

State of Caring 2022

A snapshot of unpaid care in the UK

November 2022



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Each year Carers UK carries out a survey of unpaid carers to understand the state of caring in the UK.

A record number of carers and former carers shared their experiences this year, with over 13,400 carers taking part in the survey. 12,424 of these are currently providing care. This makes this the largest State of Caring survey carried out by Carers UK to date.

About this research

Carers UK carried out an online survey between July and September 2022. A total of 13,415 carers and former carers responded to the survey. Of the respondents to the survey:

- 59% live in England, 18% in Scotland, 14% in Northern Ireland and 9% in Wales. We received many more responses from carers in Scotland this year compared to 2021 (18% vs 8%) and Northern Ireland (14% vs 10%).
- 80% are female, 18% are male, and 1% describe their identity in another way.
- 27% consider themselves to have a disability.
- 3% are aged 0-34, 11% are aged 35-44, 24% are aged 45-54, 34% are aged 55-64, 19% are aged 65-74 and 9% are aged 75 and over (a slight increase from 7% last year).
- 4% identified as lesbian, gay or bisexual, with 1% choosing to self-describe.
- Unfortunately, we are not able to include any analysis on transgender carers due to the small sample size. However, we are interested in the experiences of transgender carers and are undertaking more in-depth research about the experiences of the LGBTQ+ community in our Making Carers Count project.
- 3% described themselves as Black, Asian or from a mixed/multiple ethnic background.
- 18% also have childcare responsibilities for a non-disabled child under 18.
- 41% of current carers are in employment. Of those, 21% work full time, 16% part-time and 4% are self-employed. 26% are looking after the home/family/dependents full-time and 26% are retired. 5% are unable to work due to a sickness or disability. 1% are unemployed/looking for paid work.
- 31% have been caring for 15 years or more, 14% for 10-14 years, 23% for 5-9 years, 28% for 1-4 years and 3% for less than a year.
- 45% care for 90 or more hours each week (a slight decrease from 48% last year), 15% care for 50-89 hours, 24% care for 20-49 hours and 16% have been caring for 0-19 hours.
- 74% care for one person, 19% care for 2 people, 4% care for 3 people and 2% care for 4 or more people.

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 13,415 carers.

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The State of Caring: context

Across the UK, millions of people provide unpaid care for an ill, older or disabled family member or friend. The number of unpaid carers has been increasing as the population ages and healthcare continues to improve.



We estimate that the total number of carers in the UK today is around 10.6 million, which means that 1 in 5 adults are providing care.¹ Later this year, updated data on caring will be published as part of the Census 2021, giving us new insights on the number of carers in the UK.

Carers' support was valued at a £530 million per day during the pandemic, or £193 billion a full year – exceeding the value of the NHS.² But this comes with high personal costs. Many carers find that their relationships are impacted, that they often struggle to balance work and care, and that they are facing their own health problems as a result of their caring role.

There are also significant financial costs associated with caring, with carers often using their income or savings to pay for support services and care equipment.

We already know that carers face poorer health outcomes, with a high proportion of carers struggling with mental and physical health problems, and experiencing low levels of wellbeing. However, 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 may not be getting the support they need.

¹ Carers UK (2022) Make Caring Visible, Valued and Supported (https://www.carersweek.org/media/qf0p5u4t/carers-week-2022-make-caring-visible-valued-and-supported-report_final.pdf)

² Carers UK (2020) Unseen and undervalued (https://www.carersuk.org/images/News_and_campaigns/Unseen_and_undervalued.pdf)

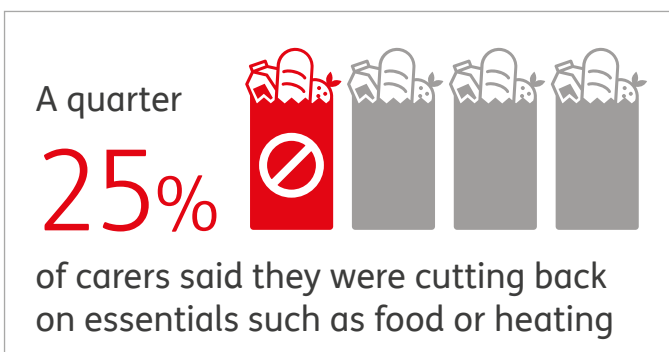
Executive summary

This report contains a snapshot of carers' experiences in 2022, capturing the impact that caring has on carers' lives and evidencing the policy recommendations that would improve this.



This year, with the cost-of-living crisis, carers have faced unprecedented pressure on their finances. A quarter of carers (25%) said they were cutting back on essentials such as food or heating, and over three-quarters (77%) said that the rising cost of living is

one of the main challenges they will face over the coming year. Many carers have been finding ways of saving money, but this can be difficult for those who need to use life-saving care equipment or ensure the person they care is kept warm.



Over half of carers (63%) said they were extremely worried about managing their monthly costs. Carers with an income of under £1,000 were even more likely to be ‘extremely’ worried (87%). These financial worries have been having a negative impact on carers’ mental and physical health. 62% of carers agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health. Nearly all carers who were struggling to make ends meet (93%) agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health.

With the health and social care system under intense pressure, many carers have experienced delays in accessing healthcare appointments and services. A fifth (19%) of carers who had requested a GP appointment said they had had to wait over a month for this, and over a third (34%) of carers who were waiting for specialist treatment or assessment had been waiting for over a year. This has caused additional stress and anxiety and resulted in many carers feeling isolated and forgotten about. 67% of carers waiting for specialist treatment or assessment said that waiting was having a negative impact on their mental or physical health, with 38% of those strongly agreeing. Many carers told us that they were experiencing considerable physical pain as a result of an untreated condition, making their caring role more difficult.

Many carers are struggling with poor mental and physical health. A fifth said their physical health was bad or very bad (21%) and 30% said their mental health was bad or very bad. Over a quarter of carers (29%) said they felt lonely often or always. Although carers are providing many hours of support to the person they care for, few are taking a break from caring, resulting in tiredness and, in some cases, exhaustion and burn-out. 41% of carers haven’t taken a break from their caring role in the last year. Many carers would like to do more physical activity, to improve their health, but simply don’t have the time to do so. Nearly half of carers (45%) said they had been less active in the last six months, which may be due to increased anxiety and stress as a result of the cost-of-living crisis.

Nearly two-thirds

63% 

of carers said they were extremely worried about managing their monthly costs

Over a third

34% 

of carers who were waiting for specialist treatment or assessment had been waiting for over a year

Two-thirds

67% 

of carers on an NHS waiting list said it was impacting negatively on their mental and physical health

Nearly a third

30% 

said their mental health was bad or very bad

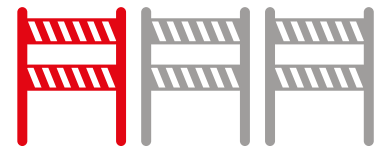
While public health measures around COVID-19 have significantly reduced, the pandemic continues to impact on carers' lives, with some carers still shielding or reducing their contact with others to protect themselves or the person they care for. A fifth of carers (20%) said that concerns over catching COVID-19 were a barrier to accessing services. Although many support services may have now reopened, many carers are unaware of the support that is available, or reluctant to access it due to concerns that services do not meet their needs or are unaffordable. Over a third of carers (36%) said that not knowing what services were available was a barrier to accessing support. With many services being reduced or cut completely, carers are extremely worried about the future: 61% said they were uncertain about what practical support they might be able to access in the next 12 months.

This year, only a quarter (25%) of carers said they had undertaken a Carer's Assessment in England and, of those who had, many were concerned that the assessment has not led to any improvements in the support provided to them. 39% of carers who had not had an assessment said that a barrier was not knowing what an assessment was.

Many carers do not recognise themselves as a carer, which can mean they are not getting the support they need. Half of all carers (51%) took over a year to recognise their caring role, with over a third (36%) taking over three years to recognise themselves as a carer. 71% of carers stated that seeing themselves primarily as a family member or friend was a barrier to identifying themselves as a carer.

Over a third

36%



of carers said that not knowing what services were available was a barrier to accessing support

Three-fifths

61%



said they were uncertain about what practical support they might be able to access in the next 12 months

Only a quarter

25%



of carers said they had undertaken a Carer's Assessment in England



Women are still most likely to be providing care and most likely to be providing more hours of care. Supporting carers to stay in, or return to, paid work, is essential to ensure that female carers can live a life free from poverty in older age. While increasing numbers of employers are recognising the importance of supporting carers in the workplace, it is essential that employers maintain flexibility as they welcome employees back to the office, so that people can juggle work and care. Concerningly, 75% of carers worry about continuing to juggle work and care.

To help those with caring responsibilities to continue working, Carers UK continues to advocate for better support in the workplace, including Carer's Leave. This year, Wendy Chamberlain MP introduced a Private Member's Bill that would introduce a landmark new right for employees in Great Britain with caring responsibilities of up to one week of unpaid Carer's Leave each year, which we are strongly supporting. Two fifths (40%) of carers say they need paid Carer's Leave to help them balance work and care, while a quarter (24%) say they need unpaid Carer's Leave to do so.

Governments across the UK have taken a range of actions to provide carers with help and support, but this report shows that more must be done. While Government has confirmed that the funding committed for health and social care in England last year will be maintained, and that there is an additional £500 million for hospital discharge, it still falls far short of what is needed, particularly given the cost of living crisis, workforce shortages and the pressures on the NHS.

Half

51%



of all carers took over a year to recognise their caring role, with over a third (36%) taking over three years

Three-quarters

75%



of carers worry about continuing to juggle work and care.

Recommendations

UK Government should launch a funded National Carers Strategy for England to provide medium and long-term changes to improve the lives of unpaid carers, including matched funding for similar strategies in the UK Nations.

Finances

- UK Government should review the level and eligibility rules for Carer's Allowance and other carers' benefits to ensure these adequately value and support unpaid carers to continue to provide care and to look after their own needs and wellbeing. This should be accompanied by the publication of the Government-commissioned research on Carer's Allowance as soon as possible.
- UK Government should uprate all benefits, including Carer's Allowance and the Carer Element of Universal Credit, in line with current levels of inflation before next April – ideally as soon as possible – to ensure that vulnerable groups can survive the winter months.
- UK Government should raise the earnings limit for Carer's Allowance to the value of 21 hours work a week at the National Living Wage rate (ie £10,374 per year), to allow carers to work more hours a week where they wish to do so, without losing their entitlement. Regulations must be introduced to uprate the earnings limit annually in line with the National Living Wage.
- UK Government should ensure that unpaid carers with an entitlement to Carer's Allowance should receive a top up payment to support them through the winter and recognise the additional costs they are facing amid the unprecedented cost of living crisis.
- UK Government should commission an independent inquiry into the relationship between carers and poverty, to explore longer-term solutions to bringing more unpaid carers out of poverty, including food poverty. This should include consideration of higher intensity caring and longer-term carers' needs, and should be part of positively reforming Carer's Allowance.
- UK Government should review pension rules for unpaid carers with implementation of initiatives to get carers up to similar pension levels as non-carers. This should include:

- *Ensuring that the state pension age does not increase, as this would significantly disadvantage carers.*
- *Creating a mechanism by which carers are able to receive their state pension up to five years early.*
- *Creating auto-enrolment payments for carers in receipt of Carer's Allowance to ensure that they continue to contribute to additional pensions.*

Juggling work and care

- UK Government should continue to support the passage of Wendy Chamberlain MP's Carer's Leave Bill, which makes provision about unpaid leave for employees with caring responsibilities.
- UK Government should continue to support the passage of the Employment Relations (Flexible Working) Private Member's Bill and implement a day-one right to request flexible working as this would help carers to juggle work and care, potentially return to work and help foster a better culture for carers in the workplace.
- Employers should consider becoming early adopters for unpaid Carer's Leave – or go one step further and provide paid Carer's Leave, making it even more accessible to their employees with caring responsibilities.
- Employers should adopt Carers UK's Carer Confident benchmark, run by Employers for Carers, to move towards becoming a carer-friendly employer. In Scotland, we recommend employers use Carer Positive run by Carers Scotland.
- Employers should recognise the range of skills that carers gain through their caring role, to support carers return to work.

NHS

- UK Government to 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.
- 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 pro-actively. 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. Systematic identification must include flagging on the patient's and the carer's own patient records.
- The NHS should also increase 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.
- GP practices should prioritise appointments for carers and offer flexibility with appointments to ensure that carers can get the help they need at a time that suits them.
- 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 carers to the list of patients prioritised for treatment appointments 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.
- NHS should increase awareness of the NHS Constitution to ensure that carers are aware of their rights when seeking treatment.

Health and wellbeing

- The UK Government should ensure that caring is considered as part of programmes to combat health inequalities, with more targeted work recognising caring as a social determinant of health.
- Employers should include carers' support as a targeted part of their staff wellbeing approaches, using the good practice from Employers for Carers.

Physical activity

- UK Governments should ensure that addressing the profound health inequality between carers and non-carers and enabling carers to live healthy lives is part of the national and local health prevention agenda. Carers should be considered when devising strategies for public health, including social prescribing policy.
- Support services and local voluntary organisations should signpost carers to different physical activities that range from light to high intensity, and that can be done in shorter chunks of time, to engage carers of all abilities. Carers should be able to access both in person and online physical activities.
- Physical activity service providers such as leisure centres, gyms and community facilities should offer subsidised or free activities for carers and flexibility around times. Making both in person and online activity sessions free or subsidised can help offset the financial barrier to carers being active, which will almost certainly increase with the growing cost of living crisis.

Support and services

- UK Government should 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.
- UK Government should bring forward a Recovery and Respite plan immediately to bring unpaid carers the help they urgently need.
- UK Government should accelerate their plan for social care reform and ensure there is adequate funding for social care over the winter as well as longer term, to meet increased needs that have developed during the COVID-19 pandemic for both the person being cared for as well as carers. A workforce strategy should also be introduced to ensure that there are enough skilled social care staff to provide social care. Ensuring carers are able to access the services they need will also help those in employment to juggle work and care.
- HM Treasury should have a specific focus regarding investment in care 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.
- Primary care and local authorities should target carers when raising awareness about their services.

Carers assessments

- UK Government should review carers' assessments to ensure all carers get the help they need. At present, only 1 in 4 receive assessments, and even those who do say that they often do not meet their needs. It is vital that carers' health and wellbeing and ability to take a break is considered as part of their assessment.

Digital

- The UK Government should ensure that carers have access to super-fast broadband to maximise the potential for carers to access services and work remotely. Ring-fenced investment must be adopted to ensure that carers who want to connect digitally, but are unable to because of low incomes, are supported with hardware, wifi and sufficiently fast broadband.
- The UK Government should ensure that carers are a key part of any digital inclusion strategies. Since digital has the potential to improve many carers' lives and support them in their caring role, we recommend a carer led approach to the design and identification of new digital mechanisms which might support them in their caring role.
- Digital strategies and delivery of systems need to also offer choice for carers who find that digital engagement is not the best method for the delivery of support and to recognise that for some, this can make caring harder.

Identification and equality

- UK Government should amend the Equalities Act 2010 to include caring as the 10th protected characteristic.
- UK Government should support awareness campaigns, like Carers Week, Carers Rights Day and other initiatives that aim to reduce the time it takes for a carer to identify themselves and seek support.

Financial impact of caring



Our latest survey found that carers are continuing to face financial difficulties, with over a quarter of carers struggling to make ends meet. Carers face additional costs as a result of care equipment and increased fuel costs, and the cost-of-living crisis has meant that many carers are no longer able to afford utility bills or food.

Key findings

- Over a quarter (27%) of carers said they were struggling to make ends meet. Carers in receipt of Carer's Allowance were more likely to be struggling to make ends meet (39%). 14% carers said they were unable to afford utility bills (an increase from 6% last year).
- Carers who had been caring for longer were much more likely to be struggling financially. 19% of people caring for over five years were in debt as a result of caring, compared to 9% of people caring for less than five years.
- Compared to last year, carers who were struggling to make ends meet were more likely to be cutting back on spending. A quarter of carers (25%) said they were cutting back on essentials such as food or heating, nearly twice as many compared to 13% last year. Carers receiving Carer's Allowance were even more likely to be cutting back on food and heating (35%).
- The majority of carers (63%) said they were 'extremely' worried about managing their monthly costs. 77% said that the rising cost of living was one of the main challenges they would face over the coming year.
- 62% of carers agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health. Nearly all carers who were struggling to make ends meet (93%) agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health.
- Over half of carers (52%) said that they need more financial support. 84% of carers in receipt of Carer's Allowance said that an increase in the value of carers' benefits would be one of the main financial changes that would make a difference to them.

An overview of carers' finances

69% of carers said they were worrying about living costs and whether they would be able to manage in the future. Over a quarter (27%) of carers said they were struggling to make ends meet. 14% said they were unable to afford utility bills (a significant increase from 6% last year), 16% said they were in debt as a result of caring and 18% said they were struggling to afford the cost of food.

- “I have had to use my savings to make ends meet, but my savings have run out...”
- “I’ve had to use credit cards to try to keep us above water and now we’re in horrendous debt.”
- “I have had to rely on family members to cook meals for us when money has run out, or taken out unaffordable loans that we know I am not going to be able to pay back just so I can ensure that the people I care for are adequately clothed & kept warm with a roof over their head.”

Carers in receipt of Carer’s Allowance were more likely to be struggling to make ends meet (39%), more likely to be struggling to afford the cost of food (29%) and more likely to be unable to afford utility bills (23%).

Carers who were providing more hours of care were much more likely to be struggling financially. 31% of people caring for over 35 hours were struggling to make ends meet compared to 16% of people caring for less than 35 hours. Similarly, 17% of people caring for over 35 hours were unable to

afford utility bills compared with 6% of people caring for less than 35 hours. Carers who had been caring for longer were also much more likely to be struggling financially. 19% of people caring for over five years were in debt as a result of caring compared to 9% of people caring for less than five years.

Carers from underrepresented groups were more likely to be struggling financially. Carers from a Black, Asian and minority ethnic background were more likely to be struggling to make ends meet than White carers (37% vs 27%). Lesbian/gay and bisexual carers were more likely to be struggling to make ends meet than heterosexual carers (44% vs 27%).

As the table below shows, compared to last year, carers who were struggling to make ends meet were more likely to be making difficult decisions and cutting back on spending. 52% said they were cutting back on luxuries compared to 38% in 2021, while 47% said they were cutting back on hobbies/leisure activities compared to 37% in 2021.

- “I cut back everything. It is really the only way to manage as a carer.”
- “Haven’t had luxuries and hobbies for such a long time.”
- “I don’t buy anything for myself. Everything is spent on my daughter or paying bills.”
- “Our savings are being eaten away...we manage because we live all the time with our belt tightened.”

Table one: How carers who are struggling financially are

Measure taken	State of Caring 2022	State of Caring 2021	% increase over the last year
Cutting back on luxuries	52%	38%	37%
Cutting back on hobbies or leisure activities	47%	37%	27%
Cutting back on seeing family and friends	34%	27%	26%
Using savings	33%	24%	38%
Cutting back on essentials like food or heating	25%	13%	92%

A quarter of carers (25%) said they were cutting back on essentials such as food or heating, compared to 13% last year. This is nearly double the rate of last year. People caring for over 35 hours a week were much more likely to be cutting back on essentials like food and heating (28%) than people caring for less than 35 hours a week (16%). Carers in receipt of Carer's Allowance were also more likely to be cutting back on food and heating (35%).

Several carers told us that the costs of care, such as buying certain foods to meet special dietary requirements, keeping the person they care for warm, and paying for life-saving caring equipment reduced their ability to make ends meet.

“My husband’s diabetes has put extra pressure on our food budget as I try to make the best swaps for his sugar levels and carbohydrate processing.”

“There are some things as a family we can cut back on but I cannot choose to stop powering the vital equipment that keeps my loved one alive.”

“Our son has sensory and anxiety issues around food and with the cost of food increasing so quickly we are worried how we will continue to support his needs and be able to pay for it.”

Many carers who were employed said they had had to cut back on their working hours to fulfil their caring responsibilities and were struggling to manage on a reduced income.

“I am self-employed and my caring role has impacted my income as I am not able to work many hours now. My bills only get paid from savings.”

“I have had to reduce my working hours significantly to care for my daughter and it is likely my fixed term contract won’t be renewed... I am struggling to find any new work so my finances will be further impacted.”

Financial support

Over half of carers (52%) said that they need more financial support. Carers in receipt of Carer's Allowance were more likely to say they needed financial support (68%).

“It is just not possible to live on benefits – it really is not living, merely existing.”

We asked carers whether certain financial changes would make a difference to their experience as a carer. 84% of carers receiving Carer's Allowance said that an increase in the value of carers' benefits would be one of the main three things that would make a difference. Nearly a third of all carers (32%) said that a one-off payment to help with the cost of living would make a difference. Carers struggling to make ends meet were more likely to say that a one-off payment to help with the cost of living would make a difference (46%).

30% of carers felt that widening eligibility criteria for carers' benefits, so that carers in receipt of a pension can access them, would make a difference. 31% said that an increase in the earnings limit for Carer's Allowance would make a difference.

“It seems very unfair that once I am a pensioner my services as a carer are not worth SOME remuneration or recognition.”

“I do not qualify for carers allowance as I am in full-time employment. However, I spend every evening and all my weekends caring for my mother with no financial help from any organisation.”

A quarter of carers

25%

said they were cutting back on essentials like food or heating – nearly double the proportion last year



Cost of living

Almost all carers (90%) said their energy bill had increased and that they were spending more on food and drink (87%). The majority of carers (73%) also said they were spending more on transport.

Some carers were spending a significant amount of their income on energy costs: 35% of carers said that over 20% of their income went towards their gas and electricity bills.

“When the prices increase beyond belief next month I will be stretched to my limits, all my income will be used in bills...”

Carers who needed to use life-saving care equipment or ensure the person they care was kept warm were extremely concerned about the impact of further increases in gas and electricity.

“My son is incontinent... if we don't wash him in warm water several times a day this will cause him to physically decline. So how do we pay for the gas to heat the water if we are currently at max budget?”

“Very worried about gas and electricity. Adult child is ventilated overnight, we also charge an electric chair every night and hoisting requires to be permanently plugged in. How can we possibly cut back on any of these things. Also very worried about electricity blackouts when the equipment required is life saving.”

“I'm extremely worried about the looming energy price rises especially as the person I care for cannot control their body temperature and needs extra heating in colder months and air cooling in summer. She also needs a lot of hot water for baths to ease her chronic pain.”

“As my husband has terminal brain cancer, I am worried about how I will cope over the winter months as I can't allow him to be cold – I need him to be as comfortable as possible in his final months at home.”

The majority of carers (63%) said they were 'extremely' worried about managing their monthly costs. Over three quarters (76%) of carers receiving Carer's Allowance said they were 'extremely' worried. Carers with an income of under £1,000 were even more likely to be 'extremely' worried (87%). Many carers were concerned about costs increasing again in the winter. 67% of carers said that although they were able to manage expenses at the moment, they were worried about how they would be able to do so in the future, with energy prices set to increase even further. 77% said that the rising cost of living was one of the main challenges they would face over the coming year.

“I just about make ends meet now but it is increasingly more difficult and come October I don't know how we are going to manage.”



“ I am so concerned about the future, I constantly worry about us and how we will survive the future. It makes me feel constantly sick.”

62% of carers agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health. Nearly all carers who were struggling to make ends meet (93%) agreed that the increase in the cost of living was having a negative impact on their mental and/or physical health.

“ I can't sleep at night worrying about what I need to pay and how to pay it...”

“ It's creating added stress while trying to stay strong in my caring role.”

“ I am so worried about the increase cost of living that I get panic attacks, I can't sleep, I feel nauseous when I look at my bank balance.”

We asked carers to tell us more about how the cost of living crisis had impacted on them. Some carers told us how they were taking various cost saving measures, such as buying reduced price items, shopping in cheaper stores or buying second hand, wearing warmer clothes rather than putting the heating on, washing clothes by hand, sharing bath water, submitting regular meter readings to ensure their bills were accurate, growing their own food or batch cooking, and being more careful about turning lights off. However, many carers were taking more drastic measures, such as walking long distances rather than paying for a bus journey, taking cold showers, delaying dental treatment, and sitting in the dark.

“ During the winter I only had my heating on for a couple of hours a day, even though I am working from home. I was so cold sometimes that I could barely type.”

“ We only leave our home now for appointments or once a week to grocery shop...We have had to cut one meal a day to save money to put toward fuel bills. My disabled husband stays in bed to keep warm without putting the heating on. We only shower occasionally because we struggle to afford our water meter.”

“ ..throughout the winter I had to do without the heating on for a lot of the time. I spent the nights shivering.”

Concerningly, several carers told us that they were cutting back on food and skipping meals:

“ I frequently go without food/do not eat meals many times a month. I have lost more than 3 stone in weight...my child weighs more than I do.”

“ Food has gone up so I eat less, skip meals and ensure my spouse has enough food...”

“ I am going without so my kids don't have to. They think I'm trying to lose a bit of weight as I've cut back on my food.”

“ I only eat 2 bowls of cereal a day so I can provide good quality food for my disabled partner.”

“ Some days I do not eat more than a slice of toast due to the rise in food costs.”

Many carers said that the cost-of-living increases meant they were unable to spend any money on hobbies, days out and holidays. As a result, many felt their quality of life had reduced significantly.

“ We can't afford the things that give us a little respite from the daily sadness and difficulties that disability brings.”

“ Quality of life has dropped significantly as we are balancing heating and eating.”

Some carers told us they had had to give up their homes, sell their car, or drop out of university due to the cost-of-living crisis.

“ I've just had to drop out of uni and apply for universal credit...because while I was able to get by with my student loan last year, this year I can't afford what I need..”

“ I've had to sell my house to prevent defaulting on the mortgage and now stay in the properties of the people I care for.”

Caring can have a catastrophic impact on a family's finances because of the loss of work and the additional costs of caring. With disability and carers' benefits falling behind in value, it's clear that this situation is unsustainable for families throughout the UK in the short, medium and longer term. Given that there is such a clear link to mental and physical health – and that caring has been identified as a social determinant of health – this not just a financial issue, but one of health inequalities.

Recommendations

- UK Government should review the level and eligibility rules for Carer's Allowance and other carers' benefits to ensure these adequately value and support unpaid carers to continue to provide care and to look after their own needs and wellbeing. This should be accompanied by the publication of the Government-commissioned research on Carer's Allowance as soon as possible.
- UK Government should uprate all benefits, including Carer's Allowance and the Carer Element of Universal Credit, in line with current levels of inflation before next April – ideally as soon as possible – to ensure that vulnerable groups can survive the winter months.
- UK Government should raise the earnings limit for Carer's Allowance to the value of 21 hours work a week at the National Living Wage rate (ie £10,374 per year), to allow carers to work more hours a week where they wish to do so, without losing their entitlement. Regulations must be introduced to uprate the earnings limit annually in line with the National Living Wage.
- UK Government should ensure that unpaid carers with an entitlement to Carer's Allowance should receive a top up payment to support them through the winter and recognise the additional costs they are facing amid the unprecedented cost of living crisis.
- UK Government should commission an independent inquiry into the relationship between carers and poverty, to explore longer-term solutions to bringing more unpaid carers out of poverty, including food poverty. This should include consideration of higher intensity caring and longer-term carers' needs, and should be part of positively reforming Carer's Allowance.
- UK Government should review pension rules for unpaid carers with implementation of initiatives to get carers up to similar pension levels as non-carers. This should include:
 - *Ensuring that the state pension age does not increase, as this would significantly disadvantage carers.*
 - *Creating a mechanism by which carers are able to receive their state pension up to five years early.*
 - *Creating auto-enrolment payments for carers in receipt of Carer's Allowance to ensure that they continue to contribute to additional pensions.*

Support and services



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, and many essential services remain unavailable to them, are inaccessible or unaffordable, or not of sufficient quality.

Key findings

- Over a third of carers (36%) said that not knowing what services were available was a barrier to accessing support. Many carers told us that they had never accessed certain services like sitting services and day services.
- A quarter of carers (25%) said the cost of care was too high. 31% said they needed more affordable care services for the person they care for. Over half (58%) said they were worried they won't be able to afford services or practical support in the future.
- 23% of carers said that services not meeting their needs was a barrier to accessing support. Carers from underrepresented groups were more likely to feel this was an issue: 27% carers from Black, Asian or ethnic minority backgrounds said that services not meeting their needs was a barrier to accessing support compared to 23% of White carers.
- 61% of carers said they were uncertain about what practical support they might be able to access in the next 12 months.
- As we found last year, the biggest area of need identified by carers was more support to enable them to look after their health and wellbeing, with 62% saying they needed this support. 77% said the impact of caring on their physical and/or mental health was one of the main challenges they would face over the coming year.
- 60% of carers said that they would like better understanding and recognition of unpaid carers from the general public.

Access to services

Many carers told us that they had never had access to certain services and that these weren't available to them: 31% had never used sitting services, 34% had never used other breaks services, 30% had never used NHS funded care, 28% had never used day services, and 29% had never used care homes for short respite breaks.

Carers living in rural areas were less likely to access some services. For example, 29% of carers living in a rural area said that activities and support provided by local charities were not available to them, compared with 25% of carers living in a large village, town or city.

Some carers receiving support with their caring role had found this helpful, particularly those who had taken part in activities run by local carers groups.

“I have been involved with my local carers group for the first time ever and am happy to have this support.”

“I have been using the yoga services from our carers resources. This has had such a positive effect on my mental health.”

However, many carers felt that they had not received good quality support from services. Some felt that services were often short-staffed due to sickness or problems with staff retention. Others felt that organisations did not provide compassionate or sensitive care.

“The care agencies in our area that I have used before now have given mostly dreadful service. The costs to us were high, but the care workers are paid minimum wage and are under pressure to fit in an unachievable amount of care calls per day. This leads to them cutting corners, doing the essentials in 10 minutes before flying out of the house again and generally giving a very poor service....”

“I tried my husband in day care, I found the organisation completely uncommunicative and really just totally unwelcoming and money orientated.”

“A new paid carer every week and a ever changing schedule makes life very difficult and stressful...”

“....my husband has had over 80 different [paid] carers in the last nine months.”

Barriers to accessing support

We asked carers whether there were any barriers in accessing support. Over a third of carers (36%) said that not knowing what services were available was a barrier. People who had been caring for less than a year were even more likely to say that they didn't know what support was available (47%).

“I have never received support with my caring role as I never realised what support might be available.”

A quarter of carers (25%) said the cost of care was too high and 31% said they needed more affordable care services for the person they care for. Carers struggling to make ends meet were more likely to say the cost was too high (38%) and that they needed more affordable care services (35%). 19% of all carers said that a reduction in charges to care would be one of the main financial changes that would make the most difference to them.

“We did have [paid] carers to get my husband washed and dressed in the morning, and to put him to bed at night. I cancelled the night care as it was too expensive. I now have to do myself, which can be very difficult.”

“We use a L/A Day Centre for my husband twice a week. It's affordable at the moment but when winter hits with extortionate financial costs I worry I may need to cut back on The Day Centre.”

“I had difficulty recruiting a new [paid] carer for my son, and have found that the costs of carers has increased too, so the money I have from the council will not buy the same amount of respite as previously.”

23% of carers said that services not meeting their needs was a barrier to accessing support, a decrease from 28% last year.

“The services try to fit people into boxes without any thought as to whether or not they are suitable – it is a box ticking exercise to say that help was offered and nothing more.”

“The local carers centre caters for young carers under 18, and adult carers who are all 50+. All activities and support is catered to them. There is no help for younger, but not adolescent, carers.”

“Dad went to a day centre one day a week but the staff said it wasn't the right setting so he became anxious and agitated while there. We have not found another place yet that might be able to manage Dad's complex needs. This is disheartening.”

People who were caring for someone with a mental health condition were more likely to say that services not meeting their needs was a barrier (28%). Carers from underrepresented groups were also more likely to feel that services didn't meet their needs. 28% of lesbian, gay and bisexual carers said that services not meeting their needs was a barrier to accessing support, compared to 22% of heterosexual carers. 27% of Black, Asian and ethnic minority carers said that services not meeting their needs was a barrier to accessing support compared to 23% of White carers. Black, Asian and ethnic minority carers were also more likely to feel that concerns about the quality of care was a barrier than White carers (20% vs 12%).

“It's difficult to access services as my parents are Pakistani by origin and language and cultural barriers exist. Tried sending my dad to a day centre and the staff accidently gave him non halal food and that left me questioning using services and now I have a distrust of all services, I feel these services do not cater for the needs of ethnic minorities.”

A fifth of carers (20%) said that concerns over catching COVID-19 was a barrier to accessing services, indicating that the pandemic is still affecting carers' ability to access support. Some carers told us that they were still shielding or restricting their activities.

“Covid is paramount here for us...It is a living nightmare of avoidance all day every day.”

“We are still shielding, and the rest of the world is really cavalier about Covid.”

We asked carers whether there were any other barriers preventing them from accessing support. Barriers highlighted by carers included the increase in the cost of fuel preventing them from travelling to access support, and struggling to access services during working hours. Many carers told us that the person they cared for did not want them to access any support, often because they did not accept that they needed any help. Several people caring for someone with a mental health problem said that the complex needs of the person being cared for meant they found it more difficult to get support:

“My son will not let anyone in the home to help him he has social problems and will not let us get help from anyone he will not talk to other people or allow us to talk to others at all it causes him to have panic attacks and he then attacks us verbally.”

“The person I care for has very complicated combination of a degenerative physical disability and complex mental health disorders. It means she can't tolerate strangers in her home space so I have to do all the caring.”

Carers who were not receiving support told us that they felt abandoned, exhausted and stressed:

“We both feel absolutely isolated and just left to get on with it.”

“I have had no support at all, I feel so alone and then worry about how I'm coping and how much more I can deal with.”

“I have had no help for years. I often feel at breaking point.”

Support in the future

When asked about the future, 61% of carers said they were uncertain about what practical support they might be able to access in the next 12 months. 61% said they were concerned that services would be reduced and 45% said they were worried they might lose access to voluntary sector services due to funding constraints. Only 13% said they were confident that they would have the practical support they need in the next 12 months.

- “ I am terrified the council will reduce the services dramatically as they have done this to others, I am worried about my mental health and that of the people I care for.”
- “ It’s both dispiriting and stressful to think of a future without any proper care at home or care support services being provided.”
- “ The mental impact upon me & my family has been immeasurable. It’s a constant worry that we could lose vital access to the services we currently have (like has happened in the past).”

Over half of carers (58%) told us that they were worried they won’t be able to afford services or practical support in the future. Carers receiving Carer’s Allowance were more likely to say they were worried they won’t be able to afford services or practical support in the future (61%). Carers struggling to make ends meet were even more likely to say they were worried they won’t be able to afford services or practical support in the future (71%).

Carers’ needs

We asked carers to tell us more about their current needs as a carer. As we found in State of Caring 2021, the biggest area of need identified was more support to enable carers to look after their health and wellbeing, with 62% saying they needed this support. People caring for over 35 hours a week were more likely to say they needed more support with their health and wellbeing than people caring for less than 35 hours (66% vs 51%).

Table two: Carers’ current needs

Carers needs	%
More support to be able to look after my own health and wellbeing	62%
Better understanding and recognition of unpaid carers from the general public	60%
Better recognition from the local council of my needs as a carer	54%
More financial support	52%
More breaks or time off from my caring role	47%
Better recognition from the NHS of my needs as a carer	47%
More support from the social security system (eg a rise in Carer's Allowance/Carer's Element)	46%
More support from the NHS or health care professionals	45%
Increased choice in which services I can access	39%
Support to prevent/reduce my loneliness/social isolation	38%
Better quality care services for the person I care for	37%
More information and advice about caring	31%
More affordable care services for the person I care for	31%
More support so I can maintain/build my relationships with others	29%
More support from family and friends	27%
Better support to return to or maintain paid work	23%
More learning and training opportunities about caring	18%
A more supportive employer to help me stay in paid work	12%

Many carers told us that they had disabilities, health issues or mobility issues which made their caring role more difficult, while some felt that the demands of their caring role meant they were unable to look after their own health.

“*I am severely overweight, borderline diabetic, cognitive problems, very unfit – keep thinking I need to look after my wife so my health problems have to be ignored.*”

60% of carers said that they would like better understanding and recognition of unpaid carers from the general public, and over half of carers (54%) said that they would like better recognition from the local council of their needs. Many carers told us that they felt their expertise was not acknowledged by services, while others were concerned that their hard work was unrewarded and unrecognised.

“*People not involved with caring for a disabled person do not understand what caring for someone 24/7 means – it is relentless hard work.*”

“*No one understands what it's like, they either just don't get it or want to understand OR they don't see it. It's very lonely...I think carers are just forgotten about completely.*”

“*I do the same work and far longer hours than paid carers and support assistants. My labour is as valuable as theirs.*”

“*Unpaid carers are seen as 'just what you should be doing' by so many. We sacrifice our entire lives at times to support another. Life is never the same again and it often feels as though our whole identity is lost especially if it is a life long event.*”

Current challenges

One of the main challenges that carers said they faced in the coming year was the impact of caring on their physical and/or mental health, with 77% saying this would be challenging. People caring for over 35 hours a week were more likely to say that maintaining their health and wellbeing would be challenging than people caring for less than 35 hours a week (80% vs 71%).

“*I feel I'm being crushed with it all. How to stay afloat?*”

“*I am currently on sick leave as being a carer has left me exhausted and mentally unable to concentrate on work, which could at some point lead to the possibility of either having a disciplinary meeting or being sacked from my job.*”

77% of carers said that the rising cost of living would be a challenge, and 72% said that the changing needs of the person being cared for would be a challenge. We asked carers whether there were any other challenges. Several carers were concerned about no longer being able to provide care as they became older and/or if their own health deteriorated:

“*...how long can I cope and what happens when I'm gone?*”

“*I worry about being able to support my mum in the future. The pressure I have been put under over the last few years with no respite has made a lasting damage physically and mentally. I have no energy or fight left.*”

Many carers who were employed said that returning to the office would be challenging and would impact on their caring role. Other challenges identified by carers included coping with the person they care for moving into a care home, arranging end of life care and coping with bereavement.

One of the main challenges that carers said they faced in the coming year was the impact of caring on their physical and/or mental health, with 77% saying this would be challenging.

Social care reform

In 2021, the Government set out their vision for adult social care in England in their White Paper *People at the Heart of Care*.³ In this vision, they included statements which they would like unpaid carers to be able to say in the future. Concerningly, the majority of carers felt that these statements did not match their lived experiences of caring. For example, 65% carers disagreed that they have access to appropriate support that suits their needs, including respite care and carers breaks, and 69% disagreed that their needs are equally recognised and their goals and aspirations are respected and fulfilled.

This shows that these goals are a long way off from being delivered for carers. Other research has also found that carers' satisfaction with support and services has fallen year on year.⁴



Table three: Carers' agreement with the white paper on social care

Measure taken	Strongly agree /agree	Neither agree nor disagree	Strongly disagree /disagree
I am supported to provide care as I wish and do so in a way that takes into account my own access to education, employment, health and wellbeing	14%	27%	59%
I have a life outside of caring and I am able to remain connected to the people who matter to me	26%	17%	57%
I know my needs are equally recognised and my goals and aspirations are respected and fulfilled	9%	21%	69%
I have the right information and advice to be able to make informed decisions	21%	29%	50%
I have access to appropriate support that suits my needs, including respite care and carers breaks	11%	25%	65%

³ UK Government (2021) *People at the Heart of Care: adult social care reform white paper* (<https://www.gov.uk/government/publications/people-at-the-heart-of-care-adult-social-care-reform-white-paper>)

⁴ Nuffield Trust (2022) *Carers' views of social care quality* (<https://www.nuffieldtrust.org.uk/resource/carers-views-of-social-care-quality#background>)

Recommendations

- UK Government should 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.
- UK Government should bring forward a Recovery and Respite plan immediately to bring unpaid carers the help they urgently need.
- UK Government should accelerate their plan for social care reform and ensure there is adequate funding for social care over the winter as well as longer term, to meet increased needs that have developed during the COVID-19 pandemic for both the person being cared for as well as carers. A workforce strategy should also be introduced to ensure that there are enough skilled social care staff to provide social care. Ensuring carers are able to access the services they need will also help those in employment to juggle work and care.
- HM Treasury should have a specific focus regarding investment in care 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.
- Primary care and local authorities should target carers when raising awareness about their services.

Access to NHS services



Many carers are struggling with their own physical and mental health issues, yet too often are not getting the support they need. Long waiting times within the NHS and concerns about the quality of health and social care services are causing carers additional stress, negatively impacting their health and wellbeing, and impacting their ability to work.

Key findings

- 51% of carers disagreed that NHS services are well-coordinated, and that information is shared effectively. 49% disagreed that NHS staff provide them with the information, advice and support they need to be able to care well and safely.
- 19% of carers who had requested a GP appointment said they had had to wait over a month for this. 16% said the person they cared for had had to wait over a month.
- 34% of carers who were waiting for specialist treatment or assessment had been waiting for over a year. 31% said the person they care for had been waiting for over a year.
- 67% of carers waiting for specialist treatment or health assessment said that waiting was having a negative impact on their mental or physical health, with 38% of those strongly agreeing. 32% said that not receiving treatment was affecting their attendance at work.
- 22% of carers who said that the person they cared for had been admitted to hospital in an emergency said that the admission could have been prevented through higher quality and more reliable care and support.
- 43% of carers who had experienced hospital discharge for the person they care for disagreed that they had been involved in the decisions about the discharge from hospital and the care and treatment needed, with nearly a quarter (23%) strongly disagreeing. 63% disagreed that they had been asked about their ability and willingness to provide care.
- Over a quarter of carers said it was unlikely or very unlikely they would complain about a health service (27%) or social care service (26%). 50% of carers said the main barrier was feeling like complaining would make little difference.

Carers' views on NHS services

We asked carers about their experiences of NHS services. 51% of carers disagreed that NHS services are well-coordinated, and that information is shared effectively, while 49% disagreed that NHS staff provide them with the information, advice and support they need to be able to care well and safely. Only 11% of carers were aware of their rights under the NHS constitution.

40% of carers disagreed that NHS staff recognised their knowledge and treated them like a partner in care. Carers who were lesbian, gay or bisexual were less likely to agree that NHS staff recognised their knowledge and treated them like a partner in care compared to heterosexual carers (26% vs 31%).

Primary health care

We asked carers about their experiences of getting primary care appointments. Of those who had requested a GP appointment, 44% had waited less than a week and 50% said the person they care for had waited less than a week.

However, 19% of carers said they had had to wait over a month for their appointment, while 16% said the person they cared for had had to wait over a month. Wait times were longer for dental appointments, where 60% of carers who had requested an appointment had waited over a month.

- “ I had a dental appointment in March 2020 which was cancelled due to Covid and haven't been able to get one since. 3 of my teeth have crumbled away since the initial date.”
- “ More and more difficult to get an appointment with GP as we keep getting texts saying they're operating on an emergency only basis due to high levels of absence... It's so difficult to get to speak to someone and everything has gone digital whether you can access it or not.”

One in three

32%



unpaid carers on NHS waiting lists said it was affecting their ability to work

One in five

22%



unpaid carers said the emergency admission to hospital of the person they cared for could have been prevented with more care and support

We asked carers to tell us more about any challenges in making or attending primary health appointments. Many carers told us that it was very difficult to contact GP surgeries to request an appointment, with calls going unanswered or put on hold. Several carers said that their GP surgery operated a first-come first-serve appointments system, but because of the needs of the person being cared for, they were unable to call early in the morning. Some carers told us that telephone calls from GPs were often made at times that weren't convenient when they were busy with their caring role or when they were in a public place and unable to talk openly about their symptoms.

Nearly half

49%

of unpaid carers felt that NHS staff didn't provide them with the information, advice and support they need to be able to care well and safely



“GP appointments must be made on the phone at 8.30am on the day... often I am busy at 8.30 with caring and school run as a lone parent, the phone line is always engaged and you may not get through until 9.10 or later, then all the daily appointments will be gone.”

“Appointments are often in the form of a phone call that can come at any point that day which means I have had to discuss sensitive matters in front of my children.”

Several carers said that GP facilities were not sufficiently accessible to disabled people. Others told us that they or the person they care for would prefer a face-to-face appointment rather than telephone appointment, particularly those who were deaf or hard of hearing or who had learning disabilities, but that these were not always available. Some carers also told us that they found it difficult to take the person they care for to appointments because they were anxious or distressed or reluctant to leave the house.

As a result of these difficulties in obtaining appointments, many carers are feeling stressed and anxious.

“Long queues on the phone just to get through to request an appointment. I find this makes me very anxious and afraid I will not be able to get the access to a Dr.”

“Most calls involve lengthy waiting times, up to 1 hour or more.....This is stressful and anxiety inducing, especially for my spouse who has anxiety and complex needs.”

In some cases, health problems have worsened because carers, or the person they care for, have not received the support they need, leaving them in pain, unable to carry out their caring role or their day-to-day activities.

“My son lost part of his leg due to infection spread while waiting for an angioplasty.”

“I find it difficult to care for someone else when I am being crippled with pain.”

“..Mum’s appointments are regularly cancelled and then she has to wait another month. We are still waiting now and her breathing problem is deteriorating.”

“I have chronic health issues and used to be classed as a vulnerable patient able to get a same day appointment with a GP at my surgery. I can no longer get a face to face appointment with a GP.”

Due to frustrating experiences in trying to get appointments, some carers have decided not to seek help, which means they are not getting the treatment they need.

“I mostly ignore any symptoms as much as possible for myself.”

“I haven’t even bothered trying to get an appointment as it seems impossible.”

“As I work in a role where I can not drop everything for a call I can only call on a day when I can be at home with no other commitments to sit and wait. So I often do not bother seeking medical help.”

Other carers have paid for private healthcare which has impacted on their finances and ability to make ends meet:

“I couldn’t get a local NHS dentist appointment for my mum when she lost her dentures. After ringing over 15 practices with no luck, in the end we had to go private. The treatment and replacement dentures cost her several hundred pounds.”

“Had to go private for emergency dental treatment for my husband and cost equivalent of a month food shop!”

Secondary health care

We asked carers whether they, or the person they care for, were currently waiting for specialist treatment or assessment by a hospital doctor. 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 letter. However, it is clear that many carers have been waiting much longer than this. Of those who were waiting for an appointment for themselves, 32% had been waiting less than 18 weeks. However, 34% had been waiting for over a year. Of those who said the person they care for was waiting for an appointment, 34% said they had been waiting less than 18 weeks and 31% said they had been waiting for an appointment for over a year.

67% of carers said that waiting for specialist treatment or assessment was having a negative impact on their mental or physical health, with 38% of those strongly agreeing. 65% said that waiting for specialist treatment or assessment was having a negative impact on the mental or physical health of the person they care for.

- “Every day I become more anxious, withdrawn and depressed. My physical and mental cognitive fitness has vastly deteriorated.”*
- “I have no idea what’s going to happen, constantly in a cycle of fear and worry and stress.”*
- “I wake in the night worrying about my health and ability to be a carer.”*

Many carers felt stressed or anxious because they were worried about their condition getting worse, while others said that the uncertainty of not having a diagnosis or treatment plan meant they were unable to plan for the future.

- “My partner has a primary diagnosis of MS and is still waiting for confirmation. It’s been weeks and he is eager to know the outcome so we can plan for the future as we have 2 disabled sons living at home.”*
- “The unknown waiting creates anxiety and fear that conditions are developing without treatment which may also impact on existing conditions, I then have to manage that anxiety for both of us which is exhausting.”*

“I feel like our life is on hold until my child completes his autism assessments. We cannot access support, we cannot get financial support, we can’t do anything until the assessment is completed and we have a diagnosis but this is years away at the minute.”

“My father has been trying since March 2022 to get a diagnosis to his shortness of breath, which he suffers with when walking around.... He’s now waiting for a CT scan, the wait time is 8-10 weeks. This period of uncertainty and endless waiting has triggered chronic anxiety and panic attacks which have impacted on his daily emotional well-being and have made caring for him 24/7 emotionally and physically exhausting.”

Several carers told us that waiting for treatment or assessment made them feel isolated.

- “I feel like I have been forgotten.”*
- “Feel helpless and that we do not matter.”*

32% of carers said that not receiving treatment for themselves or the person they care for was affecting their attendance at work. This rose to 45% of carers who had been waiting for treatment for themselves for over 18 weeks.



“ I get tired easily so have had to cut back work hours.”

“ I have had to go on long term sick and leave my job.”

“ I can't work...some days I can't move, think or function at all.”

Many carers told us that waiting for specialist treatment had left them in pain and unable to carry out their caring role.

“ I have joint and nerve pain and it is impacting the way I can care for my daughter. I am in desperate need of pain management.”

“ The impact of waiting to see a consultant means I'm trying to work and care for my husband while in pain.”

“ 3 years awaiting hip surgery, I am in constant pain.”

“ I am in constant pain awaiting surgery for mesh removal. Lifting and turning my son puts pressure on my back and contributes to my nerve pain and cramps.”

Some carers had decided to pay for private health care as a result of long wait times in the NHS, often using their savings to pay for this.

“ We chose to pay for private treatment as we weren't able to get enough sleep and it was having a major impact on our lives.”

“ I had to go private for ADHD treatment due to how long the wait on the NHS was, and ended up spending £2,000 of my savings.”

“ I waited 3 years and ended up going for a private diagnosis.”

“ I have recently paid privately to get some answers on a cancer scare as I have been waiting over a year to get to the bottom of a problem I have.”

In some cases, due to problems getting an appointment, carers were not seeking help for their condition or illness.

“ I have ran out of energy to chase up my own postponed specialist assessments and treatment and can't face the barriers and battle to ask my GP for help.”

Emergency care

We asked carers whether the person they care for had experienced an emergency admission or unplanned visit to hospital since April 2021. Of those who had, 56% said this was because the health of the person they care for had deteriorated and 56% said this was due to an accident or unplanned emergency. 3% said this was because the impact of caring on their health meant they were unable to continue caring, and 3% said that health and social services had broken down, making it unsafe for the person they care for.

We asked carers whether the emergency admission was a result of any other reasons. Some carers told us that the person they care for had attempted suicide or expressed suicidal thoughts. Others said that the hospital admission was related to COVID-19.

We also asked carers whether anything could have prevented the emergency admission. The majority (58%) felt it could not have been prevented. However, 22% said that it could have been prevented through higher quality and more reliable care and support, and 21% said it could have been prevented by having more health services at home.

“ The district nurse could not change dad's catheter properly and he went into retention which damaged his kidneys.”

“ Doctor was called to assess my mum but did not do a blood test, two weeks later she collapsed and ended up in hospital.”

“ My father in laws diabetic nurse who administers his insulin 2 x day failed to turn up all over a long weekend period and he subsequently became very unwell and was admitted for 4 weeks.... after this episode, the GP changed the insulin to a once a day slow release dose, unfortunately, the diabetic nurse wasn't informed of this and called the usual 2 x day giving a double dose so he again, overnight went into a coma and was admitted into hospital.”

Hospital discharge

We asked carers whether they had experienced hospital discharge for the person they care for since April 2021 and, if so, what their experience had been like. Although 36% agreed that they were involved in the decisions about the discharge from hospital and the care and treatment needed, 43% disagreed that they had been involved, with nearly a quarter (23%) strongly disagreeing. However, this was an improvement from last year, when 56% disagreed they had been involved.

“Discharged with meds changed without prior discussion.”

63% of carers disagreed that they had been asked about their ability and willingness to provide care (compared to 68% in 2021), and 57% disagreed that they felt listened to about this (compared to 66% in 2021).

Several carers were concerned that the hospital discharge process had been rushed and that they were unprepared to provide care:

“My mum was discharged without appropriate care support at home (I was covid positive). She had not had the appropriate assessments in hospital (physio and OT) and I had to spend hours on the phone rectifying the issue before she was released home in a taxi, unable to access the house, no care in place and still only a few hours after a medical procedure. It was horrendous and extremely damaging to everyone’s mental health.”

“I knew nothing about the support services available to me. My mum was discharged far too quickly and we were ill prepared for the stress of having her living with us.”

“I was expected to undertake medical duties which I feel are outside my remit as a carer. I was never consulted about his discharge. I was just told to come and collect him.”

“I was given one and a half hours notice. No consultation no advice no referrals. Terrifying experience as mum was discharged with a terminal illness. No palliative nurse, no GP follow up, no advice how to manage her.”

“My Mum was unaware that she was being discharged and this caused distress. I was told very little of her condition and was handed a long discharge letter by someone who knew nothing about my mum’s condition or care. On leaving the hospital my Mum was incontinent and unable to walk – she was worse on discharge than before she was admitted. I was given no advice or support and felt very let down.”

Many carers also told us that they felt the person they care had been discharged too soon, often resulting in them going back into hospital because their condition had worsened.

“My husband was discharged as being fit to go home, two days later I had to get GP and he actually did a home visit. He had a chest infection which was treated with antibiotics, but he deteriorated and ended up in hospital again with pneumonia. Obviously he was not fit for discharge the first time.”



Complaints

We asked carers whether they had made a complaint or expressed concerns about a health or social care service in the last year. Just under a quarter (24%) said they had complained about a health service and 18% had complained about a social care service. The majority of carers had not made a complaint about a health service (76%) or social care service (82%).

We asked carers whether they felt they would make a complaint or raise concerns if they were unsatisfied with a service. While over half of carers felt that it was likely or very likely that they would complain about a health service (56%), or social care service (56%), over a quarter said it was unlikely or very unlikely they would complain about a health service (27%) or social care service (26%).

We asked carers what might prevent them from making a complaint or raising concerns if they were unhappy with a service. Carers felt the main barrier was feeling that complaining would make little difference, with 50% of carers saying this would prevent them from complaining or raising concerns about a health service and 47% saying this would prevent them from complaining or raising concerns about a social care service.

“ Having had to make a complaint in the past, it is emotionally draining and time consuming and can impact negatively on your mental health without achieving anything for the person you are caring for.”

“ Everyone closes ranks, no one will take responsibility. No one listens or cares. They all protect their own backs and worry about their jobs.”

“ Disappointed with responses to previous complaints that have not been taken seriously, not worth the time to be fobbed off by the people who should be listening and learning!”

Nearly a third of carers said they would be worried about the consequences of making a complaint about a health service (32%) or social care service (32%).

“ I gave the provider honest feedback when requested by them and a care manager bullied me and threatened to withdraw care.”

“ Terrified to make a complaint about social work, it would be used against you.”

“ I had to complain once about how I was treated in hospital, worst thing I've ever done. I regret bitterly that I made that complaint, definitely effected [sic] the care I've gone onto receive since.”

Nearly a third

32%



of carers said they would be worried about the consequences of making a complaint about either a health service or a social care service



Recommendations

- UK Government to 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.
- 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. Systematic identification must include flagging on the patient's and the carer's own patient records.
- The NHS should also increase 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.
- GP practices should prioritise appointments for carers and offer flexibility with appointments to ensure that carers can get the help they need at a time that suits them.
- 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 carers to the list of patients prioritised for treatment appointments 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.
- NHS should increase awareness of the NHS Constitution to ensure that carers are aware of their rights when seeking treatment.

Carers' health and wellbeing



Carers' health can be impacted by their caring role. This could be due to the physical demands of caring, limited opportunities to take a break, or the stress and anxiety of making ends meet. Many carers have poor physical and mental health, but are not always receiving the support they need. Carers' life satisfaction is also significantly lower than the national average. There is increasing evidence that caring should be considered a social determinant of health.⁵

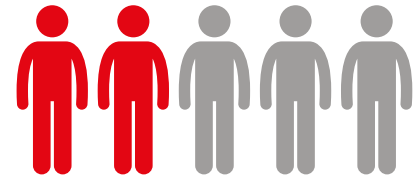
Key findings

- 21% carers said their physical health was 'bad' or 'very bad' and 30% said their mental health was 'bad' or 'very bad'.
- Carers receiving Carer's Allowance were more likely to report 'bad' or 'very bad' physical health (26%) and mental health (37%). Carers with a household income of less than £1,000 a month were even more likely to report 'bad' or 'very bad' physical health (31%) and mental health (40%).
- 41% of carers haven't taken a break in the last year. Of those, 26% of carers haven't tried to take a break because they felt it was too difficult.
- 29% of carers said they felt lonely often or always. 33% of people caring for more than 35 hours a week said they felt lonely often or always, compared with 17% of people caring for less than 35 hours a week.
- 51% of carers said that being able to take a break would help them feel less lonely.
- Carers have lower levels of wellbeing compared with the general population.

⁵ Public Health England (2021) Caring as a social determinant of health (https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/971115/Caring_as_a_social_determinant_report.pdf)

41%

of carers haven't taken a break in the last year. A quarter of carers (26%) haven't tried to take a break because they felt it was too difficult.



Carers' physical and mental health

Just over a fifth of carers (21%) said their physical health was 'bad' or 'very bad'. Carers rated their mental health as worse than their physical health, with 30% saying their mental health was 'bad' or 'very bad' (no change from 2021).

People who were caring for over 50 hours a week were more likely to report 'bad' or 'very bad' physical health than people caring for less than 50 hours a week (25% vs 16%), as well as 'bad' or 'very bad' mental health (32% vs 25%).

“ This last year I have become very aware of how I am no longer coping as well as I used to: migraines, hormones, brain fogs daily, etc.”

“ Responsibility of my son is massive. No one can appreciate the impact this has on my mental health.”

Carers receiving Carer's Allowance were more likely to report 'bad' or 'very bad' physical health (26%) and mental health (37%).

Carers with a household income of less than £1,000 a month were even more likely to report 'bad' or 'very bad' physical health (31%) and mental health (40%).

Carers who said they were not struggling to make ends meet reported better physical and mental health than carers who were cutting back on spending.

For example, 48% of carers not struggling to make ends reported 'good' or 'very good' physical health compared with 19% of carers who were cutting back on spending. Similarly, 40% of carers not struggling to make ends reported 'good' or 'very good' mental health compared with 12% of carers who were cutting back on spending.

Carers who were employed were more likely to report 'good' or 'very good' physical health (40%) and mental health (28%).

Male carers were more likely to report 'good' or 'very good' mental health compared with female carers (31% vs 25%).

Carers' health concerns

We asked carers which three aspects of their health and wellbeing they were most worried about. Carers were most worried about feeling stressed or anxious (60%), followed by not having time to prioritise their physical and mental health (36%), being unable to take a break (35%) and getting enough sleep (33%).

People caring for over 35 hours a week were more likely to worry about being able to take a break than people caring for less than 35 hours a week (38% vs 25%).

Carers in employment were more likely to worry about not having the time to prioritise their physical and mental health (42%) compared to those who were looking after family or dependents full time or unable to work (36%).

Table four: Carers' self-reported physical and mental health

	Very good	Good	Fair	Bad	Very bad
Physical health	6%	27%	45%	17%	4%
Mental Health	5%	21%	45%	23%	7%

Carers with an income of less than £1,000 per month were more likely than carers with an income of over £1,000 per month to worry about feeling lonely or isolated (27% vs 22%) or feeling depressed (27% vs 22%).

Breaks

We asked carers whether they had tried to take a break in the last 12 months. 42% said they had taken a break. However, 41% said they had not taken a break. Of those, 8% said they had tried to take a break but hadn't been able to, 7% felt they didn't need a break, and 26% hadn't tried to take a break because they felt it was too difficult. 17% said they had taken a break but this hadn't been enough for them to look after their mental or physical health.

“My break is when I sleep – 7 hours of broken sleep a night if I'm lucky.”

The amount of care being provided by an individual affected how likely it was that they had taken a break. 69% of people caring for less than 35 hours a week had taken a break compared with 56% of people caring for over 35 hours a week.

Carers who were gay, lesbian or bisexual were less likely to have taken a break than heterosexual carers (53% vs 60%).

Carers with an income of less than £1,000 a month were more likely to say they hadn't taken a break because they think it is too difficult than carers with an income of over £1,000 (24% vs 36%).

Some carers felt that there was too much effort involved in making arrangements to take a break, or that taking a break meant they had too much to catch up on when they returned.

“I went away for an overnight last year and it was fraught with problems...spent more time trying to sort out my replacement carer than having a break.”

“Breaks are time limited and mean extra work on my return.”

Many carers felt that they were unable to fully relax while taking a break because they were worried about the person they care for.

“When you are a carer you never get a break – going to the shops for groceries is a break but the mind is always on the person you are carer to.”

“Sometimes I buy a coffee and drink it in my car in the car park, but I feel guilty and anxious about being away for a second longer than I need to.”

Of those carers who had been able to take a break, most had done so when a friend or family member provided care. Few carers mentioned using respite or sitting services. Some carers told us that taking a short break was not enough to allow them to look after their physical and mental health.

“I get 3 hours every 4-6 weeks when other family comes.”

“I have a 3 hour sitting service once a week. As I live in a rural area this does not give me enough time to do what I need to do as at least an hour of this time involves travel time.”

Some carers felt that any time they had to themselves needed to be spent doing chores, such as doing the weekly shop or catching up on financial admin. However, many carers told us about the small amounts of time they were able to take for themselves that were beneficial, like walking the dog, going to a knitting group or art class, gardening, going to the hairdressers, or doing yoga. Some carers had been able to take longer breaks, including holidays, which had improved their mental health and wellbeing.

“I had 5 days away last month and it made a huge difference to me. It made me feel I could carry on with the things I must do. It lifted my mood and reduced my anxiety.”

“I have had a two night break which was wonderful. I felt like me when I came back. Able to cope and had a more positive attitude.”

Loneliness

We asked carers how often they felt lonely. 29% of carers said they felt lonely often or always, while 48% said they sometimes felt lonely and 13% said they hardly ever felt lonely. Only 8% said they never felt lonely. 38% of carers said they needed more support to prevent or reduce their loneliness, while over a quarter (29%) said they needed more support so they can maintain and build their relationships with others.

Carers who had been caring for longer were more likely to feel lonely. 31% of people caring for over five years said they felt lonely often or always, compared with 23% of people caring for less than five years. Carers who were providing more hours of care were also more likely to feel lonely. 33% of people caring for more than 35 hours a week said they felt lonely often/always compared with 17% of people caring for less than 35 hours a week.

We asked carers what might help them to feel less lonely. The majority of carers (51%) said that being able to take a break would help them feel less lonely. This was followed by more understanding and recognition from society about the role of carers (47%), being able to take part in physical and leisure activities (33%) and having access to emotional support services (33%).

We asked carers whether they had any other suggestions that might help them feel less lonely. Some carers felt that regular contact with family or friends would be helpful, while others suggested that being able to access counselling services, being supported to take a break, finding flexible employment, or taking part in activities for over 60s would be beneficial.

“ Being involved in a group that understand without judgment what life is like. Access to more exercise as weight gain has effect my mental health.”

“ I work and then have to do my caring, no time left for me.”

Many carers felt that it was difficult for other people to understand the pressure they faced in their caring role, particularly if they hadn't been a carer themselves.

“ People have no idea how much of a struggle it is.”

“ Very hard to join in general chat with non-carers, they generally don't understand why I don't holiday, go out, buy new things etc. Hard to find common ground anymore.”

Wellbeing

We asked carers to rate different aspects of their wellbeing on a scale of 0-10, where 0 was 'not at all' and 10 was 'completely'. These indicators of national wellbeing are used by the Office for National Statistics (ONS) to explore how people in the UK are doing across different aspects of their lives. By asking carers the same questions we can compare their experiences to the general public.⁶

Carers rated their life satisfaction at an average of 4.7, significantly lower than the UK average of 7.5. Carers rated their happiness at an average of 4.8, lower than the UK average of 7.4. When asked to rate the extent to which they felt the things they do in their life are worthwhile, carers rated this as 5.5, lower than the UK average of 7.8. When asked how anxious they were, carers rated this as 5.1, higher than the UK average of 3.2.

Carers with an income of less than £1,000 a month rated their life satisfaction as 4 out of 10, in comparison with carers with an income of over £1,000 a month who rated it as 4.8. Carers with an income of less than £1,000 a month also had a lower happiness rating of 4.2 compared to 4.9 for carers with an income of over £1,000 a month.

Recommendations

- The UK Government should ensure that caring is considered as part of programmes to combat health inequalities, with more targeted work recognising caring as a social determinant of health.
- Employers should include carers' support as a targeted part of their staff wellbeing approaches, using the good practice from Employers for Carers.

⁶ <https://www.ons.gov.uk/peoplepopulationandcommunity/wellbeing/articles/measuresofnationalwellbeingdashboardqualityoflifeintheuk/2022-08-12>

Physical activity

The Chief Medical Officer recommends that each week adults take part in at least 150 minutes (or 2.5 hours) of moderate intensity cardiovascular activity (an activity that raises the heart rate, makes breathing faster and a person feel warmer, such as a

brisk walk, dancing, a light cycle, or climbing upstairs), or 75 minutes of vigorous intensity activity (an activity that takes hard physical effort and makes you breathe much harder than normal, such as heavy lifting, running, gym work, fast cycling or aerobics).



Many carers want to be more active and recognise that physical activity can improve physical and mental health, but face barriers to being active, including lack of time, resources, or energy.

Key findings

- 65% of carers said they had not undertaken any vigorous activity in the last week, and 35% had not undertaken any moderate activity.
- Carers with poor physical and mental health were less likely to be active. Just over half (51%) of carers who said they had bad or very bad physical health had done no moderate physical activity in the last week.
- Nearly half of carers (45%) said they had been less active in the last six months. Carers who were struggling to make ends meet were more likely to say they had been less active over the last six months (50%).
- Only 16% carers said that they use leisure facilities sometimes or often. The main barrier to using facilities was carers feeling that they did not have the time (59%).

Levels and type of physical activity

Sport England classify inactive people as those that do less than 30 minutes of physical activity per week. As we have found in previous research, carers are more likely to be inactive than the general population.

We asked carers how many days in the last week they had done light, moderate and vigorous physical activity for 10 minutes or more. 65% of carers said they had not undertaken any vigorous activity, and 35% had not undertaken any moderate activity. Most carers had done some light physical activity, with only 12% saying they had not undertaken any light physical activity.

35% of carers said they had done vigorous exercise at least once a week, 65% said they had done moderate exercise at least once a week, and 88% had done light exercise at least once a week. While only 3% of carers had undertaken vigorous activity every day in the last week, and 10% had undertaken moderate activity every day in the last week, over a third (34%) of carers said they had done light physical activity every day in the last week.

Carers with bad or very bad physical health are unsurprisingly less active, and this may be due to the strain of carrying out a caring role or a long-term health condition. Just over half (51%) of carers who said they had bad or very bad physical health had done no moderate physical activity in the last week, compared with a quarter (25%) of those with good or very good physical health. Similarly, 21% of carers who said they had bad or very bad physical health had done no light exercise in the last week, compared with just 6% of those with good or very good physical health. This highlights the importance of supporting this group of carers to be active, as research shows that physical activity can help reduce and lessen physical health conditions such as arthritis, diabetes and Parkinson's.

The reduction in activity can also be seen in carers who have bad or very bad mental health. 44% of carers who said they had bad or very bad mental health had done no moderate physical activity in the last week, compared with 25% of those with good or very good mental health.

Carers who were struggling to make ends meet were more likely to be inactive, with 40% not undertaking any moderate activity in the last week, compared to 35% of all carers.

Carers from a White background were much more likely to have done light exercise every day in the last week, compared with carers from an ethnic minority background (35% vs 18%).

Carers who were caring for over 50 hours a week were more likely to be inactive. The time constraints on carers are such that being able to carve out time and energy to be active can be challenging, and not being able to take a break means there is limited opportunity for carers to consider their own health. A higher number of carers caring for over 50 hours a week are doing no vigorous (67%) or moderate (38%) activity per week, compared with 62% and 31% of carers caring for less than 50 hours a week.

Loneliness also has an impact on how physically active carers are. A higher number of carers who said they were often or always lonely were doing no vigorous (69%) or moderate (43%) activity in the last week. Only 28% of carers who said they were often or always lonely were able to do a light form of activity every day over the previous seven days, compared to 46% of carers who said they never felt lonely.

Table five: Carers' physical activity compared to the national population ⁷

Activity level	Carers	National population (based on Active Lives survey)
Inactive	51%	27%
Fairly active	19%	12%
Active	30%	61%

⁷ This table was calculated by combining the intensity of activity with the number of minutes carers had done that activity on one day to estimate the total amount of active minutes in one week.

When comparing to last year's findings, carers seem to be less active this year. 47% of carers have cut back on hobbies and activities as a result of the cost-of-living crisis, which may have impacted on physical activity. Other barriers which may impact carers' ability to undertake physical activity are similar to those identified last year. The majority of carers report not having the time or energy to take part in physical activity. Other barriers include guilt, anxiety, tiredness, injury or illness. There is also a lack of awareness about how much and which types of physical activity to do to maintain health and wellbeing.

“ I don't feel comfortable leaving my spouse and doing something for me.”

Nearly a quarter of carers (23%) said that worrying about getting enough exercise was one of their main concerns in relation to their health and wellbeing.

Changes to physical activity levels

We asked carers whether there had been any change to the amount of physical activity they had done over the last six months. Nearly half of carers (45%) said they had been less active in the last six months, and only 16% said they had been more active. 40% said there had been no change to their physical activity levels.

Carers who were struggling to make ends meet were more likely to say they had been less active over the last six months (50%). This may be due to carers having to juggle caring responsibilities alongside the stress of the rising cost of living, resulting in carers feeling anxious or less motivated.

Carers who said they had bad or very bad physical health were also more likely to say they had been less active over the last six months (55%) compared with those who had good or very good physical health (34%).

Of the carers who said they had been more active over the last six months, 28% said they use leisure facilities sometimes or often, indicating that leisure facilities may help people to be physically active.

Use of local leisure facilities

As part of the Carers Active project, we are keen to explore the ways in which carers are able to access opportunities to be physically active so that we can identify any barriers. Leisure facility sites, such as swimming pools, sports halls, gyms, aerobics studios, leisure centres and saunas, provide a wide range of activities and ways to be physically active. Significantly, three quarters of carers (75%) never use any local leisure facilities. Only 16% say that they use them sometimes or often.



Carers who said they feel lonely often or always were even less likely to use local leisure facilities, with 81% saying they never used these. This suggests that carers who feel lonely may feel detached from these types of facilities.

Carers with a disability were more likely to say they never used local leisure facilities (80%) compared to those who were not disabled (72%).

Carers who were struggling to make ends meet were slightly more likely to say they had never used leisure facilities (79%) compared to all carers (75%).

We asked carers whether there were any barriers to them accessing local leisure facilities. The main barrier identified was carers feeling that they did not have the time to use facilities (59%).

“I am tired, I struggle to get any free time and I can't afford it. I really miss being able to swim or go to a class.”

The other main barrier identified was the cost of leisure facilities being too expensive (38%), which is likely to worsen with current cost of living crisis.

“I can't afford to use any leisure facilities, it would be good if they could offer free time late in the evening before or after it closes.”

“Not able to leave unless carers in the house, can't afford to pay for membership and potentially not being able to use it (spent 5 months on and off at hospital last winter/spring).”

A quarter of carers (25%) said they were worried about catching COVID-19, demonstrating that the pandemic is still impacting on carers' lives.

“I am still trying to avoid catching COVID due to the risks it poses to the people I care for.”

“One of my biggest concerns is bringing covid home. That means that I severely limit my outside the flat time!”

Recommendations

- UK Governments should ensure that addressing the profound health inequality between carers and non-carers and enabling carers to live healthy lives is part of the national and local health prevention agenda. Carers should be considered when devising strategies for public health, including social prescribing policy.
- Support services and local voluntary organisations should signpost carers to different physical activities that range from light to high intensity, and that can be done in shorter chunks of time, to engage carers of all abilities. Carers should be able to access both in person and online physical activities.
- Physical activity service providers such as leisure centres, gyms and community facilities should offer subsidised or free activities for carers and flexibility around times. Making both in person and online activity sessions free or subsidised can help offset the financial barrier to carers being active, which will almost certainly increase with the growing cost of living crisis

Carer's assessments

In England, the Care Act 2014 gives anyone over the age of 18 who is looking after another adult who is disabled, ill or elderly the right to a carer's assessment. Young carers and parents of disabled children also have the right to an assessment by their

local council under the Children and Families Act 2014. These assessments are carried out by Local Authorities and should cover topics such as carers' mental and physical health, their ability and willingness to care, and their relationships with others.



However, too many carers still face barriers to receiving an assessment, and many of those who are assessed feel that the assessment does not sufficiently consider their needs or lead to meaningful support. Many carers also face long waiting times for assessment.

Key findings

- 25% of carers surveyed reported having a carer's assessment or re-assessment in the last 12 months in England.
- 39% of carers who had not had a carer's assessment said that a barrier to having an assessment was not knowing what an assessment was. Nearly a fifth of carers (19%) said that they had not requested a carer's assessment as they didn't think it would be beneficial to them.
- A third of carers (33%) who had received an assessment felt that the need to take regular breaks from caring was not properly considered in their assessment or the support they receive.

Assessment take-up

We asked carers whether they had a carer's assessment, review or reassessment in the last 12 months. 25% of carers surveyed reported having a carer's assessment or re-assessment in the last 12 months in England. This is a very slight increase from 24% of carers in 2021 but is still a decrease from 27% of carers in 2019 and 31% in 2016.

While the majority of these carers (81%) waited less than six months for a carer's assessment, 19% of carers were still left waiting for over six months to have their needs assessed by their local council. These are the exact same percentages as those in State of Caring 2021.

The number of hours of care someone was providing each week had an impact on whether they had received a carer's assessment, with 28% of people caring over 35 hours a week having an assessment, compared to 17% of people caring less than 35 hours.

Carers from a Black, Asian or minority ethnic background are less likely to have a Carer's Assessment (21%) compared to those from a White background (25%). Lesbian, gay and bisexual carers are less likely to have an assessment (19%) than heterosexual carers (25%). There was little difference between carers who identify as having a disability and carers that do not have a disability (25% vs 24%).

The older a carer is, the more likely they will have an assessment. Carers aged 65+ are more likely to have an assessment (28%) than carers aged 18-64 (23%). There was no difference between male and female carers in the rate of assessment take-up (25%).

28% of carers in receipt of Carer's Allowance have had an assessment.

Barriers to having an assessment

We asked carers who had not had an assessment whether various barriers had prevented them from doing so. The main barrier was not knowing what an assessment was, with 39% of carers saying this was a barrier.

“I did not even know it existed or that I was entitled, and I have been a carer for 24 years”

“I didn't realise I was a carer and didn't know my entitlement”

Nearly a fifth of carers (19%) said that they had not requested a carer's assessment as they didn't think it would be beneficial to them. Lesbian, gay or bisexual carers were more likely to think that an assessment wouldn't be beneficial to them compared with heterosexual carers (25% vs 19%).

We asked carers whether there were any other barriers to them having an assessment. Some carers told us that they were afraid the process would be too upsetting.

“Talking to anyone about everything that has happened in the last year would be too distressing and I am afraid I would cry during the assessment.”

Other barriers identified included the COVID-19 pandemic, being too busy with caring, feeling judged and not having the energy to go through the process. Some carers also said that the person they care for did not want an assessment.

Carers' views on the assessment process

We asked carers who had undergone a carer's assessment whether they felt the assessment process had considered various areas.

A third of carers (33%) felt that the need to take regular breaks from caring was not properly considered in their assessment or the support they receive. Just under a third (32%) said that their ability to maintain relationships with friends and family was not properly considered in their assessment or the support they receive. 31% said their ability to have time to themselves was not considered, and 31% said there had been no consideration of what needs to be put in place in case of an emergency.

In general, many carers felt the assessment process was not helpful.

“It seemed more of an exercise in ticking boxes.”

“It was pointless and a token gesture.”

Some carers felt that although things had been considered in the assessment, insufficient support had been provided.

“Whilst the assessment covered lots of these topics, it doesn't necessarily mean there has been much of an improvement in, for instance, actually having regular breaks!”

“The assessment considered most of these, but no support has been provided so it has made no difference.”

“I felt this was a tick box exercise rather than something genuinely seeking to be helpful. A benefits advisor has contacted me since, however nothing else I asked for has happened.”

“Find them an absolute waste of time... in terms of lessening the burden, offered nothing.”

“Previous carers assessment resulted in no additional help / support, and I felt like I had shared very personal information and got no benefit or support from having done so.”

Many carers felt their specific needs had not been considered.

“The whole system took me for granted and assumed that I could do everything. There was a lack of communication and careful consideration regarding my needs.”

“My age and physical conditions to do the caring was not considered.”

“My acute mental and physical health needs were not properly assessed, and I have subsequently had a physical and mental breakdown earlier this year from which I am starting to recover but I had to press all the warning bells to get health and social care support.”

“I found the carers assessment almost useless. As far as I am concerned, it did not cover any of the things that I need to discuss.”

Recommendations

- UK Government should review carers' assessments to ensure all carers get the help they need. At present, only 1 in 4 receive assessments, and even those who do say that they often do not meet their needs. It is vital

that carers' health and wellbeing and ability to take a break is considered as part of their assessment.

Employment and skills



Millions of people in the UK juggle their unpaid caring responsibilities with paid employment. For many, balancing work and care can be a real struggle – as a result, carers tell us they are tired, stressed and struggling to manage their own physical and mental health.

Carers – particularly women – urgently need more support to ensure they can remain in work, including through better access to affordable and accessible social care services. People also need to have the ability to work flexible and take Carer's Leave to manage their combined responsibilities more easily. Without more support, many more people will have to give up work or reduce their hours to care.

Key findings

- 75% of respondents worry about continuing to juggle work and care.
- 65% of respondents have given up opportunities at work because of caring.
- Nearly a quarter (23%) of respondents said they needed better support to return to or maintain paid work.
- Two fifths (40%) of respondents say they need paid Carer's Leave to help them balance work and care, while a quarter (24%) say they need unpaid Carer's Leave to do so.
- A quarter (26%) of respondents said they needed affordable and accessible alternative care in order to work. A further 15% said they were at risk of reducing their hours at work or of giving up work completely without access to it.
- 29% of respondents said they had already reduced their hours at work, while a further 11% felt they needed to, to help manage their caring responsibilities.
- 43% of respondents agreed (17%) or strongly agreed (26%) that not being able to work from home would make them consider leaving their employment.
- 44% of respondents said that their employer has introduced new measures since COVID-19 which really help them juggle work and care.
- 1 in 8 (12%) respondents said they needed a more supportive employer to stay in work.
- Women are three times as likely to be in part-time work (18%) as men (6%).

The impact of juggling work and care

We asked carers about the impact that juggling work and care had on them, and the extent to which they agreed or disagreed with a number of different statements. 65% of respondents either agreed (30%) or strongly agreed (35%) that they have given up opportunities at work because of caring. Female respondents (66%) were significantly more likely to agree or strongly agree with this than men (57%). Those working part-time (71%) were also much more likely to say they had given up opportunities at work because of caring than full-time employees (59%), while it was the case for 77% for those who indicated they ‘cannot afford utility bills like electricity, gas, water or telephone bills’.

“I have passed up many promotion opportunities due to my caring responsibilities.”

“I have had to pull out of 2 internal recruitment drives with promotion.”

65% of respondents either agreed (41%) or strongly agreed (24%) that work gives them a break from their caring role. Women were more likely to say this than men, as were those working part-time, rather than full time. However, 65% of respondents either agreed (45%) or strongly agreed (20%) that they feel anxious about caring while they are working, while three quarters (74%) of respondents either agreed (46%) or strongly agreed (28%) that they feel tired at work because of their caring role.

The support carers need to juggle work and care

Many carers have had to reduce their hours at work, or quit their job entirely, because they do not get enough support in work, or with their caring responsibilities, to be able to juggle both successfully. 75% of respondents either agreed (39%) or strongly agreed (36%) that they worry about continuing to juggle work and care. This was a particular concern for women – more than three quarters (76%) of female respondents said continuing to juggle work and care was a concern, compared to 67% for male respondents.

“I am not able to juggle work and being a carer as life is so unpredictable and demanding”.

“It is exhausting trying to do both – I end up feeling I’m failing at work and being a carer, and have no energy left for anything else.”

“I am burnt out with caring and teaching. I can not afford to stop. I am getting ill.”

Nearly a quarter of respondents (23%) said they needed better support to return to or maintain paid work. Male respondents (18%) were less likely to prioritise saying they needed more support to remain in or return to work than female respondents (25%). Those struggling to make ends meet were 50% more likely to prioritise saying they needed more support to stay in or remain at work (36%) than all respondents.

Flexible working

Positively, over half (52%) of respondents said they already have flexible working arrangements at work – this did not vary when we compared responses from men and women. However, one in six (17%) respondents say they need flexible working arrangements. Concerningly, a significant number did not have access to flexible working, meaning 3% of respondents said they are at risk of reducing their working hours, while 5% said they are at risk of giving up work altogether.

Carers working for a large organisation were more likely to say that flexible working was offered (57%) than those working for a medium (40%) or small organisation (42%). Carers working for a not-for-profit/voluntary sector or public sector organisation were more likely to say flexible working was offered (56%) than those working in the private sector (45%).

“Every day is different at work because it depends on my Mum’s needs on any given day. Some days she can need a lot of care and attention, this can cause difficulties and problems when working full time.”

Carer's Leave

Having access to paid or unpaid Carer's Leave is an important way for carers to balance their working and caring responsibilities. Over a quarter (28%) of respondents already can take paid Carer's Leave. However, two fifths (40%) of respondents say they need paid Carer's Leave to help them balance work and care; 5% say they are at risk of reducing their working hours, and 6% say they are at risk of giving up work completely without paid Carer's Leave.

When looking at unpaid Carer's Leave – again, it is positive that two fifths (40%) of respondents already can take unpaid Carer's Leave. Less encouragingly, a quarter (24%) say they need unpaid Carer's Leave to balance work and care; 4% said they are at risk of reducing their working hours, and 5% say they are at risk of giving up work completely, without unpaid Carer's Leave.

Those who said they were full time employees were more likely to have access to paid Carer's Leave (31%) than those working part-time (25%). However, respondents who said they were full time employees had the same access to unpaid Carer's Leave (40%) as part time employees (40%). Men were less likely to have access to paid Carer's Leave (21%) compared to women (29%), and also less likely to have access to unpaid Carer's Leave (34%) compared to women (41%).

“*The flexibility to work from home and have flexible hours has been absolutely essential to allowing me to continue my caring role, and my employer has been good about this. My biggest gripe is there is no access to paid carers leave other than for unexpected, short term emergencies, whereas parents with childcare difficulties are allowed access to special paid leave (and during COVID some people were granted months of special paid leave for this). This frustrates me as I've spent nearly all my annual leave this year on taking the person I care for to hospital appointments so there's inequality between different groups, and doesn't leave me any annual leave to actually have a break from work.”*

Carers working for a large organisation were more likely to say they were able to take paid Carer's Leave (32%) than those working for medium (19%) and small (20%) organisations. Carers working for a large organisation were also more likely to say they were able to take unpaid carers leave (44%) than those working for medium (31%) and small organisations (29%). Carers working for a not-for-profit/voluntary sector organisation or public sector organisation were much more likely to say they were able to take paid carers leave (31% and 33% respectively) compared to those working for a private sector organisation (15%).

An understanding line manager

Encouragingly, over half (57%) of respondents said they already had an understanding line manager or employer which helped them to balance work and care. However, a quarter (25%) said they needed an understanding line manager or employer to help them juggle their responsibilities, while 1 in 8 (12%) of respondents said they needed a more supportive employer to stay in work.

“*My employer is understanding and accommodating regarding my caring responsibilities. I and other carers at work have set up a carers network, this in its early stages and the organisation has been supportive so far.”*

Affordable and accessible care

Having access to affordable and accessible care services which carers can rely on while they go to work is essential for many people juggling work and care. A quarter (26%) of carers in employment said they needed affordable and accessible alternative care in order to work. A further 7% said they were at risk of reducing their hours at work and 7% said they were at risk giving up work completely, without access to it. Not having access to affordable and accessible care was the primary reason that people said they would have to either reduce their hours, or give up work completely – and combined was selected by 1 in 7 (14%) of respondents.

Reduced hours at work

One way in which respondents said they were better able to juggle work and care was by reducing the number of hours they worked. 29% of respondents said they had already done this, while a further 11% felt they needed to. 5% of respondents said they are at risk of giving up work altogether if they don't reduce their hours at work. Men were much less likely to have already reduced their hours at work (19%) than women (31%).

“ I did work full time but couldn't juggle caring on top of that so I reduced my hours. But every week I say to myself I will have to give up work entirely to do the caring role properly, but can't because of the financial implications. So I feel I am failing at work and at caring. My husband has since reduced his hours too. It's nearly impossible to juggle both roles.”



Working from home

61% of respondents either agreed (24%) or strongly agreed (37%) that working from home has enabled them to balance work and care more effectively. Encouragingly, the vast majority of respondents said they already had the ability to work from home some, most, or all of the time. Over a third (37%) said they had access to home working most or all of the time, while just under half (45%) said they could work from home some of the time.

However, a significant number of respondents said they needed access to home working to help them balance their work and care. 43% of respondents either agreed (17%) or strongly agreed (26%) that not being able to work from home would make them consider leaving their employment. This was the case for nearly half (47%) of full-time employees, compared to 36% of part-time employees. 1 in 10 respondents said they were either at risk of reducing their hours (5%) or giving up work completely (5%) if they couldn't work from home most or all of the time. Full time employees were much more likely to be working from home most/all of the time (44%) than part-time employees (30%).

When asked about having to return to the office if they had been working from home during the pandemic, 59% of respondents either agreed (22%) or strongly agreed (37%) that returning to the office will make caring more challenging.

“ I have only recently returned to work having given up because of caring. The main reasons I have been able to return to work is the shift to being able to work from home, very flexible working hours, part time hours, understanding employer and very understanding line manager.”

“ My employer wants to introduce hybrid working... This would not work for my circumstances and I would not be able to attend the office more than one day a week so the possibility of hybrid working is causing me a lot of stress and anxiety.”

Carers working for a large organisation were more likely to say they were able to work from home most/all of the time (40%) than those working for medium (30%) and small (30%) organisations. Carers working for a not-for-profit or voluntary organisation were more likely to say they were able to work from home most or all of the time (51%) than those working for a private sector organisation (34%) or public sector organisation (37%).

Changes since the COVID-19 pandemic

44% of respondents either agreed (26%) or strongly agreed (18%) that their employer has introduced new measures since COVID-19 which really help them juggle work and care – and 32% of respondents either agreed (20%) or strongly agreed (12%) that their employer has become much more understanding about caring since the pandemic.

Carers and employment status

We asked carers about their employment situation. 1 in 5 (21%) said they were a full-time employee, 16% said they were a part-time employee, and 4% were self-employed. 26% were retired.

We found that there was a correlation between those providing fewer hours of care and the likelihood that they were in full or part-time employment, including a significant difference between those providing more or less than 35 hours of care a week. Those providing under nine hours of care a week were the most likely to be a full-time employee.

In terms of gender, a key difference between men and women was how likely they were to be retired. 38% of men said they were retired, compared to just 24% of women. This may be due to the fact that male respondents were older: only 23% of female respondents were aged over 65 compared to 40% of male respondents. Women were also slightly less likely to be in full-time employment (20%) compared to men (22%), but three times as likely to be in part-time work (18%) as men (6%).

When comparing responses by ethnicity, we found that White carers were more than twice as likely to be retired (27%) as those who identified as an ethnicity other than White (9%). This difference may be due to the fact that Black, Asian and minority

ethnic carers were less likely to be aged over 65 (10%) compared to White carers (26%). We also found that respondents who identified as White were significantly less likely to be a full-time employee (21%) than those who identified as an ethnicity other than White (34%).

Carer's financial situation also had a significant impact on their employment status. Carers who said they were 'struggling to make ends meet' were three times less likely to be retired (9%) than all respondents (26%), and twice as likely to be unable to work due to a sickness or disability (10%) than all respondents (5%). Carers who said they 'cannot afford utility bills like electricity, gas, water, or telephone bills' were nearly twice as likely to say they were looking after the home/family/dependents full-time (46%) than all carers (26%), and nearly three times as likely to say they were unable to work due to sickness or a disability (14%) as all carers (5%). Those in receipt of Carer's Allowance were more than twice as likely to be looking after the home/family/dependents full-time (60%) than all respondents (26%).

Skills gained from caring

We asked carers which skills they felt they had gained from their caring role. The skills prioritised by most carers are shown in table six below.

Table six: Skills gained through caring

Skill	%
Empathy (eg the ability to understand and share the feelings of another person)	66%
Resilience (eg the ability to cope under pressure)	64%
Advocacy (eg the ability to communicate another person's concerns and act on their behalf)	62%
Risk management (eg the ability to identify and manage potential risks and challenges)	56%
Communication skills (eg the ability to communicate effectively with a range of people)	54%
Time management (eg the ability to juggle different commitments)	51%
Financial management (eg the ability to budget effectively and/or identify and apply for financial support)	33%
Partnership working (eg the ability to work in partnership with support services)	27%
None of the above	12%

Most of the skills listed, including empathy, resilience, advocacy, risk management, communication skills, and time management were all selected by over half of all respondents – demonstrating the wide range of skills that people gain from providing unpaid care.

Women were more likely to say they had developed all of the above skills than men – however, both genders prioritised the same skills in the same order, in terms of how likely they were to have gained them through their caring role.

“Form filling such as grant applications, the ability to wade through endless and soul destroying bureaucracy, the ability to adapt and to creatively work around problems, the ability to improvise, and the ability to pick yourself up after a failure, mentally set it aside and try things another way.”

“Endurance, anger management, blood sugar monitoring, oxygen management, secretarial skills and diary management, transport & logistics.”

Recommendations

- UK Government should continue to support the passage of Wendy Chamberlain MP’s Carer’s Leave Bill, which makes provision about unpaid leave for employees with caring responsibilities.
- UK Government should continue to support the passage of the Employment Relations (Flexible Working) Private Member’s Bill and implement a day-one right to request flexible working as this would help carers to juggle work and care, potentially return to work and help foster a better culture for carers in the workplace.
- Employers should consider becoming early adopters for unpaid Carer’s Leave – or go one step further and provide paid Carer’s Leave, making it even more accessible to their employees with caring responsibilities.
- Employers should adopt Carers UK’s Carer Confident benchmark, run by Employers for Carers, to move towards becoming a carer-friendly employer. In Scotland, we recommend employers use Carer Positive run by Carers Scotland.
- Employers should recognise the range of skills that carers gain through their caring role, to support carers return to work.

Digital and technology



While many carers have benefitted from online services, particularly during lockdown periods, others may find it more difficult to use technology and are at risk of being left behind, without access to the support they need.

Key findings

- There has been a slight increase in carers' feeling like technology makes their caring role easier. For example, 41% of carers said that digital ways of keeping in touch with friends and family had made their caring role easier, compared to 39% in 2021.
- Over a quarter of all carers (27%) said that not knowing what was available was stopping them from using certain technologies.
- A quarter of carers (25%) said the person being cared for does not want to use technology or digital services.

Use of technology

We asked carers to tell us about the different technologies they have been using and whether these have had a positive or negative effect on their caring role.

As the table below shows, there has been an increase over the past year in the use of digital technology, a slight increase in carers' feeling like technology makes their caring role easier and a slight drop in carers feeling like technology is making caring harder.

For example, compared to 2021, carers were more likely to feel that remote monitoring, voice assisted devices, digital ways of keeping in touch with family, online patient records and the NHS app made their caring role easier. While these may only be small shifts in attitudes, this shows that there is greater potential for the adoption of technology in some areas.

Despite this small shift in attitudes, there are still important considerations. One in ten of all carers (11%) said that online consultations for health and social care made caring harder. This was also the case for remote GP appointments, which one in ten carers (11%) said made their caring role harder.

Table seven: Current carers' experiences of using digital technologies 2022 and 2021 (brackets) by % of respondents

	<i>Makes my caring role easier</i>	<i>Makes my caring role neither easier nor harder</i>	<i>Makes my caring role harder</i>	<i>I don't use this</i>
Remote health care such as online GP appointments, repeat prescriptions	41 (42)	24 (23)	11 (14)	24 (21)
Online video consultations for health and social care eg Zoom, Teams, FaceTime, WhatsApp	22 (23)	18 (16)	11 (14)	48 (48)
Online mental health services	9 (9)	12 (11)	7 (8)	72 (72)
Being able to see an online summary patient record	15 (13)	13 (14)	2 (2)	70 (71)
NHS App	14 (12)	21 (23)	4 (3)	61 (62)
Apps such as for pain management, mood management, care coordination	5 (4)	10 (9)	2 (2)	83 (85)
Environmental monitoring such as heating and lighting control, door video systems, smart appliances	12 (10)	10 (9)	1 (1)	77 (80)
Remote monitoring and alerts such as motion sensors, fall detectors, personal alarm, GPS trackers	18 (15)	9 (9)	1 (1)	71 (75)
Voice assisted devices eg Amazon Echo (Alexa), Google Home	17 (15)	18 (19)	1 (1)	63 (66)
Digital ways of keeping in touch with friends and family / the person I care for eg Zoom, Teams, FaceTime, WhatsApp	41 (39)	28 (32)	2 (3)	29 (26)
Medication management tools such as medication dispensers or medication reminders	26	12	1	61

Barriers to using technology

We asked carers whether various barriers prevented them from using any of the above technologies. Nearly 1 in 3 carers (30%) said that none of the barriers listed prevented them from using these technologies. This group were much more likely to be using the technologies, as well as more likely to feel that they made caring easier. 54% of this group found online GP appointments made caring easier compared with 41% of all carers. They were also more likely to be using an online patient record (38% compared to 30% of all carers) and more likely to say this made caring easier (22% compared with 15% of all carers).

“ I am very techno-savvy this has been a huge advantage for me.”

Carers in employment were more likely to say there were no barriers to using technology or digital services compared with those who were unemployed or unable to work (31% vs 23%). Carers who are struggling to make ends meet were less likely to say that there were no barriers to using technology or digital services (22%).

A quarter of carers (25%) said the person being cared for does not want to use technology or digital services. This was higher for carers who don't live with the person they care for and are more likely to be caring for older parents (37%).

“ I am very confident with technology and digital services, but my husband does not and can not use them because he does not know how to and does not want to know how.”

“ The person I care for is unable to use any technology including things that would have been easily mastered a year ago.”



1 in 5 carers (21%) said that certain technologies don't meet their needs/the needs of the person being cared for, which rose to 1 in 4 for carers who don't live with the person they care for (25%).

“ My parents are visually and hearing impaired so video appointments and phone calls makes it harder, than face to face appointments.”

“ The care needed is personal/physical company, so online devices won't make any difference.”

“ I am autistic, I can't cope with meetings on line, nor can I fill in on-line forms unless there are highly specific questions. Forms do not allow deliberation or explanation whereas direct in person conversation and discussion do.”

Over a quarter of all carers (27%) said that not knowing what was available was stopping them from using certain technologies. This was higher amongst carers who were struggling to make ends meet (32%).

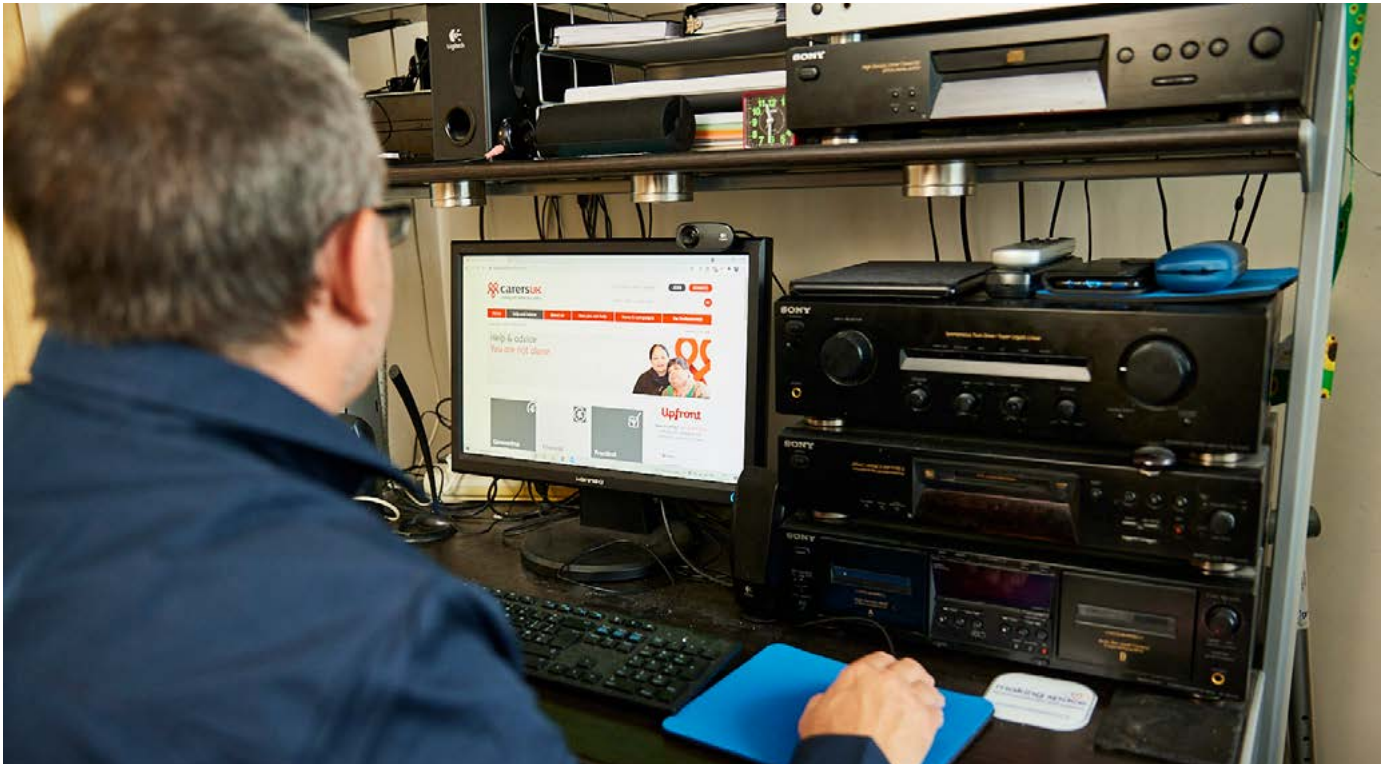
“ We would love to know what is available and to have a contact person to discuss this with.”

“ I think my husband who is registered blind would benefit from Voice activated/text to speech technology but I don't know how to access the help/advice.”

“ My mobile is too old to download the NHS app and video consultations are impossible because my phone's OS is out of date and can't be upgraded without spending more money on a newer phone.”

1 in 8 carers (12%) said they could not afford the appropriate technology, but this was over twice as likely for carers who were struggling to make ends meet (28%). Surprisingly, carers who said affordability was a barrier had very similar usage rates to all carers and were slightly more likely to be using the NHS App, online patient record and remote consultations.

Carers who were struggling to make ends meet were more likely to say they didn't have the right devices (12%) compared with all carers (7%). This was also more likely to be a barrier for households with an income of less than £1,000 a month (11%).



“ I have spent lots of time and energy applying for funding to help with the cost of technology to support CGM monitoring device remotely.”

17% of carers said they didn't feel confident using technology or digital services. These carers were less likely to be using the technologies listed. For example, they were around half as likely to say that technologies such as remote healthcare and online video appointments made caring easier, and nearly twice as likely to say that technologies such as online mental health services made their caring role harder. Only 10% of carers in paid employment did not feel confident about using technologies compared with 21% of carers who were not in paid employment, and 22% of households with an income of less than £1,000 a month.

“ I would like to improve my digital ability. I am poor at using on line aids.”

“ Digital just gives more chan[c]e for something to go wrong. I'm FED UP with having to be a digital connectivity expert. Just let me speak to a real person without the tech.”

Intermittent or no internet access was less of an issue for most carers (6%). However, this was more of an issue for carers struggling to make ends meet (9%).

“ I use what is available but would make a plea for the good old fashioned BT landline! Internet access is not good in many rural areas. My son's digital equipment only worked during the big storms earlier in the year because the system was linked to a landline!”

In a world that is moving ever closer to a digital future, it is clear that there are additional opportunities to continue to build better solutions through digital options and technology to make carers' lives easier. However, this is only if the technology is useful and tailored to needs. Awareness raising of different types of technology is important, as well as learning and training to help carers to feel more confident around different types of technology. This could be targeted to specific groups of carers.

One of the biggest barriers, however, is the affordability of technologies, which is a particular problem for carers on low incomes. Those who are not using technologies may be left behind, particularly where they prefer to not to use particular types of technology. As services such as virtual wards develop, which place a heavy emphasis on technology enabled care, it is essential that carers are involved, feel confident, and have the right hardware, as well as good internet connections, to reduce stress, improve confidence and ultimately improve the outcomes of care.

Recommendations

- The UK Government should ensure that carers have access to super-fast broadband to maximise the potential for carers to access services and work remotely. Ring-fenced investment must be adopted to ensure that carers who want to connect digitally, but are unable to because of low incomes, are supported with hardware, wifi and sufficiently fast broadband.
- The UK Government should ensure that carers are a key part of any digital inclusion strategies. Since digital has the potential to improve many carers' lives and support them in their caring role, we recommend a carer led approach to the design and identification of new digital mechanisms which might support them in their caring role.
- Digital strategies and delivery of systems need to also offer choice for carers who find that digital engagement is not the best method for the delivery of support and to recognise that for some, this can make caring harder.

Carer identification



One of the main barriers to carers getting support with their caring role is identification. This includes people self-identifying as a carer, and GPs and other health professionals identifying people as carers. Many carers view their relationships with the person they care for as a family relationship or friendship and don't necessarily see themselves as a 'carer' who may need more support.

Key findings

- Half of all carers (51%) took over a year to recognise their caring role, with over a third (36%) taking over three years to recognise themselves as a carer
- 71% of carers stated that seeing themselves primarily as a family member or friend was a barrier to identifying themselves as a carer.

Identification

Many carers do not recognise their caring role until some time after they start undertaking caring responsibilities. Half of all carers (51%) took over a year to recognise their caring role, with over a third (36%) taking over three years to recognise themselves as a carer. Only a third (31%) recognised their caring role immediately.

“ I have only just been advised to apply for carers allowance – I didn’t know I could get it.”

“ I was working full time when I started this so it didn’t seem possible that I was also a carer.”

Compared with previous years, there has been a slight improvement in how quickly carers identify themselves, with 54% saying they took over a year to identify themselves in 2019 and 52% in 2021.

The speed at which carers identify themselves as being carers can vary greatly amongst different types of carers. Carers with caring responsibilities of over 35 hours a week are significantly more likely to have recognised themselves as a carer immediately, with 33% doing so, compared to 1 in 4 (24%) carers caring for less than 35 hours a week.

The relationship to the person being cared for can also have an impact. People caring for a partner or ex-partner were marginally more likely to recognise their caring role immediately (33%) compared to people caring for a parent or parent-in-law (28%) or a child or child in law (28%). Conversely people caring for children are much more likely to take over 16 years to recognise their caring role (10%) than people caring for parents or parent-in-law (4%) or partner/ex-partner (4%).

1 in 3 carers who live in the same house as the person they care for report recognising their caring role immediately (32%), compared to just over 1 in 4 (27%) carers who live away from the person they care for.

1 in 3 (34%) of carers in receipt of Carers Allowance recognised their caring role immediately, compared to 27% of carers who receive no support from the benefits system. 34% of carers with a monthly household income of under £1,500 recognised their caring role immediately, compared to 28% of carer households earning over £1,500 per month.

Carers in any form of employment were considerably less likely to immediately recognise their caring role (24%) than carers not in work (35%). Over a third (37%) of older carers, aged over 65, recognised their caring role immediately as opposed to 29% of carers under 65.

Female carers were less likely to recognise their caring role immediately (29%) than male carers (36%). 1 in 4 lesbian, gay and bisexual carers (24%) recognised their caring role immediately compared to 31% of heterosexual carers.

Barriers to recognition

We asked carers whether various barriers might prevent them from identifying as a carer. For carers who didn’t immediately recognise themselves as a carer, 7 out of 10 (71%) stated that they saw themselves primarily as a family member or friend. This was the main barrier identified by carers and was a particular issue for people caring for a parent/parent-in-law or a child/child-in-law. 79% of carers caring for a parent or parent-in-law and 77% of people caring for a child or child-in-law stated that they didn’t recognise themselves as a carer because they primarily saw themselves as a family member or friend, compared to only 60% of people caring for a partner, or ex-partner.

“ I thought it was just part of my role as a wife.”

“ I thought it was just part of being a parent then realised, after having a second child that things were different and things I was doing for my older son was caring for his needs and not just being his mum.”

“ It wasn’t until I was told he may be able to apply for DLA (as was) that I put down in writing all the needs he had and realised how much I was providing over and above the usual parental role. To this day, 20 years later, I still meet families all the time who do not consider themselves carers when they provide hours and hours of supplemental support for their autistic children. We are not encouraged to think of ourselves at any point in the process.”

Carers in receipt of Carer’s Allowance were slightly less likely (69%) to state that they saw themselves primarily as a family member or friend compared to 71% of all carers. Carers on higher household incomes (over £1,500 per month) were more likely (73%) to have seen themselves as a family or friend compared to 68% of carers on incomes under £1,500.

Carers in employment were significantly more likely to state that they did not recognise themselves as a carer as they saw themselves as being a family member or friend (77%) compared to carers not in employment (67%). Carers aged under 65 were more likely (75%) to say they didn’t recognise their role as a carer because they saw themselves as primarily a friend or family compared to 60% carers over the age of 65.

Female carers were more likely to have considered themselves primarily family or friends (72%) than their male peers (66%).

Over half of carers (53%) stated that their caring role developed gradually so it took time to realise they were a carer. Carers in receipt of Carer's Allowance were much less likely (44%) to state that their caring role developed gradually so they didn't recognise themselves as being a carer.

White carers were more likely to state that their caring role developed gradually (54%) than carers of a Black, Asian or minority ethnic background (41%). Male carers were more likely (62%) to state that their caring roles developed gradually than female carers (52%).

“ It evolved until it became the norm.”

“ I thought it was temporary and my mum would get better.”

“ It was a slow realisation that my partner's condition would not improve and was life-long.”

A third of carers (32%) who did not immediately recognise their caring role state that they were never told that they were a carer.

Many carers did not feel like they deserved to be known as a carer with over a third (35%) of carers saying they didn't feel they were providing enough care to be identified as a carer while a quarter (26%) didn't feel like they deserved recognition for their role.

40% of carers said they were so busy caring they didn't recognise the role they were undertaking. For carers who care for over 35 hours a week, 43% stated that they were so busy caring they didn't recognise the role they were undertaking, compared to 34% of carers providing less than 35 hours a week. Almost half (48%) of lower income carers stated that they had been too busy to recognise themselves as a carer, compared to 38% of higher income carers.

“ It had to be done and it was urgent and required much effort. There was not much energy for thinking left.”

“ I just got on with it and didn't think.”

5% of carers said they had been told they were not a carer. Carers in bad or very bad physical and mental health were over twice as likely (8%) to have been told that they were not a carer than carers in good or very good health (3%). Over half of carers in good or very good mental and physical health (59%) stated that their caring responsibilities developed gradually so they didn't recognise being a carer, compared to 48% of carers in poor health.

We asked carers whether there were any other barriers to identifying themselves as a carer. Some carers said they were uncomfortable with the idea of being 'labelled' as a carer:

“ I don't like labels as they restrict how others see you.”

“ I didn't want the label.”

“ I don't like labels as they are restrictive – they limit my potential and other people see only a carer not a person with her own life, experiences and potential.”

“ I don't like being labelled as it narrows other people's perceptions of you and shapes their attitude toward you. It's a label that denies all other identities.”

Recommendations

- UK Government should amend the Equalities Act 2010 to include caring as the 10th protected characteristic.
- UK Government should support awareness campaigns, like Carers Week, Carers Rights Day and other initiatives that aim to reduce the time it takes for a carer to identify themselves and seek support.

Conclusion

The State of Caring 2022 report demonstrates the daily challenges that carers are facing. With the rise in cost of living, carers' finances are under more pressure than ever before, causing additional stress and anxiety and leaving carers to face unprecedented financial hardship this winter.



Issues around accessing healthcare appointments and social care services means that many carers are feeling lonely, isolated, undervalued and unrecognised, and many are not getting the support they need. Several carers have told us that their physical health is poor and that they are waiting for specialist treatment. As a result of health conditions being untreated, many carers are in pain, and unable to carry out their caring role. Concerningly, some carers have been forced to pay for private healthcare, often by using their savings, which has impacted on their ability to make ends meet.

While many services have reopened in the last year, 1 in 5 carers are still reluctant to access support due to concerns over COVID-19. Several carers are still shielding or reducing activities to protect themselves and the person they care for. As we found last year, not knowing what services are available is the main barrier to accessing support, with many carers unaware of what help is available locally.



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