severely disabled person. This element will be paid in addition to the claimant's standard Universal Credit entitlement meaning that carers can receive a higher rate of Universal Credit than other recipients. The carer element is also protected by being linked to the CPI and has therefore increased per assessment period to £148.61 from April 2014.
- 3.46 In common with all other departments and agencies, the Department for Work & Pensions has been tasked by the Cabinet Office with improving its digital services. The original Carer's Allowance e-Service had not had any IT or business improvements since its launch in 2007. The service was therefore not as efficient or effective as it should have been. Carer's Allowance is now one of 25 Exemplar Services across Government which are being supported directly by the Government Digital Service.
- 3.47 In August 2013 a new service went live, making it easier to make claims - digital claim uptake has increased by 11% and customer satisfaction with the system is running at 80%. Work is ongoing to build on the new online service and explore ways of transforming the Carer's Allowance business to make processing of claims, change of circumstance and other business activity more automated.

3.48 As part of the 2012 welfare reforms, the Government said it will carefully consider whether changes to Carer's Allowance will be necessary to take into account the introduction of Universal Credit and provide clearer, more effective support for carers. To support this process of evaluation, the Department for Work & Pensions commissioned the Social Policy Research Unit at York University to conduct qualitative research into the household finances of Carer's Allowance recipients. This research was published in July 2014<sup>68</sup>.

3.49 The Department of Health and the Department for Work & Pensions have also agreed to explore the available evidence to assess the impact of caring roles on people's broader circumstances. This will provide future governments with a better understanding of the position of carers across a range of outcomes and so provide a robust basis for assessing the need for and direction of any future policy changes.

### **Summary of key actions**

3.50 The Government will:

- through joint work between the Department for Health and the Department for Work & Pensions, explore the available evidence to assess the impact of caring roles on people's broader circumstances.
- work with the integration pioneer sites to consider how models for integrated health and social care can deliver better outcomes for carers.
- support local partners to make use of the opportunity presented by the Better Care Fund to develop shared approaches to identifying and supporting carers.
- support local authorities to prepare for implementation of their responsibilities in the Care Act, by developing practice guidance and other types of practical support.

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<sup>68</sup> <https://www.gov.uk/government/publications/household-finances-of-carers-allowance-recipients>

## Priority area 4: Supporting carers to stay healthy

*“Supporting carers to remain mentally and physically well”*

### **Key Issues**

- Impact of caring on health and well-being
- Prevention and early intervention for carers within local communities
- Supporting carers to look after their own health and well-being

### ***Impact of caring on health and well-being***

- 4.1 While caring can be very rewarding and fulfilling it can also be emotionally and physically draining. We know that many carers, in addition to anxieties about the health of the people they care for, can experience significant stress caused by the extent and nature of their caring responsibilities, balancing caring with education or paid employment, the state of their family finances and concerns about the quality, quantity or reliability of care and support provided by others.
- 4.2 As already indicated in the Introduction, it is clear that carers' health deteriorates incrementally with increasing hours of caring. The greatest impact on general health appeared among young male adult carers up to age 24 caring for over 50 hours a week<sup>69</sup>. They were more than four and a half times likely to report poor health as their peers with no caring responsibilities. A similar pattern of poor health was also apparent among young carers under 18 years of age<sup>70</sup>. Those caring for more than 50 or more hours a week were more than five times likely to report they were not in good health compared to their peers without caring responsibilities. 80% of the respondents to Carers UK *State of Caring* Survey in 2014 said that caring had a negative impact on their health.

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<sup>69</sup> [http://www.ons.gov.uk/ons/dcp171776\\_310295.pdf](http://www.ons.gov.uk/ons/dcp171776_310295.pdf)

<sup>70</sup> <http://www.ons.gov.uk/ons/rel/census/2011-census-analysis/provision-of-unpaid-care-in-england-and-wales--2011/sty-unpaid-care.html>

## ***Community support for carers***

- 4.3 Carers should be supported to pursue leisure and sport activities and to access local NHS and local authority public health services such as weight management and smoking cessation sessions in order to maintain their physical health. It is also important for carers to be supported to look after their own mental well-being and maintain and develop social contacts.

## ***Supporting carers to look after their own health and well-being***

- 4.4 Carers often feel they do not have time to look after their own physical and mental health. As well as being supported to take breaks from caring responsibilities, it is important that carers are supported to have their own health checks and to attend appointments for maintaining good health, including dentist and optician appointments, as well as being supported to attend to their own health problems and long-term conditions in a timely and convenient way.
- 4.5 The provision of information and advice is key in supporting carers to look after their own physical health at an early stage of caring and throughout their caring roles. They may, for example, need practical information and advice on moving someone safely (both safe for themselves and safe for the person who needs help with moving), including information on how to obtain equipment to help with lifting and other assistive technology and how to arrange simple adaptations that can assist mobility.
- 4.6 Being helped to gain a better understanding of the condition or illness of the person they are caring for can help to ameliorate stresses associated with caring and enable carers to develop better coping skills. Carers may also benefit from a wide range of support, including stress management, relaxation classes and psychological therapies to help restore and maintain their emotional resilience.
- 4.7 Poor mental and physical health are often associated with caring for someone at the end of their life and during a period of bereavement, so it is also important that they receive support to cope with the end of a period of caring.

## **Progress since 2010 and next steps**

### ***Prevention and early intervention***

- 4.8 Since 2010, the Department of Health has committed £400 million through the NHS to support the provision of breaks from caring responsibilities. From April 2015, this funding will be part of the Better Care Fund.

**Cambridgeshire Family Carers Services Prescription – Winner of the 2012 Charity Awards award for Effectiveness**

All GPs in Cambridgeshire have signed up to using the Family Carers Prescription Service. GPs can refer carers of all ages to Carers Trust Cambridgeshire to discuss the most appropriate form of support for them which could include a free short break from caring and where appropriate, signposting carers to further sources of information and advice about benefits, services and other forms of support.

The scheme was developed by Carers Trust Cambridgeshire in partnership with NHS Cambridgeshire and GPs and is funded by NHS Cambridgeshire and Cambridgeshire County Council

<http://www.carerstrustcambridgeshire.org/our-services/support-for-carers/family-carers-prescription/>

- 4.9 The Department for Education has invested over £800 million in short breaks for disabled children over 4 years, in unring-fenced grants which can also help parents and other members of the family have a break from their caring responsibilities. Short breaks have been shown to prevent more expensive later interventions by keeping families together.
- 4.10 Local authorities' short breaks services provide opportunities for disabled children and young people to have enjoyable experiences which help them become more independent and form friendships outside their family. They also give parents and carers a valuable break from caring responsibilities and allow them the time to do normal things which other families take for granted.
- 4.11 Short breaks can be day, evening, overnight or weekend activities and may take place in the child's home, in the home of an approved carer, or in a residential, specialist or mainstream community setting.

**Disabled children in Luton enjoy camping short breaks**

Buddies Go Camping offers Luton children and young people with learning disabilities and autism, aged 8-19, short camping breaks away from home, from Friday to Sunday afternoon.

Before their weekends away, prospective campers and their families are visited by Buddies Go Camping staff to make sure that their needs are understood and safeguarded during the trip and that activities help them work towards their personal goals.

Families and campers benefit from the experience of quality time away, not only in terms of relaxation but also in terms of their ability to cope independently when the trip is over.

<http://www.shortbreaksnetwork.org.uk/Resources/Short%20Breaks/Impact/Impact%20ISP/LutonGoCamping.pdf>

4.12 Since April 2011, the Government has required all local authorities to provide a variety of short break services for disabled children. Regulations require local authorities to publish a short breaks duty statement describing what short breaks services are available in their area and how they can be accessed. Authorities must develop these statements in consultation with disabled young people and their families and review them regularly to ensure that they remain responsive to local needs.

#### FirstStop Advice for older people

FirstStop is a free and independent information, advice and casework service designed to help older people, along with their families and carers, decide how best to meet their needs for support, care and suitable housing. It is provided jointly by a voluntary alliance of local and national organisations and peer support networks.

Led by the charity Elderly Accommodation Counsel (EAC), and supported financially by the Department for Communities and Local Government since 2009-10, FirstStop reached over 200,000 clients during 2013-14 through its integrated website, national advice line, 25 local casework services and 3 pilot peer support initiatives. The Department for Communities and Local Government funding is currently committed to 2014-15, with other funding provided by Comic Relief, Nationwide, Legal & General and EAC itself.

Over 60% of FirstStop's clients are family members, of which around half are also carers. FirstStop's service offers comprehensive information, discussion, and support to help carers access care services, practical and emotional support, or financial help. Where appropriate, it is able to signpost them to a wide range of local services, including carers centres, drawing on its own extensive directories. FirstStop has plans for a dedicated area for carers on its website.

<http://www.firststopcareadvice.org.uk/>

4.13 A strong theme in the Care Act is the importance of providing services and facilities that can contribute towards preventing or delaying the development of needs for support. The focus is on prevention and early intervention rather than waiting until a crisis occurs. From April 2015, the Care Act will require local authorities to arrange services, facilities or resources to prevent or delay the development of needs for support for their local populations, including adults caring for adults.

### **St John Ambulance Carers Support Programme**

St John Ambulance is preparing to rollout a successful training programme for carers across the whole of the South West region.

The Carers Support Programme has been running in various forms for a decade – most notably in Dorset, where the programme is funded by local authorities and the Clinical Commissioning Group.

Since 2003, the scheme has provided 4,500 carers with first aid and other practical skills, such as managing continence, safe handling, prevention of falls, stress management, understanding memory loss, infection control and medicine management.

Using that success as its foundation, the Carers Support Programme has recently been remodelled to make its delivery more flexible and demand-led. These developments are designed to make the training more financially sustainable and enable a greater number of carers to benefit from the project in future. [www.sja.org.uk](http://www.sja.org.uk)

### **Support for carers in Camden**

Camden Council and Camden Clinical Commissioning Group are committed to working together to support carers. The strategic direction for carer support is brought together through a joint commissioning process.

The local carer service, Camden Carers Service (CCS) is funded equally by the Clinical Commissioning Group and council. Clinical Commissioning Group investment ensures carers access breaks from caring, health checks and healthy living activities.

A referral form has been developed to support early identification and referral of carers to the service.

Camden Clinical Commissioning Group is proactive in ensuring carer engagement and carers are represented in patient participation groups, integrated care and hospital discharge services.

Carer quality of life has been agreed as a local priority within the Better Care Fund submission.

<http://www.camden.gov.uk/ccm/content/social-care-and-health/support-in-your-home/information-for-carers/camden-carers-support-organisations.en?jsessionid=F0A05EB2B657B94C4F5E11FC2130838E>

## **Kensington and Chelsea – supporting carers to be healthy**

### Getting Fit Getting Healthy

This new project provides access to exercise and health education to adult carers. The project will engage carers in a structured exercise plan, facilitated by a qualified fitness instructor. It is expected that this will result in individuals reporting a better sense of well-being and potentially, a reduced risk of other health related conditions such as obesity, coronary heart disease and diabetes.

The provider has made available fifty memberships to facilitate access to carers to carers. Carers in receipt of memberships will be able to access exercise classes, gym equipment and swimming facilities.

Carers will receive information in relation to nutrition and its connection to exercise and associated benefits.

Staff working with carers will be trained in carer awareness to enable them to work effectively with carers and to understand the barriers that carers face in leading a healthy lifestyle and participating in an exercise regime.

The project will ensure there is a referral system in place for carers who may benefit from other carer support services and accept referrals from carer organisations and the Local Authority and GPs.

### Fun and Fitness for Young Carers

The aim of the project is to increase the awareness of the value of exercise and nutrition and to improve the health and well-being of young carers. The overall aim is to improve knowledge of physical activity and its health benefits. This will be achieved by ensuring the development of structured individual and group exercise plans. The project includes 26 gym memberships, group classes, private tutoring and activities at a community based sports centre for young carers.

The deliverables of the project include:

- improved knowledge of physical activity and its health benefits amongst young carers
- identification of perceived barriers to exercising amongst young carers
- young carers participation in fitness opportunities within a community setting with their peers
- feedback from young carers about their satisfaction and experience of each session
- a quarterly report on progress including feedback on the health and well-being of the young carers involved
- an annual report on the outcomes achieved for young carers.

## **NHS England**

4.14. NHS England's Business Plan up to 2015-16<sup>71</sup> explains how it will fulfil its mandate from the Government. A number of core priorities are very relevant to improving the support provided to carers, including help in looking after their own health. These include:

- obtaining feedback from patients and families about the support they receive from the NHS. The 'friends and family' test will help to ensure that patients and families can help to secure better health services.
- enhancing the quality of life of people with long term health conditions and those who care for them, for example through increased use of personal health budgets.
- supporting earlier diagnosis, including the roll out of NHS health checks.
- increasing the use of technology to help people manage their health and care, for example online ordering of repeat prescriptions, online booking of GP appointments, and online access to health records.

Macmillan nurses specialise in cancer and palliative care, providing support and information to people living with cancer and their carers. This includes:

- Empowering carers to support people living with cancer
- Assessing the needs of carers and working with them to agree care plans
- Building a partnership between patients, carers and professionals
- Supporting them to cope with the emotional and psychological impact of a cancer diagnosis

Macmillan nurses also signpost cancer carers to Macmillan's programme of support for carers – for more details see: [www.macmillan.org.uk/carers](http://www.macmillan.org.uk/carers)

4.15 NHS England is also working in partnership with NHS Improving Quality on the *Seven Day Services Improvement Programme*<sup>72</sup>, which was set up in collaboration with all healthcare

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<sup>71</sup> <http://www.england.nhs.uk/2014/03/31/ppf-business-plan/>

<sup>72</sup> <http://www.nhs.uk/resource-search/publications/every-day-counts-seven-day-services.aspx>

commissioners and providers in January 2014. A number of 'early adopters' are exploring ways of delivering key health services over weekends as well as Monday to Friday.

4.16 The Better Care Fund will be a key enabler of change and help to secure a health and social care system that provides people with the care and support they need, at the right time and in the right place. As part of the process for accessing the Better Care Fund, clinical commissioning groups and local authorities will have to demonstrate that they are meeting a number of national conditions. These include seven day health and social care services to support hospital discharge and to prevent unnecessary admissions or readmissions at weekends.

4.17 In its *Commitment to Carers* NHS England has made clear it will:

- consider how carers can be supported through the commissioning of primary healthcare, including through future developments to the GP contract and Enhanced Services.
- include an offer of a health check for carers in a revised GP Enhanced Service for dementia.
- include support for bereaved carers and relatives in its new ambitions for End of Life Care which was published in summer 2014.

### **Summary of key actions**

4.18 The Government will:

- support local partners to maintain a focus on breaks from caring through delivery of the Better Care Fund in 2015/16.

NHS England will:

- include an offer of a health check for carers in a revised GP Enhanced Service for dementia.
- repeat the survey of bereaved people to measure quality of care provided to people at end of life and their relatives and carers.

## Conclusion and next steps

A major shift has begun in the last few years in how support for carers is considered in terms of national strategy and policy development. We have made significant progress in 'mainstreaming' consideration of carers' needs for support in major Government initiatives and this is particularly evident, for example, in the way that Part 1 of the Care Act and associated regulations and guidance have been prepared, deliberately embedding consideration of carers in all the relevant sections of the legislation to help reinforce the message that supporting carers is an intrinsic part of care and support, and their well-being is as important as that of the people they support. This approach was strongly welcomed in the passage of the legislation through Parliament.

We are building on this approach further, for example, through joint working between the Department for Education, the Department of Health, the voluntary sector, local government, and NHS England in developing a whole family approach to assessments and identifying and supporting young carers, so that they are not undertaking excessive or inappropriate caring tasks.

New initiatives planned for 2014-15 to explore how young adult carers can be better supported to fulfil their education and employment potential and how people in their 40s and 50s can be better supported to remain in paid work alongside caring responsibilities, will involve the Department for Business, Innovation and Skills, the Department for Work & Pensions, and the Government Equalities Office as well as the Department of Health and the Department for Education.

There is still a lot to do to achieve the vision and outcomes for carers set out in the introduction to this document. But taking forward the actions identified below, working in close partnership with a wide range of stakeholder organisations and carers themselves will take us nearer to that vision of enabling carers to maintain a balance between their caring responsibilities and a life of their own alongside caring.

## Next steps

The Government is committed to taking the following actions:

### **Priority area 1: identification and recognition**

Action	Leads	Milestones
<p>Publish regulations and guidance to support local authorities to carry out their responsibilities under the:</p> <ul style="list-style-type: none"> <li>▪ Care Act</li> <li>▪ Children and Families Act</li> </ul>	<p>Department of Health</p> <p>Department for Education</p>	<p>Regulations and guidance published on 23 October</p> <p>January 2015</p>
<p>Work with local authorities to help them prepare for the implementation of the Care Act and the Children &amp; Families Act, including developing practical guides and toolkits, assuring readiness and reviewing progress</p>	<p>Department of Health</p> <p>Department for Education</p>	<p>Implementation commences April 2015</p>
<p>Work with the Health &amp; Care Voluntary Sector Partner Programme to improve identification and involvement of carers</p>	<p>Department of Health</p>	<p>Up to March 2015</p>
<p>Provide funding for the final year of the DH programme to test approaches to identification of carers by healthcare professionals, and disseminate learning from the programme to support future work</p>	<p>Department of Health</p>	<p>Funding agreed for 2014-15</p> <p>Learning from the programme to be disseminated in 2015-16</p>
<p>Provide funding for ongoing work by The Children's Society and Carers Trust to identify young carers</p>	<p>Department for Education</p>	<p>Funding agreed for 2014-15</p>
<p>Encourage local partners to develop or refresh carers' strategies that consider how the actions of different organisations can identify and support carers of all ages.</p>	<p>Department of Health</p>	<p>ongoing</p>

<p>Encourage the identification of carers as part of work to implement the vision set out in <i>Transforming Primary Care</i></p>	<p>Department of Health NHS England</p>	<p>ongoing</p>
<p>Support NHS England in delivering its plans to improve identification and recognition of carers of all ages through delivery of its <i>Commitment to Carers</i></p>	<p>Department of Health NHS England</p>	<p>ongoing</p>

**Priority area 2: realising and releasing potential**

Action	Leads	Milestones
Support The Children's Society and Carers Trust to deliver a series of workshops for local managers and other professionals to deliver a 'whole-family' approach to assessment and support for young carers	Department for Education	ongoing
Commission research to better estimate the number of young carers in England, and the nature and impact of the care they provide	Department for Education	By September 2014
Train 150 more school nurses to be champions for young carers, taking the total to 300	Department of Health	By March 2015
Set up a Task & Finish group to consider issues of particular relevance to young adult carers, and what further actions can be taken by national and local government and other partners to enable them to fulfil their education and employment potential	Department of Health Department for Business, Innovation and Skills	Task & Finish Group to report to the Inter-Ministerial Group on Carers Summer 2015
Following introduction of the right to request flexible working for all employees from 30 June 2014, continue to explore other ways of increasing flexible working opportunities	Department for Business Innovation and Skills Department for Work & Pensions	ongoing
Initiate a pilot scheme to explore ways in which local authorities and other local partners can support carers to maintain paid employment.	Department of Health Department for Work & Pensions Government Equality Office	Establish pilots Autumn 2014 Interim reports Autumn 2015 Final reports Autumn 2016
Promote the new carer-specific pledge in the Public Health Responsibility Deal, to increase uptake amongst organisations in the scheme	Department of Health	From Autumn 2014

**Priority area 3: a life alongside caring**

Action	Leads	Milestones
Explore the available evidence to assess the impact of caring roles on people's broader circumstances	Department of Health Department for Work & Pensions	ongoing
Work with the integration pioneer sites to consider how models for integrated health and social care can deliver better outcomes for carers	Department of Health	ongoing
Support local partners to make use of the opportunity presented by the Better Care Fund to develop shared approaches to identifying carers	Department of Health	ongoing
Support local authorities to prepare for implementation of their responsibilities in the Care Act, by developing practice guidance and other types of practical support.	Department of Health	From autumn 2014

**Priority area 4: supporting carers to stay healthy**

Action	Leads	Milestones
Support local partners to maintain a focus on breaks from caring through delivery of the Better Care Fund in 2015/16	Department of Health	Ongoing
<p>Include an offer of a health check for carers in a revised GP Enhanced Service for dementia</p> <p>Repeat the survey of bereaved people to measure the quality of care provided to people at end of life and their relatives and carers</p>	<p>NHS England</p> <p>NHS England</p>	<p>March 2015</p> <p>March 2015</p>

## Annex A

### **Recommendations from the final report of the Carers in Employment Task and Finish Group: *Supporting Working Carers: The Benefits to Families, Business and the Economy***

#### ***Employment practices:***

1) The Confederation of British Industry and the British Chambers of Commerce should assist employers to support carers in their workforces by making available information provided by Employers for Carers on the business case for supporting carers and the ways in which employers can help and retain them.

2) The Chartered Institute of Personnel and Development (CIPD) should raise awareness amongst, and capture expertise from, HR practitioners about supporting carers in the workplace.

3) The Department for Business, Innovation and Skills should work to embed good practice around flexible working, including through the ACAS Code of Practice on Flexible Working, and should continue to monitor the impact of flexible working practices through studies such as the Workplace Employment Relations Survey (WERS) and the Work-Life Balance Survey and continue to identify the impact on carers.

4) The Department for Work & Pensions should improve provision of information and support to businesses to enable them to support carers in their workforce including through a page on gov.uk signposting to Employers for Carers.

5) The Department for Business, Innovation and Skills and the Department for Work & Pensions should support inter-departmental working and continue to work with business on promoting flexible working, which has significant benefits to carers, following the introduction of the universal right to request flexible working arrangements.

6) The Department of Health should include a pledge in the Responsibility Deal Health at Work Network on the promotion of the health and well-being of unpaid carers as part of its work on the health and well-being of vulnerable groups in the workforce.

7) The Department of Health should champion membership of Employers for Carers among Government departments.

8) Skills for Care should continue to work with employers in England, and in partnership with other Sector Skills Councils, to develop and implement carer focussed workforce support for care sector businesses (including small and medium-sized enterprises and start-ups) to ensure that workforce skills needs in relation to supporting people as employees and carers are addressed on an ongoing basis.

#### ***Care and support services:***

9) The Local Government Association and the Association of Directors of Adult Social Services should encourage effective joint working between local authorities and care providers, and the sharing of best practice on how they can work with Local Enterprise Partnerships (LEPs),

Health and Wellbeing Boards, Chambers of Commerce, local business and other stakeholders in their area to support carers to remain in employment.

10) The Department of Health should work with key stakeholders in a number of local authority areas to explore ways in which people can be supported to combine work and care, and the market for care and support services can be stimulated to grow to encompass their needs.

11) Government guidance on promoting a diverse range of services and providers should include explicit reference to services that enable carers to work.

12) The Treasury should consider how care market growth can be embedded in ongoing and future strategies.

13) The Treasury and the Department for Business, Innovation and Skills should keep under review the option of potential initiatives to incentivise and accelerate growth in the care and support sector.