



advice and support for older age
**Independent
Age**



**"You don't stop
the worrying"**

The difficulties of
caring in later life

 carersUK
making life better for carers

 Carers Week

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Introduction and overview

“...It's getting harder and harder because he is saying to me, 'Mum when you're not there what am I going to do?' and things like that... I can't even prepare, I just say, 'What will be, will be,' and I try my best, to do my best for him.”

Woman, over 70, caring for son with mental health issues

As people live longer with disability and illness, the number of unpaid carers is rising fast. Statistics show that three in five of us will likely end up caring for partners, family members or friends who are too frail, sick or disabled to manage on their own¹. Coping with the demands of this is challenging at any age, but older carers have particular concerns which are rarely discussed.

There are almost 1.3 million carers aged over 65 in England and Wales². They save the NHS and care systems billions of pounds every year³, but often pay a heavy price for their caring, facing a range of issues including:

- poor health
- loneliness and isolation
- reduced incomes
- problems accessing support services⁴.

The impact of caring on older people can be particularly acute because it comes on top of a range of other issues which often affect people in later life including reduced income, the onset of long-term conditions and reduced social networks. In addition, research shows that the older the carer is, the more hours of care they tend to provide – with more than half of carers aged over 85 providing 50 or more hours-a-week of care, further increasing the strain on them⁵.

1 Carers UK (2001), *It Could Be You* – A report on the chances of becoming a carer. Carers UK

2 Census 2011

3 Age UK (2010), *Invisible but Invaluable*, Age UK

4 Princess Royal Trust for Carers (2011), *Always on call, always concerned*, Princess Royal Trust for Carers

5 Age UK / Carers UK (2015), *Caring into later life: The growing pressure on older carers*, Carers UK

Furthermore, many older carers are currently coping without any support. A recent report by Independent Age and the Strategic Society Centre estimated that some 380,000 of the nearly half-a-million older carers in England providing more than 50 hours-a-week of care, do so without any support from their council⁶.

It is perhaps unsurprising, therefore, that analysis of the English Longitudinal Study on Ageing by University College London and the International Longevity Centre-UK (ILC-UK), showed that long term caregiving was associated with a decline in quality of life and life satisfaction for older carers and with an increased risk of depression. It also found that older people who had given up caregiving were at increased risk of depression – suggesting that the negative impacts of caring on people's later lives continue beyond the time that their loved ones move into care settings, or pass away.

However, still too little is known about the reality of older carers' lives, or about precisely how having been a carer continues to impact on older people after they stop providing day-to-day care. Too often older carers can remain hidden from view. Issues including low income and loneliness and isolation can leave them cut off from their wider communities – so their needs remain invisible.

Furthermore the tendency of many older carers to see the work they do as just another aspect of being a mother, brother, wife or friend, means that many do not recognise their 'carer' status, and do not access the support to which they are entitled.

For the first time, in 2015, Carers Week will include a special day dedicated to older carers. To ensure the work on this day was informed by the voices of older carers and reflected their experiences, Independent Age commissioned a series of focus groups and interviews with older carers to explore their experiences in more detail. We wanted to get behind the statistics to find out what issues most concern older carers, where they find support in their caring, and what more support is needed. We also wanted to explore the experiences of carers whose loved ones have moved into care settings, and of those who had been bereaved.

This report sets out the findings of this research and considers what action is needed, and what tools are available, to improve the experiences of older carers.

6 Lloyd J (2014), *The Bigger Picture: Policy insights and recommendations*, Strategic Society Centre and Independent Age, London

Some of the key findings are outlined below:

Impact of caring in later life

Older carers agreed that caring took a heavy toll on them, and had multiple impacts on their quality of life. It was clear that carers perceived that some of the impacts of caring were exacerbated by their age.

Particular impacts affecting older carers included:

- **difficulties keeping up with family and friends:** caused by limitations on free time, and a diminishing sense of shared experience with family and friends, and exacerbated by declining social networks associated with ageing
- **financial constraints:** caused by a lack of income and increased costs associated with caring, and exacerbated by the fact that carers in receipt of a state pension do not receive Carers Allowance
- **poor health:** caused by the strains of caring and failure to maintain health, and exacerbated by the onset of increased health problems due to ageing
- **stress:** caused by concern for loved ones and exacerbated by fears for the future, in particular about what would happen to loved ones when they could no longer provide care.

Support for older carers

Older carers identified a range of **gaps in support** available to them:

- carers made clear that the greatest cause of stress for them was the fear that their loved ones' needs were not being met – shortcomings in the care and support system were therefore a significant problem
- they highlighted problems in accessing care and support, with many feeling they had ultimately found support by accident and highlighting the complexity of the system as a real barrier
- they highlighted a lack of support from the wider community in their role as carers, highlighting help with accessing medical care as a key area where support would be valuable.

Former carers

'Former carers' made clear that there were important differences between the experiences of those whose loved ones moved into residential care or supported / independent living, and those who were bereaved.

Carers whose loved ones had moved into care settings explained:

- that they did not consider their caring role to have ended – as they still took on significant responsibility for their loved ones and experienced real impacts of caring

- that a loved one's move into care led to a range of stresses – including guilt and worry about their loved one and whether their needs would be met
- that many carers experienced a sense of bereavement when their loved ones moved away, but felt that this was not well understood by professionals and within the wider community
- that they were not supported in dealing with the ongoing issues affecting them when their loved ones moved out.

Carers who had been bereaved explained:

- that losing their loved one had a very significant effect as they had not only lost someone they loved, but also a whole way of life
- that they experienced a significant period of ill-health following their bereavement – with many feeling that the issues they had put off for some time “caught up with them”
- that little support was available to them in thinking through how to rebuild their lives following bereavement – and many feeling that some options including work and volunteering were no longer open to them due to their age.

Improving support for older carers

In considering ways to improve older carers, and bereaved carers' quality of life, a range of recommendations were set out.

Older carers' priorities included:

- improving carers' access to support, in particular by ensuring GPs play a part in identifying carers and signposting to support
- addressing inadequacies in care and support services available to carers' loved ones
- developing a 'carers' friend' service to provide one-to-one practical and emotional support for carers
- improving support for bereaved carers, offering them opportunities to find mutual support among those with similar experiences.

The number of older carers is only set to grow – with a recent report by Carers UK and Age UK projecting that there would be over 1.8 million carers aged 65 or over by 2030, with significant increases in the numbers aged 85 or over⁷.

We hope this report will prompt fresh action to address the needs of older carers, including those whose loved ones have moved into care settings, and bereaved carers, to reduce the burden on them and lessen the impact on their health and wellbeing.

⁷ Age UK / Carers UK (2015), *Caring into later life: The growing pressure on older carers*, Carers UK

How the research was undertaken

Two focus groups and four interviews were arranged with support from Islington Carers' Hub and Action for Carers (Oxfordshire), during April and May 2015. In total, we spoke to 28 older carers.

In Islington, carers known to the hub were invited to take part in a special focus group. In Oxfordshire, we joined a pre-arranged meeting for the focus group. These discussions were supplemented with face-to-face and telephone interviews with bereaved carers known to the Islington Carers' Hub.

All participants were notified that the focus of the research was 'older carers'. Carers taking part ranged from age 51 to age 90, with the majority aged 65 or over. They included people caring for spouses, siblings, adult children, cousins and friends, with a wide range of mental and physical conditions including dementia, multiple sclerosis, schizophrenia and cancer. Many cared for individuals with multiple complex conditions.

The impact of caring on quality of life

1

Older carers described a wide range of impacts of caring on their lives – with effects on their physical, emotional, social and economic wellbeing. Many carers identified particular impacts related to caring in later life, and spoke of how the impacts of caring were exacerbated by other factors associated with ageing such as loss of income, the onset of long term conditions and loss of social networks.

"For me, my experience with my son coming down 20 odd years, it was a heavy burden on me at times."

Woman, over 70, London
Caring for son with mental health issues

Emotional strain

Older carers described a wide range of stress factors related to their caring roles, including feelings of loss and guilt, as well as loneliness linked to a sense that others did not understand, or did not support, the work they were doing.

"It's very painful for them – and for us – to see the changes. My husband used to be a very social person; he used to have a lot of friends around and now he's very lonely... he's dependent on me..."

Woman, 52, London
Caring for husband

"But you feel guilty sometimes that you're struggling, you're working to get things for the people you're caring for and you think, 'Maybe I'm going about it the wrong way', so you feel guilty, then you feel low in yourself."

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother and husband

Several carers described the considerable strain that comes from caring for someone whose behaviour is unpredictable and who could be violent or aggressive. This particularly affected those caring for people with mental health issues and dementia.

“Even now on some days it’s so terrible and it’s surprising, the next day is just completely [different]; he’s so nice.”

Woman, over 70, London
Caring for son with mental health issues

However, the strongest theme emerging from consultations was the stress caused by poor care for people's loved ones, and by the fear of services being withdrawn or changed. Carers made clear that the greatest worry came from a fear their loved one's needs would not be met.

“Every time something’s taken away from a person you care for or threatened to be taken away... that puts stress on the carers. It’s not themselves, it’s the people they’re caring for.”

Man, over 65, Oxfordshire
Caring for 46-year-old son with severe learning disabilities

“I think it depends on how the care is going. When we’ve been through this Independent Living Fund thing I’ve had terrible depression and my quality of life... it’s been absolutely awful.”

Woman, 74, Oxfordshire
Caring for 38-year-old son who is quadriplegic and blind and who lives independently

A particular issue for older carers was the strain of worrying about the future and the fear of what would happen to their loved ones should they no longer be able to provide care.

“I said, ‘Oh my gosh, all these health conditions I have to cope with! I hope they wouldn’t get any worse than they are and, if they do, what would happen with him?... What would happen to him if I should pass away and he is then left on his own?’”

Woman, 74, London
Cared for husband with dementia.
Bereaved in 2009

“I would say at 50 plus I was caring; I was just start caring for my son... Yes, it was hard but as the years going on its getting harder and harder because he is saying to me, ‘Mum when you’re not there what am I going to do?’ and things like that... I can’t even prepare, I just say, ‘What will be, will be’, and I try my best, to do my best for him.”

Woman, over 70, London
Caring for son with mental health issues

Many carers described ways they had found to cope with stress including reliance on faith, coming together with other carers in support groups and getting involved with campaigning for better care.

Physical strain

Older carers clearly recognised the impact caring had on their physical health, and several argued that health considerations were a particular problem for those caring in later life.

"Well obviously as we get older our health is going to deteriorate anyway so it's bound to be more stressful and difficult at an older age."

Man, over 65, London
Cared for parents. Now caring for brother with severe disability

Carers recognised a range of features of caring which were detrimental to their health, including:

- sleep deprivation
- injuries caused by lifting
- failure to keep up medication and other care regimes leading to worsening of long-term conditions
- stress-related illness and mental health issues.

"It reminded me of being a day and night nurse at the same time, which is impossible... it's unbearable at times."

Woman, 74, London
Cared for husband with dementia.
Bereaved in 2009

"It's taken a physical toll on my health with all the problems that I went through with my mum, then has taken its toll on me now."

Woman, 65, London
Cared for mother who lived in sheltered accommodation.
Bereaved in 2014

Carers also acknowledged that they neglected their own health, in order to keep up their caring responsibilities. Several described instances when they had been forced to resume caring duties more quickly than advisable after periods of hospitalisation, because of a lack of appropriate services.

"I didn't have time to deal with my own issues, I had to put those aside and I was living on a knife edge because I was wondering what I was going to face the next day, what phone call was I going to get."

Woman, 65, London
Cared for mother who lived in sheltered accommodation.
Bereaved in 2014

I've recently been in hospital for a major operation. I started in January trying to get care for my husband because he can't be left. The day before I went into hospital I got the final say so that he could have the money from his personal budget to pay a local lady to come in to be with him when my daughter couldn't be around. The stress that caused to me when I'm going into hospital and I kept asking, 'When I come out what help can I get?', 'They'll arrange that in hospital.' But when I asked in hospital I was told, 'Oh you'll have to stay in an extra two weeks while we arrange that care.' So I had to come out... so I then had to go straight in and cope with everything."

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother and
husband

You've lost so many things that you participated in and suddenly you just can't do it. That's a bit of frustration but you can't help it"

Woman, 74, London
Cared for husband with dementia.
Bereaved in 2009

From an intellectual point of view it gets narrower and narrower because you cannot get out to things that might stimulate you intellectually. We can't any longer get down to town to the galleries, anything like that so you become intellectually moribund."

Woman, 68, Oxfordshire
Caring for husband with MS

I think the problem is when you start caring you never think about getting old and the stress when you are older is far more because you're very alone."

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother and
husband

Impact on social wellbeing

Carers explained that becoming a carer had a very serious impact on their lifestyles: on their ability to maintain relationships with family and friends and to keep up activities they enjoyed. For many carers it was clear that it was easier to give up their own activities and relationships than to arrange alternative care. Carers described feeling cut off and even imprisoned.



I don't have any family, I don't have any friends anymore – they've got fed up with the circumstances in which I had found myself. So they walk away, they walk away with the family."

Man, over 65, London
Cared for parents. Now caring for brother with severe disability

For many older carers we spoke to, it was clear that taking on caring duties had derailed their plans for later life, putting an end to the retirement they had envisaged.

I thought when we retire we had big plans because both of us were travellers – every year we'd go to Portugal or some country and I said, 'Oh when we retire we'll be travelling the world' but it never happened."

Woman, 74, London
Caring for husband with dementia

Carers identified the simple lack of time to keep up with other activities, as the main constraint on lifestyle. Several highlighted the failure of social services to provide timely and reliable respite care as a real barrier to keeping up a decent quality of life.

I can't understand that we've ever had a quality of life because if you've got a son who's 46 who can't be left on his own and that he gets 35 nights a year respite which quite often gets cancelled at the time he's going, even the day before, or it did on the same day once."

Man, over 65, Oxfordshire
Caring for 46-year-old son with severe learning disabilities

Impact on economic wellbeing

The impact of caring on family finances was raised by a number of older carers. Most carers hadn't been able to keep up work while caring, and now found themselves with limited resources for their later lives. Carers described a number of additional costs they faced as a result of caring for loved ones, including additional costs of heating, food, and equipment and travel costs incurred in visiting loved ones in hospital or in care settings.

I haven't had to think about the financial implications before but now I'm having to plan – 'Will our money last? How are we going to be?' and it all causes stress."

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother and husband

Every week I travel to Gloucester, apart from a weekend once a month when [son] comes home. It's all stress and finance."

Woman, 71, Oxfordshire
Caring for son with learning disabilities, now placed out of county

Positive impacts on quality of life

While carers were clear that caring was difficult and many felt it took a heavy toll on them, several also said that they derived pleasure from looking after people, and from the confidence that their loved ones were well looked after.

I would say when I was caring for my mum it was a pleasure because we got on so well we were like friends and she was very positive."

Woman, 65, London
Cared for mother. Bereaved in 2013

Implications for policy and practice

The issues raised in our discussions bear out the findings of previous studies with regard to the heavy burden borne by those taking on caring responsibilities, particularly in later life.

It is notable that our findings demonstrate the impact of caring on a range of areas which have been explicitly recognised as central to wellbeing in the definition the government adopted in the Care Act 2014. They also show the considerable detriment to older people's health that results from caring – with caring causing both ill-health directly, and health-harming issues such as loneliness and isolation. In this way it's clear that meeting the needs of older carers ought to be a core concern for a health and care system that is seeking to prevent avoidable ill-health and promote wellbeing.

And yet, far from being offered support to maintain their health, and to avoid crises, at present, many carers struggle to even access acute services effectively.

It's clear that reaching older carers and intervening early to meet their needs, must be recognised as a priority for the health and care system, given the huge implications of caring in later life for carers' health and wellbeing and the consequent costs to the system.

Older carers need tailored packages of support which enable them to keep up the activities and relationships that are important to them, and to give them space and time to maintain their own health and wellbeing.

To alleviate the particular strains caused by fears for the future **carers must be supported to make appropriate contingency care plans to give them certainty about what will happen to their loved ones if they should be unable to care.**

However, as they also made clear, they also need to be able to rely on a day-to-day basis on more effective services for their loved ones. These issues are discussed in more detail in **Section 3**.

Support for older carers

2

In this section we set out older carers' views about the support that is made available to them as carers – including financial support; packages of care and support provided by local authorities to meet carers' own needs and for respite purposes; carers' support services provided by the voluntary sector; and wider support from families and communities. Section 3 discusses the support for carers' loved ones.

It's notable that when we asked older carers about support which would make a difference to their lives, most tended to focus on the support that was available to their loved ones, rather than to them personally. It's clear that older carers do not themselves draw a clear distinction between the care that they receive themselves as carers and the care their loved ones receive.

Getting access to care and support

It had taken some time for several of the carers to recognise their carer status, and to become aware of the support available for carers. The majority had eventually accessed support following contact with a voluntary agency and many felt that statutory agencies tended to try to hide the support available to carers.

"

We was four years before they even said, 'You get this and you get that', and I said, 'We don't get anything, what are you talking about?' They don't want to tell you there's help, the social workers."

Man, 83, London
Cared for quadriplegic daughter for 30 years. Now caring for another daughter

Many carers argued the system was overly complex and that this created a barrier to getting appropriate help. Carers described being passed from department to department and having to keep up with a constantly changing picture of support.

"

There's no one place to go to get all the information. There are different organisations who provide different types of support but no one group or association provides all the information."

Man, over 65, London
Cared for parents. Now caring for brother with severe disability

Gaps in provision

Older carers' overall sense was that the support available to them was extremely limited. Those who had been offered services by statutory agencies, generally found their experiences to be poor. Problems included:

- poor quality services
- lack of flexibility
- services being cancelled or withdrawn without warning
- infrequency of respite
- services being inappropriate to their or their loved ones' needs.

Very few older carers spoke about receiving respite care and several of those who did receive it found it to be in adequate. Some carers had refused respite services due to poor quality.

Frequent respite... I make use of it but it's only once every nine months to a year and I feel... we were there a couple of months ago and I'm feeling the need already to have a break which I won't get."

Woman, 68, Oxfordshire
Caring for husband with MS

"They did say to me, 'Try and get away on holiday'. How could I get away on holiday when I... I couldn't relax on holiday knowing that my mum wasn't being cared for? When she could have messed herself and be sitting there in it?"

Woman, 65, London
Cared for mother who lived in sheltered accommodation.
Bereaved in 2014

Several carers reported frustration with having to pay for services which they felt would improve their quality of life. Some had turned down services because they had to pay. Others had experienced cuts to the services on which they relied.

You have to pay for anyone that comes in... everything, you have to pay for it. I need help in my garden and to Hoover because, you know, it would help, but I would have to pay for it. So what is the point speaking about help."

Woman, 52, London
Caring for husband

Most of the carers we spoke to were not in receipt of Carer's Allowance. Some had not accessed it at all and others did not receive it as a result of the 'overlapping benefits' rules. This was generally perceived to be grossly unfair.

"There's no acknowledgement from the government of what I'm doing, saving the nation billions. They don't really care do they?"

Man, over 65, London
Cared for parents. Now caring for brother with severe disability

However, others had less positive experiences. Some described high turnover of GPs leading to carers being forced to explain their circumstances over and over again. Others felt their doctor was indifferent to their situation, failing to recognise the potential impact of caring on their health and to offer support to them in their roles.

Support from health services

Many older carers recognised the important role that GPs could play in helping carers to access services, and to maintain their health. However, older carers reported very mixed experiences in seeking support from their GP and other health professionals. Those who had positive experiences mentioned the importance of GPs:

- remembering their circumstances
- being understanding
- offering flexibility around appointments
- being responsive.

"If I'm in trouble I phone up they say, 'We'll get the doctor to call,' and, 'I'll come round later and I'll have a look,' and things like that."

Man, 83, London
Cared for quadriplegic daughter, now caring for another daughter

"I don't go to my doctor really because they don't understand. I say they don't understand me or the situation so we don't bother them."

Woman, over 70, London
Caring for son with mental health issues

"Two months ago I had to have a scan on my shoulder which I've torn the ligaments on as well and when I pointed out that I was a carer they looked at me and said, 'Well, so what?'... They said to me, 'So what? Why are you telling us that?' And our GP never remembers. It's supposed to be there in front of them but I constantly – when I say constantly I don't often go – but when I do I have to remind them."

Woman, 68, Oxfordshire
Caring for husband with MS

Support from carers' organisations

The older carers we spoke to clearly valued their contact with carers' organisations very highly, finding solace and understanding in the company of other carers as well as accessing practical advice in how to deal with their loved ones and with the statutory agencies with which they had contact. Forms of support mentioned by carers included:

- access to social contact and social activities
- information and advice on entitlements and services
- mutual support from fellow carers.

"My biggest support is the [name] Carers Support Group which is a voluntary group... I think they saved my life actually."

Woman, 76, Oxfordshire
Cared for mother and husband, both with dementia. Bereaved in 2014

"My close family and them that he grew up with – I couldn't get to them. They doesn't understand the situation so I decided to leave it. Where I get my consolation is going to the groups to get some understanding and to meetings."

Woman, over 70, London
Caring for son with mental health issues



Given the fact that the carers we interviewed were identified via carers' organisations, it's unsurprising that most had accessed their services, joining support groups and /or receiving information about their entitlements. However, carers recognised the limitations of this support – highlighting the large number of older carers who never access this support. Carers also explained that this support was constantly under threat of cuts – with many carers having experienced services upon which they had previously relied being closed down.

"It's only going to get worse. I mean there's too many people needing help and no resources."

Man, over 65, London
Cared for parents. Now caring for brother with severe disability

Support from family and friends

While some older carers described receiving good support from family and friends in both practical and emotional terms, others felt let down by those around them, feeling that friends and family did not understand the reality of life as a carer.

"I have loads of support from my family and my friends, so what it's like for people who don't have that support I dread to think."

Woman, 74, Oxfordshire
Caring for 38 year old son who is quadriplegic and blind and who lives independently

[Family and friends] don't understand so I think they go along with their lifestyle what they know and just forget what the others are going through."

Woman, over 70, London
Caring for son with mental health issues

Support from the wider community

Experiences of support from the wider community were mixed. Some had positive experiences, with help from faith organisations mentioned by a number of carers; others described the limitations of community support, highlighting help with accessing healthcare as a key area where more support would be welcome.

I had a lot of help from the church, great friends, a great help."

Man, 90, Oxfordshire
Caring for wife with dementia

"As for community support, I think it very much depends on where you live. We find when we're up in Scotland with people we don't know we get a lot of support. I recently tried to start off in the village with the help of the Rural Community Council, a system whereby if anybody has an accident and needs to get to [hospital] and an ambulance won't come, there's a transport service within the village. And the parish council is not interested. There is no community support in our village at all."

Woman, 68, Oxfordshire
Caring for husband with MS

"Yesterday I had to go to the hospital. You don't want to always ask your friends, 'Could you come with me? Could you come with me?' ... My daughter was working and there just wasn't anybody there to say, 'Would you come with me?'"

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother and husband

Implications for policy and practice

It's clear that getting **access to carers' support** in the first place remains a very significant challenge for older carers. Evidently too many health and care professionals missed opportunities to recognise the work being done by the carers we spoke to, and to offer them support. It's vital we improve this situation so that older carers can receive timely support to minimise the impacts of caring on their health and wellbeing.

One way to do this is to empower older people with the knowledge of their rights as carers, and how to access them. However, it's in the interests of the wider health and care system for professionals to take a proactive approach, given the considerable impact of caring on health and wellbeing.

Current system reform offers a number of opportunities to improve the identification of older carers and these must be grasped.

The first opportunities come through the roll-out of the Care Act 2014.

The Act makes clear that new information and advice services for care and support should act as a resource to carers. However, our research shows that simply making a new service available will not guarantee older carers are reached.

Instead councils should treat older carers as a priority group for the proactive provision of information and advice.

The Act requires care and support services to focus on prevention, and gives carers new rights to assessment and support. This should lead to more carers being offered support to keep healthy and well, but we will need to monitor this carefully to ensure it is happening in reality. **Healthwatch England should consider launching an investigation into the impact of the Care Act 2014 on support for older carers.**

Another opportunity comes in the form of new responsibilities being taken by GPs for their most vulnerable patients, under the Transforming Primary Care programme, and the NHS Five Year Forward View, which makes clear that GPs and other health professionals need to take more responsibility for identifying carers, and particularly those aged over 85.

The majority of older adults – including some of the most isolated – have some contact with their family doctor. GPs could, therefore, play a vital role in connecting older carers with support services. NICE have recommended that two new indicators – around registering carers and providing information to them – be added to the Clinical Commissioning Groups Outcomes Indicator Set (CCG-OIS). Given our findings, **NICE's recommended indicators should be added to the CCG-OIS as a priority.**

Measuring GPs' performance would be helpful start in driving better standards, however **there is also a case for considering a wider duty on the NHS to identify carers and refer them to appropriate support.**

Our research also demonstrates that there are significant **gaps in the provision of support to carers.**

It's clear that older carers feel their roles are not adequately recognised by the statutory system – with no financial recognition of their caring work, or of the demands on their finances associated with caring, including the cost of paying for services. While some older carers acknowledged the role that carers allowance entitlement played as a 'passport' to other benefits, this did not mitigate the sense that the system was unfair. **The government should revisit how to better recognise carers' contributions, through the social security system.**

The carers we spoke to valued the support they had received from the voluntary sector and through mutual support organisations; however it was interesting that they did not feel that support for carers extended into the wider community. **One of the main themes of Carers' Week 2015 is creating carer-friendly communities, and it's clear from our research that this will be vital in ensuring that older carers do not feel cut off.**

Care and support services

The accessibility, availability and quality of care and support services for carers' loved ones came up time and again in our discussions. The majority of carers described difficult experiences for the family members and friends they cared for, including:

- problems accessing care and support
- unreliable and poor quality services
- threatened cuts to care packages.

Older carers made clear that these problems had a heavy impact on them, as well as on their loved ones.

Accessing care and support

Older carers described challenges in accessing appropriate care and support for their loved ones. Many had experienced being sent from one department to another trying to find the right person to speak to and several described a sense that authorities were trying to "pass the buck".

I think the other thing that would be helpful with all the problems that my husband has had for long enough before the cancer, we had never had a dedicated social worker.

We have always had a different person turning up who then has to ask the same questions. They don't even seem to pass the file on."

Woman, 68, Oxfordshire
Caring for husband with MS

And suddenly... you can read all these leaflets, you can ring all these people but when it comes to actually helping, there's very little."

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother
and husband

Several of the carers we spoke to had taken direct payments to support their loved ones, but some had experienced problems in using these flexibly, and others felt they placed unnecessary burdens on carers:

I think the other thing about these payments which we have refused to take, these direct payments, is it puts so much more onto the carer which is why we've refused to have it."

Woman, 68, Oxfordshire
Caring for husband with MS

Those carers who had been able to access care and support which they were happy with often described a "battle" with social services.

"That's me, I'm a Rottweiler when it comes to this. I've done it all myself."

Woman, 74, Oxfordshire
Caring for 38 year old son who is quadriplegic and blind and who lives independently

Others felt that they had stumbled upon good provision by chance, rather than by design.

"I think things can happen that I don't think everybody gets the same sort of things happening... It's very haphazard as to what sort of help you get when."

Woman, 79, Oxfordshire
Cared for husband.
Bereaved in 2015



Several carers highlighted instances in which they had turned down services because they felt they were not appropriate to meet the needs of their loved ones, either because they weren't the right quality, or because they were not provided in a suitable location.

"They wanted to send my husband to Timbuktu, you know, miles away from me, and I've done such an excellent job, I mean caring, and you want to then like separate us?"

Woman, 74, London
Cared for husband, with dementia.
Bereaved in 2009

Quality of services

Older carers raised a wide range of concerns about the quality of services and described experiences of poor care and support from a range of providers including home care services; district nurses; occupational therapy and care homes.

The poor quality of care created burdens for carers, many of whom had had to step in when care-workers had not provided quality care.

"...for me the carers were alright but not brilliant. They weren't brilliant because I've had to supervise them, tell them what to do and had to keep an eye on them."

Woman, 65, London
Cared for mother. Bereaved in 2013

"We had an incident... where she took him out of bed in a sling... he was doubly incontinent on the floor and she was just leaving him swinging in the hoist because she didn't know what to do... It's demeaning for him, he's a very particular person with regard to personal hygiene, he always has been, so this kind of thing doesn't help."

Woman, 68, Oxfordshire
Caring for husband with MS

"Going in one day when they said they were feeding my aunt to find a beaker caught up in a towel, a blanket with a straw pointing towards her mouth and a biscuit on her shoulder. Is that care?"

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother and husband

The closure of the Independent Living Fund, and resulting cuts to the services available to carers' loved ones were a cause of particular concern for some of the older carers we spoke to.

"We've been having quite a battle to get his care paid for since the closing of the Independent Living Fund... They wanted me to leave [my son] alone at night in his place in [village] which is not a home. The bungalow's in a remote area; he can't move, he can't see, they wanted me to leave him alone all night. They weren't prepared to pay for that and I said, 'That's just not going to happen.'"

Woman, 74, Oxfordshire
Caring for 38 year old son who is quadriplegic and blind and who lives independently

Carers felt that the system was not geared up to meeting individual needs, with several highlighting particular concerns around:

- inflexible systems
- high staff turnover
- lack of handover
- inadequate time allocated to care visits.

"As I say, a quick dab, a stale sandwich and a cup of cold tea and they're onto the next clients... Fifteen minutes is ridiculous... you need an hour at least."

Man, 83, London
Cared for quadriplegic daughter for 30 years. Now caring for another daughter

"Some of them, the ones who've been in it for longer are very competent but the shadowing is not sufficient, it's not enough training."

Woman, 68, Oxfordshire
Caring for husband with MS

Positive experiences

However others made it clear that not all experiences of care and support services were negative, attributing the main difference to the character of the individual providing the services, rather than any institutional factors.

"During all the time you're meeting people who are perhaps helping you, who are paid to do it but also volunteers there, and there are some of them who've got this ability to be carers and this extra little bit of the caring because they are carer-people, makes a lot of difference to you who are suffering if you like."

When you meet it, it helps your day and it helps the patient's day, even if they've got dementia they can recognise it."

Man, 90, Oxfordshire
Caring for wife, with dementia

Implications for policy and practice

It's clear from our research that the well-documented shortcomings of the care and support system don't just impact on people in need of services, but also on their carers.

The Care Act 2014 promises significant changes in the care and support system, which have the potential to improve the care and support available to individuals, and their carers. However, local councils risk being unable to realise the full potential of the Care Act reforms given the parlous state of care funding.

Without action to close the £4.3bn funding gap which, according to projections from the Local Government Association (LGA) and Association of Directors of Adult Social Services (ADASS)⁸, will open up in the care system in the next decade, we cannot hope to lessen the burden on older carers.

But funding is not the only solution, carers made clear that quality of care was also a significant issue and this cannot be improved with money alone.

It is, therefore, extremely positive that NICE are currently working on guidelines for home care which we hope will drive improvements in some of the key areas identified by carers. Given our findings, we believe it's **vital that these bring an end to inappropriate 15-minute care visits, and give people a reasonable expectation of continuity of care.**

It is also vital commissioners in local councils give regard to the importance of reliability of care, given the heavy burden that can fall on carers when they are unable to rely on formal care arrangements. **Commissioners should measure performance against indicators of reliability and timely care planning in contracting with home care organisations.**

⁸ LGA / ADASS (2014), Adult social care funding: 2014 State of the nation report, LGA / ADASS

4

Former carers

We held discussions with a number of older carers who were no longer involved in day-to-day caring activities. Some of these had loved ones who had moved into residential care or supported / independent living. Others had been bereaved.

Carers made clear that there was an important distinction between the experiences and needs of those whose loved ones had moved into residential care or supported / independent living – who still considered themselves to be carers – and those who were bereaved. Many felt this was not properly recognised, either by support services or the wider community.

Impact of loved one moving to care

Older carers discussed a range of issues which affected them when their loved one moved out of the family home. For some the experience had been positive, as finding a good placement had meant they could relax knowing their loved one was well cared for. However, carers felt strongly that they didn't stop being carers when their loved ones moved out, and that they still faced a range of issues.

Emotional strain was still a significant issue for many carers. Carers described experiencing ongoing worry and also feelings of guilt at the thought that someone else was now caring for their loved ones.

"When my father went into care, putting him directly from an episode of illness in a hospital and having to go and find a care home in itself was a difficult experience but when he got into the care home, we found the difficulties of letting go and giving care to somebody else; giving the responsibility of looking after my dad in the right way and how we would like him to be looked after and his lifestyle that he used to have, that caused huge emotional waves on me, not least the financial side of it and the guilt feelings but also that emotional feeling that the quality of care that he was going to get was not going to be right."

Woman, 51, Oxfordshire
Cared for father

"You don't stop the worrying."

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother and husband

Carers described experiencing a sense of loss akin to bereavement, which was made more difficult by their sense that their loss was not acknowledged or understood by those around them.

"When my husband went into care that actually felt like a bereavement because that was when I really lost him. I'd lost him a long time ago in that he had dementia but his physical presence was there but when he went into care then it's getting used to being by yourself at home and not having anybody you can say, 'Oh you know so and so...', that kind of thing. But on the whole people didn't treat it as though it was a bereavement because he was still there and so I was very much left on my own."

Woman, 76, Oxfordshire
Cared for mother and husband, both with dementia. Bereaved in 2014

"They just said, 'You've got a life now [name].' I said, 'I've always had a life.' I just felt, 'You don't understand.' ...People don't realise you've always had the life

but your life has been so taken up with your children, with your husband, you just don't look outside for anything more. When they've suddenly been taken away from you, but they're not dead they're still there, it's such a hard thing to accept."

Woman, 71, Oxfordshire
Caring for son with learning disabilities, now placed out of county

Impact of bereavement on carer

For those older carers who had been bereaved, it was clear that many had struggled to come to terms with their loss. Many felt their grief was intensified by the fact that they had not only lost their loved one, but also a way of life they had known over many years.

"People think once a person has died: 'Oh that's a release, nothing to think about', 'You are alright, you are fine'. It's not true for everyone... It was like a turmoil, just, that would be the word. Your whole life is just turned around and you have to know, again you have to look at coping, coping mechanisms or coping strategies."

Woman, 74, London
Carer for husband with dementia.
Bereaved in 2009



Carers described a lack of support around this period. Many had struggled with the practical requirements, both leading up to, and following their loved-one's death. They also described a sense of support falling away immediately following bereavement.

Because you haven't been through it before you don't quite know what to ask for – although I'm pretty good at asking when I know what to ask for. I think you just get so tired and also I had had interrupted sleep for a long time. I think actually when he died I was in an awful state."

Woman, 79, Oxfordshire
Cared for Husband.
Bereaved in 2015

You've often had quite intensive support in some ways around you in the lead up to the death because they are so very ill and then suddenly everything stops and suddenly you're absolutely cast adrift from the networks that had become quite strong to you and who have provided a lot of emotional support."

Woman, 61, Oxfordshire
Caring for daughter. Cared for another daughter who passed away 10 years ago

Several older carers described a period of intense ill-health following bereavement – partly caused by the strain of caring especially in the last days, and compounded by the grief. This ‘health crash’ lasted a number of months for many carers, and required intensive support from health professionals and from friends and family to overcome.

I'm gradually getting there. The main thing is I'm trying to get myself together now; get my health back into shape. I'm hoping to go and see my daughter. I'm able now to meet up with a few of my friends now and that."

Woman, 65, London
Cared for mother who lived in sheltered accommodation.
Bereaved in 2014

Support for bereaved carers

Most older carers who said that they had been supported following bereavement flagged the efforts of family and friends, rather than agencies. However, some had found family and friends to be demanding, rather than supportive.

All my time was taken up, then the person has gone and you find that you're not getting any support from friends or family. I mean I had a situation where even though I was grieving friends still wanted me to do things for them."

Woman, 65, London
Cared for mother. Bereaved in 2013

Those who had received support from organisations, had accessed this through organisations or professionals they had known prior to their bereavement, rather than through specialist agencies.

I give a lot of credit to my GP... I would say GP and consultants. If you are giving a score I'd put them number 1... they have realised that, 'Oh you need a lot of attention, continued attention."

Woman, 74, London
Cared for husband with dementia.
Bereaved in 2009

I went to my doctor and I had three sessions with a bereavement counsellor which helped, that helped, and I was told if I needed more I could come back."

Woman, 65, London
Cared for mother. Bereaved in 2013

Rebuilding lives after bereavement

Following bereavement, older carers had had to find new activities to fill their time. Most described social and leisure activities as their main pastime, and many had been able to re-engage with activities, and with friends and family, that they had not kept up with while they were caring.

"Well, I still see friends and get around a bit and go on the buses and have a drive and go to the seaside when the weather's good and things like that, yes. So I think I'm doing what I want to do... I think I have more time for that."

Woman, 65, London
Cared for mother. Bereaved in 2013

However many carers felt constrained by their age and health, perceiving that many options were no longer open to them, or that they were no longer well enough to consider them.

"I would love to work if I could get a job but someone at my age wouldn't even be considered. I did try and you don't even get a response."

Woman, 65, London
Cared for mother who lived in sheltered accommodation.
Bereaved in 2014

“For me, I think I’m too exhausted to even think about going to look for work but some people might want to do it and that’s the option that they should take.”

Woman, 65, London
Cared for mother. Bereaved in 2013

Several older carers also found their options constrained by their financial position. Many had given up work and depleted all of their assets during their time caring.

"There's loads of things I would like to do but the money is a problem because I'm only on a pension and at the moment my savings are going down at a rate of knots and I'm going to have to go on benefits soon so I've been ringing up to find out what I'm entitled to and I've just found out that I might have to pay bedroom tax and things like that. Money again is an issue."

Woman, 65, London
Cared for mother who lived in sheltered accommodation.
Bereaved in 2014

Notably several carers who had started caring for one family member had gone on to care for others following bereavement.

There were mixed feelings about this, with some finding caring a pleasure, and others feeling burdened by the need to take on further caring.

I started really caring when my mum got Alzheimer's, so I looked after her at home for 15 years. As a result, it snowballed with other people and so she died in 1985 but I still do things for other people. I'm told I should keep my mouth shut because I'm doing too much but I get pleasure out of it."

Woman, 85, London
Cared for mother. Bereaved in 1985.
Now caring for friends

I think people probably thought that, 'you're a carer come and care for me', and I thought I don't want to care. I did it for my mum but if I can help you in any other way I will. But to expect it of me was a bit too much, especially after I'm still grieving."

Woman, 65, London
Cared for mother. Bereaved in 2013

Implications for policy and practice

Still too little is known about older carers, let alone how older carers cope when their involvement in providing day-to-day care comes to an end. From the research we carried out, it became clear much greater consideration needs to be given to 'former carers', particularly when they support a loved one to move into a formal care setting, or when they are bereaved.

It's clear that older carers who are bereaved require a different response from policymakers, providers and the wider community, to those whose loved ones move into care settings. It's inappropriate to consider both groups simply to be 'former carers'.

For carers whose loved ones move into residential care or supported / independent living there is a **need for greater awareness, particularly among professionals, of the ongoing roles these individuals play in care provision**. It's important for carers' emotional wellbeing that these roles are acknowledged, and that they can be facilitated to provide ongoing support. But there is also a need for support beyond this.

The failure to take account of the ongoing role of the carer in their loved one's life can leave them carrying a heavy burden without any support.

These issues need to be factored into assessments of carers and their loved ones, particularly as developing and / or maintaining relationships is recognised as a key outcome within the eligibility criteria for care and support in the Care Act 2014. It's therefore vital that in assessing the suitability of placements for carers' loved ones consideration is given to the carer's role; and, **in assessing carers whose loved ones have moved into a care setting, consideration is given to the impact on carers ability to maintain relationships – so that support can be provided to enable carers to visit and keep in touch.**

For bereaved older carers it's clear that there are substantial gaps in provision, and huge missed opportunities to offer appropriate support. Older carers need a range of support with both practical and emotional issues, both in the period immediately following bereavement and in the months beyond when they start to rebuild their lives. Many older carers have built up enormous expertise during their period of caring, which if they wanted, could be very usefully channelled into paid work volunteering, or other fulfilling roles. Given our ageing population, and the increasing reliance of the nation on older workers and volunteers to maintain the economic and social wellbeing of our communities, it's short-sighted not to support older carers to rebuild their lives.

There is enormous potential for targeted social, emotional and practical support to enable older carers to rebuild their lives following the death of their loved ones. However, given the common experience of a 'health crash' following bereavement, careful consideration will be needed to establish how and when it is best to offer support to bereaved older carers. **Statutory bodies and voluntary sector organisations should work together to consider how to target 'former carers' with appropriate support with a view to enabling people to rebuild a sense of purpose and connection to their community.**

Priorities for improving support for older carers

5

We asked carers what they felt should be the priorities in improving the situation of carers in later life. Few of the carers we spoke to spontaneously suggested new services for carers, and instead focussed on the wider system. Perhaps unsurprisingly, given the emphasis they placed on their loved one's happiness as a factor in their wellbeing, many were keen to see improvements in the provision of formal care and support.

"I think more money into social care because until more money goes into social care the National Health will remain a mess."

Woman, 78, Oxfordshire

Cared for son until he moved into independent living in early 30s. Now caring for husband with undiagnosed memory issues.

However, when encouraged to think about support for carers themselves, most prioritised increasing the capacity of the voluntary sector to respond to their needs.

"I would think because of personal experience it seems to me support from non-government organisations is more consistent and more helpful than what you ever seem to get from officialdom who seem to view some of us with suspicion."

Man, 51, Oxfordshire
Caring for friend with mental health issues

A 'Carer's Friend'

During the focus groups, the idea of a 'Carer's Friend' was raised and received a lot of support. Carers wanted a named individual to "stand alongside" them in their role as carers, providing practical support in navigating the system – taking away the burden of calling multiple agencies to answer one query – and also provide emotional support, especially when times were hard. Carers argued that this role may well be suited to volunteers, drawn from among those who had also "been there" as carers.

"I'd like to see a carer's friend; somebody who would be there to help you look up things; would be the person who helped you with all the things that need doing; would point you in the right direction. If every carer had somebody that they could actually befriend, like a befriendeer really, it wouldn't cost that much and in fact probably you could get volunteers but it would be somebody that they could ring, they could rely on, there may be two people that work together."

Woman, 71, Oxfordshire
Cared for aunt. Bereaved in 2015.
Now caring for mother and husband

"If you had one person – you go to somebody for that, somebody else for this and that – and if you had that one person that would be great."

Man, 90, Oxfordshire
Caring for wife with dementia

A 'former carers' group

In conversations with older carers who had been bereaved several said they would have liked to have access to a 'former carers' group, which would bring people with a similar experience together, for mutual support. It was clear that bereaved carers wanted to have the opportunity to share their experiences with others in a similar position, and weren't able to explore these issues in detail in general carers' groups, where others were still actively caring.

"I still attend the Carers' Hub but I feel that there could be some – after the person has passed – there could be some sort of group for people who are grieving... If there could be something that in the area that you could come, the carers could come and share their experiences after the person passed away and talk that would be helpful."

Woman, 65, London
Cared for mother. Bereaved in 2013

Implications for policy and practice

It's clear that, while older carers value the support of voluntary organisations and mutual support groups, they would also value more one-to-one support in their caring roles.

Concepts similar to that of the 'Carer's Friend' have been tested in other areas – for example, through Timebank's 'Carers Together' programme, and through peer-to-peer schemes run by carers' organisations. And these have had some positive results, including improved emotional resilience and reduced social isolation⁹. However there is clearly potential to build on these models, widening access to such support.

The NHS Five Year Forward View endorses the need for improved support for carers and recognises the potential of volunteer-led schemes in taking this forward. As this programme rolls forward **the statutory and voluntary sectors should work together to explore possibilities for a Carer's Friend approach**. Such a scheme would be most likely to be effective if developed from within pre-existing carers' support organisations, which could offer training and offer support to Carer's Friends, with the volunteers recruited from among those with prior experience of caring.

Volunteer-led schemes, along the lines of the Carer's Friend could offer a rewarding way for bereaved older carers to apply their expertise, and to find a new routine, or sense of purpose. However, it's clear that a wider range of support will be required, if we are to meet the needs of all carers.

From our discussions it is clear that older carers feel the voluntary sector could play a role in developing more mutual support groups for 'former carers'. Many carers' organisations already run such groups, offering 'former carers' a time-limited ongoing connection with a familiar organisation. However, there are concerns that in some cases these can unhelpfully 'lock' carers into a relationship with their past rather than supporting them to look to the future.

It would therefore be fruitful to explore how 'former carers' groups might be developed in a way that linked more explicitly to outcome-focussed support, designed to help bereaved carers find new ways of using their time, talents and resources in later life. This should include support for mental wellbeing alongside opportunities to explore options including reskilling and employment, wider volunteering and social and leisure opportunities.

⁹ <http://timebank.org.uk/sites/timebank.org.uk/files/Carers%20Together%20evaluation%20report%20FINAL.pdf.pdf>

Conclusions

Our discussions have helped to illuminate in more detail the complex web of issues faced by older carers, and some of the particular concerns faced by those caring in later life.

It's clear that there are significant missed opportunities to reach and support older carers and that the consequences for individuals' health and wellbeing are profound, and sometimes devastating.

The reform of the health and care system currently underway as part of the NHS Five Year Forward View and the implementation of the Care Act 2014, offers opportunities to improve support for older carers, and to reduce the burden of preventable ill-health and dependency within this group. There are also real opportunities to better support 'former carers' contributions to the wider community, and particularly to increase opportunities for older carers' to use their skills and experiences.

Drawing on our findings, we make the following recommendations:

For older people

- Older people need to be empowered with the knowledge of their rights as carers, including their new rights under the Care Act 2014.
- Older people need to be mindful of the impact of caring on their health, and ready to speak out when support is needed.

For the voluntary sector

- Organisations supporting older carers should look at expanding or creating "Carer's Friend" type services, to give older carers access to one-to-one practical and emotional support.
- Organisations supporting carers should explore how 'former carers' groups might develop more links to outcome-focussed support for bereaved older carers.

For local authorities

- Older carers should be treated as a priority group for the proactive provision of information and advice regarding care and support for them and their loved ones under the Care Act 2014.
- Local authorities must ensure older carers are able to make contingency care plans to give them certainty about what will happen to their loved ones if they can no longer provide care.
- Local Health and Wellbeing Boards should consider how the areas within their responsibility can work towards becoming 'Carer-Friendly Communities'.
- Commissioners should measure performance against indicators of reliability of care visits and timely care planning in contracting with home care organisations.
- In assessing the suitability of residential care placements for carers' loved ones, consideration should be given to the carer's ongoing role in their lives and how this can be facilitated.
- In assessing older carers whose loved ones have moved into a care setting, consideration should be given to the impact on carer's ability to achieve outcomes around maintaining relationships, as recognised within the eligibility criteria set out in the Care Act 2014.

For Healthwatch England

- Healthwatch England should consider launching an investigation into the impact of the Care Act 2014 on support for older carers.



For the health and care system

- Reaching and intervening early to meet the needs of older carers must be recognised as a priority for the health and care system, given the huge implications for their health and wellbeing and the consequent costs to the system.
- To incentivise GPs to be proactive in identifying and supporting older carers, NHS England should include the two new indicators around identifying and providing information to carers – recommended by NICE – in the Clinical Commissioning Groups Outcomes Indicator Set.
- The NICE guidelines for Home Care should support an end to inappropriate 15-minute care visits, and give people a reasonable expectation of continuity of care.
- Professionals must recognise the ongoing roles that carers play in the lives of loved ones who have moved into care homes / supported living.

For central government

- The Department of Health should consider the case for a wider duty on the NHS to identify older carers and refer them to appropriate support.
- The government should look again at how to recognise the contribution of older carers in the social security system.
- The government must act to close the £4.3bn funding gap which, according to projections from the LGA and ADASS, will have opened up in the care system in the next decade.



For joint working between the statutory and voluntary sector:

- The statutory and voluntary sectors should work together to consider how best to meet the current gap in provision of targeted social, emotional and practical support to enable older carers to rebuild their lives following the death of their loved ones, with a view to enabling people to rebuild a sense of purpose and connection to their community.
- The statutory and voluntary sectors should work together to explore possibilities for a 'Carer's Friend' approach for carers who may benefit from additional support.

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