

State of Caring 2023

The impact of caring on: health

November 2023



About this research

Carers UK carried out an online survey between June and August 2023. A total of 11,667 carers and former carers responded to the survey.

This report summarises the responses from the 10,751 people who are currently providing care.

As not all respondents completed every question in the survey, a number of the figures given in this report are based upon responses from fewer than 10,751 people.

Of respondents to the survey:

- 61% were in England, 17% in Scotland, 12% in Wales and 10% in Northern Ireland
- 39% of carers were in receipt of Carer's Allowance
- 80% were female, 19% were male
- 1% had a different gender identity than their sex registered at birth
- 29% had a disability
- 89% of respondents were White: English/Scottish/Northern Irish/British. 4% were White Irish and 3% were from another White background. 1% were from a mixed or multiple ethnic background. 2% were from an Asian/Asian British background (Indian, Pakistani, Chinese, Bangladeshi or other) and 1% were Black/Black British (African, Caribbean or other)
- 5% were lesbian, gay, bisexual or defined their sexual orientation in another way
- 16% had childcare responsibilities for a non-disabled child under 18
- 3% were aged 0-34, 10% were aged 35-44, 22% were aged 45-54, 35% were aged 55-64, 20% were aged 65-74 and 11% were aged 75 and over
- 34% were employees (18% were full time and 16% part time), and 4% were self-employed
- 32% had been caring for over 15 years, 15% had been caring for 10-14 years, 24% had been caring for 5-9 years, 26% had been caring for 1-4 years and 3% for less than a year
- 47% cared for 90 hours a week or more, 15% cared for 50-89 hours, 24% cared for 20-49 hours and 15% cared for 19 hours or less
- 74% cared for one person, 19% cared for two people, 5% cared for three people and 2% cared for four or more people.

Thanks

Carers UK would like to thank each and every carer who contributed to this survey, from those who helped us develop and test the survey to every single person who took the trouble and time to tell us about their experiences. Your experiences will be used to help build a society that recognises and supports carers more.

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Introduction

Across the UK, millions of people provide unpaid care for an ill, older or disabled family member or friend. The recent ONS Census 2021 for England and Wales found that there has been an increase in the proportion of people caring for more hours.¹



Caring can come with high personal costs. Many carers find that their friendships and relationships are impacted, with less time to spend with family and friends. This can lead to loneliness and isolation, with carers feeling unsupported and undervalued.

Carers are also often providing many different types of care, from clinical tasks to dealing with medication, and providing practical and emotional support. Juggling many different aspects of care, alongside other priorities such as paid employment or childcare, can be stressful, particularly if carers are not receiving the support they need.

Many carers have their own health conditions and some feel that the demands of caring mean they are unable to prioritise their own health and wellbeing, by taking breaks or doing the things they enjoy. Concerningly, the huge pressures placed across the NHS, resulting in delays in obtaining both primary and secondary health care appointments, together with the record levels of demand for social care services, means many carers are not getting the support they need.

¹ ONS (2023) Unpaid care, England and Wales: Census 2021 <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/unpaidcareenglandandwales/census2021#:~:text=In%20England%20and%20Wales%20an,2011%20to%204.4%25%20in%202021.>

Summary

This year we found that carers were struggling even more with their physical and mental health, their consideration at the point of hospital discharge has not improved significantly despite new rights and they are taking more on than ever before.



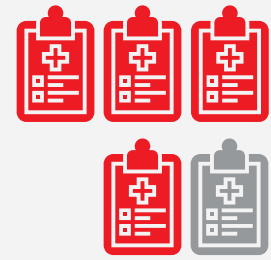
Many carers are feeling stressed, depressed and lonely. A significant proportion of carers are not seeking support with health conditions due to the demands of their caring role, and many are unable to take a break from caring to do the things that might improve their wellbeing. Carers with poor mental health are continuing to care despite being at breaking point. Many carers are uncertain about the future, and anxious about the demands of their caring role, particularly if they are facing challenges such as carrying out clinical tasks, supporting the person they care for when they are discharged from hospital, or managing caring alongside their own health conditions.

This evidence from carers suggests that their health and wellbeing is being damaged as a result of caring - some of which is preventable with the right interventions, information, advice and support from the NHS, social care and the wider voluntary sector. There are clear and positive public health outcomes if unpaid carers are better supported and we set out our recommendations with that in mind.

Carers' health and wellbeing

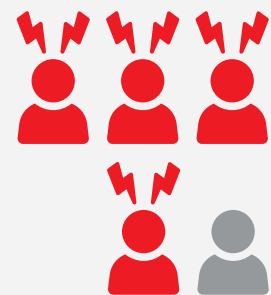
- 82% of carers said the impact of caring on their physical and mental health would be a challenge over the coming year – an increase from 77% last year.
- A significant proportion of carers said their mental health has been affected by caring. Over three quarters (79%) of carers feel stressed or anxious, half of carers (49%) feel depressed, and half of carers (50%) feel lonely.
- Over a quarter of carers (27%) said their mental health was bad or very bad.
- Over a third of carers (36%) whose mental health was bad or very bad said they had thoughts related to self-harm or suicide.
- 39% of carers whose mental health was bad or very bad said they were not receiving any support with their mental health. Nearly three quarters (73%) said that they continued providing care even though they felt they were at breaking point.
- 69% of carers said they found it difficult to get a good night's sleep. This increased to 74% for people caring for over 50 hours a week.
- 54% of carers said their physical health had suffered, and 22% said that caring had caused them injuries.
- 61% of carers said that being able to take regular breaks from caring would be a challenge over the coming year.
- 53% of carers said that maintaining their relationships with their partner, family or friends would be a challenge - an increase from 48% last year.

At a glance...



82%

of carers said the impact of caring on their physical and mental health would be a challenge



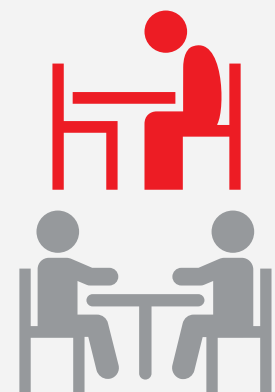
79%

of carers said that they feel stressed or anxious



49%

of carers said that they feel depressed



50%

of carers said that they feel lonely

Supporting carers with health and wellbeing

- 61% of carers said they needed more support to be able to look after their health and wellbeing.
- 44% of carers said they had put off health treatment because of their caring role.
- 50% of carers said they were receiving support with their caring roles from family and friends – a higher proportion than those receiving support from healthcare services (19%) and social care services (37%).
- 42% of carers said they needed more support from the NHS or healthcare professionals.
- Just under a third (30%) of carers waiting for hospital treatment or assessment for themselves had been waiting for over a year.
- 78% of carers agreed they were worried about being unable to provide care in the future. Over half (55%) of carers said they weren't sure how to plan for the future and would like more support with this.

At a glance...



61%

of carers said they needed more support to be able to look after their health and wellbeing



44%

of carers said they had put off health treatment because of their caring role



42%

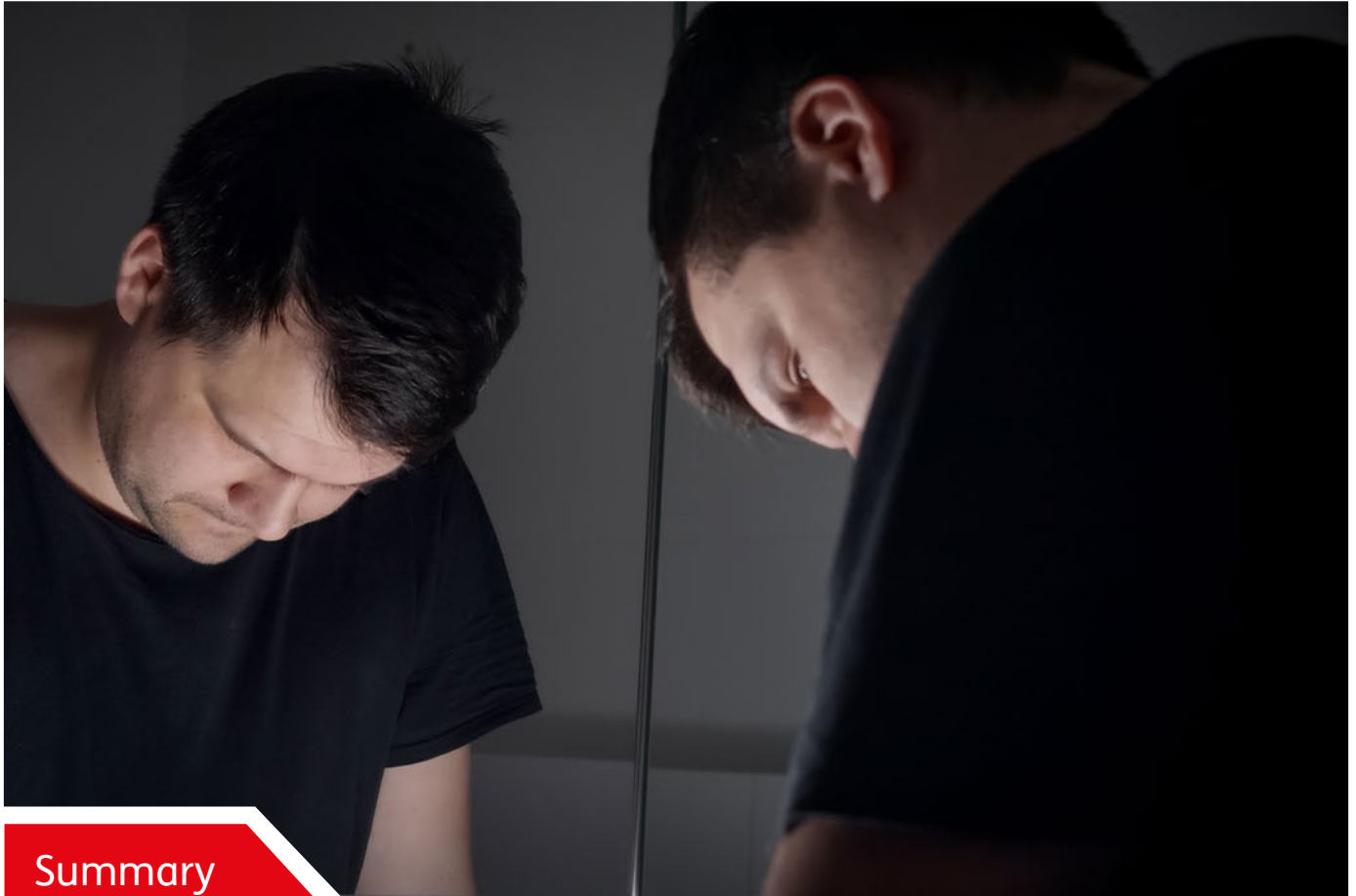
of carers said they needed more support from the NHS or healthcare professionals



78%

of carers were worried about being unable to provide care in the future

Impact of caring on health and wellbeing



Summary

- 82% of carers said the impact of caring on their physical and mental health would be a challenge over the coming year, an increase from 77% last year.
- Over three quarters (79%) of carers feel stressed or anxious, half of carers (49%) feel depressed, and half of carers (50%) feel lonely.
- Carers who were struggling to make ends meet were even more likely to feel stressed or anxious (87%).
- 69% of carers said they found it difficult to get a good night's sleep. This increased to 74% for people caring for over 50 hours a week.
- 54% of carers said their physical health had suffered, and 22% said that caring had caused them injuries.
- 44% of carers said they had put off health treatment because of their caring role.

We asked carers what they felt were the main challenges they might face over the coming year. **The most commonly reported challenge was the impact of caring on physical and mental health:** 82% of carers said this would be a challenge. This was an increase from last year, when 77% of carers said that the impact of caring on physical or mental health would be a challenge.

“Caring alone all these years has been detrimental to my mental health.”

“I feel so physically worn out and old before my time at 49.”

95% of carers who said their health was bad or very bad said the impact of caring on their health would be a challenge, and 89% of carers who were disabled said that the impact of caring on their health would be a challenge. People caring for over 50 hours a week were more likely to say that the impact of caring on health would be a challenge compared with those caring for less than 50 hours a week (85% compared with 77%).

We asked carers what, if any, impact caring had on their health and wellbeing.



Table 1: impact of caring on health and wellbeing

Impact on health and wellbeing	% of carers who said this had an impact
I feel stressed or anxious	79%
I find it difficult to get a good night's sleep	69%
I have reduced the amount of exercise I do	63%
My physical health has suffered	54%
I have found it difficult to maintain a balanced diet	52%
I feel lonely	50%
I feel depressed	49%
I have put off health treatment because of my caring role	44%
I have experienced an injury	22%
Caring has no impact on health and wellbeing	4%
Caring has improved my health and wellbeing	2%

A significant proportion of carers told us that caring had impacted on their mental health. **79% of carers said they feel stressed or anxious.** Carers who were struggling to make ends meet were even more likely (87%) to feel stressed or anxious. People caring for two or more people were also more likely to feel stressed or anxious (84%).

Several carers told us that they worried about their ability to provide care in the future. Others said they felt anxious about the person they cared for and found it difficult to relax or switch off from their caring role. Many carers also said that issues with support services, or difficulties juggling work and care, caused them stress or anxiety.

“I don’t like to think about what comes next and how I will deal with this. I can get stressed or anxious when I have to fit all my responsibilities, including my carer role, into each day. I feel I don’t have sufficient time to address things I need to.”

“I am constantly worrying about my relative and if I am making the right choices for him.”

“While my uncle was in hospital I felt totally ignored in his care. I had a near breakdown as I was not listened to or involved in decisions for his care.”

There is a clear need for Government to deliver more sustainable long-term planning for social care, including better funding, so that carers are more able to plan their futures.

50% of carers said they feel lonely. Women were more likely to feel lonely than men (53% compared with 45%). People who were caring for over 50 hours a week were more likely to feel lonely than people caring for less than 50 hours (57% compared to 40%). 31% of carers said they feel lonely often or always – a similar proportion to last year (29%). This increased to 36% of carers caring for over 15 years.

“I have become completely isolated as a result of my caring situation and quite frequently do not see anyone but my father for weeks.”

“As I have no family to turn to, I feel lonely and alone in dealing with my carer role.”

49% of carers feel depressed. People who were caring for over 50 hours a week were more likely to feel depressed than people caring for less than 50 hours (54% compared to 42%). Some carers said that they enjoyed doing activities less because they were too tired or preoccupied with caring, while others said they were unable to take time to do activities that improved their happiness.

“When I have time to do things for myself, I enjoy them less than I used to.”

“My freedom to do what I want, when I want is seriously affected. A carer has little or no freedom and for anyone who is independently minded, this has an impact on their mental health.”

50%

of carers feel lonely



69%

of carers said they found it difficult to get a good night’s sleep



69% of carers said they found it difficult to get a good night’s sleep. Those who were caring for more hours were more likely to struggle with sleep: 74% of people caring for over 50 hours a week found it difficult to get a good night’s sleep compared to 61% of those caring for less than 50 hours. Carers who were struggling financially were also more likely to struggle with sleep: 79% said this was an issue. Many carers said that they were too anxious to sleep, or that they needed to provide care during the night.

“Very stressful not knowing what to expect day to day. Walking into a constantly negative situation is very hard and demoralising. I don’t sleep thinking about how much worse it will get.”

“Mum has falls in the care home regularly and it’s hard to settle on a night knowing she may have a fall again.”

“I have a baby monitor for my mum at night, so I can sleep in my own bed instead of with her, but every time she moves or makes a noise it wakens me. I can’t lower the volume in case I don’t hear her.”

54%



of carers said their physical health has suffered

54% of carers said their physical health had suffered, and 22% said that caring had caused them injuries. People who had been caring for more than 10 years were even more likely to say that their physical health had suffered (59%) and that they had experienced an injury (27%). Several carers said they had experienced injuries while lifting the person they cared for, or when operating equipment.

“I tried to protect my brother from falling and wrenched my own back, still suffer with back pain years later.”

“I have inflamed tendons in my arms from lifting and holding my husband many times a day.”

Many carers said that caring had impacted on their health by making their existing health conditions worse.

“My arthritis is getting rapidly worse due to the physical role.”

“I have an auto immune condition which prior to my caring role becoming full time, I had under control, took my medication and managed my symptoms with a good diet. Since my caring role my symptoms have worsened, I regularly forget to take my own medication and my diet is inconsistent. Added to this my sleep is very poor which has a knock-on effect with my condition.”

“I myself have M.E. but I have to largely ignore this due to caring pressures. Hence my condition gets worse.”

Many carers said that caring had impacted on their health by making their existing health conditions worse.

22%



of carers said their caring role had caused them injuries

44% of carers said they had put off health treatment because of their caring role. People caring for over 50 hours a week were even more likely to put off health treatment (51%). Several carers told us that they didn't have time to seek help or support with their own health issues, while others said they were unsure they would be able to find replacement care.

“Last year I suffered a very severe diabetic abscess. My doctor wanted me to be hospitalised as I was developing a fever and was really unwell. I refused because there would be no one to look after my husband.”

“I have been putting off referrals from the doctor for treatment, ultrasound scan and blood tests because I don't have time or the energy to deal with [them].”

“Unable to organise hip replacement as unable to leave my husband who would not cope alone day or night.”

“I have cancer but couldn't have an operation to remove it as I can't care for myself or my wife. I am having radiotherapy and chemo instead. I am worried now this will affect us both.”

44%



of carers said they had put off health treatment because of their caring role



52% of carers said they found it difficult to maintain a balanced diet. Carers struggling to make ends meet were much more likely to find it difficult to maintain a balanced diet (70%).

“I feel unhealthy as I’m eating unhealthy snacks to try and de-stress.”

52%



of carers said they found it difficult to maintain a balanced diet

It is clear that carers face poorer health outcomes as a result of caring. These health inequalities are particularly prominent amongst carers who are struggling financially, caring for more hours, and caring over a longer period of time.

Many carers are stressed, anxious, and depressed, and several have untreated physical health conditions of their own. It is unsustainable for these carers to continue providing high levels of care whilst struggling with their own health. The NHS must consider the needs of carers and take a preventative approach to carers' health and wellbeing.

Carers' mental health



Summary

- 27% of carers said their mental health was bad or very bad.
- Carers who were struggling to make ends meet were much more likely to say their mental health was bad or very bad (45%).
- 88% of carers whose mental health was bad or very bad said they were experiencing increased tiredness, and 87% said they were having difficulty sleeping.
- 84% of carers whose mental health was bad or very bad said they had continuous low mood, 82% had feelings of hopelessness and 71% regularly felt tearful.
- Over a third of carers (36%) whose mental health was bad or very bad said they had thoughts related to self-harm or suicide.
- 39% of carers whose mental health was bad or very bad said they were not receiving any support with their mental health, with the most commonly reported barrier for this group being too busy caring (50%).
- Nearly three quarters (73%) of carers whose mental health was bad or very bad said that they continued providing care even though they felt they were at breaking point.

We asked carers how they would describe their mental health. Only 4% of carers said their mental health was very good, while 20% said it was good. 49% of carers said their mental health was fair, while 27% said it was bad or very bad. This is similar to the results of the 2021 Census in England and Wales, in which 28% of carers said their health was not good.

Carers who were struggling to make ends meet were much more likely to say their mental health was bad or very bad (45%). Carers who have been caring for over 10 years were also more likely to say their mental health was bad or very bad than those caring for less than 10 years (31% compared to 24%). People caring for over 50 hours a week were more likely to say their mental health was bad or very bad compared to people caring for less than 50 hours (31% compared to 23%).

We asked carers who reported their mental health as bad or very bad to tell us whether they had experienced certain symptoms.

36%



of carers with 'bad' or 'very bad' mental health had experienced thoughts related to self-harm or suicide

Table 2: symptoms experienced by carers with 'bad' or 'very bad' mental health

Symptoms	% of carers affected
Increased tiredness	88%
Difficulty sleeping	87%
Continuous low mood	84%
Feelings of hopelessness	82%
Inability to switch off from worrying about caring	81%
Irritability and mood swings	77%
Low self esteem	76%
Eating too much or too little	76%
Restlessness and difficulty concentrating	74%
Regularly feeling tearful	71%
A sense of fear or dread	68%
Thoughts related to self-harm or suicide	36%



The most commonly reported symptom was **increased tiredness (88%)**, followed by **difficulty sleeping (87%)**.

“I am permanently exhausted.”

84% of carers who said their health was bad or very bad said that they had continuous low mood, and 82% experienced feelings of hopelessness.

“I don’t know how to snap myself out of it and have no enthusiasm for anything constantly feeling “what’s the point”.”

“Feel constantly low, lonely, exhausted and can’t see a way out.”

81% of carers with bad or very bad mental health said they had an inability to switch off from worrying about caring. Many carers said they were worried about their ability to care in the future, or anxious about the condition of the person getting worse over time.

“Difficult to switch off, constantly thinking about my husband’s needs and solving issues as his condition worsens.”

“It seems never ending; it feels like my life has no future except doing this and it is only going to get worse (my wife has MS).”

“Very fearful about the death of the parent I care for and its impact on me in the long and short term.”

Concerningly, many carers said they felt overwhelmed, and at breaking point. **36% of carers who said their mental health was bad or very bad said they had experienced thoughts related to self-harm or suicide.** It is vital that carers struggling with their mental health are able to speak to their GP, yet our results show that many carers are concerned about long waiting times and delays in accessing services.

Many carers told us that they felt they had lost their sense of identity as a result of the demands of their caring role, which affected their self-esteem, confidence and wellbeing.

“I try not to think about how my life used to be, it’s unbearable because I will never get back what I’ve lost.”

“I feel my life is running away from me and I am unable to take full advantage of my time because of my caring responsibilities.”

“I feel like my life is repetitive and pointless. I am just here for others.”

Supporting carers with their mental health

We asked carers who said their mental health was bad or very bad whether they were receiving support to help manage their mental health. **Just over a quarter (26%) said they were receiving help from NHS health services.** 8% were receiving help from local mental health services or charities, and 4% were receiving private mental health care. However, **39% of carers said they were not receiving any support with their mental health.**

In addition, many carers (25%) were receiving support from a partner, friend or relative rather than a health service.

“I talk to a couple of friends who have been carers for now deceased parents and who understand my struggles.”

“I initially received support from my GP and my employers counselling service but this only last for 6 to 8 weeks. Since then I only get support from friends and family.”

Many carers said that they had struggled to access support for their mental health, due to long waiting times for counselling, or services not meeting their needs.

“I’ve contacted helplines, spoken with my doctor and tried to find help online. The waiting list for counselling is ridiculous and only provides 6 hourly sessions. How can six hours help long term? Doctors want to prescribe antidepressants and advise self care but don’t help you to get it.”

“I had a very bad experience with NHS therapy service, which was delivered through typing on a computer to a remote therapist. Was alienating and frustrating. I also didn’t think they understood how difficult it is to be a carer and the wide range of obstacles facing us daily. She was cross with me for not doing my daily homework!!”



Barriers to seeking help

We asked carers who had bad or very bad mental health whether there were any barriers to seeking help with their mental health.

Table 3: Barriers to seeking help experienced by carers with 'bad' or 'very bad' mental health

Symptoms	% of carers who felt this was a barrier
I am too busy caring	50%
I am concerned about long waiting times for support services	31%
I don't think support services would meet my needs	28%
I don't feel comfortable talking about my mental health	24%
I don't think my problems are serious enough	18%
I'm too embarrassed to ask for help	18%
I don't know where to go to access help or support	17%

The most commonly reported barrier was being **too busy caring (50%)**. People who were caring for over 50 hours a week were more likely to say that being too busy caring was a barrier to seeking help than those caring for less than 50 hours (56% compared with 38%).

“My mental health has to take a back seat. I just don't have time to stop and think about it.”

“I have mental health difficulties of my own that need treatment and support but due [to] my caring responsibilities I don't have the time or energy to get the support I need, so I am getting worse.”

The other most commonly reported barriers were **concerns over long waiting times (31%)** and **carers feeling that services would not meet their needs (28%)**.

“I know I could ask for counselling, which I've had several times over the years through my GP and other organisations. But the waiting lists are very long.”

50%



of carers with 'bad' or 'very bad' mental health said they were 'too busy caring' to seek help with their mental health



Nearly a quarter of carers (24%) whose health was bad or very bad said they didn't feel comfortable talking about their mental health and 18% said they didn't think their problems were serious enough. 18% said they were too embarrassed to ask for help.

“I don't like to bother people with my problems.”

“Can't talk in front of my husband, he feels bad enough already.”

“I don't like talking about my feelings.”

Men were more likely to feel embarrassed about asking for help than women (24% compared to 16%), and more likely to say they didn't feel comfortable talking about their mental health (32% compared to 22%).

17% of carers said they didn't know where to go to access help or support.

Some carers also told us that they felt too anxious about seeking help with their mental health because they were worried about the consequences, or because asking for help was pathologised rather than being seen as a responsible thing to do. Carers are entitled to an assessment of their needs, especially if they feel these are worsening.

“Social service would take my children away if I asked for help.”

“I'm worried that social care might just remove the young adult that I care for, which they hinted at when I told them continuing without paid carer support was not sustainable.”

24%

of carers with 'bad' or 'very bad' mental health said they didn't feel comfortable talking about it



17%

of carers with 'bad' or 'very bad' mental health said they didn't know where to go to access help or support



Capacity to care when experiencing poor mental health

We asked carers whose health was bad or very bad whether any issues related to their mental health may have affected their capacity to care. **Nearly three quarters (73%) said that they continued providing care even though they felt they were at breaking point.**

- “I know I am low but I just have to keep going, there is no other option.”
- “I’m feeling very low and drained mentally and physically. I can’t let the person I care for see that so have to put on a happy face but I’m definitely struggling and worry about what will happen to the person I care for if I break.”
- “I’m pushing through – anything in order to continue to care for my son.”

Just over a quarter (27%) of carers said that they weren’t able to provide the same quality of care due to issues with their mental health.

- “I am not able to provide the emotional support needed.”
- “I became snappy and tearful and often hid in the afternoons so I could cry for a while without my son knowing.”

73%



of carers with ‘bad’ or ‘very bad’ mental health said they continued caring when they were at breaking point

27%



of carers with ‘bad’ or ‘very bad’ mental health said mental health issues affected the care they could provide

21% said they had to leave their job or reduce their working hours because of poor mental health affecting their ability to care, while 16% said they had to take time off paid employment. Carers in paid employment with ‘bad’ or ‘very bad’ mental health were more affected: 24% had to leave their job or reduce their working hours because of poor mental health affecting their ability to care, and 37% had to take time off from paid employment.

- “I was signed off work for four months due to poor mental health from my caring situation and having no support.”

Many carers are struggling with their mental health. While caring can be rewarding, it can also be stressful and unpredictable, and many carers feel they have lost their own identity as a result of providing high levels of care. Carers providing high levels of care and carers who are struggling financially are even more likely to have poor mental health, and some are providing care despite being at breaking point.

Concerningly, although many carers feel they have poor mental health, only a small proportion are seeking help: many feel unable to look after their own wellbeing due to the demands of caring, or reluctant to seek help due to concerns over long waiting times. It is vital that the health service treats carers’ needs as a priority.

Improving carers' health and wellbeing



Summary

- 61% of carers said they needed more support to be able to look after their health and wellbeing.
- 72% of carers said that getting a good night's sleep improves their wellbeing.
- 68% of carers said that spending time with family and friends improves their wellbeing.
- 47% of carers said they needed more breaks or time off from caring.

We asked carers what their main needs are at the moment. **61% of carers said they needed more support to be able to look after their health and wellbeing.** This was also the biggest area of need identified in last year's State of Caring survey (62%). 79% of carers who said their health was bad or very bad said they needed more support to look after their health and wellbeing, and 73% of carers with a disability said they needed more support to look after their health and wellbeing.

People caring for more than 50 hours were more likely to say they needed support to help with their health and wellbeing than those caring for less than 50 hours (66% compared with 54%). Carers who had been caring for over 10 years were more likely to say they needed support with health and wellbeing than those caring for less than 10 years (64% compared with 59%). Carers who were caring for more than one person were also more likely to say they needed help with their health and wellbeing than those caring for one person (68% compared with 59%).

What helps to improve carers' wellbeing

We asked all carers whether there were certain things they felt improved their wellbeing.

Table 4: What improves carers' wellbeing

What improves wellbeing	% of carers who said this improved wellbeing
Getting a good night's sleep	72%
Spending time with family or friends	68%
Being valued as a carer	59%
Taking a break from caring	58%
Engaging in my hobbies or interests	58%
Being physically active	57%
Having good quality care services for the person I care for	45%
Eating a balanced diet	43%
Having a pet	40%
Speaking to other carers	31%
Being in paid employment	28%
Counselling, therapy or listening support services	25%
Having a faith or religion	18%
Taking part in education/training opportunities	16%

The most common response was **getting a good night's sleep (72%)**, followed by **spending time with family and friends (68%)**, **being valued as a carer (59%)**, **taking a break from caring (58%)** and **engaging in hobbies and interests (58%)**.

However, many carers felt they did not have the time, energy or motivation to do the things they knew would improve their wellbeing. Several carers also said they felt guilty about looking after themselves.

“It is morally difficult and practically impossible to put my own needs ahead of others.”

“The first things that are reduced when you have a caring role are the things that bring joy, happiness and health to the carer. Those things that improve your own life. Exercise, healthy eating and socialising. These seem unimportant when compared against another persons immediate personal needs.”

Some carers said they found it difficult to relax, while others said they were too exhausted from caring. Many carers told us they were unable to find replacement care to enable them to take a break.

“There is no time for me to participate in any activities outside of the home as I’m still waiting for adult social care to provide appropriate care and support for the person I care for.”

“I’ve been offered lots of wonderful support...but haven’t time to participate in any of it as I’m a mum to a young child and am trying to maintain 2 part-time jobs with inconsistent childcare and a father who depends on me as his only living relative.”

“I force myself to do good things for me, but its difficult to switch off and I often feel rushed.”

We also know that financial wellbeing has a direct impact on carers’ overall wellbeing. In our [State of Caring finances report](#), we set out carers’ responses to our survey questions about finances, as well as recommendations that would improve carers’ lives such as increases in the levels of carers benefits, better access to financial support and lower costs of care.

Recognition

Some carers said that a lack of recognition about their caring roles affected their wellbeing: some felt invisible or forgotten about. 55% of carers said they needed better understanding and recognition of unpaid carers from the general public.

“I feel as if I’m invisible, I’m only existing to be a carer, and who I am is slowly disappearing.”

“My caring role controls everything in my life and my needs are never a priority therefore it’s a massive impact on my mental well-being. I’m so undervalued.”

72%



of carers said getting a good night's sleep would improve their wellbeing

59%



of carers said that being valued as a carer would improve their wellbeing

47%



of carers said they needed more breaks or time off from caring



Breaks

47% of carers said they needed more breaks or time off from caring. This increased to 58% for carers who said their health was bad or very bad. People who were caring for over 50 hours a week were more likely to say they needed a break from caring compared to those caring for less than 50 hours (54% compared with 35%).

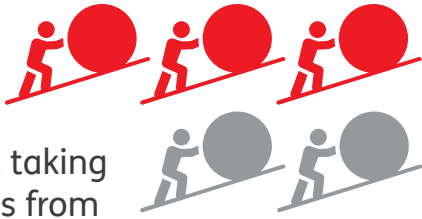
Some carers who had received support from respite services or paid care workers had found this helpful in improving their wellbeing.

- “I get 4hrs respite a week for one of my children which isn't long but does enable me to sit and relax with a cuppa and spend 1:1 time with my other child.”
- “Just a few hours respite a week can make a big difference to my mental and physical wellbeing.”

However, many carers said that support services that would enable them to take a break were often unavailable or unsuitable. Just over a quarter (27%) of carers have relied on family or friends to provide replacement care, and only 10% received replacement care from a health or social care service.

- “I cannot get any respite care so far this year for me to have a break. The nursing homes no longer have respite beds apparently and can't take short term bookings as they have waiting lists for long term clients.”
- “A carer role is 24/7, 7 days a week, however many support service only offer Monday - Friday limited daytime hours services”
- “Although the person I care for received two sessions of paid for care in a day (morning and evening), I feel I need to be present due to inadequate training and familiarity of staff.... I do not feel comfortable going out and leaving person alone.”

61%



of carers said taking regular breaks from caring would be a challenge

36%



of carers haven't tried to take a break because it would be too difficult

61% of carers said that being able to take regular breaks from caring would be a challenge over the coming year. This was an increase from last year, when 55% of carers felt this would be a challenge. **Over a third of carers (36%) haven't tried taking a break because they think it's too difficult.** This increased to 52% for carers who said their mental health was bad or very bad, and 52% of those who are often or always lonely.

“My daughter has long covid on top of other disabilities and cannot be left on her own. She is with me 24/7 unless another family member is at home. I worry about how this can be sustainable in the long term.”

“I have been a full-time carer since 1992 but have never had a break of any kind. The only time that I am away from caring for my wife is when I am admitted to hospital for operations or other treatment.”

People caring for 50 or more hours a week were more likely to say that taking a break from caring would be a challenge compared with people caring for less than 50 hours a week (68% compared with 50%).

Some carers were also concerned about COVID-19 and were still shielding or reducing their activities to keep the person they care for safe. 28% said that keeping the person they care for safe when there are fewer public health measures to reduce COVID-19 would be a challenge over the coming year.

“We are still shielding, the covid pandemic hasn't ended for us, there is no recognition of this or how difficult it is.”

53% of carers said that maintaining their relationships with their partner, family or friends would be a challenge. This was an increase from last year, when 48% felt this would be a challenge. 25% of carers said they needed more support so they can build and maintain relationships with others.

“The impact on my mental and physical health from years of intensive caring (so to speak) is already causing damage to my marriage, with no possibility of respite.”

“I have a family, so it has an impact on them when I have to leave my house.”

Many carers are providing high levels of care without taking a break, sacrificing their own health and wellbeing to support their loved ones. While there are things that carers can do to improve their wellbeing, such as spending time with family and friends, our recent report on carers and poverty found that carers are often having to cut back on the things that might be beneficial for their health.

Our research suggests that taking a break can be beneficial for wellbeing, yet carers often feel unable to do so because they can't find suitable replacement care services. It is vital that we have a fit-for-purpose social care system that protects the health and wellbeing of unpaid carers across the UK. It is unsustainable for carers to continue to provide hours of care each week with little support in return.

Support from the NHS for unpaid carers



Summary

- 74% of carers said they would like systems that make managing appointments and speaking to health professionals easier.
- Just under a third (30%) of carers waiting for hospital treatment or assessment for themselves had been waiting for over a year, only a slight decrease in the last year. More carers were waiting for treatment compared with the person being cared for.
- The lack of carer involvement at hospital discharge remains high and has not significantly changed in the last year. 60% of carers disagreed they were asked about their ability and willingness to care during the hospital discharge of the person they cared for.
- 42% of carers said they needed more support from the NHS or healthcare professionals, and 42% said they needed better recognition from the NHS of their needs as a carer.
- A majority of unpaid carers felt virtual wards would mean providing more care but 56% of carers agreed that virtual wards would give them and the person they care for more ownership of care being provided.
- There is greater potential and use for carers in accessing online patient records for themselves or the person they care for and a need for greater awareness raising.



We asked carers what their main needs are at the moment. **42% of carers said they needed more support from the NHS or healthcare professionals and 42% said they needed better recognition from the NHS of their needs as a carer.** Some carers said they would appreciate more flexibility when making appointments, allowing them to balance their own health needs with their caring role.

“To get priority GP Appointments would be ideal. We as carers need to be able to have good health ourselves to continue caring.”

“I am unable to sit for hours in the morning on the phone and then wait for a call back. Then drop everything to go to an appointment. GP will not make reasonable adjustments for carers.”

42%



of carers said they needed more support from the NHS or healthcare professionals

Some carers also said they needed more support and guidance from healthcare professionals on how to manage their own health conditions alongside caring.

“I am also disabled with a condition that causes me extreme tiredness and chronic pain. I get no help to cope.”

“[Need] more recognition from my GP about my stress and health as a carer and to monitor my health annually.”

Online patient records and identifying carers

We asked carers whether they were accessing online medical records. 37% of carers said they hadn't thought about accessing medical records online for themselves, and 41% said they hadn't thought about doing so for the person they care for. 31% said they didn't know how to access medical records online for themselves, and 34% said they didn't know how to access medical records online for the person they care for.

74%



of carers said they would like systems that improve managing appointments or speaking with health professionals

Table 5: Carers' experiences of online medical records

Type of help	% of carers who agreed (re themselves)	% of carers who agreed (re the person cared for)
Accessing medical records online was helpful	29%	19%
It was difficult to access or understand medical records	9%	9%
I wasn't able to access the record as I didn't have permission	9%	16%
I haven't thought about accessing medical records online	37%	41%
I don't know how to access medical records online	31%	34%

In State of Caring 2021 we found that carers were keen to access online medical records and that they felt this would make caring easier. This year, 29% of carers said they found accessing online records for themselves helpful, and 19% said accessing the records for the person they cared for to be helpful. This suggests that more work needs to be done in raising awareness of how carers can use online technology to help their caring journey.

We also asked carers whether other forms of online support would be helpful. 74% said that they would like systems that identify them as an unpaid carer on the record of the person they care for, and 71% said they would find it helpful to have systems that identify them as a carer on their own patient record. **74% said they would like systems that make managing appointments and speaking to health professionals easier.** 64% said they would like systems in which information about them or the person they cared for was shared across services.

“We need to be able to make appointments online not spend ages on the phone at an inconvenient time ie in the morning when we have to get the person we care for up, dressed, fed, toileted etc.”

“Having to repeat myself constantly with different medical professionals in hospitals and across the services has been extremely stressful.”

“I'd like something that supports communicating with health practitioners - where I can update an electronic record from my observations for those I care for and which is assimilated in real time by health professionals so that when we arrive at services everyone has the info over the time since patient was previously seen.”

Hospital treatment/assessment

We asked carers whether they or the person they care for were waiting for specialist treatment or assessment (eg a scan or consultation) in hospital. In England, the maximum waiting time for non-urgent consultant led treatments is 18 weeks from the day an appointment is booked through the NHS e-Referral Service, or when the hospital or service receives the referral letter². However, it is clear carers have been waiting much longer than this.

35% of carers said they were waiting for specialist treatment or assessment, either for themselves or the person they care for. **Just under a third (30%) of carers waiting for treatment or assessment for themselves had been waiting for over a year.** This is a slight decrease from 2022, when we found that 34% of carers waiting for treatment or assessment for themselves had been waiting for over a year.

26% of carers said the person they care for had been waiting for over a year for specialist treatment or assessment – a decrease from 31% last year.

There is now a slightly higher proportion of carers who are waiting for treatment, compared with the person they are caring for.

We also asked carers how many times they have supported the person they care for to attend a hospital appointment in the last 12 months, by booking an appointment, prompting someone to attend, or helping them get to their appointment. **14% of carers said they had supported the person they care for to attend a hospital appointment more than 20 times in the past year.** 19% had supported them between 10 to 19 times, and 25% between five and nine times. 31% had supported them less than five times.

Emergency treatment

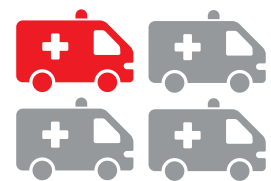
We asked carers whether the person they care for needed to attend A&E in the last 12 months. Some carers had experienced long waiting times for ambulances to arrive, for handovers with A&E staff to take place, and to see qualified doctors.

The national standard sets out that all ambulance trusts must respond to Category 1 calls (those which are life threatening and needing immediate attention, such as cardiac arrests) in seven minutes on average, and Category 2 calls (those that are classed as an emergency or potentially serious condition, such as a stroke or major burns) in 18 minutes on average³. Although there is no target for average response time for Category 3 calls (those classified as urgent and need treatment to relieve suffering, such as pain control), the national standard states that all ambulance trusts must respond to 90% of Category 3 calls in 120 minutes.

28% of carers had waited over an hour for an ambulance to arrive, with 7% waiting for over 8 hours. A fifth (20%) had waited over an hour for the ambulance to hand over care to A&E staff, and 43% had waited over an hour for an initial examination by a doctor or nurse.

The role of Urgent and Emergency Care planning is essential in ensuring that unpaid carers are integral.

28%



of carers had waited for more than an hour for an ambulance to arrive

² NHS. Guide to waiting times in England. <https://www.nhs.uk/nhs-services/hospitals/guide-to-nhs-waiting-times-in-england/#:~:text=The%20maximum%20waiting%20time%20for,you%20choose%20to%20wait%20longer>

³ Nuffield Trust (2023) Ambulance response times. <https://www.nuffieldtrust.org.uk/resource/ambulance-response-times>

Hospital discharge

We asked carers whether they had experienced hospital discharge for the person they care for. Last year, many carers had told us that hospital discharge could be a stressful experience, particularly if they felt unprepared or unsupported to provide care at home.

This year, 38% of carers agreed they were involved in the decisions about the discharge from hospital and what care and treatment they needed. One fifth (20%) said they were asked about their willingness and ability to care, and 17% felt listened to about their ability and willingness to provide care. 14% said they received sufficient support to protect the health and wellbeing of the person they care for as well as their own health, and 14% said they were under no pressure to care and felt fully prepared and supported.

Table 6: Carers' experiences of hospital discharge over the last three years

Statement	% of carers who 'agree' and 'strongly agree'			% of carers who 'disagree' and 'strongly disagree'		
	2023	2022	2021	2023	2022	2021
I was involved in the decisions about the discharge from the hospital and what care and treatment they needed	38%	36%	30%	36%	43%	56%
I received a Carer's Assessment	18%	11%	11%	63%	73%	82%
I was asked about my ability and willingness to care	20%	20%	21%	60%	63%	68%
I felt listened to about my ability and willingness to care	17%	16%	16%	55%	57%	66%
I received sufficient support to protect the health and wellbeing of the person I care for as well as my own health	14%	15%	19%	58%	60%	61%
I was under no pressure to care and felt fully prepared and supported	14%	13%	N/A	56%	58%	N/A

These results are very similar to last year in terms of carers positively agreeing. This suggests there has been little improvement in ensuring carers are consulted with and supported in the hospital discharge process. Many carers disagreed that they were involved in the hospital discharge: **60% disagreed they were asked about their ability and willingness to care**, and 58% disagreed that they received sufficient support to protect the health and wellbeing of the person they cared for.

“My mother-in-law broke her hip. she was very poorly post op. she wanted to go home and the staff facilitated this but too soon, meaning she required more care from us on discharge. I have a medical qualification (out of date) and I think they relied on this.”

“...the specialist was absolutely horrible to me and took no notice of my concerns, likening them to an unwillingness to care.”

Some carers said the person they cared for had been readmitted to hospital following discharge.

“They sent my husband home without all medication needed, they did not tell me he couldn't have his compression stockings left off so I did this and he became extremely swollen and in pain. The ambulance took 14 hours to get to us and told us it was a failed discharge by the hospital.”

“I had to call an ambulance the day after discharge as the hospital had discharged him with an acute UTI infection and severely dehydrated.”

“He came home by taxi, then had a fall getting to the front door so the ambulance had to be called to take him back in again to be checked over.”

It is now one year on from new rights in England for carers to be involved at the point of hospital discharge through the Health and Care Act 2022. However the results are not showing any great improvement for unpaid carers yet. This is a sign of a system under extreme pressure with the lack of a long-term sustainable funding solution for social care and an NHS under similar staffing pressures compared with social care.

Virtual wards

This year, for the first time, we asked carers about their experiences of virtual wards. A virtual ward is online care, monitoring and treatment offered in someone's own home, and is provided, when appropriate, as an alternative to NHS in-patient care, to relieve pressure on healthcare systems. It can also include more intensive support at home with care for a short period of time.

We found that **very few carers have experienced virtual wards (3%)**. This low proportion is because the numbers overall still remain small in relation to the numbers of NHS patients with treatments. The NHS has been shifting towards using the term ‘hospital at home’ which may be easier to understand.

Although few carers had experienced virtual wards, we asked all carers what they thought about the idea of providing care, monitoring and treatment at home. **The majority of carers (55%) felt that virtual wards would result in them having to provide more care.** This increased slightly to 57% for carers in paid employment. However, many carers felt there would be benefits to virtual wards: 56%, for example, agreed that the person they care would receive care in a more comfortable environment, and 48% agreed it would prevent the person they care for going into hospital unnecessarily.

“I could see Virtual Wards being very helpful for the person I care for who finds it extremely difficult to get out the house. Hospital appointments are always very difficult for the person I care for; they're extremely painful due to physical conditions and it ends up where recovery for a 'simple' appointment takes days, if not weeks.”

“I feel this would help tremendously as my son never leaves the house due to sensory overload.”

“I strongly support this. I care for two parents and the impact on the other of either being out of the home is massive. As long as the care needed can be provided at home I fully support these wards.”

“Hospital at Home NHS Fife cared for my husband during a recent bladder infection, being able to receive IV antibiotics at home was a huge help with his mental health and it also freed up a bed for someone in hospital who needed it more. Staff were incredibly friendly and helpful.”

46% of carers agreed that virtual wards would allow them to provide personalised care, and 45% agreed that virtual wards would give them and the person they care for more ownership of care being provided.

While many carers felt that virtual wards could be beneficial, some carers disagreed this was the case. 17% of carers disagreed that that virtual wards would provide more personalised care, and 17% disagreed that virtual wards would give the person they care for more ownership of care being provided. Some carers also felt that the extra responsibilities for them would be difficult to deal with. Those who had already experienced virtual wards felt that it had created more work for them.

“We’ve used the Home Treatment service a few times in the past, it worked well and preferred it to hospital but it did mean all the responsibility of my mum fell on me instead of hospital.”

“Last year, my mum was assigned to Hospital at Home. It was a disaster. I am a carer, not a nurse, yet I was expected to step up to provide the work of multiple nurses, without any prior discussion with me about my personal circumstances or position to do this.”

Some carers were also concerned about using technology.

“I am scared of technology and phobic of cameras. I want to speak in person with real people, with real body language.”

Whilst there are benefits to virtual wards or hospital at home, there are also clear risks for families in providing more care. This may not be possible for many reasons, including paid work, other family responsibilities, cost, and health reasons. Carers need to be an integral part of any virtual ward care pathway, and given a clear choice about providing care. Any attempt to reduce support for virtual wards would be potentially catastrophic for unpaid carers.



Our health and care services are facing unprecedented challenges, and it is unpaid carers across the UK who are bearing the brunt of this crisis. The recent ONS Census in England and Wales found that the proportion of carers providing over 50 hours of care per week has increased over the last 10 years, and carers' health and wellbeing is suffering as a result. Many carers are concerned about their health but unable to get help due to concerns over long waiting times.

Carers have also told us how difficult it can be to find help for the person they care for, particularly when services are not joined-up, and they are not recognised as a carer. Many carers can find it challenging to provide care when their loved one has been discharged from hospital, and it is vital that carers are given the support they need with this. While virtual wards may enable people to receive the care they need at home, in a more comfortable environment, carers must be given a choice about how care is provided.

Supporting carers with their caring role



Summary

- The most common source of support for carers was family and friends. 50% of carers said they were receiving support with their caring roles from family and friends.
- 36% of carers disagreed that the social care support met their needs and the needs of the person they care for.
- Over a quarter of carers (27%) said they received support from a local carers organisation, with many carers telling us how beneficial this support had been.
- However, nearly half (48%) of carers said they needed to know what support might be available for them and how to access it.
- 78% of carers agreed they were worried about being able to provide care in the future. Over half (55%) of carers said they weren't sure how to plan for the future and would like more support with this.
- Many carers said they needed more training and support to carry out clinical tasks, which could often cause stress or anxiety.
- 55% of carers said they needed better understanding and recognition of unpaid carers from the general public

A huge proportion of carers told us that caring can be stressful. For some carers, issues with health and social care services can create additional stress. This can result in carers providing more care themselves and not prioritising their own health and wellbeing. For other carers, a lack of knowledge about where to go for help and advice means they may not be getting the support they need to take a break.

We asked carers whether where they were receiving support with their caring roles.

Table 7: Where carers are receiving support with caring

Where carers are receiving support	% of carers receiving support
Family, friends or neighbours	50%
Social care services (eg residential care, day/drop in centres, sitting services, paid care workers)	37%
A local carers organisation (eg a carers group)	27%
Healthcare services (eg NHS funded services)	19%
A national charity for unpaid carers (eg Carers UK)	11%
A local charity or community organisation	8%
A faith organisation or place of worship	4%

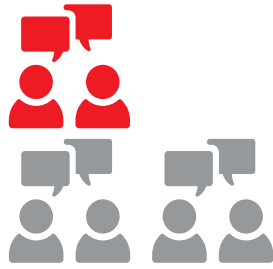
The most commonly reported source of help and support was family, friends or neighbours (50%). More carers said they received support from family, friends or neighbours than health or social care services.

- *“My husband supports me in my mental and physical health. Without him to keep me sane I could not do all that I do for my parent.”*
- *“My neighbour has been more help than anyone else.”*
- *“Family is key. Statutory services are reliant on funding and people doing their job while family powers support through with love.”*

Carers who said they were often/always lonely were less likely to receive support from family, friends or neighbours (40%). In addition, although 50% of carers said they were receiving support from family, friends or neighbours, a quarter of carers (24%) said they needed more support from family and friends.

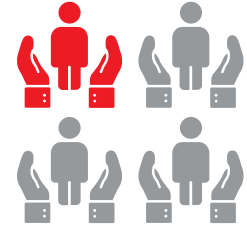
37%

of carers were
receiving support
from social services



27%

of carers were
receiving support from
a local carers organisation



37% of carers were receiving support from social care services. We asked those carers whether they were satisfied with the support they were receiving from social care services. Over half (55%) agreed they were satisfied with the quality of care provided, and over half (55%) agreed that the support was consistent. However, a quarter (24%) disagreed that they were satisfied with the quality of care, and over a third (36%) disagreed that the support met their needs and the needs of the person they care for. 30% disagreed that they would be listened to if they had any concerns about the quality of care.

“The people that come out to us clearly haven’t looked at our files which inevitably means our precious time off caring for our daughter is taken up answering questions that wouldn’t need asking if they’d done their homework. Very occasionally we get someone who does read our file prior to visiting but they rarely stay in post very long.”

“The [paid]carers who come to do the leg washing and dressings are very variable in experience and some have caused problems/ small wounds when apply compression stockings. There are some that seem to have been taken on with no health care experience and I wonder how much training they get. They also are under so much time pressure, new systems of appointments put in place that seem to cause them stress.”

“[The paid] carers cannot seem to read the notes around the house to help care for my relative. Every time I go in there is something not done properly. They do not follow the care plans in place. They do not put my relative on the commode so when I go in I have to hoist my relative on my own to toilet. I have spoken to the manager on more than one occasion but nothing changes. I have to hoist my relative after a 12 hour shift when I am really tired. My relative has been left with food on her face, teeth not brushed, put back on a soiled chair. The list is endless.”

42% of carers receiving support from social care services said the support enabled them to take a break from caring. However, 39% disagreed that they can rely on social care services and 28% disagreed that the support is consistent.

“A dementia patient would be much better helped with the same [paid care worker] coming in every day. Even two to share the week. So far it is very random and we are lucky if the same one appears more than once.”

“They are under pressure with recruitment and retention and that occasionally translates into no shows or timings that don’t fit into the contract we have.”

“Care worker always in a hurry and don’t stay the full time allocated. Consistency of care workers varies.”

Over a quarter of carers (27%) said they received support from a local carers organisation and 8% said they received support from a local charity.

Many carers said they had taken part in health and wellbeing activities organised by local groups or charities, while others had benefited from listening support and counselling.

“Newcastle Carers have given me wonderful support for the past eight years: information course, counselling, days out, monthly peer support meetings, therapy treatments.”

“Kingston Carers Network have been amazing throughout the 11 years since I was made aware of them. Their activities, information sharing and support have all helped me to feel more energised and most definitely to feel that I can carry on. Feeling that someone is there to turn to, even if you don’t need to always, is very comforting. I feel safe & that I belong whenever I do any activities with KCN.”

“Carers First have been an absolute lifeline for me - with both emotional and practical support.”



Other carers said that local carers groups or local charities had helped them to identify and obtain support by signposting to other services.

“Carers Outreach, Bangor, have been very helpful over the years with general advice on navigating the system of benefits.”

“Cornwall Carers Service have been amazing at getting me some coaching from PROMAS which was incredibly helpful in getting me to understand my carers role, how it was affecting me and giving me some positive actions to take to improve my mental health, making me more resilient in my caring role.”

“Falkirk Carers Centre has been helpful in providing emotional support and suggestions about sources of funding for things my cared for people can benefit from such as equipment to help their mobility.”

Some carers said that local carers groups enabled them to speak to other carers about issues and challenges.

“Meeting up with other carers in a walking group - sharing feelings and experiences with others who truly have/do live daily with the realities of caring.”

“Brighton Carers Centre hold a monthly working carers support group. I’ve found this to be a vital space to let off steam.”

While some carers were already receiving support in helping them connect with others, 34% said they would like support to prevent or reduce their loneliness/social isolation, and 35% said they would find it helpful to have online support groups and activities for carers.

Carers UK runs a number of different groups for carers as do many local carers organisations who have a combination of online and in-person activities since the pandemic.

Information and advice

48% of carers said they needed to know what support might be available and how to access it. This increased to 53% for carers who had been caring for two years or less. 22% of carers said they needed more information and advice about caring. Some carers said that information and advice about financial support and the benefits system would be helpful, while others said they needed more guidance on what practical support with caring might be available.

“It would be beneficial to know what criteria is required to get additional respite than I presently have.”

“Advice about what benefits I and those I care for are eligible for, plus support with applying for these benefits.”

“The key problem is how to find out what’s available. There is no ‘one point’ contact. A lot of research and networking is required to find out what services and organisations can help the carers and persons being cared for.”

Some carers said they needed more information and advice about managing the condition of the person they cared for.

“I care for my mother who was diagnosed with dementia in 2017. Since then, there has been no regular scheduled follow up monitoring or review of her changing needs and advice on how I can cope and manage her condition. It would really help to have this.”

“People with Parkinson’s often behave differently in front of relatives and others. The disease is not understood by the medical, nursing or general public. It is not just the shakes and a wobbly walk. It is a change of the personality, it is hurtful and painful for the carer and there is NO support.”

We asked carers where they got information and advice from about caring.

Table 8: Where carers get advice about caring

Where carers get information and advice from	% of carers
Internet search	45%
A local carers organisation (eg a carers centre or carers group)	36%
A national carers charity (eg Carers UK)	25%
GP or health professional	24%
A charity specialising in a particular illness, condition or age group (eg Age UK, MS Society, Mind)	19%
Other carers	18%
Family or friends	17%
I don’t know where to get advice or information	13%
Local authority	6%
Pharmacy	5%

The most commonly reported source of information and advice was the internet (45%), followed by a local carers' organisation (36%) and a national carers charity (25%).

Carers aged over 65 were less likely to get information and advice through an internet search (38%, compared to 49% of carers under 65). Carers aged over 65 were more likely to get information and advice from a local carers organisation (41% compared to 35% of carers aged under 65) and from a GP or health professional (28% compared with 22% of carers aged under 65).

Although 50% of carers said in a previous question that they received support from family and friends, only 17% said they got information or advice about caring from family and friends. This suggests that the support provided by family is emotional support, or practical support (such as providing replacement care).

18% of carers said they received information and advice from other carers. This increased to 31% for carers who were receiving support from a local carers' organisation, suggesting that local carers centres or groups can play an important role in bringing carers together and allowing them to share information and advice.

Several carers said they found it hard to access information and advice.

“Still trying to navigate through the varied info on net. So much to do and read it's overwhelming and very time consuming. And time is something I don't have.”

“Most organisations can only deal with one aspect at a time.”

32% 

of carers said they weren't sure how to plan for an emergency

Planning for the future

We asked carers whether they considered what might happen if an emergency prevented them from being able to support the person they care for. 43% said they had identified people to provide care in their absence, and 21% said they had a plan in place if they were unable to provide care in an emergency. However, a third **(32%) said they weren't sure how to plan for an emergency and would like more support with this, and 24% had never considered planning for an emergency.** Some carers said they were too busy to plan for an emergency, while others said they didn't want to think about the future as it caused them anxiety.

“I would like to have a plan in place for my husband's care if something should happen to me. I don't know who would provide this care and how to set up such a plan.”

“As I am a carer juggling a full-time job and full-time caring I do not have any spare time to think of the future just the here and now, I do need help to plan this.”

“I desperately need to plan for an emergency and have requested support with this many times! I am so, so worried about what would happen if there was an emergency, I am a single mother.”

“It's too stressful to think about this scenario.”

Many carers expressed anxiety about what would happen to the person they care for if an emergency prevented them from providing care. Some carers felt that other family members would be too busy or live too far away to provide care. Others felt that health and social care professionals wouldn't understand the needs of the person they cared for, or the person they cared for wouldn't accept support from someone else.

“I think about this everyday and it terrifies me as we have no extended family or children who could help out. I pray every day that I stay well and have the strength to keep going.”

“I have absolutely no idea what would happen to my daughter if anything happened to me. This is an ongoing nightmare worry for me as she would not last more than a few weeks in a care home.”

“There would be no support. My son would suffer greatly. My biggest fear is exactly this and the fact he needs 1-to-1, 24 hour care and support but is highly challenging, and care services would place him on sedative medications instead of meeting his needs.”



We asked carers whether they had considered what might happen if they were unable to provide care in the future, or had to cut back on the amount of care provided. **78% of carers said they were worried about being unable to provide care in the future.** Many carers felt their ability to care might change over time as they got older.

“I’m getting older – I need to have support in place for my autistic son but this can’t be organised until we have a crisis.”

“I worry about how I can continue caring as I am 80 years old.”

“I am now 76 and have been caring for my daughter for 49 years. She is getting more immobile and I and my husband - who is 77 - are getting frailer. It is more difficult and painful to do everything.”

A quarter of carers (24%) agreed they had a plan in place if they were unable to provide care in the future. However, **70% said they don’t like thinking about the future as it makes them feel anxious or stressed, and 46% said they don’t have time to think about the future. Over half (55%) of carers said they weren’t sure how to plan for the future and would like more support with this.** 21% said they had tried to put a plan in place but didn’t receive support from health and/or social care services.

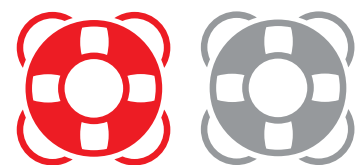
“I constantly worry about what will happen to my son if I can no longer drive or am ill as I will not be able to reach him and I am his sole carer.”

78%



of carers said they were worried about being unable to care in the future

55%



of carers said they would like more support with planning for the future

Clinical tasks

We asked carers whether they carry out any clinical tasks as part of their unpaid caring role. The most common clinical task was monitoring health and wellbeing, with 64% of carers saying they performed this task. A quarter (25%) of carers said they monitored blood pressure or blood sugar, 23% made decisions about whether to give emergency or specialist medication, and 20% dressed a wound.

Table 9: Carers' experiences of clinical tasks

Clinical task	% of carers who do this
Monitoring mental health and wellbeing	64%
Monitoring blood pressure or blood sugar	25%
Making decisions about whether to give emergency or specialist medication	23%
Dressing a wound	20%
Using equipment such as hoists to lift someone	11%
Giving injections as medicine	7%
Using an oxygen or CPAP machine	5%
Tube feeding	2%
Suctioning	1%
Helping someone on dialysis	1%

Carers providing 50 or more hours of care were more likely to carry out clinical tasks. 27% of carers caring for 50 or more hours made decisions about whether to give emergency or specialist medication compared with 17% of carers caring for less than 50 hours.

Carers who lived with the person they cared for were also more likely to carry out clinical tasks. 26% of carers who lived with the person they cared for were involved in monitoring blood pressure or blood sugar, compared with 21% of those not living with the person they cared for.

Many carers felt that they lacked any training to do clinical tasks and were anxious about whether they were performing these tasks correctly.

“No support at all - terrified every time I give an injection.”

“No support, feel anxious, frustrated and sometimes frightened, makes caring more difficult and no choice but to take on this role.”

“I am not medically trained and feel out of my depth.”

“I worry about doing them, I have very little training. I was not given a choice I just do them. I feel really isolated/stressed on bank holidays etc as I know there is less medical back up if I need it.”

Of those who had received training, many had had this through prior employment in health and care services. Some carers had received support from healthcare professionals or local charities. Others had taught themselves, through the internet. However, many carers said that more training and support would be helpful. Over a quarter (27%) said that vital signs monitoring such as blood pressure monitor, blood glucose monitor and heart rate monitor would be helpful.

64%



of carers said
they were involved in monitoring
mental health and wellbeing

“I am an ex-nurse so I have good knowledge of most clinical aspects. But up to date training on new types of wound dressings etc would be really useful.”

“Some training (eg use of mobile hoist) has been provided but in general you pick it up as you go along. Our community nurse team are very helpful and approachable. In general, however, I do think [unpaid] carers lack opportunities for training - we do the same work as paid carers but without access to the same training (and the training some paid carers get is pretty basic).”

“Taught myself from Internet. Didn’t have a choice about doing these. Combination of diabetes and dementia makes blood sugar monitoring more difficult and is a big responsibility. Often treated by health professionals as not good enough.”

64% of carers said they were involved in monitoring mental health and wellbeing.

Some carers highlighted a lack of support for this.

“I feel completely out of my depth when my eldest was self-harming and taking overdoses. The NHS are so overwhelmed that they just discharged her into our care. I had no choice whatsoever in this and felt completely alone.”

“I don’t have the support or training to monitor my son’s mental health and wellbeing. Although I’m his mum and understand him better than he understands himself I still don’t have the qualifications to predict or help very serious life-threatening situations, and these cause me extreme anxiety.”

“I have had no support or training in carrying out monitoring tasks of mental health and wellbeing. I rely on instinct as a parent and carer. I feel very unsupported in this role and worry that I could be underestimating the mental health issues that I am presented with at any given time. I am not trained in how to approach and deal with mental health issues. I wonder if I may be making a situation worse or if I am responding in the ‘correct’ way. I often ask myself ‘when should I ask for intervention?’”

Support with medication

Many carers said they were providing support with medication. **The most reported task was ordering medication** (72% of carers did this), followed by collecting prescriptions (70%) and checking that medication has been taken (70%).

Table 10: Carers' support with medication

Type of support with medication	% of carers who did this
Ordering medication	72%
Collecting prescriptions	70%
Checking medication has been taken	70%
Collecting medication	69%
Prompting the person I care for to take medication	68%
Administering medication	48%
Sorting medication into correct doses and/or refilling a medication dispenser	45%
Checking for contradictions, allergies and conflicts between medications	34%
Arranging for a medication dispenser to be refilled	18%

Some carers told us about other tasks they did in relation to medication not mentioned in the table above, including assessing symptoms and requesting changes in medication; monitoring side effects; helping the person they care for to take the medication if they have difficulty swallowing; making sure that paid care workers are administering medication correctly; and preventing the person being cared for from taking an overdose.

We asked carers whether they received support from their pharmacy with the above tasks.

Table 11: Support from pharmacists

Type of help	% of carers needing more help	% of carers who asked for help but weren't satisfied with service provided	% of carers who received help	% of carers who said this was not applicable
How to get a flu vaccine	4%	3%	40%	53%
How to order and collect repeat prescriptions	5%	6%	34%	56%
How to treat minor health concerns	12%	5%	30%	54%
How to dispose of unwanted or out of date medication	10%	4%	28%	59%
How to take a medicine safely	4%	2%	2%	72%
How to administer medication	4%	4%	20%	73%
How to store medicines safely	4%	1%	18%	76%
How to deal with devices such as inhalers	2%	2%	14%	83%
How to live healthily (eg manage weight or stop smoking)	13%	4%	12%	71%

Many carers had received support from their pharmacists: 40% said they had received help with how to get a flu vaccine, and 34% had received help with how to order and collect repeat prescriptions. However, some carers said they needed more support. 13% said they needed more support with how to live healthily, and 12% needed more help with treating minor health concerns.

“Over the past few years I have had to beg for help in regards to medications. GP surgeries has pharmacist attached who makes many mistakes. She doesn’t understand the medical conditions, allergies, interactions and I have to spend much time ringing, repeating myself, requesting and often takes five months to rectify.”

Some carers said that medication was not always available.

“Constantly going back to GP and pharmacy when drugs prescribed are not available... Having to pay hundreds of pounds for private prescriptions each month as delays with NHS waiting lists.”

“We have multiple problems sourcing some the medications. It can take a lot of time contacting pharmacies to find out if they can order the medications. Suppliers seem to have no stock of certain medications frequently.”

Carers often need practical support to enable them to carry out their caring role and to look after their own health and wellbeing. However, many carers are not getting the support they need, particularly with complex caring tasks like clinical tasks and support with medication. Many carers are also unsure about how to plan for the future in the event of an emergency, or if their own health declines, particularly as they get older.

Carers charities, carers centres and carer support groups can provide much-needed support for carers, reducing loneliness and isolation. But carers can only take advantage of these services if they receive appropriate and affordable replacement care. It is vital that carers get the help they need with their caring roles, to help reduce carers’ stress and improve wellbeing.

Conclusion

This report shows that carers' mental and physical health is getting worse, and for some it's at rock bottom. A staggering proportion of unpaid carers are putting off health treatment and not seeking help for health issues. Many carers talked about this making caring harder in the future. Caring should be part of any public health programme. There are clear opportunities to identify unpaid carers and use this information for risk stratification and targeted support which could transform carers' experience.

Unpaid carers' experiences could be transformed with the right identification processes of unpaid carers, joined up data systems that identify them, shared information (where appropriate) to enable them to care safely and well, and provide tailored personalised care.

Carers' experiences suggest that there are systemic and systematic failures within the NHS to identify and support carers, and a clear lack of understanding of caring being a social determinant of health. Whilst there are areas of good practice, there are also missed opportunities around prevention and ensuring carers get the help they need before their conditions worsen and they reach crisis point. These issues will also be affecting the NHS workforce, where nearly one in three staff members provides unpaid care for an older, disabled or ill relative or friend, not as part of their work. Given that retention is a key issue – tackling issues affecting unpaid carers will also help NHS employees directly.

With an ageing population, there is an imperative to ensure that every opportunity is taken to prevent conditions from developing as well as better management conditions which do exist. With the peak age of caring being 45 to 64, this will have a positive impact on workers' health and wellbeing when they are most likely to take on caring during their working life. Supporting carers better will promote healthier and longer working lives.

The NHS is not solely responsible for carers' health and wellbeing. There are other key aspects which contribute to carers' ill-health – income and carers' benefits which are the lowest of their kind, the support they receive from their employer, the environment around them.

Recommendations

Carers UK's vision is for the NHS to become the most carer friendly health service in the world both for the unpaid carers that the NHS supports and relies upon, but also for all workers with caring responsibilities, including the 1 in 3 staff working in the NHS in England.



Currently, there is an imbalance of rights across health and social care – unpaid carers have parity of esteem with those they care for in the Care Act 2014, but have little visibility within NHS legislation.

Too often, this means unpaid carers do not receive the recognition and support that they need and deserve from the NHS. Instead, they feel invisible, misunderstood and unsupported despite the huge contribution that they make to the NHS. A fresh approach is needed which regards unpaid carers both as people with their own needs in their own right where caring is a significant factor in their lives, but also as a key provider of care who needs to be treated as an equal partner in care.

They are not currently systematically treated as expert or equal partners in care and they need to be.

This leads to poorer outcomes for patients and people needing care, carers, the NHS and social care, but also employers where carers' own health and wellbeing is affected.

There needs to be an integrated approach to the identification, assessment and support of carers' health and wellbeing needs, across all NHS settings – if we are to properly support unpaid carers and those they provide care to. As health and care services become increasingly integrated, we need the legislation to reflect a similar approach, increasing visibility of unpaid carers across the NHS. Carers UK's recommendations in this report, reflect that approach which we believe will deliver better outcomes not just for unpaid carers and their families, but for public services and the economy as a whole.

The UK Government should have a clear strategic objective around improving carers' health and wellbeing and ensuring carers get the support they need.

As a matter of urgency, the UK Government must instigate a rapid review of carers' mental health and wellbeing and commit to a developing National Carers Strategy, developing long term outcomes for carers, including improving wellbeing.

The government should also:

- Ensure there is a nationally funded public health-orientated programme to support carers throughout the NHS. This targeted support should enable carers to receive an annual health check, and ensure that carers are targeted in flu vaccine rollouts.
- Introduce a specific targeted fund so that unpaid carers can access free social care services or additional health services when carers need to receive urgent or critical healthcare treatment.
- Invest an additional £1.5 billion in carers' breaks so that carers are able to access the breaks they need and improve their mental and physical health and wellbeing.
- Create a social security system to support carers which is fit for the 21st century, as well as providing targeted financial support to carers, to prevent financial difficulties leading to poor mental health.
- Urgently provide the necessary investment in the National Health Service in order to reduce waiting times for treatments for unpaid carers and the people that they care for.
- HM Treasury should have a specific economic focus which looks at the value of social care to helping carers and disabled people to remain in work, as well as providing investment in local areas.
- Introduce new legislation which promotes carer identification and a duty to promote health and wellbeing as a direct public health goal. The primary purpose of this is to boost carer recognition and intervention in an increasingly integrated health and care system.
- Ensure that there are clear strategic objectives for NHS England eg amending the NHS Mandate to include clauses which support unpaid carers.
- Ensure that there is clear oversight of the duties in the Health and Care Act 2022 in relation to carers to ensure that the law is being implemented as intended.
- Create incentives for secondary and primary care to identify unpaid carers, including through the GP contract. On identification, there should be mechanisms to provide carers with information, self-care and digital resources to support them.
- Require the NHS to collect more systematic data on unpaid carers, including in relation to their health and wellbeing, their experiences of care, and experiences of hospital discharge.
- Amend and improve references to carers within the NHS Constitution, which should be used proactively to improve outcomes for carers
- Make caring a protected characteristic. This would help carers access their rights, and provide a further incentive for services to provide a better offer of support to carers.

Support for carers from the NHS

- The NHS needs a strategic and clear delivery approach to identifying carers, across all its structures and delivery mechanisms, so that it is identifying carers systematically and proactively. This must include an approach that treats carers as partners in care, ensuring they have a choice about caring as well as having the information, advice and support to care safely and well.
- The NHS should ensure there is a systematic identification of carers. This must include flagging on the patient's and the carer's own patient records. The NHS should also introduce a specific piece of work which considers the extent to which patient records and shared care records can be and are being used to identify carers.
- Carers own experience of caring and interacting with the NHS must be systematically collected and a robust national tool developed to measure carer outcomes and experience of the NHS. This should be developed into a core data set which is then used throughout the NHS. This could be used to complement outcomes monitoring for social care.
- The NHS should ensure there is mandatory training for frontline professionals to ensure they are able to identify, signpost and support carers when they encounter them, particularly in relation to carers' health and wellbeing.

- The NHS should enable the safe and secure sharing of carers' health and care information as they move between different parts of the NHS and social care. The NHS should also ensure that carers are given the information they need to care safely and well in the home.
- In line with the Equality Act 2010, GP practices should have a system offering flexibility with appointments to ensure that carers can get the help they need at a time that fits in with the demands and requirements of their caring role.
- The NHS should ensure that all teams involved in hospital discharge have a responsibility for carers and that all relevant staff are Carer Aware ie that they have an understanding about carers. Carers' support and specific workers are necessary at the point of discharge from hospital and should have strong links to community health and care services, and the voluntary sector, particularly carers' support services.
- NHS should add being a carer as a risk factor for treatment in recognition of the fact that waiting for a necessary treatment is likely to hinder the ability of carers to care for the people that they support as well as exacerbate particular conditions.
- NHS should increase awareness of the NHS Constitution to ensure that carers are aware of their rights when seeking treatment.
- The UK Government and the NHS should ensure that pharmacy services are better supported to deliver improved outcomes for unpaid carers as they are a particularly accessible form of support with high satisfaction rates.
- The EHRC should conduct an inquiry into the accessibility of healthcare services for unpaid carers on the basis of our evidence about the lack of equality and accessibility of services mirroring the work on social care.. This should consider whether carers experience associative discrimination within the healthcare system.
- Primary care and local authorities should target carers when raising awareness about their services.
- Before care is provided through virtual wards, or hospital at home, the NHS must ensure that carers are given a choice in the provision of care at home, that this is tailored to their individual needs, and that this does not increase the amount of care they need to provide.
- The NHS should ensure that carers are given primarily choice about whether or not to carry out tasks, and if they are willing to do so support, advice and training in relation to carrying out clinical tasks in the home.
- The NHS must recognise the important role that carers provide in supporting the medication journey of the person they care for, and equip them with the skills they need to carry out this role.

Local carers and voluntary organisations

- Local organisations who support carers need funding and support to be able to deliver further wellbeing support for unpaid carers, to continue their work to identify unpaid carers and ensure that they are knowledgeable about what support is available.
- In order to provide scrutiny over measures to improve carers wellbeing, local carers organisations and unpaid carers should be funded so that they have capacity to feed into and challenge local Integrated Care Systems, as these currently do not include unpaid carers sufficiently.
- Local Healthwatch organisations should ensure that carers are a clear and distinct part of their evidence and reporting on the NHS.

Employers

- Employers should include carers' support as a targeted part of their staff wellbeing approaches, using the good practice from Employers for Carers to ensure that carers feel supported in the workplace.

Further support for carers

If you are a carer whose mental health is affected by your caring situation, there are sources of support for your mental health. The first person to talk to is your GP. The NHS website also has lots of helpful information on it. If you are in a crisis, you can ask for an urgent appointment with your GP, or call your local NHS urgent mental health helpline. It is okay to go to A&E or call 999 if you can't keep yourself safe. **Samaritans** have a listening service on 116 123, or you can text "SHOUT" to 85258 to contact the **Shout** Crisis Text Line.

There is also further information relating to mental health on the **Carers UK website**. Our **local directory** also has details of local organisations which support carers in each area.

For **carers in England**, the **Mind website** and the **Rethink Mental Illness website** both have information and contacts relating to mental health problems.

Carers in Scotland can contact **Breathing Space** or the **SAMH information service**.

For **carers in Wales**, the charity **Adferiad** supports people with mental health problems.

Carers in Northern Ireland can contact **Action Mental Health Mindful Carers Project** or **MindWise carer support**.

This is the second of a series of reports based on data from State of Caring



Across the UK today 5.7 million people are carers – supporting a loved one who is older, disabled or seriously ill.

Carers UK is here to listen, to give carers expert information and tailored advice. We champion the rights of carers and support them in finding new ways to manage at home, at work, or in their community.

We're here to make life better for carers.

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ISBN: 978-1-873747-75-9 | Publication code: UK4127_1123 | © Carers UK, November 2023

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