

Retirement on Hold

Supporting Older Carers



Acknowledgements

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Introduction



The 2011 Census (UK Census, 2011) revealed that there are over 1.8m carers aged 60 and over in England including:

- 151,674 between 80–84.
- 87,346 over 85.

The number of older carers is growing all the time, those aged 85 and over grew by 128% in the last decade (Carers UK and Age UK, 2015).

Older carers have their own specific needs. They often go unidentified because they do not recognise themselves as carers or are not identified by services. With an ageing population and the increase in the life expectancy of people with disabilities; people are caring for longer and later in their lives.

Carers Trust has been funded through The Dulverton Trust and The Headley Trust to undertake work around the needs of older carers. We wanted to increase the knowledge of their needs and look at what we need to do to help them and potential carers plan for the future. This included finding out:

- What issues were faced by older carers?
- What if anything they wish they had known sooner?
- Did they plan ahead for caring?
- Had they discussed future care needs with family/friends for themselves and others?

The information will be used as part of a campaign which aims to increase awareness and recognition of the issues faced by older carers, and to influence policy affecting them.

Although the research findings apply to England the general guidance is applicable across the whole of the UK.

Methodology



During our consultation we held six focus groups with older carers in England:

- Birmingham Dementia Information and Advice Service (Crossroads Care Sandwell, Walsall & Wolverhampton, Carers Trust Network Partner).
- Sutton Carers Centre (a group for former carers) (a Carers Trust Network Partner).
- Suffolk Family Carers (a Carers Trust Network Partner).
- Camden Carers Service (a Carers Trust Network Partner).
- Hadleigh Peer Support Group.
- Forget Me Not Group for carers and people with dementia (Suffolk).

Profile

92 people attended the groups in total from a mix of rural and urban areas. The majority of carers were aged 60–80 and a small number over 80. The oldest carer was 88.

There was a range of carers from different Black, Asian and minority ethnic groups, and social backgrounds and the focus groups included carers from England, other European countries, Asia and the Caribbean. The Birmingham group was particularly diverse with approximately one third identifying as Asian, one third African or Caribbean and one third white British and white Other.

In addition to the focus groups, seven carers and one former carer were interviewed in person, over the phone or via e-mail.

About Carers Trust

Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, **unpaid**, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners, through our unique online services and through the provision of grants to help carers get the extra help they need to live their own lives. With these locally based Network Partners we are able to support carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is that **unpaid carers** count and can access the help they need to live their lives.

Issues raised by older carers



Care coordination

The issue of care coordination came up at all the groups and with most individuals. Older carers explained that it was exhausting looking after someone, and that often the most difficult part was the organisation of replacement care and health and social care appointments. Older carers tend to be caring for older relatives, who often have multiple health problems (co-morbidities), including dementia. Carers of people with dementia were responsible for all their appointment arrangements and in addition had to accompany them wherever they went. One older carer explained how her husband, who has dementia, had five different appointments in one week, this is not uncommon and can be a particular challenge for older carers. Carers spent a lot of time rearranging appointments that clashed or were impossible to attend due to lack of transport.



“Having to get someone ready to go out is really difficult and you can spend an hour getting up and ready then the person you care for has an accident or soils a pad and you have to start all over again.”

Carer

Carers felt they were acting as care coordinators and they found it difficult to navigate the health and care system, due to the range of organisations and different services. Some explained they had become so frustrated they had given up seeking a service because they felt it was confusing, required a lot paperwork and took too long.

“This role is harder than any I had when I was employed, I am supposed to be retired now but it doesn’t feel like it. I am happy to care for my husband but it is all the rest – the endless calls just to be passed on – that get me down.”

Carer

Having a care coordinator or a single point of contact was cited by carers as something that would really help. Having a person to help navigate the system and tailor advice would save carers a significant amount of time and stress, allowing them to concentrate on the day-to-day needs of the person they care for as well as themselves. Carers noted that there was an inconsistency in service delivery not only across England but also at county level.

Sarah, 60, cares for her mother aged 92

Sarah, who is 60, returned from Canada where she had spent all her working life, to care for her mother Alice aged 92. Alice has dementia and needs 24-hour care. Sarah took at least a year to understand how the health and social care system worked and what support was available in the UK. She was surprised at the lack of customer service in the sector, and how people didn't complain. Eventually she found Suffolk Family Carers, where she attended a programme for people caring for someone with dementia.

“It was great. I met other carers, learnt about dementia and what support was available locally for me and Mum. I had been floundering for a year with no support.”

Carers' health issues

Over half the carers attending the focus groups and five of the seven individuals had at least one health condition, these included high blood pressure, arthritis and heart problems. Carers explained that as they grew older they started to encounter new issues. They experienced loss of strength and mobility, found they tired much more quickly and didn't sleep well. Carers said it was really important to be organised as a carer but adjusting to change when you are older is much harder.

Amy, 75, cares for her daughter aged 50

Amy, who is 75, has been caring for her daughter Jane aged 50 who has had a severe and enduring mental health condition for a number of years. Jane's support plan was reduced in the last year, while at the same time Amy's own health has deteriorated.

“During really difficult times, I have had fleeting thoughts that it may be better if I and my daughter went together. I worry about her vulnerability, will she look after herself, I really don't want her to go into residential care.”

One of the biggest concerns for carers was about what would happen to the person they cared for if something happened to them; yet the majority of carers admitted they neglected their own health issues due to their caring role.

- Carers found it difficult to take time out to exercise, and had given up social activities.
- They delayed going to the GP about symptoms they were experiencing.
- They postponed operations because of concerns about support available for the person they cared for.
- Carers of people with dementia worried that the disruption to care would lead to a deterioration in the condition of the person they care for, making caring harder in the future.

Transport

Carers in rural areas identified transport as one of the top issues for them. Carers found that traveling to the GP or hospital appointments could be expensive or in some cases not possible. Older carers relied predominantly on taxis which proved very expensive. For carers living in rural areas a lack of public transport was a significant issue. As well as using taxis, carers relied heavily on lifts from neighbours, other carers and family members to get to appointments or support groups. A number of older female carers spoke about how they had never learnt to drive, or if they had, were not the main driver, and once their husband could no longer drive they were stranded.

“I really wish I had kept up my driving, I have now lost all my confidence and won’t drive, it leaves us stranded, I would always say to people keep up the driving you never know when you need it.”

Carer

Being able to drive and having access to a car was really treasured by older carers, it allowed them to visit friends, or just get out for a drive. Many worried about how much longer they would be able to drive, and a number had been advised by worried relatives to stop.

Eddie, 88 cares for his wife aged 84

Eddie, who is 88, cares for his 84-year-old wife Ivy who has multiple health conditions. They have always enjoyed getting out in the car together. Eddie is no longer able to push his wife in the wheelchair but he still drives them to the coast where they sit in the car, enjoy the view and have a snack.

“At least we feel we are out. I am dreading the time when I can no longer drive, it will be like cutting my arm off, and I know the time is coming.”

Carers identified hospital transport as a significant issue; carers stating that it is only available to the person with the health need and not their carer. This was a real concern, especially for carers of people with dementia. If unaccompanied, many people with dementia can become confused on arrival at hospital and as a result miss their appointment. Therefore, many carers chose not to book hospital transport and incurred an additional expense by using taxis so that they could accompany the person with dementia.

Transport for hospital appointments was also an issue for carers in London. A number of carers were afraid of using busy public transport, as they feared they would be knocked over, or the person they care for would become disorientated. They found parking at some London hospitals expensive and trying to find a parking space extremely stressful, therefore carers who did drive still opted for a taxi.

Even when there was a good bus service many carers or the person they cared for often couldn't manage the walk to the stop. One carer in her 80s who had her own health problems explained that she and her disabled daughter could no longer go out without the help of a family member or the care support worker.



Benefits and other allowances

Information and advice about benefits for carers and for those they cared for appeared to be patchy. Carers were evenly split among those receiving good information and support and others who felt they were left trying to work it out for themselves. A significant number of carers found they had not been informed of all the benefits they were entitled to early on, and had missed out on income to which they were entitled. One carer explained she had only just found out that she was entitled to a Council Tax reduction which she could have been receiving for the past three years. A small number of carers interviewed said the person they cared for did not, or refused to, recognise their condition and therefore would not claim the benefits to which they were entitled.

Steff, 74, cares for her sister aged 76

Steff, who is 74, cares for her 76-year-old sister Grace who has an acquired brain injury which has affected her thinking, reasoning and emotions. Grace will not apply for Attendance Allowance as she will not acknowledge her disability.

“The extra income would be really helpful as everyday costs such as transport and heating go up when someone has a disability.”

A duty to care

A small number of older carers said they were caring for a spouse, partner or parent who they had a challenging and difficult relationship with. This group of carers spoke about how they felt it was a duty to care as there was no one else to fulfil this responsibility if they did not.

“It’s what we do, our generation have always just got on with it.”

Carer

A few carers who had come to the decision that they were no longer able or willing to care felt they had not been well supported to make this decision and were harshly judged by relatives and some professionals.

“We should not be made to feel we are responsible for a relative’s care – professionals do not know the personal circumstances of the carer, you’re made to feel guilty though and so have to be quite strong willed to push against the flow of conversations.”

Carer

Liz, 64, cares for her husband aged 71

Liz, who is 64, had cared for Gregg, her 71-year-old husband who has had Parkinson’s, for many years. Liz cared for him for a long time despite being unhappy in the marriage. When he became very unwell and went into hospital Liz felt she was no longer able to care.

Liz felt she was put under a lot of pressure to care for him at home and felt judged when she refused.

“I am getting older and caring for him has become really difficult, he is not easy, never has been, I want a little time to enjoy life and see my family.”

Managing finances

Carers highlighted a number of issues around managing finances. They felt they had not received information about handling finances early enough. A significant number of carers explained how they had had to learn to manage finances, as it had always been the role of their partner. For some carers this was a positive challenge they enjoyed and for others it was a complicated chore they struggled with.

“It is difficult to learn new things as an older person, I had to learn very quickly to manage all our finances following my wife’s stroke, it’s something I don’t enjoy, it’s a shame as my wife loved it and was good at it.”

Carer

Typical issues were:

- Difficulties accessing and managing the finances of the person they cared for (even when they had a lasting power of attorney in place).
- Liaising with utility companies who insisted on speaking to the person they cared for even after the carer had made it clear that that person’s dementia would make it impossible for them to understand.
- Carers using their own money to pay for respite or personal care services, because they were not able to access the finances of the person they cared for or were unaware that the person receiving the service should be assessed for the cost.
- Some older carers felt they had no choice but to carry out personal care and not to take a break as the person they cared for refused to pay for support.

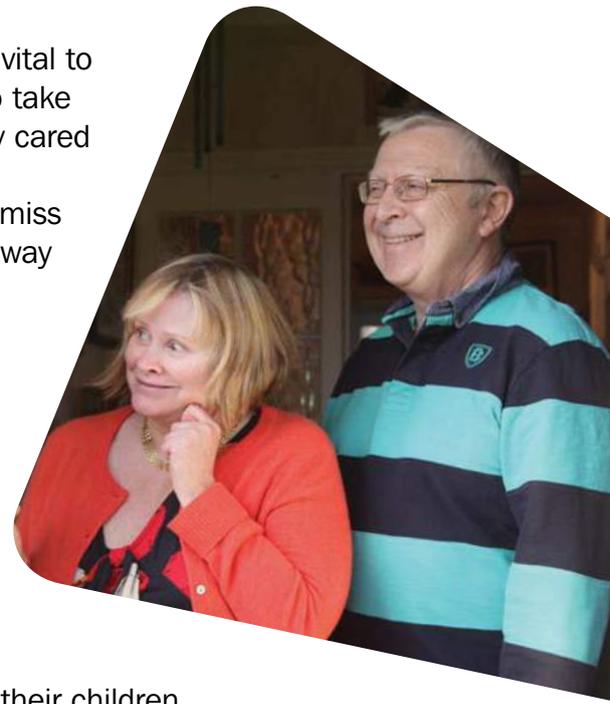
Jim, 68, cares for his sister aged 79

Jim, who is 68, cares for his sister Joy, aged 79, who has dementia. Joy has never acknowledged her condition and did not consider putting a lasting power of attorney in place. She has now lost capacity to make decisions about financial matters and Jim is unable to access her money.

“I am having to use my own savings to pay for respite care and equipment at the moment, I have made an application to the court of protection, it’s an expensive and time consuming process though a lasting power of attorney would have been so much more straightforward.”

Taking a break

Carers identified that the need for a break was vital to their health and wellbeing but were reluctant to take one unless they were confident the person they cared for would receive the appropriate level of care. A number of older carers explained they would miss the person they cared for if they took a break away from them. Those caring for a partner also felt they would not know what to do as they had always done everything as a couple. The majority of carers said they preferred to take a few hours during the day so they could get on with things that needed doing around the house, spend time with grandchildren or pop into town. Some carers were often only able to take a short break if the person they cared for had a sleep during the day.



Older carers in their late 80s spoke about how their children, now in their 60s, helped out enormously and how they worried that their children did too much and about the impact on their health.

A number of carers interviewed were not sure how to go about having a break or what was available. One had asked the GP who was unable to help while another carer in the same area was offered respite on prescription through the GP.

Carers explained that the cost of replacement care or specialist holidays made it prohibitive to take a break either with or without the person they cared for. Carers of people with dementia were reluctant to take a break as it caused anxiety to the person they cared for and so consequently to themselves.

“I was given respite on prescription from the GP, it was for three days, it was not long enough to have any benefit by the time I had relaxed, then having to manage the stress from the person I cared for on his return home. I didn’t feel it was worth taking the break.”

Carer

Jeff cares for his wife Jean, they are both in their 70s

Jeff cares for his wife Jean who has dementia. They are both in their 70s. Jean is still physically well and active but Jeff finds her behaviour (as a result of her dementia) particularly challenging. Jeff was desperate for a break and could feel his own health deteriorating. Jean spent time in two different specialist dementia care homes, neither of which could manage her needs. Jeff was called to pick her up after only three days at the first home and after two days at the second. Staff explained they could not manage Jean’s behaviour.

Carers who had received a carer's assessment felt there was a lack of professional knowledge about options available and assistance with arrangements for taking a break.

Planning for the future

In previous research undertaken by Carers Trust, the lack of preparation or planning relating to becoming a carer was identified (Carers Trust/You Gov, 2015). As part of our recent consultation with older carers, we wanted to gather more specific information relating to this and found:

- The majority of carers consulted had made wills or trusts, or discussed finances with the person they cared for and the wider family.
- Approximately half the carers had a lasting power of attorney in place for them and the person they cared for.
- None had spoken about the possible need for care until they became carers, and even then most had not spoken to relatives about how much care they would be prepared to give or receive from people close to them.
- A number of older carers did not want to discuss what may happen in the future to the person they care for, if something were to happen which would affect their ability to continue caring – the subject was just too difficult to discuss.
- Carers of people with dementia, mental health conditions and learning disabilities found it difficult to have conversations with them as it made the person who was being cared for, anxious or distressed. They consequently avoided conversations even, though they knew they were important.
- A small number of carers cared for people who were not able to communicate their wishes about care.
- Carers were anxious about anything happening to them which would mean they would need to access residential or supported living for themselves. They were advised a place of choice could not be guaranteed as it would depend on availability at the time.

“You don't go into a relationship planning for the worst, you go in planning for the best and hoping the worst won't happen, when it happens you then deal with it the best way you can.”

Carer

Members of a group of former carers were asked if their caring experiences had prompted them to have conversations with their families about the care they would be happy to receive from them or that they would be comfortable to give. None of the carers present had, they just assumed and hoped their families would take care of them. They had however, all arranged a lasting power of attorney and completed a will.

Beryl, 80, cares for her husband aged 84

Beryl, who is 80, cares for her husband Frank who is 84 and has dementia. She worries about the future and is concerned that as she is elderly herself she may not be able to care for her husband at home for ever. Beryl has tried to have conversations about future care arrangements with her husband but it has proved difficult. As a result, nothing has been put in place for the future which causes Beryl concern.

“He becomes very upset, he is then upset all day which makes caring more difficult, he has forgotten why he is distressed but he is still distressed.”

Housing provision

Carers felt that preparing their home in general for older age was important as having any work done while someone is unwell causes a great deal of stress and anxiety. Carers had put off or rejected adaptations because they felt they, or the person they cared for, could not cope with the disruption. Having adaptations or moving was something they said they would advise new carers to do early.

It was felt that moving to a better equipped or more suitable house for their needs had to be considered carefully if people had built up support networks in their local area. Carers of people with dementia or sensory loss explained that moving can make them disorientated, bringing additional difficulties.

Claire, 62, cares for her husband aged 67

Claire, who is 62 cares for her 67-year-old husband Martin who has Alzheimer’s disease. They have made the decision not to move, although the layout of their house is not the best for an older person, because Martin is familiar with his local area which means he is able to go out and this gives Claire a break. Martin is known to other local residents and if they see him they can give help if needed. The support from the community is a significant reassurance to Claire.

Support

Older carers felt that the day-to-day caring responsibilities, albeit tiring, were not the most challenging part of their role, instead it was the challenge of finding and identifying different types of support services. The majority of older carers said there was too much emphasis placed on using the internet, with a significant number only using the internet with the support of their children or relying on them to find the information.

Support accessed by older carers included:

- Help with the garden and housework.
- Support from children – this was common and in some cases vital among carers in their late 80s. They did however worry about placing too much strain on their children as many were now in their 60s and still working full time.
- Paid care from an agency.
- A sitting service.
- Support from friends – this was rare with the majority of older carers pointing out that their friends were now elderly or had passed away.
- Support from local carer services.



Bill, 75, cares for his wife aged 76

Bill, who is 75, cares for his wife Iris who is 76 and has dementia. He explained that he had had no experience of older people needing care when he was young:

“Back home in the Caribbean people were either well and working, or they had died, there was sometimes an old aunt or grandmother, but she was at home looking after the children, people just didn’t live that long.

“When we came to England as young men and women there was no older people in our community so again we had no experience of caring. I would say caring for elderly people is a new thing for our community. The support from the carers group has been lifeline for me, it’s where I get all my information and support, the weekly carers group.”

Carers had found their local carer service invaluable, and valued the support, advice, and replacement care they received from it. Once they had made contact they started to get the tailored information they needed. Many carers felt that they had not received information about carer organisations early enough and felt that referrals from GPs or other health services should be more consistent and timely.

Carers overwhelmingly received their information and support from carer groups managed by local carer organisations. Peer support featured as an important aspect of the groups, helping carers feel less isolated.

“The group keeps me going from week to week. I look forward to seeing everyone I know. I can be honest about how I feel, and you always get such good advice from the workers and other carers.”

Carer

Conclusion and recommendations



Conclusion

Older carers are often reluctant to come forward for help and as a result it becomes even more pressing for health and social care professionals to identify them at an early stage and ensure they have access to information and support in their own right. Many carers felt asking for help was an indication of failure and a loss of pride and worried about losing control. Older carers are also less likely to recognise themselves as carers or be identified by professionals as carers.

It is clear that some of the issues experienced by older carers are also experienced by younger carers, however their age and own health issues exacerbates the challenges for older carers. Older carers found navigating services confusing if not impossible, struggled to adjust to change and received vital information too late.

The availability and cost of transport and their own poor health contributed to increased isolation. Although older carers saw the value in a break they were often reluctant or unable to take one.

It was clear that few people plan or think about a future in which they will be disabled and need care or one in which they become a carer. This lack of planning can contribute to problems later on for older carers with plans and support not being in place when it was most needed. With the growing numbers of older people taking on a caring role it is vital that they are given appropriate support to meet their specific needs.

Recommendations

- Access to a 'care coordinator' – many older carers felt this would help them navigate the health and care system. Although it is recognised that with limited resources this may not be feasible, however, earlier referral to a carer organisation may help improve the situation for carers. Better collaboration between health and social care, with clearer integrated systems (including IT) could alleviate a number of the challenges for carers.
- Appropriate and timely access to information and advice about support, available both locally, nationally and UK wide, which recognises that not all older carers are able to access the internet. Health and social care professionals working collaboratively as well as being able to identify and refer older carers can make significant improvements for carers.
- Timely information, advice and assistance in relation to benefits and finances.
- Better coordination of hospital appointments for older carers and the person they care for, with a more holistic approach to health and wellbeing.

- Improved access to appropriate and good quality replacement care.
- Better identification of older carers and good referral systems to carer services.
- Improved access to hospital transport and hospital parking for carers.
- Awareness raising and information to assist people to consider and plan for the future.

Further information



You can find your nearest Carers Trust Network Partner by using our Find local care and carer services facility at Carers.org (any time) or calling 0300 772 9600 (Monday–Friday, 9am–5pm).

You can also access our online services, 24 hours a day, every day of the year. These are open to all carers wherever they live in the UK.

- Carers Space (<https://space.carers.org>) is for carers aged 18 and over.
- Babble (babble.carers.org) is for young carers aged under 18.
- Matter (matter.carers.org) is for young adult carers aged 16–25.

Carers can also get email support by contacting support@carers.org.



References



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