

# Consultation Response

## Carers Strategy: call for evidence

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## **About this consultation**

The Department of Health is seeking evidence from informal carers and individuals that they support, as well as professionals and organisations working with and for carers, in order to update and refresh the Carers Strategy: *Second National Action Plan 2014-2016*.

## **Key points and recommendations**

- There are an estimated 2.75 million older people in England who need some form of help and support, the vast majority of whom rely, at least in part on informal help from family and friends.
- A growing older population, combined with decreasing availability of publicly-funded social care services, means the contribution of informal carers is critical and only set to increase in the future.
- Many carers are older people themselves and may face additional challenges. There are more than 2 million carers aged 65+, 417,000 of whom are aged over 80.
- Improving practical support for informal carers is critical if we are to safeguard the health and wellbeing of individual carers, the individuals that they support and ensuring that families and friends can continue to make a sustainable contribution towards the care and support of a loved one.

## **Identifying people are carers**

- There is clearly more that needs to be done to ensure that carers are consistently identified and offered support, recognised by NHS England's *Commitment to carers* in 2014. We would expect the Strategy to reflect on what progress has been made since that was published and to be clear on further steps to ensure professionals consistently recognise and support carers, particularly GPs.
- The Strategy should explicitly recognise the role and take steps to ensure better identification of carers at a distance, carers supporting individuals living in care homes and older people in co-caring relationships.

## **Access to assessment, services and support**

- It is currently unclear whether the new carers' rights set out in the Care Act 2014 are being fully realised, including those rights to receive services following an assessment. The next phase of Carers Strategy should undertake an evaluation of whether implementation of the Care Act is resulting in tangible improvements to their mental and physical wellbeing of carers.
- Assessment and subsequent decisions about how to meet the needs of a carer or the person they care for should take full account of the diversity of essential roles carried out by carers, not only those that arise as a result of delivering care deemed 'necessary' by the local authority. Evaluation of implementation of the Care Act should also look at whether local authorities are taking account of these roles.

- Severe cuts in funding for social care, and a reduction in the availability of publicly-funded services is having a detrimental impact on carers. Carers should be entitled to the support needed to be able to achieve an acceptable quality of life, which should also be taken into account when assessing the support requirements of the person they care for as well.

### **Valuing and involving carers**

- The Strategy refresh should build on the themes of the 2014 Strategy in relation to empowerment and involvement of carers, in particular the new Strategy should focus on measures to promote better communication between health and care professionals, carers and older people.
- Setting out ways to promote formal processes for shared decision-making, including training and supporting staff to carry this out, would make a significant difference to all parties in being valued and involved in care.
- The Strategy should address more formal involvement procedures such as those relating to mental capacity and deprivation of liberty. This relates not just to best interests decisions for healthcare but also to managing finances, particularly for people living with dementia.
- Strategy must also consider how the value and contribution of carers is fully recognised without compromising a person's ability to maintain autonomy and the ability to self-care.

### **Support for carers to maintain their health and wellbeing**

- Supporting carers to maintain good health and wellbeing is vital to both them and the person they care for, particularly amongst older carers, nearly two thirds of whom will be living with a health condition or disability of their own.
- The Strategy should take steps to support older carers to manage their own health and enhance their wellbeing, including measures to promote resources such as a *Practical Guide to Healthy Caring*.
- Mindful of the critical role played by GPs, the Strategy should explore how improved support can be appropriately provided through the standard and enhanced contract.
- Although the majority of carers are family members, friends and neighbours nonetheless often play a critical role in providing informal support. However there is little research on what works in identifying and supporting this group. The Strategy should seek to promote and encourage research into 'what works' in identifying and supporting non-familial carers.
- It is important to focus on supporting the health of co-carers and to recognise their role as carers in their care and support planning. The Strategy should take steps to promote greater awareness and understanding of co-caring amongst professionals and the use of models such as the comprehensive geriatric assessment (CGA) where these are appropriate.

- The Strategy should set clear expectations for the development of support services for all carers of people living with dementia, particularly emphasising the importance of access to respite care.

### **Work and financial support**

- Around half of carers combine paid work and care, however many feel they ultimately have little option but to give up work, reduce their hours or forego promotion opportunities due to the stress of trying to juggle caring and work. Lack of suitable, affordable care services and lack of leave or sufficient flexibility are also significant factors.
- Recent analysis shows that, even after controlling for factors such as age and gender, caring is a major factor in causing older carers to give up work. Furthermore, caring for as little as 5 hours a week has a significant impact on older workers' ability to remain in employment, while ten hours or more causes large numbers of older workers to drop out of work altogether.
- The public expenditure costs of carers leaving employment are also substantial at an estimated £1.3 billion a year. In addition Age UK has estimated that the additional output from carers being able to work could be as high as £5.3 billion per year.
- We would welcome a focus on supporting older workers and addressing the challenges they face in maintaining or finding employment while juggling caring responsibilities.
- The refreshed strategy should also give consideration to new initiatives to support carers of all ages such as introducing an employer 'kitemark' scheme for flexible working; greater rights to flexible working, for example through a right to flexible working by default; rights to paid and unpaid carers leave; and a full review of how the benefits system operates for carers.
- There is clearly significant scope for improvements to the benefit system for carers, including increasing the level of Carer's Allowance and reviewing the earnings rule in order to support and incentivise carers to remain in employment. There also needs to be a better system for older carers who often receive no financial support in recognition of their role, including a simpler system for those older carers entitled to claim means-tested benefits.

### **Supporting carers through transitions**

- Adjusting to a role as a carer can be practically and emotionally challenging, including adapting and maintaining the relationship between the carer and cared for person. The Strategy should reinforce the importance of emotional wellbeing within existing assessment and support services, as well as aim to deliver improved access to services such as counselling.
- Time spent caring can leave former carers at a significant financial disadvantage, particularly as a result of their significantly lower levels of private pension saving than the wider population. The refreshed Carers Strategy should consider how to improve

support for carers to ensure that they do not face life long financial disadvantage as a result of their caring role.

## Introduction

There are an estimated 2.75 million older people in England who need some form of help and support<sup>12</sup>, the vast majority of whom rely, at least in part, on informal help from family and friends. It is critical we do not underestimate the hugely important role informal carers play in supporting these older people maintain their health, wellbeing and independence in later life.

The social care system has also come to increasingly rely on the contribution of informal carers. Between 2005 and 2015 a £0.66 billion cut in spending on social care (most of which has been concentrated in the last 5 years) has led to systematic reductions in the availability of publicly funded services<sup>3</sup>. Over a similar period, we have seen trends towards a rising number of older people struggling with unmet needs and growth in both the total number and contribution of carers<sup>4</sup>.

And while it is imperative to resolve the crisis within our social care system, it is equally clear that an increasing older population will mean that informal carers will continue to play a growing part in providing help and support. Indeed, Carers UK estimates that over the next 20 years that we will see a 40 per cent increase in the number of informal carers<sup>5</sup>. Improving practical support for informal carers is therefore vital if we are to safeguard the health and wellbeing of those individual carers, the individuals that they support and ensure families and friends can continue to make a sustainable contribution towards the care of a loved one.

It is also important to recognise that many carers are older people themselves. Analysis by Age UK estimates there are now over 2 million carers aged over 65, 417,000 of whom are over the age of 80<sup>6</sup>. Meaning around 1 in 5 people (18.2 per cent) within the older population provide care for a family member or friend<sup>7</sup>.

Being an older carer can bring additional challenges. Nearly two thirds of older carers have a health condition or disability<sup>8</sup> of their own and they are often caring at quite high levels of intensity, especially those over 80 who are likely to be caring for a co-resident partner. Indeed, our analysis shows over 70 per cent of carers aged over the age of 80 are providing over 20+ hours of care a week, while 34 per cent are providing 35+ hours<sup>9</sup>.

Caring can be the cause of serious disadvantage in later life. Older carers may be affected by the impact of caring on their physical and mental health, income and leisure time. The impact of caring on income, pension accumulation and development of social networks can mean that caring at a younger age results in disadvantage in later life. Yet caring can also be a positive experience. Society should recognise carers' contribution, and ensure that they are supported to be able to live fulfilling lives whilst continuing in their caring role. Carers must not be expected to sacrifice their health and quality of life.

We welcome the commitments set out in the 2014 Carers Strategy, however we believe there is still a long way to go before all carers have access to support they need and deserve.

## Identifying people are carers

Identifying individuals as carers continues to be one of the most significant challenges to ensuring individuals receive access to services, information and support. Many individuals simply do not identify themselves with the language of 'carers and caring' but see their role as a natural part of their wider identity as a friend or family member.

There is clearly more work required to fully realise the ambitions set out in previous iterations of the Carers Strategy to ensure that those providing informal care and support are proactively identified and offered assistance. A report co-published by Age UK in 2013 showed that while over 80 per cent of carers had contact with at least one type of health professional, only 11 per cent had been first recognised as a carer by a health professional and only 7 per cent by a GP (the clinician they were most likely to have had contact with)<sup>10</sup>. As carers said at the time, a priority area for them was that there was better public understanding and recognition of carers. This issue was recognised by NHS England in their *Commitment to carers (2014)*, therefore **we would expect the strategy to reflect on what progress has been made since that was published and to be clear on further steps to ensure professionals consistently recognise and support carers, particularly GPs.**

However, there are three specific groups of carers that we believe are at greater risk of being overlooked and should be explicitly recognised within the refreshed Carers Strategy.

### ***Carers at a distance***<sup>11</sup>

Around half of carers do not live with the person they care for<sup>12</sup>. According to Carers UK's 2015 State of Caring Survey, of those 37 per cent lived within walking distance, 44 per cent lived within a 30 minute journey with the remainder living further<sup>13</sup>.

Earlier this year Age UK commissioned a survey of over 500 of carers aged 45 to 74 in order to better understand the experience of carers 'at a distance'. 60 per cent of those surveyed had experience of caring at a distance and were predominantly the adult offspring of the cared for individual, although it is worth noting that 15 per cent were friends or neighbours. The profile of these carers, the contribution that they make to supporting the person they care for, and the impact of a caring role on the carers themselves, all significantly differ from co-resident carers.

Carers at a distance provide fewer hours of care than co-resident carers, which you would expect, and are less likely to be providing personal care (though almost half were doing so). However they are more likely to be combining care with work, childcare and other responsibilities<sup>14</sup>. It is therefore perhaps unsurprising that some aspects of carer stress appear to be higher amongst carers at a distance than co-resident carers. For example, carers can find the unpredictability of care a major challenge, particularly in the long-term where it can leave their ability to remain in work in doubt. There can be added stress when the carer cannot be sure the person they are caring for is getting the right support when they are not there.

It is crucial that the strategy acknowledges this group and does not rely on assumptions about co-resident carers, particularly when identifying who is playing a caring role. For example, a carer at distance may use a different GP practice where there might be no

indication they are a carer unless the subject is raised. **The Strategy should set out further steps to ensure services and professionals all take proactive steps to identify potential carers.**

### ***Carers of those living in residential care***

An important subset of carers at a distance are those supporting someone living in residential care. It is all too often assumed that once an individual moves into a residential care setting then their family or friend's role as a 'carer' has come to an end as their caring responsibilities pass on to others. However in reality carers of those living in residential care largely continue in a caring role with, for example, 57 per cent providing support to manage finances and 53 per cent continuing to provide personal care. This strongly challenges the idea that families are increasingly unwilling to provide support to older relatives, even where it is necessary to move into residential care.

The Age UK survey found that the caring commitments of those supporting individuals living in a care home were also unpredictable and they were more likely than co-resident carers to report reduced time available for parenting or other caring roles, less time for leisure or holidays, an adverse impact on finances, and increased isolation due to reduced social opportunities.

As with all carers at a distance, fully supporting carers of those living in residential care will need a joined-up approach. Importantly, this approach should not leave people behind because of any perception that their caring role has diminished as a result of a person moving into care. **Residential care homes should be encouraged to identify carers and share this information with other professionals where necessary and with permission. Planning by GPs and other professionals should take into account the capacity of a person's carer/s, while not assuming that residents are wholly supported by the care home, and ensure the right information and support is made available.**

### ***Co-caring relationships***

Many older people live in, often long established, co-caring relationships, typically spouses or co-habiting couples (but by no means exclusively these). Mutual support, sometimes where both people have complex needs, enables such couples to continue living independently. However, this can lead to a number of additional complications. For example, such couples may not independently identify themselves as carers, seeing it as just a natural, and expected, part of their relationship. Where both have complex needs, it may not be clear to professionals if one or the other would be classified as the "carer", even though more likely than not, they both are. Where one person is outwardly well and fit, and more evidently the person playing a caring role, important issues such mental wellbeing and loneliness may be missed by professionals providing care for the other person. As such, the co-caring role (one providing support for daily needs, the other providing relational/psychological support) is not always outwardly clear.

In research we carried out with Ipsos MORI<sup>15</sup>, two households featured co-habiting families in which outwardly, there was a successful caring relationship between people living with frailty and a husband/grandchild respectively. Though basic needs were on the

whole being met, there were clear signs of poor mental wellbeing and loneliness, in the case of the carer in one instance and the person being cared for in the other.

**The Carers Strategy must be robust in identifying and supporting people living in co-caring relationships. This will mean a flexible approach to defining carers' needs that accounts for co-caring and the ability to incorporate caring responsibilities and needs into a person's own care plan where appropriate.** It must also acknowledge that small changes to a person's health and wellbeing can have a rapid and serious impact on their ability to care, thus impacting on their partner's health. Such situations can spiral very quickly, particularly for people living with frailty who will typically have lower physical reserves and recover less quickly from even minor shocks like an infection.

## **Access to assessment, services and support**

Prior to the Care Act, carers were entitled to local authority social services assessment. The Care Act 2014 added a further entitlement to receive support to meet eligible needs identified by the assessment process. Furthermore, in assessing carers' needs, local authorities should take the wellbeing of the carer into account rather than just the carers' ability to maintain their caring role. We would argue this is particularly important for older people in light of our points above on co-caring relationships.

So far, there has not been a full evaluation of the extent to which implementation of the Care Act is delivering tangible improvements in support for carers. In light of on-going and severe cuts to local authority budgets, we are not convinced significant improvements have been achieved. This is particularly the case when we consider a survey of councils in England published earlier this year that showed councils were not meeting duties to provide independent advocates<sup>16</sup>, with over 70 per cent of people expected to be eligible not receiving support. The same article highlighted the need for increased awareness amongst social workers of their statutory duties, and we would suggest there are clear parallels with carers' assessment.

Furthermore, a report by Age UK and Carers UK published last year showed that carers over 75 were less likely to have been offered a care assessment compared to 2006/2007, despite the growth in the number of carers in this group. In the same period, of those that were offered an assessment, almost 10 per cent fewer carers over 75 were then offered a service (as opposed to just information and advice)<sup>17</sup>.

**The next phase of Carers Strategy should undertake an evaluation of whether implementation of the Care Act is resulting in tangible improvements to the mental and physical wellbeing of carers.** In light of the outcome of such an evaluation, the Strategy should consider whether the duties will need to be strengthened or whether a more robust assessment process will need to be implemented, and ultimately monitored. This should include consideration of the extent to which local authorities are taking account of, and taking steps to reduce, social isolation experienced by carers.

Currently, local authorities only have to provide support if the carers' needs arise as a result of providing 'necessary' care, so much depends on whether local authorities interpret this as meaning 'necessary to ensure the cared for person's wellbeing', or more narrowly, 'necessary to meet needs which the local authority would otherwise have to meet'.



The reality is that support provided by carers goes well beyond providing 'care'. Carers provide emotional support, manage the cared for person's finances, act as advocates and represent the person's interests where they lack capacity. They can therefore be seen as supporting the status of the cared for person as a member of society and as a citizen with rights, and as far as is possible, freedom to determine how they live their lives. Carers may continue to play these roles even where a person is receiving care services such as residential care. **Assessment and subsequent decisions about how to meet the needs of a carer or the person they care for should take full account of the diversity of essential roles carried out by carers. Evaluation of implementation of the Care Act should look at whether local authorities are taking account of these roles.**

Finally, it is important that the transformation and funding of social care should not place increased demands on carers. Local authorities should not reduce local eligibility for care services where this will increase the burden on carers.

Between 2005 and 2015 the social care system has seen a £0.66 billion cut in real terms. The result has been a significant reduction in the availability of care, particularly domiciliary and community services as dwindling resources have been concentrated on those with the highest levels of need<sup>18</sup>. In 2005/06 15.3 per cent of people aged 65 and over received support with social care, this had declined to just 9.2 per cent in 2013/14<sup>19</sup>. As a result, more and more older people are reliant on a combination of informal care and paid for services. The impact is felt by both older people and carers. The Carer's UK State of Care report 2016 paints a bleak picture. 34 per cent of people surveyed reported a change in their care provision in the past year, and the majority (59 per cent) saw reductions in either their own support or services provided to the person they care for<sup>20</sup>. Those who are able to pay for support do not necessarily fare better. A recent survey for Employers for Carers and Carers UK, showed that 30 per cent of carers who had given up work, retired early or reduced working hours had done so because there were no suitable care services available, and 22 per cent because care services were too expensive<sup>21</sup>.

**Carers should be entitled to the support needed to be able to achieve an acceptable quality of life, defined in terms of mental and physical health and opportunities for social and economic inclusion. This should be taken into account when assessing the support requirements of the person they care for as well.** They should not be expected to sacrifice mental and physical health, or opportunities for education and personal development in order to carry out their caring role. The definition of carers contained in the Care Act should also be interpreted to include carers who do not live with the cared for person.

## **Valuing and involving carers**

**The Strategy refresh should build on the themes of the 2014 Strategy in relation to empowerment and involvement of carers, in particular the new Strategy should focus on measures to promote better communication between health and care professionals, carers and older people.**

We consistently hear from older people and older carers about, on the one hand, carers being excluded by health professionals from conversations about a person's care needs, even in the context of carers being central to meeting those needs; while on the other, older people being excluded from conversations, with carers or family members being

prioritised, often due to assumptions about their capacity to make decisions. The NHS and professionals must be more intelligent in how they involve carers, and the person being cared for, in all discussions about a person's needs and care plans. **Promoting formal processes for shared decision-making and training and supporting staff to carry this out, would make a significant difference to all parties being valued and involved in care.**

Further to the very basic expectation that carers are valued for their contribution and involved in decision-making, the strategy should address more formal involvement procedures such as those relating to mental capacity and deprivation of liberty. This relates not just to best interests decisions for healthcare but also to managing finances, particularly for people living with dementia. In this regard, **the Strategy must outline how people will be appropriately involved in, for example, assessments for mental capacity, including where professionals require additional training to support the process.**

The House of Lords Select Committee on the Mental Capacity Act 2005 pointed out the “general lack of awareness of the provisions of the Act has allowed prevailing professional practices to continue unchallenged, and allowed decision-making to be dominated by professionals, without the required input from families and carers”<sup>22</sup>. Carers can and should play a vital role in how this assessment takes place and under which circumstances it needs to be repeated (if for example people are better able to make decisions at certain times of the day or where someone does not have lasting power of attorney).

Finally, the **Strategy must also consider how the value and contribution of carers is fully recognised without compromising a person's ability to maintain autonomy and the ability to self-care.** In work Age UK carried out with National Voices and UCLPartners<sup>23</sup>, older people reported that daily tasks they had previously carried out themselves were “taken over” by carers, removing activities that were meaningful for them. This can risk compromising the ability to remain physically active, and could therefore contribute to physical decline. At the very least, there is a real risk to mental wellbeing where people can feel they have less value and purpose. Managing such situations, and avoiding a default to risk-averse practices (i.e. assuming someone is incapable of carrying out daily tasks or remaining active) can contribute to relieving some of the pressures on carers as well as improving the overall wellbeing of both people.

## **Support for carers to maintain their health and wellbeing**

Supporting carers to maintain good health and wellbeing is vital to both them and the person they care for. This is particularly important for older carers where we know that both whether you are caring and the length of time someone is providing care can have a severe impact on their health. Nearly two thirds of older carers have a health condition or disability<sup>24</sup> while 72 per cent of older carers report feeling pain or discomfort, rising to 76 per cent for those that provide 20 or more hours a week<sup>25</sup>. Older carers are also more likely to live with long-term back pain as well as feel anxious and depressed.

Supporting older people to engage with their own health needs is an important step to helping them improve their overall wellbeing or at the very least prevent it from deteriorating. Age UK, Carers UK, the Carers Trust, NHS England and Public Health England this year published a *Practical Guide to Healthy Caring*, which provides a helpful

template to help achieve this. **The Strategy should include measures for promoting a *Practical Guide to Healthy Caring* and other resources to help carers, particularly when they are starting out in their role.** The guide encourages people to be proactive in preventing poor health from materialising in the first place and highlights the crucial role that GP practices can play, for example in providing immunisation and referring to health check programmes.

**The Carers Strategy will, however, need to be mindful of the expectations placed on GP services and explore how improved support can be appropriately provided through the standard and enhanced contracts.** Importantly, communicating what is available to older carers and where to find additional support, is a crucial step to making sure such services are used.

All services must maintain a broad definition of who is a carer and, as such, we welcomed the focus of the 2014 Strategy on carers as part of the community. There is a considerable overlap between caring and community support. Age UK's research on caring at a distance found that 15 per cent of carers who did not live with the older person they cared for were friends or neighbours. Their health and wellbeing is no less important than those traditionally recognised as being a carer, however there is little research on what works in identifying and supporting this group. **The Strategy should seek to promote and encourage research into 'what works' in identifying and supporting non-familial carers.**

As we outlined above it is important the Strategy does not overlook the role and contribution of co-carers. There is a particular need to focus on supporting and maintaining the health of this group – i.e. where two or more people live together with similar care needs and who provide mutual support – since one person deteriorating can have a compound effect on both individual's health.

Older people, in general, are more likely to live with multiple long-term conditions and require support from health services to manage these conditions. As such, they should already be able to expect a joined-up approach to managing their health needs, though this is not always the case. When in contact with professionals, an older carer's caring role should be formally identified and incorporated into a care plan and their continued capacity to care used as a performance measure against that plan. **The Strategy should take steps to promote greater awareness and understanding of co-caring amongst professionals and the use of models such as the comprehensive geriatric assessment (CGA) where these are appropriate.**

### ***Supporting carers of people with dementia***

There are a number of steps the Strategy should consider for helping to manage and improve the health and wellbeing of carers. For carers of people with dementia, access to good respite care or support to take some time for themselves is crucial. Work that Age UK is currently undertaking engaging with people living with dementia and their carers has suggested that the availability of respite breaks makes the most significant improvement to a carer's wellbeing.

Age UK has set up 5 Dementia Service Pilot Projects in conjunction with Local Age UK's. The aim of the projects is to pilot approaches to wellbeing that could be adopted more

widely by local Age UK's. These projects support people with dementia but an evaluation shows that carers also benefit, and are indeed the main beneficiaries when the person's dementia is more advanced. Some examples of the support being offered include wellbeing coordinators; a social group project based around allotments for couples; and a dementia day care service that offers support to carers of people in the later stages of dementia. The projects also link people to Age UK information and advice services, and can extend the reach of those services by offering home visits.

These examples are not necessarily complex to set up, but do require investment and commitment from local commissioners, whether in local authorities or the NHS. **The Strategy should set clear expectations for the development of support services for all carers of people living with dementia, acknowledging their positive impact on the health and wellbeing of carers.**

## **Work and financial support**

### ***Working and care***

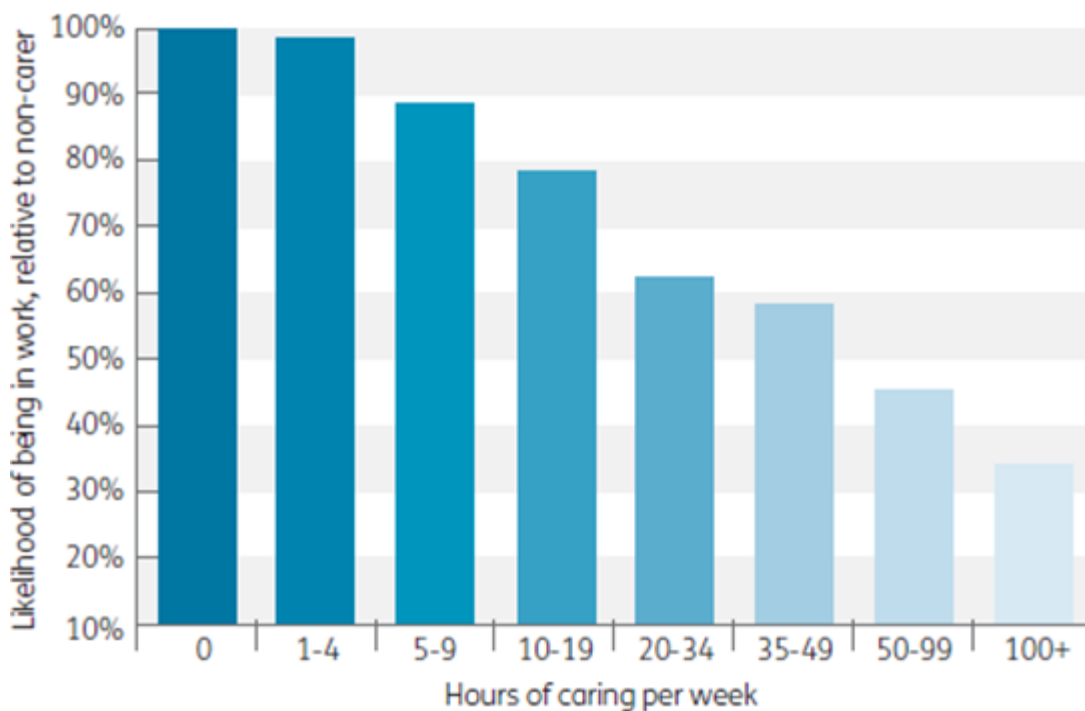
Juggling paid work and care is, more often than not, a significant source of stress for carers. Around half of carers combine paid work and care<sup>26</sup>, however many find they reach a point where they feel they have no option but to give up work or reduce their hours.

Carers UK's 2016 State of Caring report found that half of those surveyed (49 per cent) had given up work to care, a further 23 per cent had reduced their working hours while 17 per cent had taken a less qualified job or turned down a promotion to fit around caring. Of those who had given up work, taken early retirement or reduced their hours over two thirds (69 per cent) pointed to the stresses and challenges of trying to combine work and care as a contributing factor. Lack of suitable, affordable care services and lack of leave or sufficient flexibility were also significant factors<sup>27</sup>.

The public expenditure costs of carers leaving employment are also substantial at an estimated £1.3 billion a year<sup>28</sup>. However Age UK has estimated that the additional output from carers being able to work could be as high £5.3 billion per year<sup>29</sup>.

Earlier this year Age UK and Carers UK jointly published '*Walking the Tightrope*' on the challenges of combining care and work in later life, the report focuses on the experiences of older workers in their 50s and 60s. Analysis set out in the report reinforces the fact that, even after controlling for factors such as age and gender, caring is a major factor in causing older carers to give up work. However it is of huge concern that caring for as little as 5 hours a week has a significant impact on older workers ability to remain in employment, while ten hours or more causes large numbers of people to drop out of work altogether.

*Figure 1: Change in likelihood of being in paid work as a result of caring, Age UK analysis of Understanding Society<sup>30</sup>*



Sadly *‘Walking the Tightrope’* raises many familiar themes and challenges in supporting workers to remain in employment: lack of flexibility, difficulties in taking time off to manage transitions and crises, low awareness or poor attitudes on the part of employers, disincentives in the benefits system. On top of which older workers may struggle with entrenched age discrimination within employment that can see them further disadvantaged. 65 per cent of older people believe age discrimination still exists in the workplace<sup>31</sup>. Research has found that older workers are less likely to receive training than younger counterparts<sup>32</sup> and are more likely to have prolonged periods of unemployment<sup>33</sup>. In reality many older workers who leave the workforce as a result of their caring responsibilities may find they struggle to return.

The 2014 Carers Strategy had a welcomed focus on *realising and releasing potential* by focusing on strategies to support younger people and working age carers in employment; however within the refreshed strategy **we would also welcome a focus on supporting older workers and addressing the challenges they face**. This could include, for example, a commitment to additional training for Job Centre staff to better understand and support the needs of older workers who are carers or former carers. Employers too have a role to play by ensuring that carers are able to work flexibly to meet their caring responsibilities, and that their HR policies are functional and well-understood.

Nonetheless it is clear that more work is required across the board to support carers to juggle paid work and care. The refreshed strategy should give consideration to new initiatives such as **introducing an employer ‘kitemark’ scheme for flexible working; greater rights to flexible working, for example through a right to flexible working by default; rights to paid and unpaid carers leave; and a full review of how the benefits system operates for carers.**

### ***Financial Support***

Many carers who are unable to work are reliant on the benefit system, but this is complicated, and too often leaves carers having to manage on a very low income. Carer's Allowance is a benefit specifically for those who spend at least 35 hours a week caring, and is linked to the cared for person receiving Attendance Allowance, the Daily Living Component of Personal Independence Payment, or the middle or highest care rate of Disability Living Allowance. However, at just £62.10 a week, it provides little compensation for loss of earnings and it cannot be paid in addition to the State Pension. Many carers are surprised and angry to find that when they reach State Pension age, and start to receive their State Pension, the allowance stops, despite their role as a full-time carer continuing. Those with low incomes can sometimes claim means-tested benefits, including an additional amount for carers, but this can be a complicated procedure, especially for older carers. Some people have to go through the process of claiming Carer's Allowance, even though they know it cannot be paid because they receive a State Pension, in order to then claim Pension Credit with a carer addition.

There is clearly significant scope for improvements to the benefit system for carers, including **increasing the level of Carer's Allowance and reviewing the earnings rule in order to support and incentivise carers to remain in employment**. The earnings limit on Carer's Allowance (currently set at £110 per week – equivalent to 15 hours work at the National Minimum Wage (April 2016 rates) creates disincentives to work, particularly for carers whose earnings would be close to this level. A carer earning over £110 loses Carer's Allowance in its entirety. There also needs to be a better system for older carers who often receive no financial support in recognition of their role, including **a simpler system for those older carers entitled to claim means-tested benefits**.

However one key and positive feature of the current system is that, because support for carers is linked to the person they care for having been assessed and awarded a disability benefit, the actual assessment that someone *is a carer*, is relatively straightforward. However, the Government is currently considering devolving the support given through Attendance Allowance to those needing help in the future, to local authorities in England. Age UK strongly opposes such a move which could have a detrimental effect on older disabled people. We are also very concerned about the impact for carers as it would no longer be possible to link entitlement to Carer's Allowance and other benefits for carers to an older person receiving Attendance Allowance. **We therefore consider it vital that Attendance Allowance is retained as a national cash benefit that can 'passport' to Carer's Allowance.**

## **Supporting transitions**

### ***Adjusting to a role as a carer***

Adjusting to a role as a carer can be practically and emotionally challenging. Changes to life style, routine, working life and finances can all have a significant impact, as well as changes in family roles and the relationship between the carer and cared for person.

Age UK has recently undertake a series of focus groups through DEEP – the UK Network of Dementia Voices – the research involved 54 individuals living with dementia and 12 carers in order to better understand what 'makes a good life'<sup>34</sup>. The research highlighted the real importance of social relationships in maintaining wellbeing and quality of life, particularly between the carer and the cared for individual. Both carers and the individuals

they support describe difficulties in adapting to the changes in their relationship and their respective roles, particularly at the point they start to see themselves primarily as having a caring relationship rather than a partner, parent, son or daughter.

*My daughter has become my mum telling me what to do, she does my banking and everything she has taken over, she will get her leg smacked. (Individual living with dementia).*

*I find it quite difficult because I can't really have a discussion or anything. I don't bring things up. (Carer).*

*It is difficult at times, because I know what I used to do and I know what I can do and I mean my Mrs sees it now, I just feel sorry for her at times. (Individual living with dementia).*

A similar point emerged from our research into the experiences of carers at a distance<sup>35</sup>.

*I was in the weird situation of realising that my life was not what I thought it was..... We both recalibrated our relationship. It was a transition from being the child whilst my mother was the adult to the opposite. It felt like hitting a wall. (Carer).*

*It takes time to realise or accept that parents need support as it challenges existing boundaries or relationships. The point at which existing boundaries break down is often a key moment. (Carer).*

Supporting carers to adjust to changing circumstances, including adapting and maintaining the relationship between the carer and cared for person appears to be key in ensuring the wellbeing of the carer and in ensuring that the caring relationship is sustainable. **The refreshed Carers Strategy must reinforce the importance of emotional wellbeing within existing assessment and support services, as well as aim to deliver improved access to service such as counselling.**

### ***Life after caring***

Many carers have to come to terms with life after caring, often following bereavement, and it is important to recognise that the impact of the time spent caring can persist for long after the caring relationship is over.

Time spent caring can have a long lasting can leave former carers at a significant disadvantage, particular amongst women who are more likely to have taken on caring roles across the life course. Carers tend to have lower earnings, as a result of the challenges they face when in work, and these reductions in income often persist after the period of caring when individuals may find it difficult to return to work, increase their hours or regain lost ground in their career progression<sup>36</sup>.

Carers can also be left at a disadvantage as a result of their significantly lower levels of private pension saving than the wider population. According to recent research by the Pensions Policy Institute, people in receipt of Carer's Allowance have, on average, 96 per cent lower total savings in defined contribution pensions and 93 per cent lower savings in defined benefit pensions than the average saver<sup>37</sup>. And while changes to the state pension system should, over time, ensure that more carers retire on a full state pension, their



incomes overall are likely to remain lower. **The refreshed Carers Strategy should consider how to improve support for carers to ensure that they do not face life long disadvantage as a result.** This should include consideration of measures to ensure that carers who leave employment do not lose out of a private pension income in later life, for example by paying a credit for those who are eligible for Carers Allowance into a private pension account (similar to Carer's Credit which exists for the State Pension).

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<sup>1</sup> People aged 65+ in England living in the community who have difficulty with at least one activity of daily living or instrumental activity of daily living, including: dressing, bathing, walking, shopping, preparing meals, paying bills and getting in and out of bed.

<sup>2</sup> Marmot, M. et al. , *English Longitudinal Study of Ageing: Waves 0-6, 1998-2013* [computer file]. 23rd Edition. Colchester, Essex: UK Data Archive [distributor], June 2015. SN: 5050

<sup>3</sup> Age UK, *Health and Care of Older People*, 2015

<sup>4</sup> Ibid

<sup>5</sup> Carers UK, *Facts about carers*, 2015

<sup>6</sup> University of Essex. Institute for Social and Economic Research and NatCen Social Research, *Understanding Society: Waves 1-5, 2009-2014* [computer file]. 7th Edition. Colchester, Essex: UK Data Archive [distributor], November 2015. SN: 6614, <http://dx.doi.org/10.5255/UKDA-SN-6614-7>

<sup>7</sup> Calculation based on our analysis of *Understanding Society* and the *Mid-2014 Population Estimates UK Office for National Statistics*, 2015

<sup>8</sup> The Princess Royal Trust for Carers, *Always on call, always concerned: A survey of the experiences of older carers*, 2011

<sup>9</sup> University of Essex. Institute for Social and Economic Research and NatCen Social Research, *Understanding Society: Waves 1-5, 2009-2014* [computer file]. 7th Edition. Colchester, Essex: UK Data Archive [distributor], November 2015. SN: 6614, <http://dx.doi.org/10.5255/UKDA-SN-6614-7>

<sup>10</sup> *Prepared to Care? Exploring the impact of caring on people's lives*, Carers Week, 2013

<sup>11</sup> We use the term 'carer at a distance' to describe all carers who do not live with the person they care for, whatever their own age.

<sup>12</sup> NHS Information Centre for Health and Social Care, *Survey of Carers in Households 2009/10, 2010*

<sup>13</sup> Carers UK, *State of Caring 2015*, 2015

<sup>14</sup> ibid

<sup>15</sup> Ipsos MORI/Age UK, *Understanding the live of people living with frailty*, 2014

<sup>16</sup> <http://www.communitycare.co.uk/2016/01/13/social-workers-urged-review-practice-given-low-care-act-advocacy-case-numbers/> - accessed 28 July 2016

<sup>17</sup> Age UK/Carers UK, *Caring into later life: The growing pressure on older carers*, 2015

<sup>18</sup> Age UK, *Health and Care of Older People*, 2015

<sup>19</sup> Ibid

<sup>20</sup> Carers UK, *State of Care 2016*, 2016

<sup>21</sup> Carers UK and Employers for Carers, *Caring and isolation in the Workplace: Impact report and recommendations*, 2015

<sup>22</sup> House of Lords Select Committee on the Mental Capacity Act 2005, *Mental Capacity Act 2005: post-legislative scrutiny*, 2014

<sup>23</sup> Age UK/National Voices/UCLPartners, *I'm still me*, 2014

<sup>24</sup> The Princess Royal Trust for Carers, *Always on call, always concerned: A survey of the experiences of older carers*, 2011

<sup>25</sup> Age UK/Carers UK, *Caring into later life: The growing pressure on older carers*, 2015

<sup>26</sup> UK Census, 2011

<sup>27</sup> Carers UK, *State of Care*, 2016

<sup>28</sup> Pickard et al, *Overcoming barriers: Unpaid care and employment in England*, 2012

<sup>29</sup> Age UK, *Estimation of the Financial Impact of Leaving Work due to Caring Responsibilities*, 2012

<sup>30</sup> Age UK and Carers UK, *Walking the Tightrope*, 2016

<sup>31</sup> Age Concern and Help the Aged, *One Voice: Shaping our ageing society*, 2009

<sup>32</sup> Economic and Labour Market Review (February 2010) Table 6.10, Job-related training received by employees



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<sup>33</sup> 47 per cent of older people have been out of work for a year or more compared to only 33 per cent of 18-24 year olds. *Fuller Working Lives: A Framework For Action*, Department for Work and Pensions, June 2014

<sup>34</sup> Innovations in Dementia on behalf of Age UK, field work carried out between April and May 2016.

<sup>35</sup> Age UK 'Caring at a Distance' report 2016 (publication pending), focus groups carried out in North London and North East England in November and December 2015.

<sup>36</sup> Beesley L, *Informal Care in England: background paper to the Wanless social care review*, Kings Fund, 2006

<sup>37</sup> Silcock D., Popat S., Pike T. *The under-pensioned – Pensions Policy Institute*, 2016