

The experiences of former carers

A Carers UK research report



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Foreword

Foreword from Margaret Dangoor

Millions of people around the UK are providing care for family members, friends or neighbours. In fact, most people will have caring responsibilities at some point in their lives. For many people, caring is a rewarding experience. But it can also be challenging. Research has shown that providing unpaid care can impact on health and wellbeing, finances, and employment – and this impact can continue even when caring comes to an end.

For many people, caring becomes a big part of life, and so when it comes to an end, it can be very difficult. Some former carers find that their confidence and self-esteem is impacted; others feel that they have lost their identity and may be unsure about what the future holds. Some former carers may want to start or resume paid employment but feel anxious about this after a period of not working. Of course, many former carers will also be grieving the loss of their loved one and may need support during this period of bereavement.

As a former carer myself, I welcome this research report from Carers UK, which highlights some of the challenges faced by former carers. While carers' experiences can vary, it is clear that there are common challenges – particularly around health and wellbeing, with former carers feeling lost or lonely after their caring role has ended.

I'm delighted that so many people took the time to give their views and share their experiences. I hope this leads to further conversations about the experiences of former carers who I know can often feel forgotten about. It is vital that as a society we recognise the contribution that carers make, and that people are supported both during and after their caring role.



Margaret Dangoor, Trustee of Carers UK

Summary

This research report considers the experiences of former carers: ie people who used to provide unpaid care to a family member, friend or neighbour. Every year, more than 4 million people stop providing care¹. Some evidence suggests that former carers can experience ongoing challenges, including feelings of loneliness, regret, and loss of confidence, purpose and identity². Former carers can also be exposed to a range of disadvantages arising from their caring experiences, including physical ill health, loneliness, and financial hardship³.

Analysis of survey and interview data suggests that:

- When caring comes to an end, some former carers experience feelings of uncertainty, loneliness and loss of identity. A third of former carers (33%) said that their physical health had got worse since they stopped caring, and 35% said their mental health had got worse. Some former carers said they felt unsure what to do now their caring role had ended; that life felt empty or quiet, and that it could be challenging to rebuild friendships.
- Many former carers said that caring impacted on their health and wellbeing. This was often because issues with health and social care services caused them additional stress, and/or affected their ability to juggle work and care.
- Some former carers can struggle financially after their caring role has ended. Over a third of former carers (35%) said their financial situation had got worse since they stopped caring.
- Some former carers feel that more support would have been beneficial when their caring role ended, including support with bereavement and support with resuming paid employment. 57% of former carers said that support to help them cope with the loss of the person they cared for would have been helpful. Some carers felt they needed support to address the specific trauma they had faced while caring.

¹ Petrillo, M., Bennett, M. and Pryce, G. (2022) 'Cycles of caring: transitions in and out of unpaid care'. carersuk.org/media/bgolg5u2/cuk-carers-rights-day-research-report-2022-web.pdf

² Orzeck, P. and Silverman, M. (2008) 'Recognising post-caregiving as part of the caregiving career: implications for practice'. [tandfonline.com/doi/abs/10.1080/02650530802099866](https://doi.org/10.1080/02650530802099866)

³ Larkin, M. and Milne, A. (2020) 'Knowledge generation and former carers: reflections and ways forward'. kar.kent.ac.uk/80220/3/Knowledge%20generation%20and%20former%20carers.pdf

Methodology

This mixed methods research consisted of a survey with 991 former carers, and semi-structured interviews with nine former carers. It explored the following three questions:

- What, if anything, did former carers find challenging about caring?
- What, if anything, do former carers feel has changed in their lives since their caring role ended?
- Do former carers feel they had the support they needed when their caring role ended and if not, what more support might have been helpful?

Survey

The State of Caring 2022 survey ran from July 2022 to September 2022. Although the survey was primarily aimed at those currently providing unpaid care, former carers were invited to answer a series of questions about their experiences both during and after caring. The survey was published on the Carers UK website, publicised on Carers UK social media channels, and shared over email with Carers UK members, Carers UK affiliates (eg carers centres and local authorities), carers who had previously completed Carers UK surveys, employers and Carers UK volunteers and campaigners.

Interviews

Purposive sampling was used to recruit participants for interviews, in which people whose caring role had come to an end were invited to participate. Because this research considered carers' experiences of paid employment and/or resuming paid employment, only those who were in paid employment or actively looking for paid employment were contacted.

Most participants were identified and contacted through the Carers UK State of Caring 2022 survey. Only those who had given consent to be contacted about taking part in research were contacted. Further participants were then found by advertising the research opportunity in a newsletter to Carers UK volunteers, and contacting former carers who had previously been involved in Carers UK media work or who had taken part in other Carers UK activities.

Interviews were conducted between January and March 2023. Each interview took between 40 to 60 minutes and was conducted online over Zoom. All participants were sent consent forms to review and complete prior to the interviews. To protect carers' privacy, pseudonyms have been used in the report. Interviews were recorded and transcribed in full. Thematic analysis was carried out using verbatim transcripts, in which the data was coded, and a number of key themes identified.

Background: previous research on former carers

Different phases of post-caring life

Some studies have found that some former carers go through different stages after their caring role has ended. A study based on interviews with 37 former carers found that many former carers went through a 'post caring void' where they felt lost, lonely, or experienced a lack of purpose, followed by a 'closing down of caring', where they had to deal with financial and legal issues, and then a 'construction of life post-caring' where they focused on their own health and wellbeing, their hobbies and interests, and their relationships with other people⁴.

Another study, based on interviews with 14 former carers, found that many carers experienced feelings of loneliness or emptiness when their caring role came to an end, and that these feelings could last a long time⁵. Carers felt this initial period of emptiness was then followed by a movement to a new life, with new routines, in which they had to redefine their identity and rebuild their lives. Some carers said this transition took place a few years after their caring role had ended, and some felt it had been challenging, involving new relationships, new employment, or changes in personal projects.

The transition between different phases of post-caring life was also highlighted in a study based on interviews with former carers⁶. Many participants described losing aspects of their pre-caring world, resulting in a void or sense of emptiness, where they had no distinct identity anymore. Some felt that as well as losing the person they cared for, they had lost their caring role and the social relationships they had with healthcare professionals. Some participants also reported experiencing feelings of guilt about things they could have done differently. However, some former carers talked about how they were now moving on, with new activities helping them to construct a new sense of identity.

Experiences of bereavement

Research suggests social support can help people cope with grief⁷, yet many carers report feeling lonely and isolated and may struggle more as a result, particularly if they have lost touch with family or friends while caring. A study with a small sample of former carers found that socio-emotional support from family and friends played an important role in helping carers adjust to the loss of their caring role and deal with grief⁸. Another study showed that the social support received during someone's caring role was more important in helping them adjust to bereavement than the support provided after the person being cared for had died⁹. Similarly, a longitudinal study with former carers found that one of the most consistent predictors of positive outcomes post-caring was social support¹⁰.

⁴ Larkin, M. (2008) 'Life after caring: the post-caring experiences of former carers'. doi.org/10.1093/bjsw/bcn030

⁵ Mora-Lopez, G., Berenguer-Poblet, M. and Berbis, C. (2022) 'New life transition of former caregivers: positive mental health approach', *Frontiers Psychology*. frontiersin.org/articles/10.3389/fpsyg.2022.854108/full

⁶ Cronin, P. et al. (2015) 'Between worlds: the experiences and needs of former family carers'. pubmed.ncbi.nlm.nih.gov/25307354/

⁷ Cacciatore, J et al. (2021) 'What is good grief support? Exploring the actors and actions in social support after traumatic grief'. ncbi.nlm.nih.gov/pmc/articles/PMC8158955/

⁸ Jameson, S., Parkinson, L. and Banbury, A. (2019) 'After the care journey: exploring the experiences of family carers of people living with dementia'. cambridge.org/core/journals/ageing-and-society/article/after-the-care-journey-exploring-the-experiences-of-family-carers-of-people-living-with-dementia/9FE53C394C9B26BF879D5A02C23FA460

⁹ Bass, D., Bowman, K. and Noelker, L. (1991) 'The influence of caregiving and bereavement support on adjusting to an older relative's death', *Gerontologist*. pubmed.ncbi.nlm.nih.gov/2007473/

¹⁰ Robinson-Whelan, S. et al. (2001) 'Long-term caregiving: what happens when it ends'. pubmed.ncbi.nlm.nih.gov/11727947/

A study considering the experiences of former carers found that carers who had a more stressful caring role experienced greater strain during bereavement¹¹. The researchers suggested this may have been because those carers had been so busy caring that they were less likely to be able to anticipate or prepare for death, or because those carers were less able to cope with bereavement as they were already feeling stressed. Other research has found that grief and depression can be more pronounced amongst carers who had poor health before the death of the person being cared for¹² and more pronounced amongst those caring for a shorter period of time, perhaps because they had less time to prepare for the grieving process¹³. Other research has found that preparedness for death has a significant impact on post-care bereavement, with carers who are not prepared for death more likely to experience depression and anxiety¹⁴.

Research suggests that challenges related to bereavement can last several years. One study of grief, based on comparisons between current carers, former carers and non-carers, found that former carers did not improve on several measures of psychological wellbeing over time, and continued to struggle with depression and loneliness¹⁵. A study exploring the health of former carers found that sleep disturbances could last for as long as 10 years post-caring¹⁶, while research on carers' grief found that while distress reduced over time, loneliness and sadness increased, and were often triggered by auditory or visual reminders of the person¹⁷. A survey with nearly 80 former carers found that 80% reported continued feelings of stress, anxiety, depression and low mood¹⁸.

Research with former carers of people with dementia found that some respondents spent time reliving their experiences as a carer which brought back feelings of guilt and pain¹⁹. Some carers also mentioned that they found themselves maintaining some of the routines they kept while caring, such as getting up in the night to check on everything, while others said they had had to learn how to do certain things on their own, like managing household finances. Another study with former carers of people with dementia found that several carers emphasised how they missed the caring aspect of their relationship, and a significant number said that dealing with closure tasks, such as funeral arrangements and financial paperwork, had been very difficult²⁰.

11 Bass, D. and Bowman, K. (1990) 'The transition from caregiving to bereavement: the relationship of care-related strain and adjustment to death'. pubmed.ncbi.nlm.nih.gov/2311960/

12 Ling, S. et al. (2013) 'Trajectory and influencing factors of depressive symptoms in family caregivers before and after the death of terminally ill patients with cancer'. pubmed.ncbi.nlm.nih.gov/23269779/

13 Reid Keene, J. and Prokos, A. (2008) 'Widowhood and the end of spousal care-giving: relief or wear and tear'. cambridge.org/core/journals/ageing-and-society/article/widowhood-and-the-end-of-spousal-caregiving-relief-or-wear-and-tear/207CCDF9189B1B2A537662B6A135D584

14 Herbert, R., Dang, Q., and Schulz, R. (2006) 'Preparedness for the death of a loved one and mental health in bereaved caregivers of patients with dementia'. pubmed.ncbi.nlm.nih.gov/16752974/

15 Robinson-Whelan, S. et al. (2001) 'Long term caregiving: what happens when it ends?' pubmed.ncbi.nlm.nih.gov/11727947/

16 Corey, K. and McCurry, M. (2018) 'When caregiving ends: the experiences of former family caregivers of people with dementia'. pubmed.ncbi.nlm.nih.gov/28064236/

17 Waldrop, D. (2007) 'Caregiver grief in terminal illness and bereavement a mixed-methods study'. proquest.com/openview/50ccfe1b9b46e526fc3413f80d9400e4/1?pq-origsite=gscholar&cbl=47817

18 Watts, J. and Cavaye, J. (2016) 'Being a former carer: impacts on health and wellbeing'. journals.sagepub.com/doi/epub/10.1177/1054137316679992

19 Petronela Juozapavicius, K. (2001) 'A reflective study of Alzheimer's caregivers'. journals.sagepub.com/doi/epdf/10.1177/153331750101600108

20 Vlachogianni et al. (2015) 'Life after care: psychological adjustment to bereavement in family carers of people with dementia'. pubmed.ncbi.nlm.nih.gov/26648275/

Caring when the person with care and support needs moves into a care home

A survey with over 7,000 carers found that many respondents didn't want to be described as a 'former carer' if the person they cared for had moved into other accommodation, because they were still providing some form of care²¹. Research based on interviews with over 40 carers of people who had moved into a care home found that many carers continued to provide support through regular visits, placing demands on their often busy schedules²². Some researchers have argued that it is unhelpful to consider caring as a trajectory between being a 'carer' and being a 'former carer', as there is often no definitive point at which a person stops caring, and some people may be caring for more than one person²³.

Research suggests that when the person being cared for moves into a care home, this can be stressful for carers. One study with former carers found that many described it as a traumatic experience, resulting in feelings of guilt or loss, or difficulties adjusting to changes in their relationship or role²⁴. Another study based on interviews with carers of people with dementia who had moved into a care home found that carers experienced being 'caught by surprise' when the move occurred, and that negative experiences of dementia care made the separation more difficult²⁵. Other studies have shown that when the person with care and support needs moves into a care home, carers can experience feelings of guilt and sadness²⁶, as well as increased uncertainty²⁷.

Although this Carers UK research report focuses on people whose caring role has ended, Carers UK recognise that many people continue to provide care when the person being cared for moves into a care home. Some of those carers may not therefore consider themselves to be 'former carers'.

21 Kirby et al. (2021) '(How) will it end? A qualitative analysis of free-text survey data on informal care endings.' bristoluniversitypressdigital.com/view/journals/jjcc/6/4/article-p604.xml

22 Davies and Nolan (2004) 'Making the move: relatives' experiences of the transition to a care home.' onlinelibrary.wiley.com/doi/epdf/10.1111/j.1365-2524.2004.00535.x?saml_referrer

23 Larkin, M. and Milne, A. (2017) 'What do we know about older former carers? Key issues and themes', *Health and Social Care in the Community*. onlinelibrary.wiley.com/doi/epdf/10.1111/hsc.12437?saml_referrer

24 Davies and Nolan (2004) 'Making the move: relatives' experiences of the transition to a care home.' onlinelibrary.wiley.com/doi/epdf/10.1111/j.1365-2524.2004.00535.x?saml_referrer

25 Johansson et al. (2014) 'Remaining connected despite separation – former family caregivers' experiences of aspects that facilitate and hinder the process of relinquishing the care of a person with dementia to a nursing home'. pubmed.ncbi.nlm.nih.gov/24807210/

26 Dellasega and Nolan (2007) 'Admission to care: facilitating role transition amongst family carers'. onlinelibrary.wiley.com/doi/epdf/10.1111/j.1365-2702.1997.tb00341.x?saml_referrer

27 Lloyd and Stirling (2011) 'Ambiguous gain: uncertain benefits of service use for dementia carers'. pubmed.ncbi.nlm.nih.gov/21371052/

Survey analysis

In Carers UK's State of Caring Survey 2022, 991 people said that they had cared in the past but were no longer caring²⁸.

The majority of former carers (68%) had stopped caring because the person they cared for had died. 21% said they had stopped caring because the person they were caring for had moved into a care home or a setting away from home, 5% said they were no longer able to cope with providing care, 3% said the condition of the person being cared for had improved, 2% said they were receiving care from someone else, and 2% said that a change in their circumstances meant they were no longer able to provide care.

Managing finances

When asked whether their financial situation, 38% of former carers said they are better able to afford utility bills, and 26% said they are better able to afford the cost of food. However, a significant proportion of former carers (20%) said they are struggling to make ends meet, and 35% said their financial situation has got worse since caring. This suggests that former carers' experiences can vary significantly.

Some former carers said they are finding it more difficult to manage financially since caring because they now had to pay for residential care.

"...I am frantically saving to pay care home top up fees in the future"

"As my spouse's care home fees have to be fully paid for, I am having to use savings whilst also now having to fund all domestic costs myself"

"Husband's money now all going on care bills, so concerns over funding this when he runs out"

Other former carers said they are finding it easier to pay for food or fuel costs, due to a reduction in the cost of care.

"...I obviously use less heating and don't need to purchase so much food, medicines"

Some carers had also inherited money from the person being cared for.

"I inherited some money from the person I cared for (my late father) and I am in the process of purchasing a property"

Several former carers also told us that there had been no change to their financial situation.

²⁸ As not all respondents completed every question in the survey, a number of the figures given in this report are based on responses from fewer than 991 former carers

Employment

41% of former carers said they are retired. 36% said they are in employment (and were employed whilst caring), while 8% said they had started or resumed employment since they stopped caring. 8% said they are unable to work due to a sickness or disability, and 5% said they are unemployed and looking for paid work.

Some former carers told us that they had increased their working hours since caring.

“I was working part-time when I was caring, now I’m back to full time work”

“I have been able to increase my paid hours and get a better job”

Others had given up paid employment to provide care, and had not gone back to work since caring. Some former carers felt their age was a barrier to seeking employment

“I tend to tell people I am semi-retired but in truth at 60 years old it is not easy to find employment due to lack of recent references and no real support to find work as I am not on benefits”

“At 64 I’m too old to get a job...”

Others said that they were doing voluntary work.

“I do voluntary work and work with statutory services to try to improve services”

“I do 2 voluntary sessions....these keep me going”

Health

Just over half of former carers (51%) agreed that their physical health had improved since they stopped caring. However, a third of carers (33%) said that their physical health had got worse since they stopped caring. Similarly, 53% of former carers said that their mental health had improved since they stopped caring, but 35% said their mental health had got worse. Again, as the results on managing finances also indicated, it is clear that carers’ experiences can vary considerably.

Some former carers said they were struggling with feelings of guilt, sadness or loneliness

“I’m struggling with guilt (not being a good carer) and depression and finding getting out of bed a struggle”

“I feel extremely lonely, although I have a very good family I can go days without any interaction”

“I find it very lonely living on my own, my son passed away 5 months after his Dad, my other son I do not see...”

Others described how they felt a sense of loss or emptiness now they were no longer a carer.

“I don’t know who I am anymore...”

For some former carers, caring had been stressful, and they needed to recover from what had been a quite difficult experience.

“I feel traumatised by the circumstances of my mother’s death at home and that has taken longer than anticipated”

“The effects of caring and its responsibilities are overwhelming and for it to just stop damages mental health”

“I was mentally burnt out, isolated, and caring left me with more health issues. I’ve struggled to cope”

Others said that they felt their wellbeing had improved because they were able to take breaks and time to themselves, or because they no longer had to worry about caring.

“I have my life back....more time for me and my family”

“My stress levels have improved. I feel less worried and anxious”

“I have more time for myself – no disturbed nights”

“Quite frankly not being a carer means not battling with social services and health who have made my caring experience much worse....it’s a relief and a release.”

Support when caring ends

We asked former carers what support might have been helpful when their caring role ended. 57% said that support to help them cope with the loss of the person they cared for would have been helpful, 47% said support to cope with loneliness and to reconnect with family and friends would have been helpful, and 32% said support to help them cope with the loss of their caring role would have been helpful.

“Support with transition of not caring anymore, giving up responsibility to care home and agencies involved”

“After 13 years of caring, support to adjust to a new way of life.”

Other areas of support that former carers said would have been beneficial included support with practical matters such as wills and probate (29%), support with the person being cared for moving into a care home (27%), support with managing finances (24%). 14% of former carers said they would have liked support with returning to paid employment. This rose to 21% for carers aged 18-65.

When asked what other support might have been helpful, in addition to those suggested in the survey, responses included support with providing palliative care, support to address feelings of guilt, support with managing family disagreements, support to deal with traumatic experiences, financial support (such as Carers Allowance continuing for longer), more understanding from their employer, and better communication with health or care services. Some respondents felt that support during, rather than after, their caring role would have been more helpful.

Several former carers told us they had not received any support when their caring role ended.

“It was like I’d been spat out of the health and social system. “you’re no longer any use to us”

Interview analysis

A total of nine former carers were interviewed. five were female, and four were male. Six had been caring for a parent, one for a sibling, one for a grandparent and one for a spouse. Eight had stopped caring because the person they cared for had died, and one had stopped caring because the person they cared for had moved to a care home.

When caring comes to an end, some former carers experience feelings of uncertainty, loneliness, and loss of identity

Some former carers said they felt unsure what to do now their caring role had ended. Sophie said it was 'weird' to be able to do things again, and that she was 'all at sea' and 'really didn't know what to do'. Similarly, Tara described how she felt unsure what to do:

'If I get up in the morning now, it's like 'well, right, what do I do?' I don't know what to do with myself because it's all gone. And you think to yourself, what did I used to do, before I did this, and I can't remember. What did I use to do? How did I keep my days busy, because all of a sudden it's gone'

Maya described how she lost her identity when her caring role came to an end. She said that when she was a carer her 'only purpose was to get up and keep mum alive' and that she hadn't thought about her own needs for several years. Having gone from 'having so much structure to having none', she felt 'really lost, really overwhelmed':

'..I felt like I couldn't trust my decisions, I didn't know what I stood for, I didn't know who I was when I'm not caring – like, who am I? What do I like, what don't I like?...What are my views on things, what are my opinions ...it's almost like you've been plucked from your life, dropped in the middle of nowhere, and it's now 'go find your way back home' and I'm like 'I've no idea where my home is.'

Some former carers said that they had taken up new hobbies since caring, made new friendships or resumed employment. For some people, this had been a positive but quite challenging experience. Alan described how he coped with the end of his caring role by focusing on three priorities: getting back in touch with friends and family, taking care of jobs that needed doing in the house, and going back to paid employment. However, he found that things were 'getting on top' of him, making him feel 'stressed out'. He felt he needed to 'time manage properly' so that things didn't 'pile on top' of him: 'because there's so much time to make up, just trying to get the balance right, it's not always easy.'

Other former carers said that life felt empty or quiet since their caring role had ended. Sophie said that days that had previously been 'filled with other things' now felt 'empty' and that her mother passing away had left a 'massive void'. Tara said that her days had become 'incredibly empty' while David said that things were 'very quiet' and that he didn't 'do an awful lot'. Maya described how she had been very busy with caring, and that when her caring role ended 'it all stops, everything stops'. Elizabeth said that last year she 'hardly did anything' and it was only recently that she had started making future plans.

Many former carers said that they'd lost touch with friends while caring, and as a result were finding it hard to rebuild friendships. As Sophie explained, 'life went on when I wasn't available...I cannot expect people to just jump to my tune now that my tune has changed'. She also said that she hadn't 'got children to build a life', and it was 'harder' being on her own. Not having children was also something that Tara mentioned: she described herself as being 'a bit of a strange awkward age' where some social groups were targeted at older people and other groups were for mums which she didn't 'fit in to'. Tara also said she felt 'a bit disconnected' from other carers as she hadn't experienced some of the same issues, and had maybe 'had it easy compared to other people'.

Some former carers also talked about missing health and social care staff. Maya felt that she had had more contact with support staff during caring than she'd had with family or friends. When caring, she would look forward to interactions with her mother's nurse and other 'friendly faces', but when her caring role ended, healthcare staff disappeared, and this had a 'massive' impact: 'they disappear and then you're like, 'you gave me comfort and now you're not there when I need the comfort'. Tara also described how 'no one comes anymore' and that because she no longer had the 'social interaction' she'd had with care workers, 'things are probably worse in some respects'.

Some former carers feel that more support would have been beneficial when their caring role ended

i) Support with bereavement

A few former carers described their caring experience as 'traumatic'. Aaron said there were aspects of caring that were particularly difficult: 'you could call it trauma - not high-level trauma but there's still that trauma of having to go through all of that sort of stuff.' David also felt that he and his wife had gone through 'traumatic times', particularly when his wife had been very ill and in a coma: 'watching [her] suffer sometimes was really hard'. Maya described how the process of bereaving had 'a whole different element of trauma to it' and that she had 'PTSD symptoms' after providing palliative care for her mother. She suggested that specialist bereavement support targeted to carers would have been beneficial. Fiona also felt that the 'bereavement picture is a very specific one' for carers because 'there's a lot of trauma involved' in caring.

Some former carers described how they had experienced anticipatory grief. Sophie said that she 'knew it would be awful, and it was awful': that however hard she cared for her mother 'it's always going to be a bad result with an elderly person'. Alan said that he had 'braced' himself because he 'knew the day would come', while Maya felt she had experienced 'anticipatory grief' where she knew 'that day is coming'. However, while carers had prepared themselves for the death of the person being cared for, the experience was still challenging. Some said that friends and family didn't always know what to say: as David explained, 'really I was on my own, my friends didn't know what to do, they didn't know what to say'. Alan said he experienced 'delayed grief': after returning from a family event, he 'started to feel very low' and decided to seek help through counselling. While this was helpful 'to some degree', he found that it had been 'a bit of an up and down process', with his ability to cope changing over time: 'there's been periods where I've been strong and other periods where I haven't'.

A few former carers said that more empathy from healthcare staff after caring might have been helpful. Maya described how people were calling her, asking for the dialysis machine back, which was ‘not very kind’. She felt that communication with healthcare staff became ‘very business-like’. David said that although the palliative care team were ‘very, very supportive’ and had ‘checked up on’ him, there was ‘not much’ support from other hospital staff: ‘there wasn’t an offer of anything from the hospital at all. I expect they were really busy, I appreciate that. I wasn’t bothered by that, but other people might be’.

Some former carers felt that they didn’t need support with bereavement. David said he wanted to ‘just get on with it and just move on’: he described himself as ‘quite an optimistic person’ who focused on ‘a lot of good memories’ as a means of coping. However, he also acknowledged that those who provide care full time may need more support, if ‘they have that role of looking after and suddenly it’s all gone, and they don’t know what to do with themselves. I think they do need support more than most’.

Other former carers felt that instead of, or as well as, specific bereavement support, they needed opportunities to express how they felt. Maya said that sharing her story through her volunteering work with Carers UK had been ‘really empowering’ as she had lost her voice and her confidence when her caring role came to an end. Sophie said that taking part in the Carers UK listening support sessions had given her the ‘opportunity to tell my story’, while Fiona’s voluntary work for Carers UK had enabled her to tell ‘the human story’ of caring and to ‘be recognised’ for her caring role. Aaron said that opportunities to ‘speak with other people in similar situations’ might have been helpful.

ii) Support with going back to paid employment

Some former carers who had stopped working while caring felt they needed to take a break before going back to paid employment. Sophie’s previous job came to an end shortly before her mother passed away, and it took her a while before she felt ready to start another job: ‘I just didn’t feel like it, after what I’d been through’. One of her concerns was whether she would be able to cope with going through the recruitment process while she was grieving: ‘I was terrified of going for a job because I thought I’m going to cry in the interview’. Alan said that going back to paid employment was not his first priority: ‘for a start I needed a break to get my head clear and take stock of everything that’s happened, and all I wanted was normality and simplicity’.

Maya felt she needed to take a break before going back to paid employment, partly so she could ‘grieve – like really grieve’, but also because she wanted to consider a potential carer change: ‘after [caring] stopped, I had to space to say right, what do you want to do?’. Alan also said that caring changed what he wanted to do his life and that he was ‘now more into standing up for carers and things like that’, as part of his voluntary role with a local carers centre. Similarly, Fiona decided to change career and now works for a local carers organisation which she said felt ‘like a natural conclusion’, enabling her to use her ‘lived experience’ to be ‘more empathetic’. Sophie said that her priorities in relation to employment have changed. Although her new job has less responsibility, she said that as long as people are ‘friendly’ and ‘nice’ to her, then ‘it doesn’t really matter too much what I do, in terms of the job. That’s less important now’.

Some former carers who wanted to go back to paid employment were concerned how employers might perceive their caring roles. Because Maya had given up work to provide care, she was conscious of there being ‘a gap now’ on her CV, and wondered how she would explain this: ‘can I have that conversation with [an employer], will it land?’ Sophie was also worried about how she would ‘dish up’ her situation to an employer ‘in a way that’s not detrimental to me’. Fiona was also concerned about going back to work: ‘I thought, you know, who is going to want me?’

Although some former carers had been successful in resuming employment, some felt there is a lack of support to help people get back into work. Fiona suggested it would be beneficial to have ‘some kind of service’ that ‘just kept an eye on ex-carers’, supporting them to find work, to use the skills gained in caring, and to share their experiences with other former carers. She felt this would be particularly helpful for older people whose caring role had ended, who may feel anxious about going back to work later in life, but who have actually gained ‘incredible skills’ through caring: ‘not just powers of endurance, but unbelievable resilience and project-managing skills’. Maya suggested that having a division in a recruitment agency that works with former carers, or running employment workshops for former carers, would be helpful in recognising the skills gained through caring and enabling former carers to ‘reintegrate back into society.’

Many former carers felt that caring impacted on their health and wellbeing

i) Caring was stressful

Many former carers said that providing unpaid care had been stressful. Elizabeth described how she was ‘getting more and more tense with things’, and that there was ‘a certain amount of anxiety, a certain amount of stress’. Fiona said the most challenging aspect of caring was the ‘relentlessness’ and the uncertainty of not knowing when ‘the next, sort of, meteor shower would come from, or next ball in your face’. She described how ‘no day was the same’ and that a lot of her caring role was about ‘project management’. Aaron also said that the most stressful aspect of caring was ‘juggling time’ and supporting his grandmother while also working and being a husband and father.

Some former carers said that issues within the family had caused them to feel stressed or upset. Paul said that the most challenging aspect of caring was his sister resisting their mother going into a care home, which had caused him stress: ‘I was trying to do things and put things in place to safeguard mum, and experiencing hostility and anger and being bad mouthed and criticised’. Sophie said that her siblings had not supported her with her caring role, or visited their mother, resulting in her and her mother being ‘left to deal with everything’. She said this had been ‘very upsetting’ and had culminated in her siblings being ‘cut out’ from her mother’s will. Elizabeth also mentioned that she ‘didn’t get a lot of support’ from her brothers until the very end: ‘they just left me to it’.

Aaron felt that because caring caused him ‘stress, proper stress’ he felt like a ‘weight had been lifted’ when his caring role came to an end: although he grieved the loss of his grandmother, he said his caring role had been ‘taking its toll’. Similarly, while Sophie described how much she missed her mother, she also felt some relief that her mother was no longer suffering or being impacted by poor quality health services: ‘you think ‘oh god, I’m glad she’s out of that, that’s done’....you don’t want them to go, but you wouldn’t wish it on her for another day’. Paul said that it was a ‘huge relief’ when his mother moved into a care home: ‘I know that she’s looked after’.

Despite the challenges of caring, many former carers said that caring had also been a positive experience. Sophie said that ‘much as it was hard, if you asked if I’d do it again – for her, yes I would’. Alan said it was a ‘privilege’ to be with his mother, learning more about her early life. Elizabeth also said it was ‘a pleasure’ to look after her mother: ‘I’d do it all again if I had to’.

ii) Caring was tiring, with few opportunities for breaks

Many former carers said that providing unpaid care had been tiring. Elizabeth said she had felt ‘tiredness and great exhaustion’, as well as being ‘emotionally drained’. She had struggled with a lack of sleep, particularly during a period when her mother was suffering from ‘blackouts’ and she had to be ‘watching her every night’, resulting in ‘disturbed sleep’. Paul said it felt like he was sleeping ‘with one eye open’, and described a situation where his mother had phoned him at 4 o’clock in the morning ‘in a highly anxious state’. He said it was ‘difficult’ to work the next day when he hadn’t had a good night’s sleep. David also said caring could be tiring as he could ‘finish two or three o’clock in the morning and then wake up at six or seven o’clock to go to work’.

Taking a break while caring was not always possible for some former carers. Alan said he had to ‘sacrifice a lot’ while caring: ‘it did take over my life, I couldn’t do a lot of other things’. Similarly, Sophie said that her mother needed her around ‘all the time’ and that she hadn’t had a night away from home in over 11 years. Paul said that caring took up all of spare time and that ‘every spare minute’ he was at his mother’s house or answering phone calls from his mother. David said that while he and his wife used to take breaks, such as going for afternoon tea, COVID made this more difficult: ‘we practically never went out anywhere for a while’.

Some former carers said that although they tried to take breaks, it was difficult to switch off and relax. Maya said that although she ‘would try and do respite’ she found that she was watching her mother all the time through the cameras she had installed in the home, as ‘things change so quickly when you’re caring for someone’. As a result, she would be ‘glued to her phone’ and ‘still have that anxiety’. She felt it was only since her caring role ended that she had been able to ‘switch off and have a break’. Elizabeth said that although she was able to ‘go out for small periods of time’, she was ‘always rushing back’ to provide care. The changing needs of the person being cared for also meant that some former carers had limited opportunities to socialise with others. Alan said that it was difficult to make plans to see people when he often had to cancel at short notice: ‘it’s simpler just dropping out of everything really’.

iii) Caring was not recognised

Some former carers felt there was a lack of understanding from other people about what their caring role entailed. Tara said that she had to miss social events due to her mother being unwell, but that because her friends' parents were healthy, they 'didn't quite understand'. Alan said that other people 'all carried on with their own lives' and that he felt 'forgotten about' and 'abandoned'. He suggested that there was a stigma around dementia when he first provided care, and found it hard to share things with other people as a result: 'nobody can really understand what it's like looking after someone with dementia unless they've been through it themselves.' Elizabeth also said that people 'don't understand' what caring involves, particularly 'the worry' that it can cause.

Other former carers said that they sometimes felt reluctant to ask for help. Tara said it was 'difficult sometimes to ask people to do certain things', while Sophie said that she wanted to keep her mother's 'dignity' and not share too much information. Elizabeth also said she wanted to keep some things 'private': 'a lot of it you do keep to yourself. I haven't actually until the last couple of years told people exactly what I did to help my mum'. While caring, she also didn't want to invite people back to her home: 'with a commode in the living room and a bed, you know, it's not the nicest of places to bring people back to'. Other former carers felt they didn't really need any help, or had their own ways of coping. David said that he and his wife felt they 'didn't need anything' and 'just got on with it' because they were 'both quite independent'. Paul said he saw himself as 'very resilient' and was able to cope with challenges through 'meditation, breath work, body work', as well as walking in nature, and praying. He said that one of his 'mottos' is 'simply do your best' and 'do what you have to do in the moment'.

More generally, some former carers felt that society as a whole does not recognise unpaid carers. Paul said that carers were 'undervalued' and didn't 'get the recognition' they deserved: 'without carers the system would crash within, you know, 48 hours'. Maya said carers are 'practically invisible to most' and Alan felt that carers are 'always forgotten about' and 'the last to be considered'. He suggested that the pandemic had 'opened a lot of people's eyes to what carers have to go through' and that 'people's attitudes have changed.' Fiona also said that caring 'does feel invisible' but that there is a growing recognition of the role of carers, who are becoming 'a known section of society'.

Many former carers were unhappy with health and social care services while caring

i) Social care

Some former carers felt that a lack of support from social care services made their caring role more stressful. Fiona said that the carers supporting her brother were ‘absolutely hopeless’ initially and that errors they had made, such as providing medication at the wrong times or wrong doses, had ‘added to the stress’. She felt that staff ‘just weren’t well trained’ and that too many staff meant there was ‘no consistency in routine’. Because the situation was ‘unbelievably stressful’, she didn’t feel that she could relax. Maya also said that having care workers coming into the house was ‘a whole extra bit of worry’ that she had to manage.

Elizabeth said she had ‘a lot of issues’ with how staff in a care home dealt with her mother: she felt that the care provided was ‘shocking’, and resulted in her making ‘complaint after complaint’, including a complaint to the Ombudsman which has still not been resolved. She described feeling ‘intimidated’ by staff who she felt were ‘ganging up on’ her, and only concerned about ‘watching their own backs and covering their own selves’. Although Elizabeth’s caring role has ended, she said the issues she had with health and social care staff are still affecting her: ‘I’m still living with all these questions and doubts. I’ve been angry about what’s happened, really, really angry. It has affected me personally’. Aaron also said that because he had spent so much time ‘battling the system’ and being in ‘a constant fight’ with the care company about the quality of care provided, his caring role and the challenges he faced were still on his mind now.

Other former carers said that support from care workers had been helpful. Alan said that their care worker ‘became really good friends’ with his mother and they ‘couldn’t have had anyone better’. Tara said that they were ‘lucky’ to have the same team of carers, as they knew what they were doing: ‘you weren’t constantly having to say ‘you have to do this and you have to do that’’. Paul said he was satisfied with the care his mother was receiving in the care home and that he ‘got on very well’ with the carers there: ‘I’ve got no qualms about where she is, she’s in the right place’.

ii) Healthcare

Some former carers said that they had a lack of support from healthcare services. Alan described the ‘huge battle’ he had with the doctors in getting a diagnosis for his mother: ‘they behaved as if they didn’t believe a word I was saying’. He said that he was ‘met with brick walls and obstruction’, which was ‘so frustrating’ and resulted in him making a complaint to the health service ombudsman, as well as his local MP. Elizabeth also said she also had ‘quite a few struggles to get any information or any help’ and that she kept getting ‘passed from pillar to post’. She said that it took several years for her mother’s heart problem to be diagnosed, despite the fact she was experiencing ‘fitting’ and ‘blackouts’. She felt there had been a ‘lack of understanding’ from her GP, who tried to ‘impose’ a ‘one size fits all’ approach which wasn’t always appropriate. Because she has ‘no trust in any GP’ she said she is no longer seeking help in relation to her own health: ‘there may be some things in my own health that I should be going to see about, but why bother because they’re not going to treat me’.

Sophie also said she didn’t trust healthcare professionals, and had tried to keep her mother out of hospital because she wasn’t confident that good quality care would be provided. On one occasion, she felt that her mother had been given morphine unnecessarily, on another occasion she felt that doctors mistakenly decreased her mother’s medication, resulting in hospital readmission. Because she didn’t trust healthcare professionals, she tried to take care of her mother herself as much as possible and ‘act like a nurse on the ward, test the same things they test.’ Aaron also felt he was picking up on issues that healthcare staff had missed: ‘no one picked up on [her thrush], and I’m not even medical’.

In contrast, David felt he’d had good support from healthcare services. He said he had ‘lots of training’ from ‘lovely nurses who were brilliant’ to help him with his wife’s dialysis. He also said that because his wife was ‘quite independent’ they only asked for assistance if they needed it, but that if there were ever any issues with the machine ‘support was there’.

Some former carers felt that caring impacted on their employment

Some former carers said that juggling work and care had been difficult. Maya said that because her employer did not provide cover when she had to care for her mother, she was ‘really stressed all the time’, having to rush around from one thing to the next in a ‘frenzied state’. She described how she was often working from hospital waiting rooms or car parks: ‘we were in hospital appointments at least 5 or 6 times a month, we were in A&E at least twice a month... it was being on call for two sides of my world.’ Paul said that he sometimes had to take phone calls from care workers and deal with unexpected issues, and it ‘wasn’t always easy’. Elizabeth also said that she was ‘getting phone call after phone call’ at work, and she had to ‘just run when the phone went’.

Some former carers said employers could do more to support carers. Maya said that employers should have ‘an actual sit-down conversation’ with carers to find out what they need. Fiona felt that conversations needed to be ‘two way’ and that carers need to have ‘a template of what to say’ and a knowledge of ‘what their rights are’. She suggested that many employers ‘don’t really get it because they haven’t been asked’ before. Aaron said that ‘empathy goes a long way’ and that employers should try to ‘understand the situation’ and ‘have trust in that worker to make up whatever work they may miss due to their caring responsibility’. He said that his manager understood that he may ‘be called at a stupid time or an unexpected time’ and that he may need ‘to rush off’. However, he felt this support wasn’t necessarily in place across the whole organisation: ‘it just happened to be, like, potluck with managers understanding what responsibilities I had’.

Opportunities to work from home were also considered to be helpful. Tara said that being able to work from home allowed her to check up on her mother regularly: ‘it made my life a lot easier because I was here with her’. David said he had ‘very good work relationship’ with senior staff and that they’d been ‘brilliant over the years’, allowing him to work from home or work flexible hours. He said that if he had a problem he would discuss it with them: ‘they would just be really good and say ‘look, just do what you need to do’. As a result, he felt he had ‘quite a good work-life balance’ and had been ‘very lucky’. In contrast, Sophie said her employer wanted her to go back into the office after the pandemic and had certain ‘perceptions’ about working from home: ‘people are very sceptical, and they expect the worst’.

Some former carers said they were simply unable to juggle work and care. Fiona said that because she was ‘exhausted’ she didn’t feel able to ‘run these two different shows at once’ because it was already ‘like being in a tightrope in a circus, juggling plates.’ Because her role involved supporting other people, she didn’t feel she had the emotional energy to do this anymore and gave up work to care: ‘I just couldn’t dig more empathy out of my system to give people I was working with what they needed’. Alan also ended up providing full time care: after being made redundant from his previous job, he initially sought to find new employment, but realised this would be ‘impossible. He said that every time he got close to finding a new job, ‘something went wrong’ and ‘everything came crashing down’. He felt that an employer ‘would have got too frustrated’ if he’d had to keep going home to provide care when his mother was unwell: ‘I actually think it would have been too disrupting and I think the employer would have lost their patience’.

Some former carers took a while to identify themselves as carers

Not all former carers identified themselves as carers, at least initially. Maya said that she ‘resisted’ attempts by her friends to identify her as a carer because she was worried it would make her mother ‘feel bad’. She also felt there was a ‘cultural stigma’ around it, and that it wasn’t a word her family had used in the past. Although she never felt ‘proud’ or ‘comfortable’ to identify herself as a carer, she sometimes did so because she felt it helped her ‘be taken more seriously’ by healthcare professionals. Fiona also said that the word carer hadn’t previously been used by her family, meaning she didn’t really understand what the term meant: ‘I thought it was what you did wearing a uniform, going in with rubber gloves’. For Aaron, caring was ‘just doing a duty’ that he felt he needed to do. He also felt that caring was about ‘stuff like personal care, getting people dressed and all that’ and because he never did those things, and mostly provided support with advocacy and appointments, he was ‘just doing what needed to be done at the time’.

Other former carers said it took them a while to identify themselves as a carer. Elizabeth felt that the responsibility ‘sort of gradually grew’ as she already lived at home and had helped her mother from a young age. Similarly, Alan said he didn’t identify himself as a carer initially: ‘I just thought, well it’s just the way that things are, I mean her son, I’ve got to do this for her. David said that he only identified himself as a carer when he started providing the majority of the care and ‘took over everything full time’. Previously, the support he was providing his wife just felt ‘normal’ and ‘a routine.’

Some former carers said that they hadn’t expected to become a carer. As Sophie explained: ‘no one would expect to do that for 11 and a half years and give up an awful lot as a consequence’. She said she had surprised herself with her ability to provide care, having not seen herself ‘as a natural carer or someone who would be any good at dealing with it.’ Alan also said that he ‘never imagined’ he would become a carer. He said that he didn’t think he was ‘cut out’ to be a carer: ‘originally I thought....I’m not a carer, I can’t get my hands dirty, I’m an office person, I do telephone work and things like that’. He said that caring had changed him: ‘I’m a different person now.’ Elizabeth also said that caring had changed her: because she’d had to ‘shout loud’ to get help, she became ‘quite a different person’ after providing care: ‘I used to be quite a shy person and not really argumentative but after the last few years of having to deal with my mum I certainly wouldn’t stand back and not say something, if I see something that’s not right.’

Conclusion

This research shows that support for former carers is essential. This support should start while people are still providing care, to help them prepare for and cope with the loss of the person they cared for and the loss of their caring role. This support should focus on a number of areas, from finances and employment to health and wellbeing, and practical support with caring.

There needs to be a step change in the way in which carers are identified and supported. In England, Carers UK have been calling for a funded National Strategy for Carers.

Although this research focused on people whose caring roles had ended, Carers UK recognise that many people continue to provide care even when the person being cared for has moved into a care home or residential setting. Caring for a friend or relative in a care home can be an intense or stressful caring experience, and it is vital that those carers receive the support they need.

Recommendations

- Health and social care services could continue to communicate and engage with former carers, even when the caring role has come to an end. This might include acknowledging the impact that the end of caring might have on carers' health and wellbeing, and signposting former carers to further support to help them overcome these challenges.
- Carers centres and organisations supporting carers could develop specific programmes and activities supporting former carers, including peer support groups, or help and advice services to support with bereavement and/or PTSD, as well as financial and legal matters.
- Organisations supporting carers could help carers prepare for life after caring, particularly those struggling with loneliness. This might include supporting carers to plan for the end of their caring role, helping carers to manage any mental health issues while they are still caring, and creating opportunities for carers to connect with other carers and share their experiences.
- Commissioners of carers support services should consider commissioning for a short period of support for bereaved carers from carers services. This would enable carers to continue to receive support from a service which they may have found helpful while caring.
- Counselling services should ensure there is stronger bereavement support for carers, addressing issues relating to the end of caring.
- UK Government and nation Governments should consider a refresh of work around current and former carer returners, skills recognition and later life apprenticeships. This should also include further support for workers over 50 particularly where they are, or have been, juggling work and care and returning to work
- DWP could promote greater awareness and targeted support within Jobcentre Plus for carers returning to work. This could include reviewing any training received by Work Coaches on supporting current or former carers and addressing any challenges they might face.
- Employers should consider providing carer awareness and age diversity training, health and wellbeing programmes and policies to create carer friendly workplaces.
- Further research could be conducted by Carers UK, or other organisations and research bodies, with former carers who have provided palliative care at home, to understand more about their specific experiences.

Further resources for former carers

Information and advice

Carers UK have several online resources for former carers:

Coping with bereavement – this resource provides guidance on coping with grief and the practical steps to consider after a death, including benefits and housing: carersuk.org/help-and-advice/practical-support/coping-with-bereavement/

When caring ends or changes – this resource considers the potential effects that a change of circumstances might have, and includes advice on considering options such as residential care, bereavement, end of life planning and looking ahead to life after caring: carersuk.org/help-and-advice/practical-support/when-caring-ends-or-changes/

Residential care – this resource is all about how to make choices about residential care, and how to deal with the practicalities of stopping caring at home, such as managing the financial impact. carersuk.org/help-and-advice/practical-support/arranging-care-and-support-for-someone/residential-care/

Life after caring – this resource addresses the transition in life when caring ends, and outlines suggestions around from taking time out and meeting others, to reapplying skills learned from caring, re-entering work or seeking volunteering opportunities: carersuk.org/help-and-advice/practical-support/life-after-caring/.

Returning to work – this resource includes information on how to start thinking about returning to work, including identifying skills and interests, and researching roles. It also includes a link to the National Careers Service Skills Health Check, and a link to the Carers UK ‘Learning for Living’ e-learning tool which aims to help people identify skills gained through caring: carersuk.org/help-and-advice/work-and-career/thinking-of-returning-to-work/

Boosting skills - this resource includes information on developing your current skills and learning new ones: carersuk.org/help-and-advice/work-and-career/boosting-your-skills/

The Government Equalities Office have also produced a guide which aims to support carers who have taken a break from employment for over a year to get back into paid employment. This is available at gov.uk/government/publications/returner-toolkit-helping-you-back-to-work/returner-toolkit-helping-you-back-to-work

Peer support

Carers UK hold an online Care for a Cuppa session for former carers every 2 months. These are an opportunity for former carers to meet other people who have cared in the past and find mutual support. Forthcoming sessions are advertised at carersuk.org/help-and-advice/your-health-and-wellbeing/online-meetups/care-for-a-cuppa/

Volunteering

Carers UK are always keen to involve former carers in our work, as we recognise the expertise and knowledge that carers can bring. If you would be interested in becoming an Insight Volunteer, and sharing your caring experience with us to help us with our work, please find more information at carersuk.org/get-involved/volunteer-with-us/insight-volunteer/ or email volunteering@carersuk.org

Share and learn sessions

Carers UK offer online share and learn sessions for all carers, including former carers. These aim to improve wellbeing, and cover topics including yoga, singing, mindfulness, photography, songwriting, and dance. Forthcoming sessions are advertised at carersuk.org/help-and-advice/your-health-and-wellbeing/online-meetups/share-and-learn/



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