

State of Caring

The impact of caring on carers' mental health and the need for support from social care services

February 2025



About this research

Carers UK carried out an online survey with unpaid carers between June and August 2024.

This report summarises their responses. As not all respondents completed every question in the survey, some figures are based on responses from less than 12,500 people.

The survey was promoted extensively amongst both carers and organisations supporting carers. It was shared on the Carers UK website, on Carers UK social media channels, and with Carers UK members, volunteers, previous survey respondents, campaigners, affiliates, Employers for Carers members, and other organisations.

Of respondents to the survey:

- 92% are currently providing care. Of those, 63% are in England, 15% are in Scotland, 11% are in Wales, and 11% in Northern Ireland.
- 8% have cared in the past but are no longer caring. Of those, 62% are in England, 20% are in Scotland, 12% in Northern Ireland and 6% in Wales.

- Of those currently caring, 14% are caring for 19 hours or less, 26% are caring for 20-49 hours, and 61% are caring for 50 or more hours a week.
- 68% of respondents were aged 18-64 years and 31% were aged 65 and over. The biggest proportion of respondents were in the 55-64 year category (35%).
- 81% of respondents were female; 18% were male. 1% said their gender was not the same as the one assigned at birth.
- 89% of respondents were White British, 7% were from another White background, and 3% were from a Mixed/Multiple, Black/Black British, Asian/Asian British or other ethnic background.
- 91% of respondents were heterosexual/straight,
 5% were Lesbian, Gay or Bisexual, or preferred to self-describe their sexual orientation.
- 29% of respondents had a disability.

Thanks

Carers UK would like to thank every carer who took the time to complete this survey, as well as the carers who helped us test the survey. Your responses will be used in all our policy and campaigning work over the next year.



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Introduction

According to Census data, at least 5.8 million people across the UK are providing unpaid care for an ill, older or disabled family member or friend. As life expectancy increases and people are living for longer, the number of hours of unpaid care being provided has increased over the past 10 years.²



Caring can have a significant impact on carers' own health and wellbeing. With the increase in the cost of living in recent years, a significant proportion of carers are finding it difficult to pay for essentials like food and heating, and 61% feel stressed or anxious when they think about their financial situation.³

Yet carers are often unable to increase their income: without sufficient support from employers and replacement care services, many carers reduce their working hours or give up work completely. 73% of carers in employment said they had found it stressful

to juggle work and care, and 40% of all carers had given up work completely.⁴

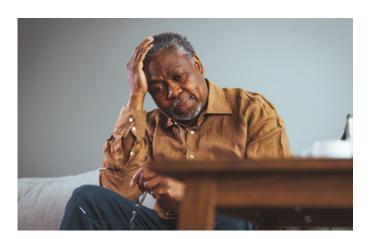
Carers often feel they are caring behind closed doors; that they are invisible, undervalued and forgotten about. This year's survey found that only 14% of carers feel valued by the general public, and just 5% feel valued by Governments. Many carers need more support from the NHS, both in terms of managing the care of their family member or friend, and in dealing with their own health issues. Carers are more likely than non-carers to be disabled,⁵ and more likely to

- 1 Carers UK analysis based on 2021 census data in England, Wales and Northern Ireland, and 2022 data in Scotland
- 2 ONS (2023) Unpaid care, England and Wales: Census 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/unpaidcareenglandandwales/census2021
- 3 Carers UK (2024) The impact of caring on finances. https://www.carersuk.org/media/umaifzpq/cuk-state-of-caring-2024-finances-web.pdf
- 4 Carers UK (2024) The impact of caring on employment. https://www.carersuk.org/media/qlsly1mc/state-of-caring-employment-web-2024.pdf
- ONS (2023) Unpaid care and protected characteristics, England and Wales: Census 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/articles/unpaidcareandprotectedcharacteristicsenglandandwales/census2021#unpaid-care-and-disability

report that they are in 'not good' health',⁶ yet carers are often unable to prioritise their own health and wellbeing because they can't take a break from caring. Our research in 2023 found that 44% of carers had put off health treatment because of their caring role.⁷

Every year carers tell us that they need a break from caring. A high proportion of carers who complete our State of Caring survey provide a significant amount of care: 61% care for 50 or more hours a week. For carers who provide a substantial amount of care, being able to access good quality, reliable, consistent social care services is crucial – to reduce the amount of care they need to provide themselves and offer an opportunity for some much-needed recuperation.

Breaks are essential in enabling carers to focus on their own needs and interests, spend time with family and friends, deal with other household duties, seek help for any health issues, and remain in paid employment if they wish to do so. However, an increase in demand for social care services, 8 together with a lack of funding available for adult social care, means that replacement care and respite services are often not available when carers need them. Concerningly, three quarters of carers have not received a Carer's Assessment, and a significant proportion of those who have had an assessment are not given any practical support.¹⁰ This research finds that, shockingly, over half of carers feel overwhelmed often or always, and over a third have bad or very bad mental health.



It is unacceptable that so many carers are experiencing poor mental health whilst providing so much for society.



It is unacceptable that so many carers are experiencing poor mental health whilst providing so much for society. Carers' health and wellbeing can only improve when they receive sufficient support from both the health and social care systems. Our forthcoming report on the NHS will highlight the changes that need to be made within the NHS to ensure that carers are fully supported. This report focuses on social care services, and the support that is needed from the Government and local authorities to ensure that carers can get a break, provide as much care as they want to, and feel less lonely, less stressed and less anxious about their caring role.

⁶ ONS (2024) Unpaid care expectancy and health outcomes of unpaid carers, England: April 2024. <a href="https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/bulletins/unpaidcareexpectancyandhealthoutcomesofunpaidcarersengland/april2024#:~:text=In%20Census%202021%2C%20around%20one,based%20on%20age%2Dadjusted%20percentages.

⁷ Carers UK (2023) The impact of caring on health. https://www.carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf

⁸ Care Quality Commission (2024) The state of health care and adult social care in England 2023-34. https://www.cqc.org.uk/publications/major-report/state-care/2023-2024

⁹ ADASS 2024 Spring Survey (2024) https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf

¹⁰ Adult Social Care Activity and Finance Report, England, 2023-23. https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2023-24/carers

Executive summary



- Many carers have poor mental health, and this
 is getting increasingly worse. Over a third (35%)
 of carers who completed the survey this year
 said they had bad or very bad mental health,
 compared to 27% the previous year.
- Carers need more support with their health and wellbeing. 66% of carers told us they need more support with health and wellbeing. This was the top need cited by carers, and an increase from 61% in the previous year. 80% of carers said the impact of caring on their physical and/or mental health will be a challenge over the next year.
- Carers who are struggling financially are more likely to report poor mental health. Over half (56%) of carers struggling to make ends meet had bad or very bad mental health compared with 18% of carers who were not struggling financially.
- Carers who are not in paid employment are also more likely to have poor mental health. 43% of carers who had given up work to care said that they had bad or very bad mental health, compared with 35% of carers in paid employment.

- A significant proportion of carers feel overwhelmed. 57% of carers stated that they feel overwhelmed often or always.
- The main reason carers feel overwhelmed is because they are not getting a break from caring. 65% of carers said that they felt overwhelmed because they haven't been able to take a break from caring. Half (49%) of carers said they needed more breaks or time off from caring, and 54% said being able to have regular breaks from caring would be a challenge over the coming year.
- Carers need more recognition for the important role they are playing in supporting health and social care systems. 57% of carers said they needed better understanding and recognition of unpaid carers from the general public. This is the second most important need cited by carers.
- More carers need to know where they can get support. 53% said they needed to know what support is available – an increase from 48% in the previous year.



- Carers are in increasing need of support from their local authority. 55% of carers said they needed more recognition of their needs from their local authority compared to 46% in the previous year, and is now cited by carers as their third most important need.
- The majority of carers have not had a Carer's Assessment. Only 23% carers had had a Carers Assessment in the last 12 months. 77% of carers had not had an assessment in the last 12 months.
- Carers who have had a Carer's Assessment find the process unsatisfactory. 42% of carers who had had a Carer's Assessment said their local authority had not supported them after the assessment.
- Local authorities are often signposting to resources rather than providing practical support for carers after a Carer's Assessment.
 47% of carers who felt they had not been supported said the assessment identified areas where they need more support, but this has not yet been provided.

- Carers are often unable to access good quality social care services when they need them.
 57% of carers who'd tried getting support had experienced long wait times, and 51% said that services were not available when they needed them. 39% of carers said that there was a lack of consistency in who was providing care and 38% of carers said they had concerns about the quality of care.
- Challenges with social care services are having a negative impact on carers' mental health and outlook on the future. 88% of carers who had experienced challenges with services said it has made them worry more about the future, and 79% said it had negatively impacted their mental health.
- Challenges with social care services also impact on carers' ability to juggle caring with paid employment. 49% of carers who had experienced challenges with social care services said it negatively impacted their ability to work. This increased to 63% for carers in paid employment.

The impact of caring on mental health



- Over a third (35%) of carers who completed the survey said they had bad or very bad mental health, compared to 27% the previous year.
- Carers who are struggling financially are struggling more with their mental health. Over half (56%) of carers struggling to make ends meet had bad or very bad mental health compared with 18% of carers who were not struggling financially.
- Carers who are not in paid employment are also more likely to have poor mental health. 43% of carers who had given up work to care said they had bad or very bad mental health, compared with 35% of carers in paid employment.
- Over half (57%) of carers said they feel overwhelmed 'often' or 'always'. 37% feel overwhelmed 'sometimes'. Only 6% said they 'rarely' or 'never' feel overwhelmed.
- The main reason carers feel overwhelmed is because they have been unable to take a break. 65% of carers said they felt overwhelmed because of this.
- Other key reasons carers feel overwhelmed are managing the different needs of the person they care for (59%) and struggling with their own health condition (50%).

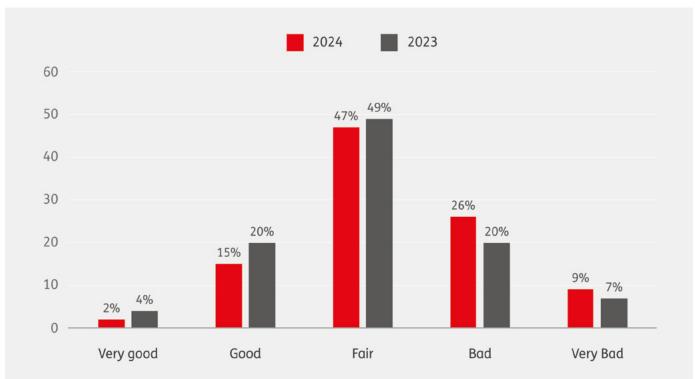
Carers' mental health

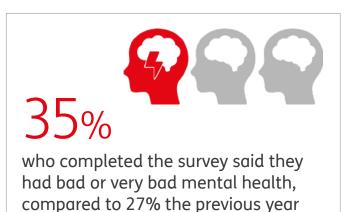
Over a third of carers (35%) said their mental health was bad or very bad. This is an increase from the previous year (27%). Just 17% of carers said their mental health was good or very good, compared with 24% in the previous year.

Many carers said their mental health has worsened due to caring.

- My mental health can get very low on medications for anxiety, panic disorder & depression, all not helped by the stresses of being an unpaid carer."
- The financial and emotional pressures of caring for someone with learning disabilities are immense and I take anti-depressants to help to cope and have done for several years. It's overwhelming and exhausting, no matter how much love you have for them and it feels as though it will never end."
- Looking after four children with a range of issues including autism, ADHD, learning difficulties, sensory issues and mental health issues is completely physically and mentally draining. I can barely think straight and feel exhausted often."









Other research has also found that carers can struggle with their mental health. The GP Patient Survey 2024 found that 18% of carers had a mental health condition compared with 13% of non-carers.¹¹

Many carers struggle with low mood or anxiety. For some carers, caring can have a significant impact on their mental health, leading to acute mental health issues which are not always being treated. Our research in 2023 found that over a third of carers (36%) whose mental health was bad or very bad said they had thoughts related to self-harm or suicide. 12 39% of carers whose mental health was bad or very bad said they were not receiving any support with their mental health. Other research has also found that some carers can struggle with acute mental health issues. Research by the University of Birmingham with 750 parent carers in England, from a range of backgrounds and caring situations, found that more than 40% have thought about suicide. 13

Caring can negatively impact mental health in several ways:

Managing the financial costs of care

Caring can result in additional financial costs, and many carers struggle to pay for essentials like food and heating. This can impact on mental health: our survey found that 56% of carers struggling to make ends meet had bad or very bad mental health compared with 18% of carers who were not struggling financially. 42% of carers in receipt of Carer's Allowance and 52% of carers receiving Universal Credit with Carer Element said their mental health was bad or very bad.

I have had a breakdown (but have had to continue in my caring role), trying to keep up with my mortgage payments. I have just managed to avoid repossession proceedings."



- 11 Carers UK analysis of GP Patient Survey 2024
- 12 Carers UK (2023) The impact of caring on health. https://www.carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf
- 13 O'Dwyer, S. et al. (2024) Suicidal thoughts and behaviours in parents caring for children with disabilities and long-term illnesses. https://research.birmingham.gc.uk/en/publications/suicidal-thoughts-and-behaviors-in-parents-caring-for-children-wi

Combining unpaid care with paid employment

Our survey found that 73% of working carers said it was stressful to juggle work and care, and 40% of all carers had given up work completely. Giving up work to care can negatively impact on mental health. Many carers feel they have missed out on progressing within their chosen career, while others find that looking after disabled, older or chronically ill relatives and friends in the home full-time can be lonely. 43% of carers who had given up work to care said they had bad or very bad mental health, compared with 35% of carers in paid employment.

- I've voluntarily taken early retirement so that I can have more time to manage everything that is going on at home and to support my caree. This has taken a toll on my mental health as I'm missing my worklife and colleagues."
- Giving up my career to care has had significant impact on my wellbeing."

Not being able to take a break

Carers often feel they are unable to spend time with friends and family because they are too busy caring, and this can cause loneliness. Carers can also struggle with depression when they are unable to focus on their own needs and pursue their own hobbies and interests. Our survey found that carers who were caring for more hours per week were more likely to have poor mental health. 38% of carers caring for over 35 hours per week had bad or very mental health compared to 26% of those caring for less than 35 hours per week.

- **66** My world as a carer has shrunk. I don't know who I am anymore. I even got mail [addressed] to 'the carer' not even a name."
- I can't do the things I had hoped to do in my life because of my caring role. I can't get a promotion, go travelling, spend time with friends. I can't relax. Ever."
- As sole carer and on 24/7 care alert it is very tiring and that makes everything else a struggle, especially as phobias make my spouse unable to accept outside help."
- **66** I have no help from family. I do not have friends. Neighbours do not bother with me. I am extremely lonely and isolated in my own home due to caring for my disabled son. I cry about this often. No one contacts me. This won't change."

Not getting enough support with caring

Caring can also be emotionally and mentally tiring, particularly when carers do not get enough advice and guidance about how to support the person they care for. Many carers feel they are left alone to deal with clinical tasks, while others find it hard to manage the changing needs of the person they care for.

- I've had to spend time and energy doing my own research on things, I feel the need to prepare for each appointment like I'm going into battle. It's exhausting and I constantly feel that I'm not being listened to or believed, it's like being gaslit by the NHS."
- I spend most evenings researching interventions, new equipment, activities suitable for my child to help him with his hypermobility, speech and language difficulties, his meltdowns and frustration etc. I feel very abandoned by the NHS."
- Oue to my husband who I care for having a degenerative neurological condition there is fluctuations in my caring responsibilities meaning from day to day I do not know how things will pan out. This causes a background of stress and anxiety."
- Staff automatically expected me to know what to do to continue with medical care at home. This caused me great anxiety and more calls to the GP as I was so unsure that I was doing the right thing.



Many carers also find that the administration involved in getting support for the person they care for can cause additional stress.

- **66** Everything is made so hard to access. We as carers have enough to do, but we have to run round to get things done. It's so tiring and exhausting."
- 66 Most of any burn out that I feel doesn't come from caring for the person I love. It comes from the constant battle for services, appointments etc."



Worrying about the future

Carers also need more support in planning for the future. It is the oldest carers who provide the highest number of hours of care a week, 15 yet many older carers worry about how they will continue to support the person they care for as their own health declines, particularly if they are not currently receiving any practical support with caring.

- 66 Overall I worry about my adult son- who I care for when I am too old/unwell to do so. I need to put things in place now and I don't know where to start."
- **66** I am constantly kept awake worrying about the family's future if something happens to me."
- **66** I have terminal Cancer. I worry about my wife who is on the late stages of dementia and what will happen to her care if I die first."

¹⁵ ONS (2023) Unpaid care by age, sex and deprivation, England and Wales: Census 2021. https://www.ons.gov.uk/peoplepopulationandcommunity/ healthandsocialcare/socialcare/articles/unpaidcarebyagesexanddeprivationenglandandwales/census2021#unpaid-care-by-age-sex-and-geography-2021

Caring for multiple people

Over a quarter (27%) of carers who responded to our survey are caring for more than one person. 41% of people caring for more than one person said their mental health was bad or very bad, compared with 34% of those caring for one person. Managing multiple needs at once can cause stress or anxiety, particularly when these needs can be quite different.

- They have opposite needs eg one wants to go out all the time, the other wants to stay in. Both are autistic but present differently & their needs compete, so I am stuck in the middle."
- It can be very challenging to provide care for them both simultaneously, because it can be difficult to determine who has the greatest need, so often one person may be given less attention than the other on these occasions, or there can be delay in being able to give them assistance when they need it immediately."
- It's a logistical nightmare. For example my mother in law is disabled and needs support to go shopping but I can't leave my wife for too long so end up dropping my mother in law off, check in on my wife and help her with the toilet and then back to help my mother in law."

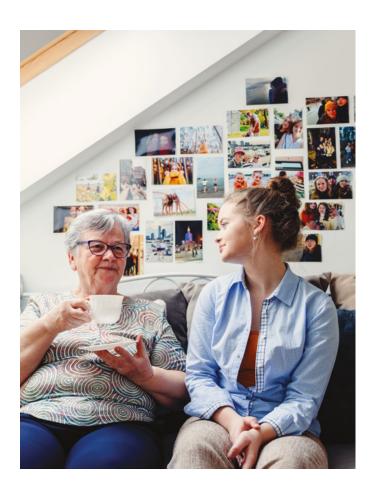
Some carers said they felt guilty or anxious about spending time away from one person to care for somebody else. Several carers said that the person they cared for could be resentful if they spent time supporting someone else, or that when they had to prioritise supporting one person, the other person could then experience challenges.

- Feeling torn between them: when I am looking after my mum I am anxious about my husband. His mental health always goes down when I visit my mum."
- Working out who needs me most and terrible anxiety when I have to ignore someone's needs to deal with somebody else."
- Conflicting needs can sometimes mean having to 'drop' support for one person because another has a more pressing demand although this invariably leads to 'fall out' of upset within the other person that needs to be managed and mitigated subsequently, adding more time to what I need to offer them."

Not receiving enough recognition

Feeling undervalued can have a negative impact on health and wellbeing. 57% of carers said they needed better understanding and recognition of unpaid carers from the general public. Many carers feel they are invisible – that they are caring behind closed doors, and that there isn't enough recognition of the vital role they are playing in supporting health and social care systems. 44% of carers who do not feel valued by the general public said they had bad or very bad mental health, compared with 25% of carers who do feel valued by the general public.

- In the UK there is a culture of people on benefits automatically being considered as scroungers, or low class or uneducated...We need to change this we need people to be our advocates rather than vilify us."
- [We need] societal change we celebrate and award new mothers with maternity leave. We don't have the same attitude to thanking and supporting unpaid carers it's shameful and not celebrated as a good deed we are doing."

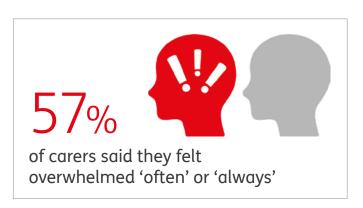


Carers feeling overwhelmed

Over half (57%) of carers said they felt overwhelmed 'often' or 'always'. 37% feel overwhelmed 'sometimes'. Only 6% said they 'rarely' or 'never' feel overwhelmed.

Carers struggling financially were more likely to feel overwhelmed. Nearly three-quarters of carers (73%) struggling to make ends meet said they feel overwhelmed often or always compared with 41% of those who are not struggling financially.

Carers caring for more hours were more likely to feel overwhelmed. 60% of carers caring for 35 or more hours a week said they feel overwhelmed often or always compared with 47% of people caring for less than 35 hours a week.



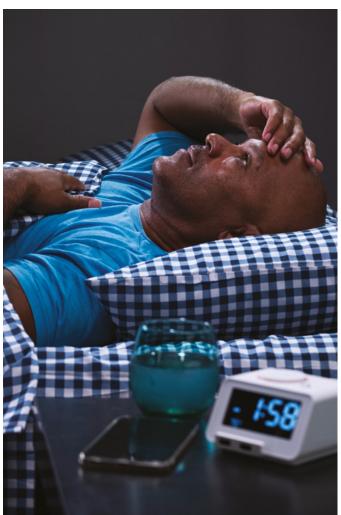
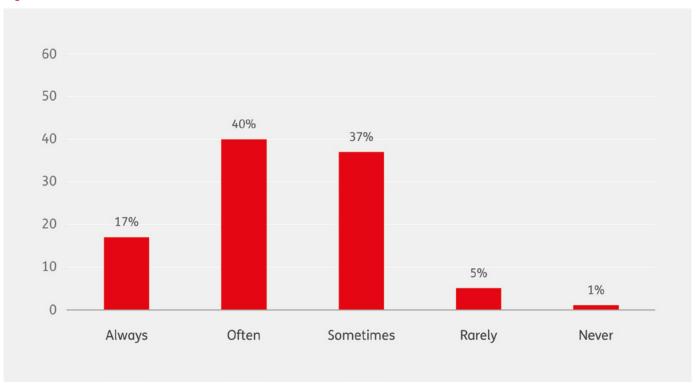


Figure 2: How often carers feel overwhelmed



Carers in paid employment were more likely to feel overwhelmed. 60% of carers in paid employment said they feel overwhelmed often or always compared to 56% of carers not in paid employment.

The main reason carers had for feeling overwhelmed was not being able to take a break from caring (65%).

- **66** I just want to get away and hide sometimes. Life can be overwhelming and I would love my freedom back."
- What being able to have a couple of hours each morning for myself when I have some energy to do some exercise. But worse having no space to take a shower, peace to concentrate and deal with household admin."

The second most reported reason for carers feeling overwhelmed was managing the different needs of the person they care for (59%). Some carers said that the person's needs were changing over time, and that as their condition worsened it was harder to cope. Carers also said that they felt overwhelmed seeing the person they care for in pain.

- The worst thing is watching my son gradually physically decline and living in fear of further lifethreatening episodes on an almost daily basis yet being unable to avoid these or help him myself. It's like living with a time bomb that could explode at any time."
- Meeting my dad's emotional needs and changes in moods is very challenging. He often argues with me and doesn't have a realistic view of his limited physical capabilities. I become upset when he takes his frustration out on me and upsets me and my family."
- **66** I feel overwhelmed by sadness due to Mum's dementia sometimes, and fear of what life holds for her and my dad in the future."
- I am on a constant state of alert; have continual calls about falls, decision making re: capacity. My cared for person says they are ok. They are far from it. I have to mediate between their needs and wants and the reality of the situation..."

The third most reported reason for feeling overwhelmed was carers struggling with their own health condition (50%). Over a quarter of carers (27%) said their physical health was bad or very bad. Other research has also found that carers are more likely than non-carers to have poor health.

The Census 2021 in England and Wales found that 1 in 4 carers reported that they had 'not good health' after adjusting for age, compared with fewer than 1 in 5 non-carers. ¹⁶ The probability of reporting being in "not good health" was higher for people providing more hours of unpaid care. Similarly, the GP Patient Survey 2024 found that 70% of carers said they had a long-term physical or mental health condition, disability or illness, compared to 59% of non-carers. ¹⁷

- **66** I'm disabled myself and the things I am forced to do are making me even more unwell."
- I have osteo-arthritis, and still waiting for hospital referral, unable to push my husband's wheelchair very far."
- My physical health has plummeted and I'm in need of surgery but the waiting list to be assessed is over nine months. I'm exhausted, in pain, can't work and coping with my caring role has become impossible."
- I suffer with Crohns & have an ileostomy...the disease is not understood, as to how debilitating it can be...no consideration is given for the situation."



ONS (2024) Unpaid care expectancy and health outcomes of unpaid carers, England: April 2024. <a href="https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/socialcare/bulletins/unpaidcareexpectancyandhealthoutcomesofunpaidcarersengland/april2024#:~:text=In%20Census%202021%2C%20around%20one,based%20on%20age%2Dadjusted%20percentages.

¹⁷ Carers UK analysis of GP Patient Survey 2024

Table 1: Reasons why carers feel overwhelmed

Reason for feeling overwhelmed	% of carers who responded
Not being able to take a break from caring	65%
Managing the different needs of the person I care for	59%
Struggling with my own health condition	50%
Dealing with all the administration involved in caring (eg arranging and managing paid care, claiming financial benefits)	38%
Not getting enough support from social care services (eg paid care workers, respite services)	37%
Not getting enough support from friends and family	35%
Not getting enough support from health services (eg GP or hospital staff)	35%
Juggling work and care (all carers who responded)	33%
Juggling work and care (carers in paid employment who responded)	80%
Struggling to manage financially	32%
Worrying about the future when my caring role comes to an end	31%
Not knowing where to go to access support	30%
Caring for more than 1 person	25%
Not knowing how to support the person I care for	25%
Not getting enough support from other organisations (eg education provider or employer)	15%

Other reasons that carers gave for feeling overwhelmed included juggling childcare responsibilities with caring and trying to manage household tasks while caring. Many carers also said that they felt overwhelmed because they couldn't see an end to their caring responsibilities.

- 66 No end in sight mum should be in a home as per the professionals but as she has full capacity we need to abide by her decision to be at home. This situation could go on for years and I don't know how many years I have left. It is impacting my whole life including my marriage."
- My caring role is unlikely to ever end as my child has a lifelong disability."



Support needed with health and wellbeing



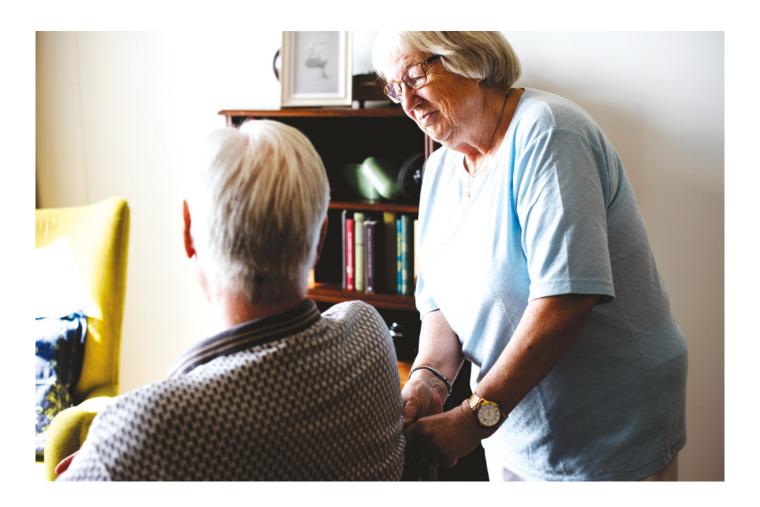
- 66% of carers said they needed more support with their health and wellbeing this is carers' most important need, and an increase from 61% the previous year.
- 80% of carers said the impact of caring on their physical and/or mental health will be a challenge over the next year.
- Over half (51%) of carers need more support from NHS or healthcare professionals.
- 54% of carers said being able to have regular breaks from caring would be a challenge over the coming year.

Two thirds (66%) of carers said they needed more support with their health and wellbeing – this is the most commonly reported need amongst carers, and an increase from 61% in the previous year. 80% of carers said the impact of caring on their physical and/ or mental health will be a challenge over the next year.

Carers with poor health were, unsurprisingly, even more likely to say they needed more support to look after their health and wellbeing – 81% of carers with bad or very bad mental health said they needed this.



of carers said they needed more support with their health and wellbeing



Carers are often unable to get the support they need with their health and wellbeing due to long waiting times for appointments, inflexible GP appointment systems, and insufficient support from replacement care services. ¹⁸ Many carers feel that their own health is not considered by healthcare professionals. Over half (51%) of carers need more support from NHS or healthcare professionals.

- I have been unable to get appointments with my GP because they require me to phone for appointment on the day. I can't get booked in advance appointments. I'm unable to just go on day because I need to arrange alternative care for my mother. My local GP practice seems to have no awareness of the needs of carers."
- I've recently been prescribed medication to help manage my anxiety but this was done over the phone. I've yet to see someone about this issue and they haven't called me in to review the situation and assess how I'm doing on the medication. It doesn't make me feel very seen or cared about."

- 66 My husband is deteriorating, but we have no contact with our GP unless I initiate it. I think there should be an annual review for both of us, as nobody monitors the stress it has on my health."
- Comparison of the profession of the stress of the articulating that distress to healthcare professionals when discussing my mother's care no one ever asks me how I am (despite having an existing diagnosis of depression)."

For several years, Carers UK has consistently set out a range of issues faced by carers within the NHS, and the support that is needed. In 2023, our State of Caring survey found that 44% of carers said they had put off health treatment because of their caring role.¹⁹

¹⁸ Carers UK (2023) The impact of caring on health. https://www.carersuk.org/media/xgwlj0gn/soc23-health-report_web.pdf

¹⁹ Ibid



In addition, when carers are unable to take a break from caring, it can be difficult for them to seek help with their own health issues. Our survey in 2023 found that 73% of carers with bad or very bad mental health had continued to provide care despite being at breaking point.²⁰ It also found that 44% of carers said they had put off health treatment because of their caring role.

- I can never get a doctors appointment for myself without having to spend ages on the phone or being told to try again tomorrow. I end up not bothering and self medicating. If I am not well how am I expected to care for others!"
- **66** Have to ignore my own health conditions (eg fibromyalgia) and prioritise caree's."
- It feels like a constant battle to be heard and get the support my child needs and I have no fight left for my own health and wellbeing."
- I feel frequently alone and depressed. There is a 6 month waiting list to see a mental health nurse so I don't bother. "

Carers are also often unable to focus on their own health because they are too busy caring. Taking a break can enable carers to spend time with family and friends, and engage with their own hobbies and interests, which can improve wellbeing. However, half (49%) of carers said they needed more breaks or time off from caring, and 54% said being able to have regular breaks from caring would be a challenge over the coming year.

- **66** Instead of more breaks, I would just like a break full stop. I haven't had a day off for 12 years."
- I have no help from family, friends or outside [paid] carers. To be honest, that's because I have no friends to call on (they've moved away or fallen by the wayside) and my family are mostly aged and have their own health issues to contend with."
- I feel like my life is on hold whilst I care for my Mum. I can't leave her therefore I can't have any sort of break or go on holiday."
- **66** Leaving my husband alone at home is becoming more worrying and something I try to avoid."

Other research has also found that carers are not prioritising their own health. The most recent Social Services Survey of Adult Carers in England found that less than half (47%) of carers felt they were able to look after themselves, and one in five (20%) carers felt they were neglecting themselves.²¹



²⁰ Ibid

²¹ NHS England (2024) Personal Social Services Survey of Adult Carers in England, 2023-24. https://digital.nhs.uk/data-and-information/publications/statistical/personal-social-services-survey-of-adult-carers/england-2023-24

Carers' Assessments



- 55% of carers said they needed more recognition of their needs from their local council. This is an increase from 46% in the previous year, and it is now the third highest need amongst carers.
- Only 23% carers had had a Carer's Assessment in the last 12 months. This proportion has not changed since we last asked carers this question in 2022.
- 42% of carers who'd had an assessment said their local authority had not supported them after the assessment.
- 47% of carers who said they hadn't been supported by their local authority said that
 the Carer's Assessment identified areas where they need more support, but this hasn't
 been provided. Some carers said there was limited support available, due to issues with
 staff shortages, while others said they had been given signposting only, rather than any
 practical support.

Recognition from local authorities

This year, more carers said they needed support from their local council. 55% of carers said they needed better recognition from their local council of their needs – now the third most commonly reported need, and an increase from 46% in the previous year.

Council operated a 'hub' system for Social Care, which means you have to deal with different people every time you call. Would greatly prefer to have a nominated social worker who we could deal with on a regular basis. Also would much prefer to have an e-mail contact. Then social workers/ myself can deal with issues in our own time, instead of having to waste hours trying to contact people who may not be at their desks."

I keep getting told I'm not entitled to any help or support from social services. I'm desperate. I'm falling to pieces. I don't have any support from family or friends. And yet I'm not entitled to anything?"



of carers said they needed more recognition of their needs from their local council

I don't feel I'm listened to enough or that my views are important & often made to feel blamed as a parent carer, especially by the local authority."

Carers in London were most likely to say they needed better recognition from their local council of their needs (63%), followed by carers in the West Midlands (61%). Carers in the East of England were least likely to say they needed better recognition from their local council of their needs, although this was still 50% of carers.

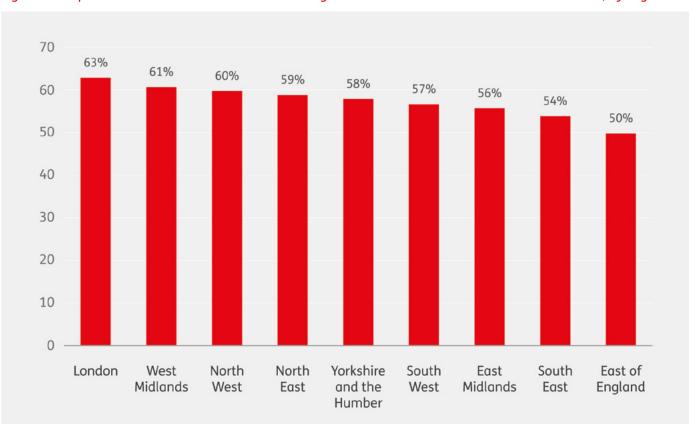


Figure 3: Proportion of carers who need better recognition of their needs from their local council, by region

Carers' Assessments

Under the Care Act 2014, carers are entitled to have a Carer's Assessment by their local authority, to ascertain whether they need any support with physical, mental and emotional needs. The assessment should also consider whether carers are prevented from achieving certain outcomes, such as staying in paid employment or having a social life.

Our survey found that less than a quarter of carers (23%) had had a Carer's Assessment in the last 12 months. Over three quarters (77%) said they had not had a Carer's Assessment. These results haven't changed since we last asked carers this question in our 2022 survey.

The Care Quality Commission (CQC) State of Care 2024 report found that within all the local authorities they have assessed so far, there is work needed to identify carers, and raise awareness that carers are entitled to an assessment and services to support them in their role.²² A recent survey conducted by Carers Trust found that staff working in local authorities said the focus within their council on carers had been high when the Care Act 2014 was first introduced, but had decreased as other priorities had taken over.²³

We asked carers who had had a Carer's Assessment whether they felt their local authority had supported them with their caring role after the Carer's Assessment. 42% of carers said their local authority had not supported them. 28% were unsure, and 31% said their local authority had supported them.

The most commonly reported reason for why carers said they had not been supported by their local authority was because support had not been provided following the Carer's Assessment. 47% of carers said the assessment identified areas where they needed more support, but this has not yet been provided. This is concerning, as under the Care Act 2014, if the local council decides that a carer has eligible needs and the carer does not have the financial resources to pay for support services, then the council has a legal obligation to meet the carers' needs and must draw up a support plan detailing how these needs will be met.

Some carers said there was limited support available, due to a shortage of paid care workers.

I was given vouchers for a sitter service, it took 6 months to find one with availability."



Only **73**0/

had had a Carer's Assessment in the last 12 months



47%





of carers who said they hadn't been supported by their local authority said that the Carer's Assessment identified areas where they need more support, but this hasn't been provided

- Assessment identified I need more support.

 Direct payment for respite given but not enough care staff available to provide the care."
- They assessed me and said I should receive two hours respite a week. Unfortunately, the agency who is contracted to provide this are struggling to do this every week. I am currently owed 20 hours from missed dates when they had no staff available."

²² Care Quality Commission (2024) The state of health care and adult social care in England 2023-34. https://www.cqc.org.uk/publications/major-report/state-care/2023-2024

²³ Carers Trust (2024) "Pushed from pillar to post – the reality of carers' rights" https://carers.org/downloads/carers-rights-carers-reality-reporthrfinal.pdf

Under Section 5 of the Care Act 2014, local authorities must promote the efficient and effective operation of a market for care services. As part of this, they must have regard to the need to ensure that sufficient services are available to meet the care and support needs of adults in their area, as well as the needs of carers in their area. This relates to both current and future needs for support. If carers are eligible for services, but are unable to secure support, their needs have effectively not been met, and this is in breach of the Care Act 2014.

Several carers also said they needed more help with accessing support following their Carer's Assessment – that they hadn't been told what the next steps were, or how they get the support they were entitled to.

- I have tried to contact assessor several times to ask for help in securing a Direct Payment without success."
- The assessment told me things to do that I do not have the time or capacity to do, on top of my current caring responsibilities."
- **66** The assessment process doesn't have a clear plan for next steps."
- **66** Once the assessment was done, I have been ignored. Emails have gone unanswered."

Some carers said they had been given a Direct Payment (i.e. a payment to purchase their own services, instead of care being provided directly), but were left to find support services themselves, with little advice or quidance.

- I feel that because they give you a grant that's it –
 I need more than the grant I need support advice."
- **66** They just threw carers direct payment at me to get rid of me."
- I cared for my mum until she recently died and I really struggled to get us both a needs and carers assessment. When we did receive them, we did get access to short breaks funding but it was a complicated system to access."
- We were forced to accept direct payments to employ [paid] carers but we did not want the extra administrative burden and responsibilities of recruiting and employing people. The hourly rate we could pay was set by the local authority and was too low to recruit good [paid] carers. Council refused to let us access other services eg respite so we ended up returning the money and discharging ourselves from their 'support' as it didn't help us."

44% of carers said that the assessment did not sufficiently consider their needs. Several carers said they felt the assessment was just a 'tick box exercise', or did not cover all their caring tasks. This raises a question about whether some assessments are being carried out in line with the Care Act 2014 and accompanying guidance.

- **66** I was rushed through the assessment and was made feel as I was a burden on them."
- **66** Assessment doesn't take into consideration all the administrative tasks such as phoning doctors, hospitals, sorting out finances, shopping, cooking etc."

22% of carers said the assessment identified areas where they need more support, but they weren't satisfied with the support provided. Several carers said the support offered wasn't suitable, because it wasn't available locally, or during a convenient time.

- **66** Support is there but during the times I am at work, so I can't access it."
- I need emotional support but it isn't available locally and I'm not able to travel to the city to join the groups available."
- Have direct payments but cannot find anyone to fulfill hours of care we have been allocated. The council the takes back all the money given."



Several carers said they had expected to be given practical support, rather than signposting information.

- Apart from sending me a list of care agencies, they have done nothing whatsoever to help me in my caring role. I have tried to discuss my mother's financial situation with them, but they just send the same letter over and over. I'm at the end of my tether."
- 66 My assessment stated "Risk of Carer breakdown" but nothing has been done for me personally, apart from a suggestion that I see my GP, which is very difficult to do as I need transport and wheelchair assistance to get to the surgery."
- **66** There are no support services. I was handed lists of telephone numbers to call etc and everyone is very sympathetic but there is no actual, physical, help."

Concerningly, data provided by local authorities in England as part of their Short and Long Term Data Return (SALT) shows that in 2023-24, 360,815 carers were either supported or assessed/reviewed.²⁴ However, 70% of those carers were only given information, advice and other universal services/signposting, or did not get any direct support at all. Local authority gross expenditure on support to carers was £183 million in 2023-24, a drop of 6.1% from £195 million in 2022-23.

Many carers also said that it had taken a long time to get the assessment or to receive any support.

- We have never had support from social services despite asking. We wrote to the director of adult services [a few months ago] in March and still have not achieved a care needs assessment."
- **66** The person I care for came out of hospital with increased needs, I contacted the local social care team who never got back to me."
- Communication with the social worker & progress towards putting support in place is very slow can take weeks to get a response so you have to spend time chasing."
- **66** I was told that the time to get a written carers assessment from the visit was 6 weeks. This is totally unacceptable as I was at breaking point."

21% of carers who said they did feel supported following their assessment said they were not satisfied with the assessment because it found they were not eligible for support, following a financial assessment.

- **66** Because we're self- funding and I've got sufficient capacity it is left to me to sort out any problems I have."
- **66** Support is available, but only if we pay for it! No free service for us as we don't fit the criteria."

Table 2: Reasons why carers do not feel supported by their local authority, following their Carer's Assessment

Reason for not feeling supported	% of carers who responded
The assessment identified areas where I need more support, but this has not yet been provided	47%
The assessment did not sufficiently consider my needs	44%
The assessment identified areas where I need more support, but I am not satisfied with the support provided	22%
The assessment found I was not eligible for support	21%

²⁴ Adult Social Care Activity and Finance Report, England, 2023-23. https://digital.nhs.uk/data-and-information/publications/statistical/adult-social-care-activity-and-finance-report/2023-24/carers

Social care support



- Over half (53%) of carers said they needed to know what support might be available and how to access it an increase from 48% in the previous year.
- 57% of carers who'd tried getting support from social care services had experienced long wait times, and 51% said that services were not available when they needed them.
- 39% of carers who had tried to access help or support from social care services said that there was a lack of consistency in who was providing care.
- 38% of carers said they had concerns about the quality of care.
- 88% of carers who had experienced challenges with social care services said it has made them worry more about the future (including 51% who strongly agreed).
- 79% of carers who had experienced challenges with social care services said it had negatively impacted their own mental health.
- 49% of carers who had experienced challenges with social care services said it negatively impacted their ability to work. This increased to 63% for working carers.

When we asked carers what their main needs were, 53% of carers said they needed to know what support might be available and how to access it – an increase from 48% in the previous year. This increased for carers who were new to caring – 59% of people caring for less than a year needed to know what support was available and how to access it, and this was the main need amongst that group.

- [Need] a black and white explanation of exactly what we are legally entitled to as it's a case locally of who shouts loudest gets noticed."
- **66** Social work gave my daughter a budget but then said I would have to source any services or [paid] carers for her but do not help in telling you what is available..."
- I want a one stop shop where people who know what they are doing can advise on what I could do."
- [Need] a single point of contact for all needs. Less paperwork. A recent email from a local authority had 10 separate attachments and four website links."



57% **XXXX**

of carers who'd tried getting support from social care services had experienced long wait times Research suggests that more and more people are not getting the support they need. The CQC State of Care 2024 report found that the number of new requests for adult social care that did not result in a service being provided increased by 27% over the last 5 years. The latest ADASS survey found that because of the challenging financial situation, combined with the increasing complexity of people's social care needs, the majority (90%) of Directors of Adult Social Care are either partially confident or have no confidence that their budgets will be sufficient to fully meet their statutory duties in 2024/25.

This has a significant impact on unpaid carers. 88% of Directors of Adult Social Care agreed that unpaid carers are coming forward with an increased level of need in their local area over the past 12 months, as a result of shortages in health and care support.²⁷

We asked carers whether they had tried to access any help or support with their caring role from social care services in the last 12 months. The majority (59%) had not, but 41% of carers had. We asked those carers whether they had experienced any challenges when accessing social care services. The main challenge was around waiting times – 57% of carers said they had experienced long wait times for assessments, reviews, care or support.

- I have had respite care twice in the past year. The first time took four months to organise a week of respite because social services don't call you back. It was almost impossible to arrange the dates with them."
- We moved area for my daughter's health needs.
 It took eight months for a care package to be put in place. I hurt my back & leg from covering all physical caring needs during this period."
- **16** There are waiting lists of several years for all the day care respite services near me, it's devastating."

Many carers said they struggled to speak to somebody over the phone, or felt passed around from one department to another.

I am being passed between adult social care, learning disabilities social care, home from hospital care. No one can actually help."

²⁵ Care Quality Commission (2024) The state of health care and adult social care in England 2023-34. https://www.cqc.org.uk/publications/major-report/state-care/2023-2024

²⁶ ADASS 2024 Spring Survey (2024) https://www.adass.org.uk/wp-content/uploads/2024/07/ADASS-Spring-Survey-2024-FINAL-1.pdf

²⁷ ibid

- Getting through to social services is well nigh impossible, telephone queues, don't ring you back, deal with different people each time. Multiple switchboards for different agencies with the same telephone number."
- **66** Ringing up and being told the person you need to talk to is [not] available and would ring back but then they don't... Much worse since covid it was ok before."
- **Continue**Trying to get through on the telephone to someone that can help with queries...you have to go all round the houses, leave a message...no response or reply from the department you want."

51% of carers who had tried to access help or support from social care services said that support services were not available when they needed them. In some cases this was because facilities had closed down, or had long waiting lists; in other cases this was because there was nothing available that met carers' specific needs.

- **66** Council respite services closed during covid and have simply not reopened. We have been abandoned."
- My daughter gets direct payments to provide a PA [Personal Assistant] to give us respite. There are no suitable PA's available. We cannot find anyone. The council won't help us find anyone. They tick their box as saying they've helped by dumping money in an account they know we can't use because we can't find a PA, then once a year they take all the money back again then claim they have provided us with support."
- **66** Adult social care that actually exists. It is nonexistent in [my area]. Any communications are met with 'services are restricted' 'there is no money.'"





[Need] more availability of suitable respite care for my child. The standard respite care services have massive waiting lists, but even if we get to the top of them then I am not sure that they will be suitable for my child's complex needs."

45% of carers who had tried to access help or support from social care services said that they didn't know who to contact or what support might be available. Some carers felt that services were not joined up, and they had to spend time explaining their situation several times.

66 So many different departments covering different aspects of care. Social services and NHS work separately and cover costs in different ways. Difficult to know who you should be dealing with."

39% of carers who had tried to access help or support from social care services said that there was a lack of consistency in who was providing care. 38% of carers said they had concerns about the quality of care.

66 A confusing mess where you never see the same person twice and there seems little communication between the various workers or agencies."



of carers said they had concerns about the quality of care

- "The care service my mother uses has high turnover of [paid] carers, and the management has been extremely poor, to the point where I have had to make a formal complaint as I believed their lack of care had endangered my mother. The complaint has been upheld but I have no guarantee of improvement."
- 66 Social Services only seem to offer personal care, no support with staying safe, managing medication or appointments, socialising and wellbeing, meal prep etc. Only help with personal care like showering and dressing."
- When the first of the second content of the

The cost of services was less of a concern than other challenges, but over a quarter of carers (27%) still said that support services not being affordable was a challenge.

Control The council give us direct payments to buy respite care, but the hourly rate they give us is £10 an hour less than the cheapest reliable agency we can find."

In addition, only those with high needs, and savings of less than £23,250 are eligible for free social care support. When people are unable to fund their own care, this increases the amount of unpaid care that family members and friends must then provide.

- I was planned to have a shoulder replacement surgery but had to cancel it because the 6 weeks of care support I required for my disabled wife was rejected and I was told to pay for it myself at a cost of around £18000. I didn't have the operation."
- **66** Support is available, but only if we pay for it! No free service for us as we don't fit the criteria."



Table 3: Challenges with social care services

Challenges with social care services	% of carers who responded
Long wait times for assessments, reviews, care or support	57%
Support services not being available when I need them	51%
Not knowing who to contact or what support might be available	45%
A lack of consistency in who is providing care	39%
Concerns over the quality of care provided	38%
Support services not being affordable	27%
None of the above	10%

We asked carers who had experienced challenges with social care services what impact, if any, those challenges had. 88% said it has made them worry more about the future (including 51% who strongly agreed that this was the case).

Challenges with social care services also had a negative impact on carers' health and wellbeing. 79% of carers who had experienced challenges with social care services said it had negatively impacted their mental health, and 79% said it meant they were unable to take a break from caring. 78% said it made them feel isolated, and 70% said it had negatively impacted their relationships.

- 66 No communication, our case feels like a number, four years after asking I still have no help. I've lost my marriage and half my job."
- 66 My son attended a day care group for a short period of time and it went very badly due to the quality of care provided. It caused both of us extreme stress and upset at the time which added great pressure to my load."

49% of carers who had experienced challenges with social care services said it negatively impacted their ability to work. This increased to 63% for working carers.



of carers who had experienced challenges with social care services said it has made them worry more about the future



Table 4: Impact of challenges with social care services

Impact of challenges with social care services	% of carers who agreed/ strongly agreed
It has made me worry more about the future	88%
It has negatively affected my mental health	79%
I have been unable to take a break from caring	79%
It has made me feel isolated	78%
It has negatively affected my relationships	70%
It has negatively affected my ability to work	49%
None of the above	10%

Conclusion and recommendations

Carers UK has consistently amplified carers' voices and experiences in relation to their health and wellbeing, and the support that is needed, since we were first started as a charity nearly 60 years ago. The evidence from unpaid carers shows that there are areas where carers' experiences have continued to deteriorate. It is also clear that carers' needs are increasing as they provide more and more care, and their health and wellbeing worsens over time.



The Care Act 2014 underpins many of carers' rights and entitlements, yet the delivery of care and support has been underfunded to the extent that carers' health, wellbeing and ability to remain in paid employment is compromised.

With carers' support worth a staggering £184 billion a year, 28 health and social care systems simply would not cope without their input. Yet the evidence in this report shows that unpaid carers face greater health inequalities than people without caring responsibilities. Given the ageing population, there is an urgent need to increase healthy life expectancy and reduce health inequalities, so that unpaid carers are better supported.

Equally, our evidence shows that a significant number of unpaid carers are struggling with

challenges around health and care whilst in paid employment. This impacts directly on their ability to work. An estimated 600 unpaid carers give up work every year to care²⁹ – in many cases this might have been avoided if better care and support had been provided. The stark difference in health between those in work and those out of work demonstrates the risks of giving up paid employment, where carers potentially face financial hardship and greater isolation.

In England, there is a real opportunity with the NHS 10 Year Health Plan to take urgent action to support unpaid carers, as well as look at medium- and longer-term measures through the independent commission on social care reform.

²⁸ Petrillo, M., Zhang, J. and Bennett, M. The value of unpaid care in the UK. https://www.carersuk.org/media/mfbmjbno/valuing_carers_uk_v3_web.pdf

²⁹ Carers UK (2019) Juggling work and care. https://www.carersuk.org/media/no2lwyxl/juggling-work-and-unpaid-care-report-final-web.pdf

In our 60th year, Carers UK wants to see 'Equality: today and tomorrow' for unpaid carers. We need Government and institutions to act swiftly to deliver our vision for unpaid carers where they are visible, valued and supported.

We recommend that the Government:

- Ensures that quick action is taken in the short term to support unpaid carers and that unpaid carers are a specific and key part of the Casey Commission into reform of social care.
- Ensures that the terms of reference for the Casey Commission also include robust cross-government support for unpaid carers, and that carers and their lived experience are included in evidence gathering and building solutions.
- Has a stated ambition to improve equity between non-carers and people who have unpaid caring responsibilities for a disabled, chronically or older relative or friend.
- Ensures that local authorities have sufficient and sustainable funding to enable them to fulfil their duties to carers under the Care Act 2014.
- Urgently invests an additional £1.5 billion in breaks and respite services in England (with consequential funding for Devolved Nations) and legislates so that carers have a statutory right to regular and meaningful breaks.
- Quickly develops a social care workforce strategy to ensure that there are enough skilled staff to provide social care, ensuring that the quality of life, health and work benefits are realised for unpaid carers and their families.
- Takes a cross-Government approach to supporting unpaid carers, with swift action across key departments in the short term. Develops a new National Carers Strategy over the next year, backed by significant investment, which sets out future commitments to supporting unpaid carers and identifies specific actions that focus on delivering tangible progress and additional support for carers, their families, and those they care for.
- Invests in a programme of activities to improve carers' mental health and addresses other factors which affect carers' mental health such as poverty, discrimination, housing and other related issues.

- Asks the Equalities and Human Rights Commission to undertake an inquiry into the accessibility of healthcare services for unpaid carers.
- Delivers a fresh new approach to supporting unpaid carers, transforming the way the NHS interacts with unpaid carers to make it the most carer friendly health service in the world.
- Implements the recommendations set out in our response to the NHS 10 Year Health Plan review process.
- Introduces new responsibilities on health services to identify unpaid carers, with robust monitoring in place.
- Places a new statutory duty on the NHS to support carers' wellbeing. Our forthcoming report on the NHS will have detailed recommendations on supporting carers within the NHS.
- Amends the Equality Act 2010 to include caring as the 10th protected characteristic.
- Supports awareness campaigns like Carers Week, Carers Rights Day and other initiatives that aim to reduce the time it takes for carers to identify themselves and seek support.
- Recognises the economic impact of social care

 the fact that social care is fundamental for carers' ability to remain in and return to paid employment.
- Develops a system of measures which looks at the extent to which the NHS is supporting unpaid carers to provide care, improving their experiences as well as supporting their health and wellbeing.
- Works with NHS England to update key practice documents; commissioning for unpaid carers through Integrated Care Systems and supporting carers through GP practices.

This is the fourth in a series of reports based on data from State of Caring 2024.



2025 is the 60th anniversary of Carers UK, and while we've achieved many successes to make life better for carers, we know there is still much more to do to ensure carers have equality in all walks of their life.

That's why our theme for the year is 'Equality: today and tomorrow'.

So, while it's good for us to look back at how things have changed, our focus is very much on the needs of unpaid carers today – and what we need do to create greater equality, support and recognition in the future.



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