

State of Caring 2024

The impact of caring on: finances

October 2024



About this research

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

A total of 12,500 carers and former carers responded to the survey. This report summarises their responses. As not all respondents completed every question in the survey, some figures are based on responses from fewer than 12,500 people.

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

Of respondents to the survey:

- 92% are currently providing care. Of those, 63% are in England, 15% are in Scotland, 11% are in Wales, and 11% in Northern Ireland.
- 8% have cared in the past but are no longer caring. Of those, 62% are in England, 20% are in Scotland, 12% in Northern Ireland and 6% in Wales.
- Of those currently caring, 14% are caring for 19 hours or less, 26% are caring for 20-49 hours, and 61% are caring for 50 or more hours.
- 68% of respondents were aged 18-64 years and 31% were aged 65 and over. The biggest proportion of respondents were in the 55-64 year category (35%).
- 81% of respondents were female; 18% were male. 1% said their gender was not the same as the one assigned at birth.
- 89% of respondents were White British, 7% were from another White background, and 3% were from a Mixed/Multiple, Black/Black British, Asian/Asian British background or other ethnic group.
- 91% of respondents were heterosexual/straight, 5% were Lesbian, Gay or Bisexual, or preferred to self-describe their sexual orientation.
- 29% of respondents had a disability.

Thanks

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



abrdn Financial Fairness Trust funds research, policy work and campaigning activities to tackle financial problems and improve living standards for people on low-to-middle incomes in the UK. It is an independent charitable trust registered in Scotland (SC040877).

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Introduction

According to the Census, at least 5.8m people across the UK are providing unpaid care for an ill, older or disabled family member or friend.¹ Many of these people have had to give up paid employment or reduce their working hours to support their family member or friend, and this can have a significant impact on finances. Previous research by Carers UK found that an estimated 2.6m people have given up paid employment to care and up to 600 carers leave paid work every day in order to provide unpaid care.²



Carers can also face many additional costs as a result of caring, from needing to heat their home for longer periods, to buying personal care products and accompanying the person they care for to medical appointments. With the increase in the cost of living in recent years, many carers are finding it increasingly difficult to pay for essentials like food and heating

and are taking drastic measures to keep on top of their finances: from skipping meals to using food banks. A majority of carers are also now cutting back on their social connections, by reducing times they see their friends and family. This has a compounding and isolating effect on unpaid carers and a profound impact on their mental health and wellbeing.

¹ ONS (2023) Unpaid care, England and Wales: Census 2021. <https://www.ons.gov.uk/peoplepopulationandcommunity/healthandsocialcare/healthandwellbeing/bulletins/unpaidcareenglandandwales/census2021>

² Carers UK (2019) Juggling work and care. <https://www.carersuk.org/media/no2lwyxl/juggling-work-and-unpaid-care-report-final-web.pdf>

Some carers are eligible for Carer's Allowance, but this is the lowest benefit of its kind, at just £81.90 per week (24/25), and not sufficient to cover the many costs involved in caring. Strict eligibility criteria for Carer's Allowance means that carers in paid employment who earn slightly over the earnings threshold lose all of their Carer's Allowance and can end up in severe debt by building up overpayments.³ Many carers would like to work more hours or return to work,⁴ not only to increase their income but to improve their health and wellbeing. However, with the inflexible earnings limit this is often not possible.

Despite the fact that carers are saving the economy an astonishing £162 billion a year in England and Wales,⁵ many carers are living in poverty. Recent research commissioned by Carers UK found that 1.2 million unpaid carers live in poverty, and 400,000 live in deep poverty in the UK.⁶ The poverty rate for unpaid carers is 50% higher than for those who do not provide care (27% vs 18%). Reliance on social security and lack of ability to continue with paid work were found to be key drivers of poverty. Around 900,000 unpaid carers who are in receipt of Universal Credit live in poverty and there is an employment gap of 38 percentage points between carers who provide 35 hours of care every week and non-carers (37% vs 75%). Carers who are women, from ethnic minority groups, are caring for more than 35 hours a week, or are caring for more than one person are also more likely to be in poverty.

1.2 million unpaid carers live in poverty, and 400,000 live in deep poverty in the UK. The poverty rate for unpaid carers is 50% higher than for those who do not provide care



Carers who are struggling financially often have to make extremely difficult decisions about spending.



Carers who are struggling financially often have to make extremely difficult decisions about spending. Many carers are turning to unsustainable solutions to cope with these challenges, such as using credit cards or going into arrears with utility bills. Caring can be stressful: financial challenges can make an already difficult situation intolerable. A significant number of carers have told us they are unable to turn their heating on or that they are skipping meals in order to make ends meet. Many more are cutting back on seeing family and friends because they feel they cannot afford it, thereby cutting a vital lifeline for their wellbeing.

It is unacceptable that so many carers are still struggling with their finances whilst providing so much for society. Without targeted support many more could fall into poverty.

In this report we consider carers' financial situations and what more support is needed to help carers cope with the costs of caring.

³ Carers UK (2024) Carer's Allowance overpayments. https://www.carersuk.org/media/2tdhojgf/ca-overpayments-report_web_small.pdf

⁴ Centre for Social Justice (2024) Creating a Britain that works and cares. https://www.centreforsocialjustice.org.uk/wp-content/uploads/2024/02/CSJ-Creating_a_Britain_that_Works_and_Cares.pdf

⁵ Petrillo, M. and Bennett, M. (2023) Valuing Carers. <https://www.carersuk.org/media/2d51e03c/valuing-carers-report.pdf>

⁶ WPI (2024) Poverty and financial hardship of unpaid carers in the UK. https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

Executive summary



- **Carers are finding it increasingly difficult to pay for essentials.** 28% of carers are cutting back on essentials like food and heating – an increase from 25% in 2022.
- **Carers often struggle to afford utility bills due to the extra costs of caring.** 60% of carers who were finding it hard to afford essentials said they were struggling to afford electricity and gas.
- **Carers who are struggling financially are finding it difficult to afford food.** 38% of carers who are struggling to afford essentials are struggling to afford food. Many of these carers are taking drastic measures such as skipping meals or not eating when hungry.
- **Carers in receipt of social security benefits are struggling even more to afford food.** 45% of carers receiving Carer's Allowance and struggling to afford essentials are struggling to afford food. 19% of carers in receipt of Universal Credit with Carer Element are using food banks compared with 7% of all carers.
- **The majority of carers are worried about their finances in the future.** 61% of carers are worried about living costs and whether they can manage in the future, and over a third (35%) do not feel confident that they will be able to manage financially over the next 12 months.
- **These worries are affecting carers' health and wellbeing.** Over half (51%) of carers said that their financial situation is having a negative impact on their mental health and wellbeing, and 61% feel stressed or anxious when they think about their financial situation.
- **Carers have been cutting back on things that improve wellbeing, and this situation has been getting worse each year.** This year, 68% of carers cut back on hobbies/leisure activities, compared to 58% in 2023 and 47% in 2022. 60% cut back on seeing family and friends, compared to 47% in 2023 and 34% in 2022.
- **Many carers said they were struggling to afford housing costs.** 21% of carers are struggling to afford their rent or mortgage payments, and 38% said they were worried about increases to their rent or mortgage.

- **Carers who are not in paid employment are even more likely to be struggling financially.** 47% of carers aged 18-64 who are looking after dependants, unemployed, in education, or unable to work due to poor health are struggling to make ends meet, and just under a quarter (24%) are in debt as a result of caring.
- **Carers who are in paid employment are also worried about their finances, often because they're concerned about having to reduce their working hours to provide more care.** 76% of carers aged 18-64 in paid employment are worried about their ability to save for the future (eg retirement).
- **The earnings limit for Carer's Allowance is preventing many carers in paid employment from increasing their income and is contributing to some carers leaving employment altogether:** 62% of carers who had experienced issues whilst being in paid employment and claiming Carer's Allowance said they had been unable to work more hours or take on higher paid work. 20% had an overpayment of Carer's Allowance. 41% said that they left their paid employment as a result of the earnings limit.
- **Carers in receipt of social security benefits are more likely than other carers to be struggling financially and worried about the future.** 42% of carers in receipt of Carer's Allowance are struggling to make ends meet, and 71% are worried about living costs and whether they can manage in the future.
- **Most carers think that Carer's Allowance is not enough to support them.** 90% of carers receiving Carer's Allowance do not think this benefit is sufficient.
- **Many carers feel the process of claiming benefits could be improved.** 67% would like more information and advice about what benefits they are entitled to and 57% would like more support with understanding the rules for certain benefits.
- **Half (51%) of carers need more financial support.** Many carers need more financial support to manage the costs of caring. For example, nearly a third (30%) need more financial support with transport costs.
- **Carers are often turning to unsustainable solutions to manage their finances:** 28% of carers have had to use credit cards and 22% have used their bank account overdraft.



Carers' financial situations



Key points

- 61% of carers are worried about living costs and whether they can manage in the future.
- Over a third (35%) of carers do not feel confident that they will manage financially over the next 12 months.
- Over a quarter of carers (27%) are struggling to make ends meet
- Some carers are even more likely to be struggling, including those caring for more hours, those caring for more people, those in receipt of social security benefits, those of working age who are not in paid employment, female carers, and carers who are renting.
- Nearly a third (32%) of carers in receipt of Universal Credit with Carer Element are in debt as a result of caring compared with 14% of all carers.
- 76% of carers aged 18-64 in paid employment are worried about their ability to save for the future (eg retirement).

A significant proportion of unpaid carers are struggling financially. Over a quarter of carers (27%) are struggling to make ends meet. 14% of carers are in debt because of caring.

“Trying to live off a Carer’s Allowance whilst caring for my husband & trying to provide for two teenage daughters is gruelling, despairing and unaffordable. I live off credit cards to make ends meet.”

“I’m terrified to put the heating on. We have so little to live off with care costs taken out of living expenses and I try to save money any way I can, even when it’s very cold outside we try not to use [heating] and buy cheaper or reduced food items.”

“I gave up work to care for my mum and then my dad. We had to downsize to enable me to give up work. It is difficult to pay all bills on our small private pension and have to use savings. I will have no savings left soon!”

Carers are also worried about the future. Over a third (35%) do not feel confident that they will manage financially over the next 12 months. 61% are worried about living costs and whether they can manage in the future. 70% are worried about their ability to save for the future (eg for retirement).

“I am worried that as more help is needed in the future, I will run out of savings.”

“I currently work part time but worry that I will not be able to do this as my husband’s health deteriorates.”

“I am worried that I will have to sell my house to pay for my husband’s care in the future.”



61%

of carers are worried about living costs and if they can manage in the future

Some carers said they were worried about their financial situation in the future if their caring role came to an end, particularly those who were older and had not been in paid employment for many years.

“I would struggle if my husband passed away as I have given up work to care for him. Would need to return to work and my skills are out of date. This is a worry for me.”

“Scared of being 63 and unemployed when my partner passes away.”

“At 65 I worry how I will manage after my mum dies. I will find it very difficult to find a job at 65 and I don’t think I could face going back into the care profession.”

Although many carers are struggling to make ends meet, some carers are even more likely to be finding it difficult to manage financially, including those caring for more hours, those caring for multiple people, those in receipt of benefits, and those who are not in paid employment.

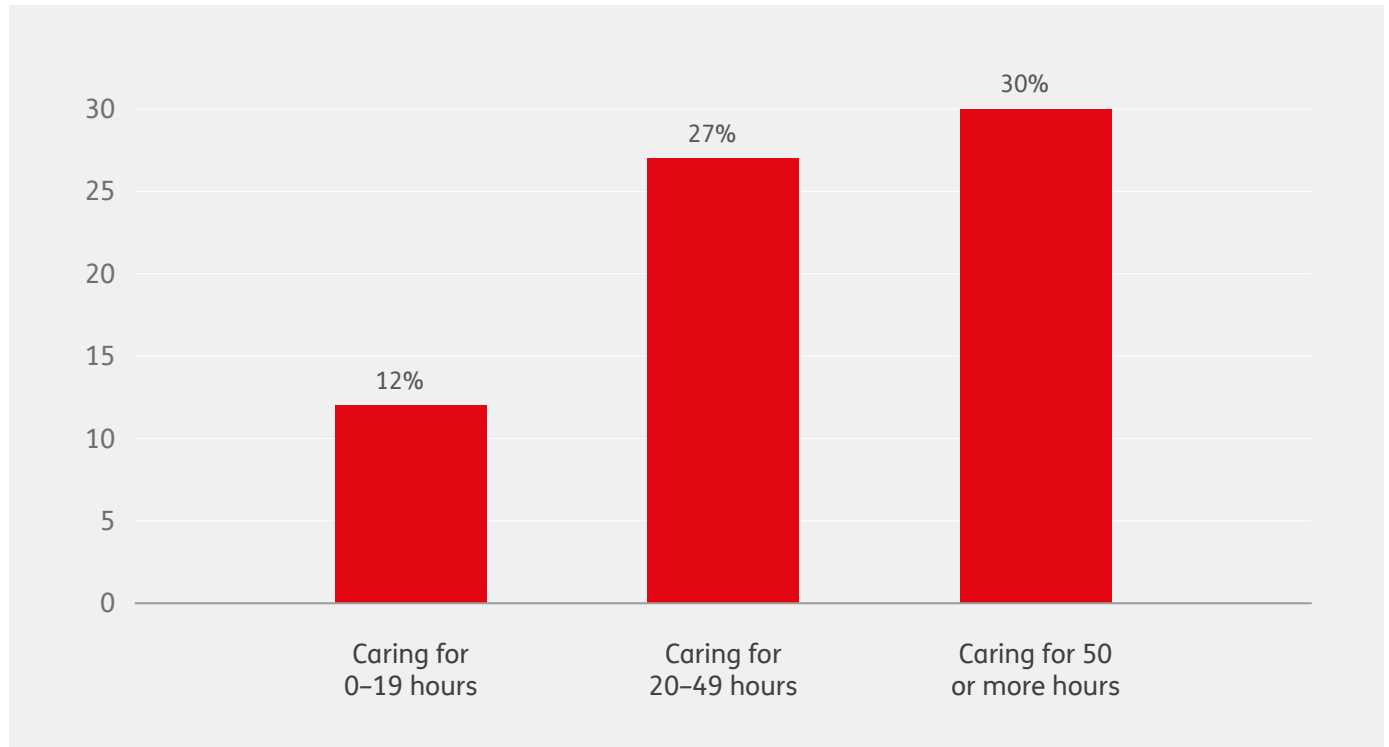


Hours of care

Carers caring for more hours are more likely to be struggling financially. As Table 1 shows, the proportion of carers struggling to make ends meet

increases with the number of hours of care provided. 30% of carers caring for 50 hours or more per week are struggling to make ends meet.

Table 1: Percentage of carers struggling to make ends meet by hours of care per week.



67% of carers caring for 50 hours or more are worried about living costs and whether they can manage in the future, compared to 59% of carers caring for 20-49 hours, and 40% of carers caring for 19 hours or less.

38% of carers caring for 50 hours or more do not feel confident that they will be able to manage financially over the next 12 months compared to 35% of carers caring for 20-49 hours and 19% of carers caring for 19 hours or less.

These findings reflect recent research commissioned by Carers UK which found that the rate of poverty amongst unpaid carers increases with the number of hours spent caring. Those who care for between 35 and 99 hours a week are more than twice as likely to be in poverty than a person who does not provide unpaid care (42% vs 18%).⁷



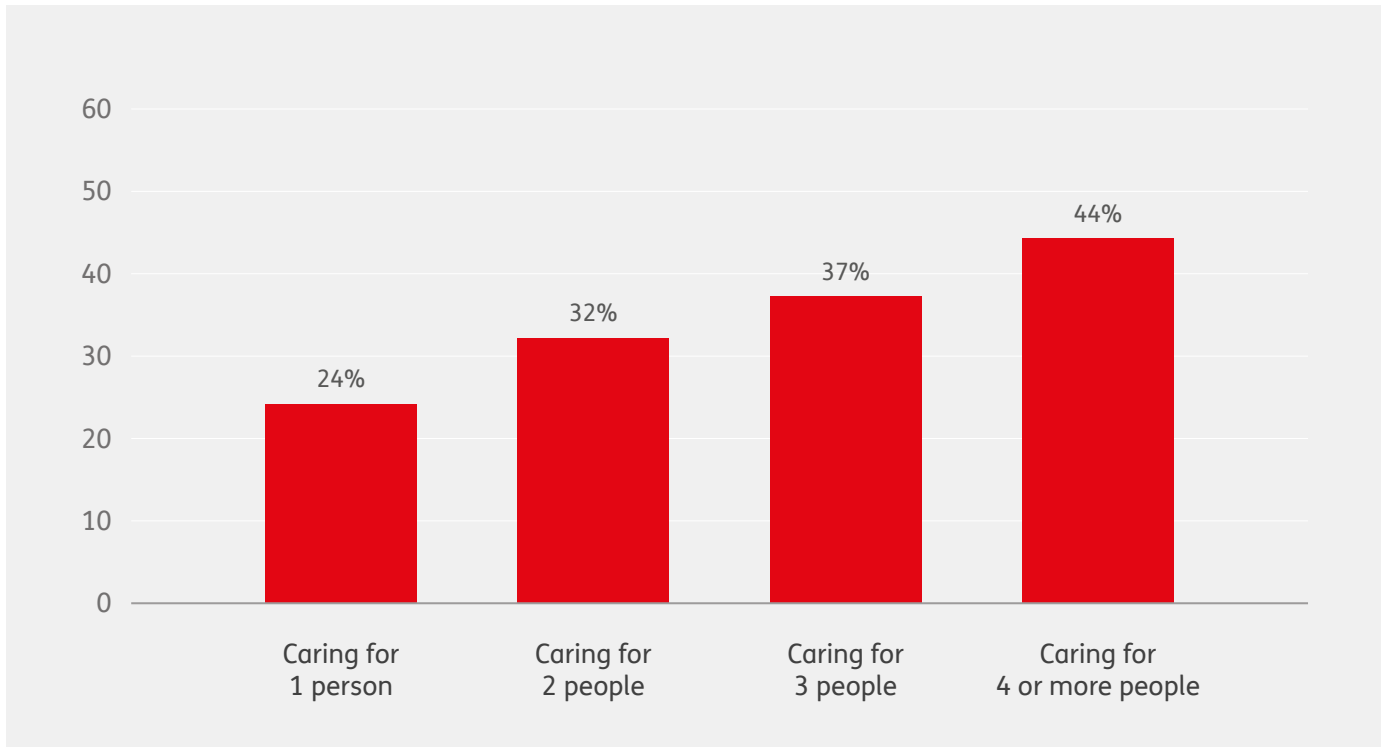
⁷ WPI (2024) Poverty and financial hardship of unpaid carers in the UK. https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

Number of people cared for

Carers caring for more than one person were more likely to be struggling financially. As Table 2 shows, the proportion of carers struggling to make ends

meet increases by the number of people being cared for.

Table 2: Percentage of carers struggling to make ends meet by number of people cared for.



65% of carers caring for more than 1 person are worried about living costs and whether they can manage in the future compared to 59% of carers caring for 1 person. 18% of carers caring for more than 1 person are in debt as a result of their caring role compared to 12% of carers caring for 1 person.⁸

These findings reflect recent research commissioned by Carers UK which found that caring for more than one person increases the rate of poverty: 26% of unpaid carers caring for one person are living in poverty compared to 35% of those caring for two people.⁹



⁸ Ibid.

⁹ Ibid.

Social security benefits

Many carers in receipt of Carer’s Allowance are finding it difficult to manage financially. 42% of carers getting Carer’s Allowance are struggling to make ends meet, and 71% are worried about living costs and whether they can manage in the future. 22% are in debt as a result of their caring role.

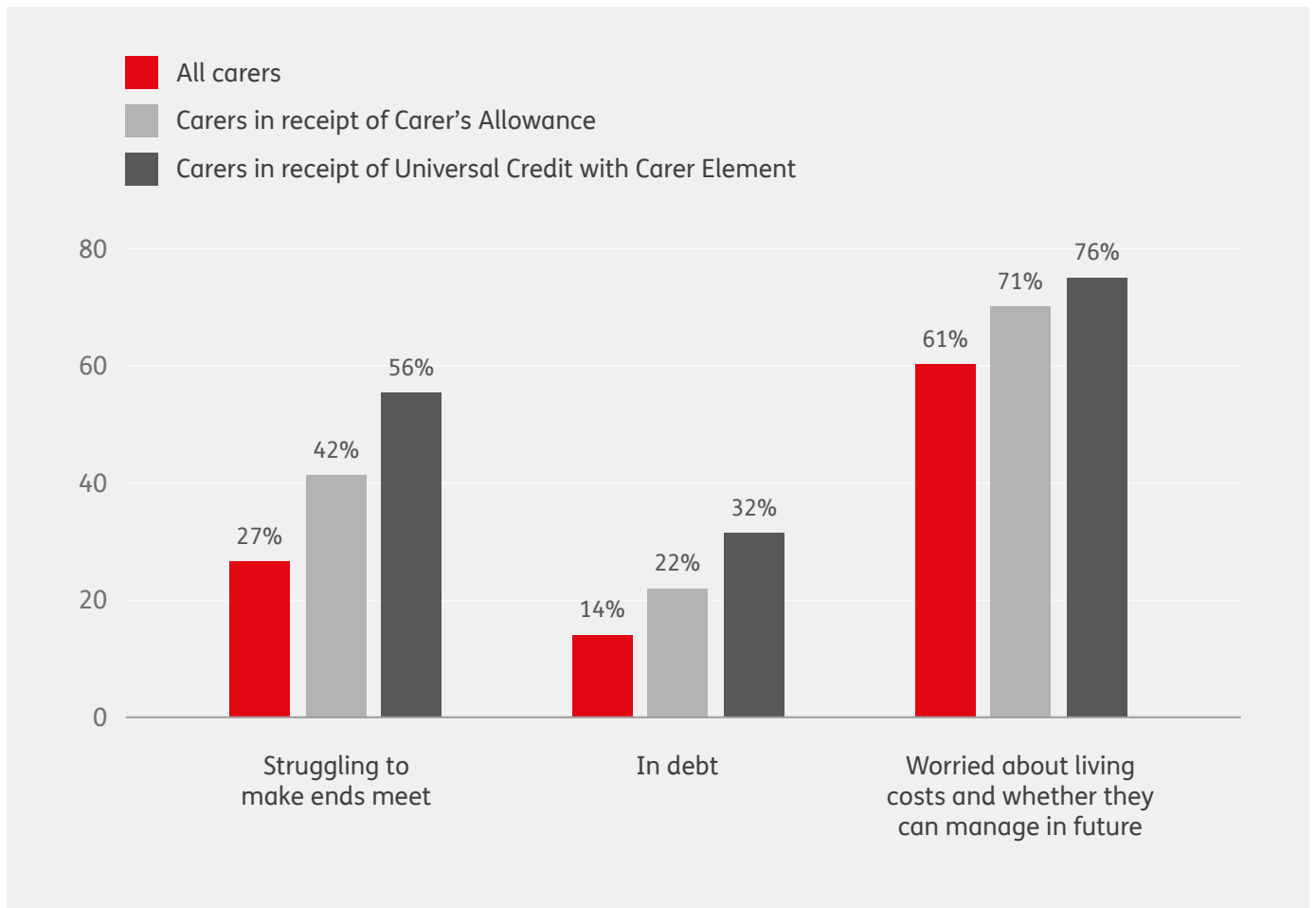
Carers in receipt of Universal Credit with Carer Element are struggling even more. 56% are struggling to make ends meet, and 76% are worried about living costs and whether they can manage in the future. Nearly a third (32%) are in debt as a result of caring.

These findings reflect recent research commissioned by Carers UK which found that the current social security system is not adequately meeting the needs of many families, especially those with unpaid caring responsibilities. Two-thirds (67%) of unpaid carers who receive Universal Credit live in poverty – around 900,000 carers. 62% or approximately 500,000 Carer’s Allowance recipients live in poverty.¹⁰

32% of carers in receipt of Universal Credit with Carer Element are in debt as a result of caring compared with 14% of all carers



Table 3: Carers’ financial situation by social security benefit status.



¹⁰ Ibid

Employment status

Working age carers who are not in paid employment are struggling financially. 47% of carers aged 18-64 who not working (i.e who are looking after dependants, are unemployed, in education, or are unable to work due to sickness or disability) are struggling to make ends meet, and nearly a quarter (24%) are in debt as a result of caring.

“As a student I am not eligible to Carer’s Allowance and I can’t work due to caring responsibility and in the long run this will probably mean I will have to drop out of my course due to being unable to afford things.”

“I am unable to work because of my duties, and have to rely on my partner’s state pension.”

“I have no income and my previous part-time job was made redundant. I’m struggling to find any work that I would be able to do along my caring...”

Many carers have to give up paid employment or significantly reduce their working hours to care. The State of Caring 2023 survey found that 40% of carers had given up work to care, and 22% had reduced their working hours.¹¹ Recent research commissioned by Carers UK found that long hours of care make it difficult for unpaid carers to stay in employment, and that this is a major driver of poverty.¹²

Although carers aged 18-64 who are in paid employment are less likely to be struggling to make ends meet (24%) than those aged 18-64 who are not in paid employment (47%), a significant proportion are worried about the future. 76% of carers aged 18-64 in paid employment are worried about their ability to save for the future (eg retirement). Previous research by Carers UK in the State of Caring Survey 2023 found that 30% of carers in paid employment said they’re saving less for retirement due to reducing working hours to care.

Many carers in paid employment were worried about reducing their working hours to provide more care, which would have a negative impact on their income.

“As a carer, and my daughter having lots of health issues, my ability to work is limited and I do not have pensions, savings for my future – I worry that my financial situation is only going to get worse as I near retirement age and how I will be able to keep a roof over my head”

“I worry about what is to come, when more hours are needed, I currently work part time so can provide the care on my non-working days – when the support required increases, I worry how I can financially do this remaining part-time.”

“I have taken a lower paid job to reduce my paid workload in order to be more available for the person I care for and am feeling the impact of the reduction in income.”

Some carers said they had already had to give up paid employment and were now struggling financially as a result.

“I have lost the bulk of my workplace pension due to giving up work early – so I worry that I will be in poverty in retirement.”

“I gave up my full time job to care for my disabled mother now I struggle to pay bills and afford food. I now use food banks and am on a debt management plan”

“I had to give up my self employed business to become a carer and have no income other than Carer’s Allowance so have limited my life choices in order to make ends meet and worry about my future financial welfare.”

76%

of carers aged 18-64 in paid employment worry about their ability to save for the future



11 Carers UK (2023) Carers’ employment rights today, tomorrow and in the future. https://www.carersuk.org/media/hiekwx0p/carers-uk-crd-employment-report-2023_final.pdf

12 WPI (2024) Poverty and financial hardship of unpaid carers in the UK. https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

Older carers

Half (51%) of carers aged 65 and over are worried about living costs and whether they can manage in future. Many older carers said they had lost access to their Carer's Allowance because they'd started receiving a State Pension. Some carers also said that they had had to take early retirement to care, which had impacted their pension. Previous research by Carers UK in the State of Caring Survey 2023 found that 40% of former carers who were retired said they had retired earlier than planned.

“I'm a pensioner therefore don't even receive carers allowance any more. No work pension as they didn't exist when I was younger. Every winter I spend most of my time in bed when not out caring. Heat or eat has become the norm and doesn't look like changing.”

“I retired early to care for my daughter. I have an occupational pension that just about covered the basics 3 and a half years ago. I was not able to afford holidays or days out since cost of living etc – my pension lasts approx 2 and a half weeks once bills are paid. So no extra to do anything at all. I have to reduce food shopping and make do. If I need clothes shop at charity shops which are becoming increasingly more expensive.”

“Our pensions are substantially less than they would have been, had we both not had health problems, and caring responsibilities have limited opportunities to try to make up for this.”

“Although I can afford things now I worry constantly about what will happen as I get older as I am eating into savings and lost a lot of my pension because I had to take early retirement”

This year, some carers aged 65 and over highlighted the loss of the Winter Fuel Payment, which would impact on their ability to pay for heating.

“The loss of winter fuel allowance really hurts when caring for a disabled person who has to have heating on all the time”

“The withdrawal of the Winter Fuel Allowance will have a big impact on heating my property, this winter!”

“With costs going up and now the winter fuel allowance has been taken off pensioners it is worrying.”

Recent research commissioned by Carers UK found that unpaid carers aged 65 and over are more likely to be in poverty compared with non-carers in that age group (20% vs 13%), which means that 1 in 5 retirement-age carers live in poverty.¹³



¹³ Ibid.

Female carers

Female carers were more likely to be worried about the future: 62% of female carers are worried about living costs and whether they can manage in the future compared to 56% male carers. 36% of female carers do not feel confident they will manage financially over the next 12 months, compared to 33% of male carers.

These worries may be because women are more likely to give up paid employment to care,¹⁴ which can have a significant financial impact.

“I had to give up employment to look after my husband because he needs care 24/7. He has dementia. The uncertainty of future employment is a concern. I have been out of work 4 years already so the future is uncertain.”

Recent research commissioned by Carers UK found that women who provide unpaid care have a higher rate of poverty (28%) than men who provide unpaid care (25%).¹⁵



Housing status

Carers who were renting their home were much more likely to be struggling to make ends meet than carers who own their home (50% compared with 19%) and much more likely to be in debt (27% vs 9%). They were also more likely to be worried about living costs and how they can manage in the future (73% vs 56%).

The Family Resources Survey shows that unpaid carers who rent either socially or privately have a higher rate of poverty than unpaid carers who mortgage or own their houses. 60% of social renters and 48% of private renters who provide unpaid care live in poverty, compared to only 12% of owner-occupiers.¹⁶



¹⁴ TUC (2023) 'Women 7 times more likely than men to be out of work due to caring commitments'. <https://www.tuc.org.uk/news/women-7-times-more-likely-men-be-out-work-due-caring-commitments>

¹⁵ WPI (2024) Poverty and financial hardship of unpaid carers in the UK. https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

¹⁶ WPI Economics analysis of Family Resources Survey 2021/22.

Struggling to afford essentials and cutting back on food



Key points

- Over a quarter (28%) of carers have cut back on essentials like food and heating in order to make ends meet. This is an increase from 25% in 2022.
- Carers in receipt of social security benefits are even more likely to be struggling to afford essentials. 19% of carers in receipt of Universal Credit with Carer Element are using food banks compared to 7% of all carers.
- Many carers struggle to afford utility bills due to the extra costs of caring, and are turning to unsustainable solutions in order to pay for utility bills and other costs associated with caring. 28% of carers have had to use credit cards and 22% have used their bank account overdraft.
- 60% of carers who are finding it difficult to afford essentials are struggling to afford electricity and gas.
- 38% of carers who are struggling to afford essentials are struggling to afford food. Carers who are struggling to afford food are skipping meals and not eating to save money.
- Many carers also said they were struggling to afford housing costs. 21% of carers are struggling to afford their rent or mortgage payments, and 38% said they were worried about increases to their rent or mortgage.

Carers are often having to make difficult decisions about what to spend money on. Over a quarter (28%) of carers have cut back on essentials like food and heating to make ends meet. This increased to 40% for carers in receipt of Carer's Allowance and 49% of carers in receipt of Universal Credit with Carer Element.

- “Am running a car as I need it in order to care but can't afford it, am behind with rent, skip meals and cut back but the cost of living has affected me badly, don't heat my house in Winter and sleep in an outdoor coat.”
- “Only my husband's room is heated. I just wear extra layers in the winter (sometimes 6 layers)!”
- “As the sole earner, I can't afford to keep the house as warm as it should be in the winter. My hubby sits under a heated throw most of the day as he needs to keep warm and I am often cold. It costs money to power things such as his mobility scooter. I do without to ensure he is warm and his equipment is maintained.”
- “I only buy basic food items. I sit with my outdoor clothes on when it is cold and limit my showers to one every 3 weeks. Sometimes it is so cold I sleep in my clothes. I can't remember when I last ate meat or cake and I never drink or eat out.”

For many carers, the cost of essentials like food, heating or transport can be even higher due to the needs of the person being cared for. Some carers need to ensure the house is warm for the person they care for, pay for additional transport costs (e.g. when going to appointments), purchase specialist food appropriate for certain health conditions, regularly wash bedsheets due to incontinence, and run equipment such as bed hoists which need power.¹⁷

- “If you care for someone who has limited mobility they need help to regulate their body temperature. As well as layers of clothing, we have the heating on most of the time as well as the coal fire.”
- “I have to drive an hour each way to see and care for my mum using a considerable amount of petrol that has increased in price. I had to purchase a bigger car to transport my parents and their equipment.”

“I have to do more washing and purchase very expensive night incontinence nappies on top of everyday items which add additional financial strain.”

“My son's ARFID [Avoidant/Restrictive Food Intake Disorder] and obsessive anxiety places extra financial demands on my pension when money is needed to provide him with food he will eat or to pay for what is needed to alleviate his stress and anxiety...”

A quarter (25%) of people whose caring role had come to an end agreed that they are now better able to afford utility bills since they stopped caring, suggesting that the cost of electricity and gas can be higher when caring.

“I am able to reduce my utility costs as I don't need to keep the home warm all the time with someone who is frail.”

“Cost of heating was massive. We do not usually have fire on in summer but had to when we were caring.”

28%



of carers have cut back on essentials like food and heating in order to make ends meet



¹⁷ WPI (2024) Poverty and financial hardship of unpaid carers in the UK. https://www.carersuk.org/media/dnxerxqv/poverty_financial_hardship_uk_web.pdf

Many carers told us that they are struggling to find ways of paying for essentials. 53% of carers have had to use their savings, 28% have used credit cards and 22% have used their bank account overdraft. 18% have used Buy Now Pay Later services (e.g. Klarna), and 18% have borrowed from family or friends.

- “ We are eating into our savings for everyday living and care costs”
- “ When using respite/care home services, I have had to take out credit cards to help with costs.”
- “ Sold items from around the house to raise money.”
- “ I am in two thousand pounds of debt for gas and electric as I couldn’t afford it.”
- “ Asked friend to come over with some food for my children.”

We asked carers who were struggling to afford essentials what they were finding it difficult to afford. As Table 4 shows, 60% are struggling to afford electricity and gas, 58% are struggling to afford clothes and shoes and 44% are struggling to afford transport.

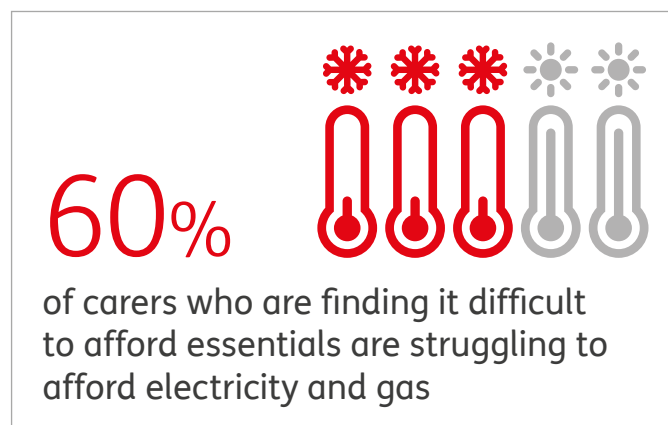


Table 4: What carers who are struggling with essentials are struggling to afford.

What carers who are struggling with essentials are struggling to afford	% of carers who responded
Electricity and gas	60%
Clothes and shoes	58%
Transport	44%
Food	38%
Communications (eg phones, broadband)	37%
Other household expenses (eg cleaning equipment, toiletries)	33%
Other heating costs (eg heating oil or burning wood)	20%
Water	17%

Some carers told us they were wearing damaged or unsuitable clothing rather than buying new clothes. Others said they were unable to afford things that might improve their lives such as dental surgery or new glasses, or home improvements.

- “ Not able to afford new glasses I need or to get crown replacement.”
- “ I own 2 pairs of trousers, 1 pair of shoes, and 3 shirts- same ones I wear till it cannot be worn anymore. I can’t afford birthday and Christmas gifts for my children, nor other family or closest friends. I’m not [able to] afford to do simple house improvements and renovations.”

“ For the past year I sleep on a mattress on the floor as I can’t currently afford a bed frame.”

Many carers also said they were having to budget and plan very carefully in order to make ends meet.

- “ Giving up a career to care had a huge impact on financial planning for retirement so have had to redefine what is essential.”
- “ I am dependant only on carers allowance and income support, and cannot afford simple luxuries...our food is as cheap and basic as possible etc.”

“ I constantly watch my money, I double check everything to make sure it’s the cheapest I can get. I have cut back on food, limit the gas & electric which is hard as I don’t want my Mum to be cold. I work off a weekly menu so I know exactly what food we have. I dilute the cleaning products to save. I rarely go out & socialise, I’m embarrassed that I can’t afford to, I make excuses not to go. It’s a constant source of stress. I repair clothes & it’s months since I had my haircut, I worry in case something breaks down & I have a large bill. It shouldn’t be this way when we carers are saving the NHS & Social Services millions.”

“ I can’t earn money, therefore I can’t replenish my savings, I have to be very careful what I spend. I can’t pay into a pension so the future is looking a bit bleak too.”



Struggling to afford food

Concerningly, 38% of carers who are struggling to afford essentials are struggling to afford food. Carers who are struggling to afford food are skipping meals and not eating to save money. 61% of carers who are struggling to afford food have skipped a meal, and 59% have reduced the size of their meals. 39% have felt hungry but didn’t eat. A fifth (20%) of carers who are struggling to afford food said they had not eaten at all for a whole day.



Table 5: What carers who are struggling to afford food have done

What carers who are struggling to afford food have done	% who responded
Skipped a meal	61%
Reduced the size of my meals	59%
Have been unable to eat a balanced diet	58%
Felt hungry but didn’t eat	39%
Have lost weight because of not eating	22%
Not eaten at all for a whole day	20%

Carers in receipt of Carer’s Allowance who were struggling to afford food were even more likely to skip a meal (67%), reduce the size of their meal (62%), and have been unable to eat a balanced diet (61%).

Many carers in receipt of social security benefits are using food banks. 19% of carers in receipt of Universal Credit with Carer Element and 12% of carers in receipt of Carer’s Allowance are using food banks, compared with 7% of all carers.

The proportion of carers using food banks has also increased - from 5% in 2022 to 6% in 2023 and 7% in 2024.

Carers told us how little they were eating some days.

- “ I skip meals daily, I have one evening meal. So during the day I drink tea and water to take the hungry feeling away.”
- “ I eat cereal twice a day and beans on toast once a day. That’s been my diet for the last year and a bit. Food for my cared for is my priority.”
- “ Only eat once a day. Have eaten unhealthy but cheap meals and cut the size of a meal just to make it cheaper. I have put on weight for not eating healthier.”
- “ Because of petrol costs travelling for caring, stress eating has had a negative impact. I barely ate one meal a day for 2 months – I only ate cereal & milk and spent the rest of the day drinking juice.”

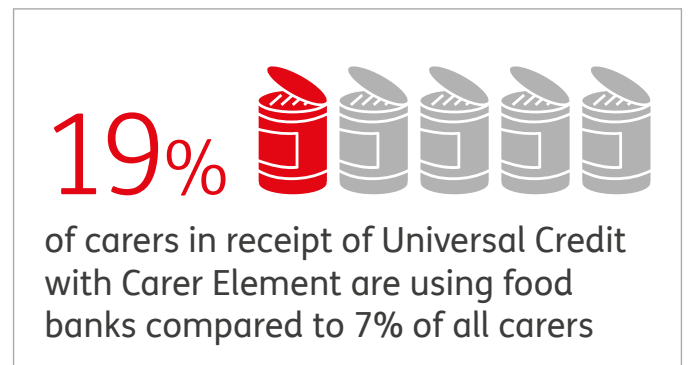
Others were having to eat unsuitable food or food that had expired.

- “ Having to eat foods that exacerbate my arthritis because can’t afford healthy food.”
- “ Eaten mouldy/bad food.”
- “ Am gluten free but can not afford Gluten free food so having to eat gluten causing my IBS to struggle.. bloating stomach cramps.”

Some carers said they were keeping the situation to themselves, and not letting people know they were struggling to afford food.

- “ I pretend that I am fasting for religious reasons so my daughters don’t know I am saving so my wife has good meals.”
- “ My husband doesn’t realise on most days that I haven’t eaten. I also have stomach problems diagnosed by doctors.”
- “ I buy the cheapest food possible and often don’t eat so that my children can eat more. I lie that I’ve already eaten.”

29% of people whose caring role had come to an end agreed that they are now better able to afford the cost of food since they stopped caring, suggesting that the cost of food can be higher when caring.



Struggling to afford housing costs

Many carers also said they were struggling to afford housing costs. 21% of carers are struggling to afford their rent or mortgage payments, and 38% said they were worried about increases to their rent or mortgage. Those in receipt of Universal Credit with Carer Element were more likely to struggle to afford their rent or mortgage (36%).

42% of carers are struggling to afford the cost of household repairs.

“My downstairs flooring is completely ruined from a leak in my water tank which I can’t afford to have repaired, my sofas are ruined from a mouse infestation which prevents me using them but I don’t have means of replacing them.”

“My windows and doors are draughty and old, some electrical sockets don’t work, my 1986 boiler breaks down frequently, I have a leak in my attic, some roof tiles need replacing, my garden fence is rotten and falling down, the kitchen sink tap is leaking. I don’t know which way to turn.”

“We have damp issues and our house needs a total revamp, but we have absolutely nothing left over every month to get any of it sorted. Damp us causing us issues but there’s nothing we can do about it.”

Concerningly, 8% of carers who had experienced issues with housing said they had to sell their home because they could no longer afford it, 6% had to move to cheaper rental accommodation, and 3% are currently or have previously been homeless.

“I had to sell my home to move in with mum and when she dies I will be homeless and that really scares me because I won’t be able to afford to rent or buy!”

“I have lived at home my whole life. I care for my father. If we have to sell our home to pay for his care I’ll be homeless.”

“We moved multiple times and were finally made homeless in private rental due to landlords deciding to sell or being priced out of rent. Thankfully after a year homeless we have a social house but that year was incredibly impactful (badly) in everyone’s health.”



Impact of finances on health and wellbeing



Key points

- Over the past few years, carers have been cutting back more and more on things which can improve wellbeing. This year 60% of carers cut back on seeing family and friends, compared to 47% in 2023 and 34% in 2022.
- Carers in receipt of social security benefits are even more likely to cut back on hobbies/leisure activities and seeing family and friends.
- 61% of carers feel stressed or anxious when they think about their financial situation. This increased to 91% for carers struggling to make ends meet.
- Over half (51%) of carers said that their financial situation is having a negative impact on their mental health and wellbeing.

Carers have been cutting back on things that are important to them, and this situation has been getting worse each year. This year, 68% of carers cut back on hobbies/leisure activities, compared to 58% in 2023 and 47% in 2022.

“We have to plan every single outgoing and there’s never anything left over for luxuries such as holidays etc. It makes you feel like an outsider looking in to “normal society.”

“I can manage at the moment, but never have a holiday – I would love one, but cannot afford it.”

“I do not have a life outside of caring because there is no money for anything but the essentials. My only time away from home is when I go to paid work which I have to do because there is no other money coming in.”

Concerningly, 60% of carers cut back on seeing family and friends, compared to 47% in 2023 and 34% in 2022. Carers are already struggling with loneliness, and not seeing friends and family is likely to exacerbate this issue. Carers UK research last year found that 50% of carers felt lonely.¹⁸ Loneliness can lead to poor mental health.¹⁹ This is concerning, as we know that carers are already more likely than non-carers to be in ‘not good health’.²⁰

“I can’t do very much socially or with family because I can’t afford professional care in order to leave my spouse.”

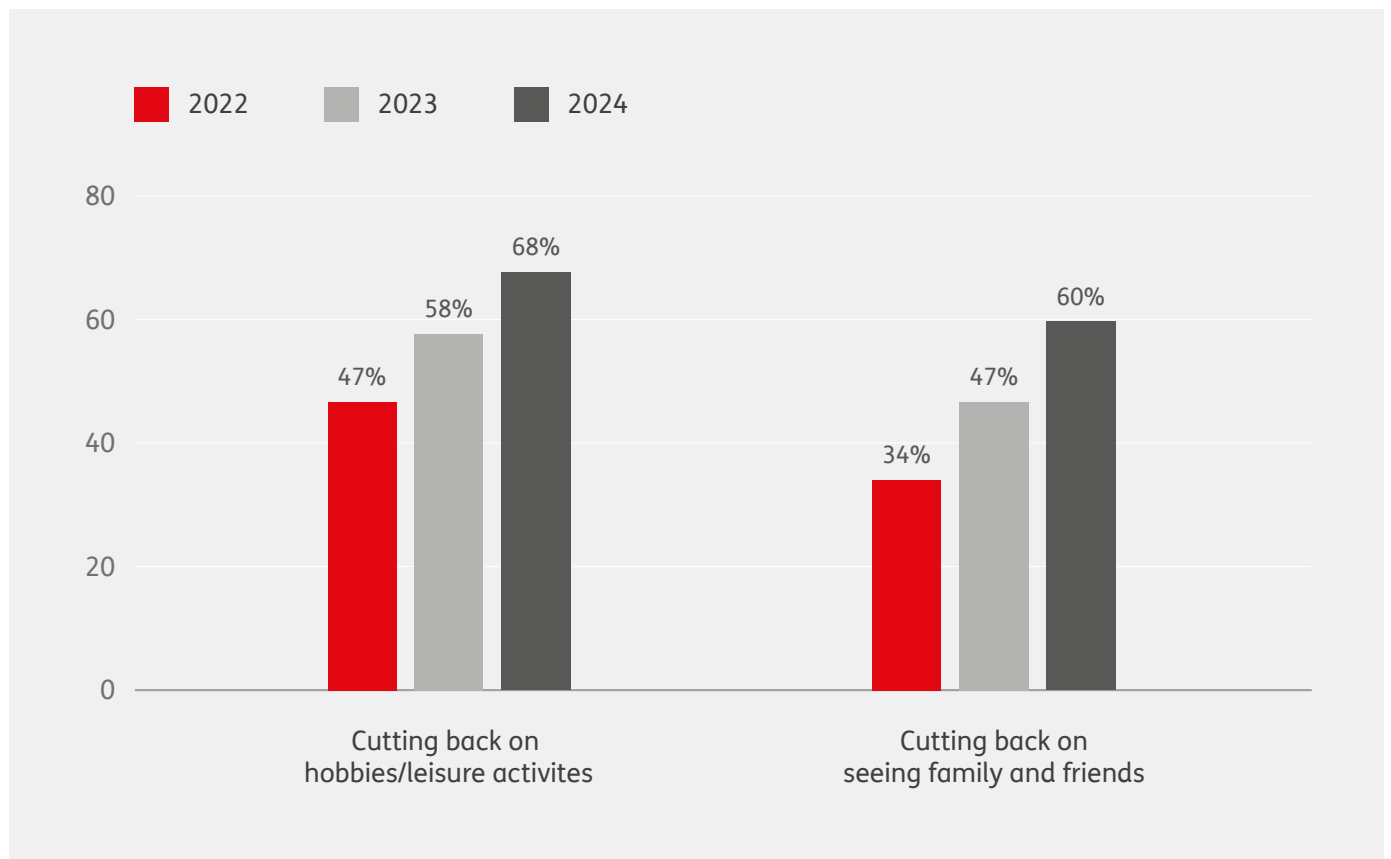
“It’s hard when others don’t have to spend their wages on caring – I can’t just go for a coffee at £5 a time so it affects my ability to do social things people take for granted...”

As Table 6 shows, the proportion of carers who are cutting back on hobbies/leisure activities and seeing family and friends has increased each year over the last three years.

61% of carers feel stressed or anxious when they think about their financial situation

Carers in receipt of benefits are even more likely to cut back on hobbies/leisure activities and seeing family and friends. 79% of carers on Universal Credit with Carer Element and 74% of carers on Carer’s Allowance are cutting back on hobbies/leisure activities. 67% of carers on Universal Credit with Carer Element and 63% of carers on Carer’s Allowance are cutting back on seeing friends and family.

Table 6: Percentage of carers cutting back on hobbies/leisure activities and seeing family/friends by survey year



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

¹⁹ Mental Health Foundation (2022) All the lonely people. <https://www.mentalhealth.org.uk/sites/default/files/2022-06/MHAW22-Loneliness-UK-Report.pdf>

²⁰ ONS (2023) Unpaid care expectancy and health outcomes of unpaid carers, England: April 2024.

Carers living in rural areas were also more likely to cut back on hobbies/leisure activities compared to those living in a town or city (70% vs 67%), and more likely to cut back on seeing friends and family (61% vs 59%). This may be due to additional petrol costs or less frequent public transport:

- “I miss seeing friends and as I live rurally, I can’t justify the expenses involved in going to see them or catching up.”
- “I am also disabled so living in a rural area taxis are expensive with public transport unreliable.”

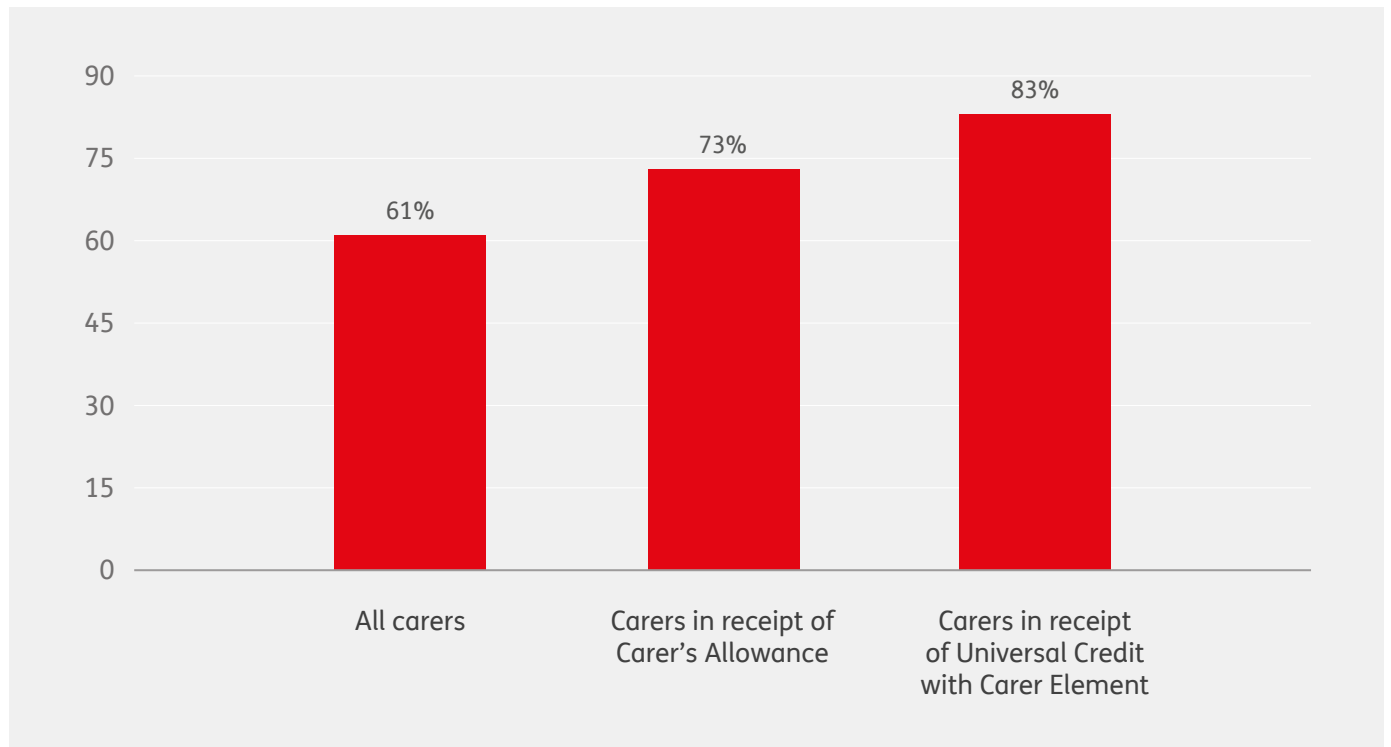
The financial impact of caring is also having a negative impact on carers’ mental health. 61% feel stressed or anxious when they think about their financial situation. This increased to 91% of carers who were struggling to make ends meet.

- “I am very stressed about money all the time. I struggle to relax and spend quality time with my son and daughter.”

51%
of carers said that their financial situation is having a negative impact on their mental health and wellbeing

Carers in receipt of social security benefits were more likely to say that their financial situation was causing them stress or anxiety. 83% of carers getting Universal Credit with Carer Element, and 73% of carers getting Carer’s Allowance, said they feel stressed or anxious when they think about their financial situation.

Table 7: Percentage of carers who feel stressed or anxious about their finances by social security benefits received





Over half (51%) of carers said that their financial situation is having a negative impact on their mental health and wellbeing. This increased to 88% for carers who are struggling to make ends meet, 75% of carers in receipt of Universal Credit with Carer Element, and 65% of carers in receipt of Carer's Allowance.

Some carers said that struggling financially affected their self-esteem: many were embarrassed to tell other people that they were struggling.

“It's just so depressing. It's constantly on my mind and I feel like I've let my family down. I have never claimed benefits in my life until this year and I'm 45.”

“Most days I live on a packet of biscuits or toast and tea because I cannot afford to eat a proper meal. My weight is going up because my diet is so deficient but I will not use a food bank warm spaces etc because I don't want people to know my situation.”

“Living with mother-in-law who pays household bills to alleviate my stress – she's still working at 70 to help me. The guilt of this is crippling and immeasurable.”

Carers also said that struggles with finances had a negative impact on their health because they weren't able to spend money on things which improved their wellbeing.

“Every penny I have is catered for. I seriously can't even go for a hair cut and my last hair cut was in 2010 as its was £25 then and that was just a small local hairdressers not anything fancy. I'm so sad and unhappy, my mental health is at rock bottom.”

“Cut out things that benefit my health; gym membership, chiropractor care, dental treatment, gardener/cleaner/window cleaner/carpet for my home, owning a car.”

“I started to become tearful whilst food shopping for Mum because I couldn't afford little things for myself.”

Support needed with finances



Key points

- Half (51%) of carers need more financial support. Many need more support to manage the costs of caring. For example, nearly a third (30%) need more financial support with transport costs.
- Not all carers were aware of what financial support might be available. 30% didn't know what support is available to help them with electricity and gas bills, and 30% didn't know what support is available to help with transport.
- Many carers felt the process of claiming social security benefits could be improved. 67% needed more information and advice about what benefits they are entitled to, and 57% would like more support with understanding the rules around claiming specific benefits.
- 90% of carers in receipt of Carer's Allowance said that this benefit was not sufficient.
- 41% of carers who had experienced issues whilst in paid employment and claiming Carer's Allowance said they had given up work due to the earnings threshold.

Cost of care

When we asked carers what their main needs are at the moment, 51% said they need more financial support. This rose to 83% for carers struggling to make ends meet, 78% for carers in receipt of Universal Credit with Carer Element, 71% for carers aged 18-64 not in paid employment, and 68% for carers in receipt of Carer's Allowance,

Although some carers are able to pay for the costs involved in caring either themselves, or through financial support such as a Direct Payment, many would like more help with this. 45% need more support to help them cope with their caring role (eg therapy and counselling costs), 30% need more support with transport costs, and 27% need more support from a cleaner.

“ I have to run a car in order to reach those I care for. The cost of fuel and maintaining my car keeps rising which leaves little left for other essentials.”

“ Free bus pass would make such a difference as 1/4 of the carers allowance is spent on travelling to and from my mother in law's per week.”

“ I sometimes need to talk to a professional counsellor to help improve my mental health on a one-off basis. I can't talk to my other children as it then causes them distress.”

“ I lack time to clean my house and find the cost of a cleaner prohibitive.”

23% of carers said they were able to pay for practical support from care workers themselves or through financial support. 22% of carers said they needed more support to pay for care workers. Affordable replacement care services can help carers combine caring with paid employment. 69% of carers in paid employment said that affordable, accessible and reliable replacement care for the person they care for would help them juggle work and care.

51%

of carers said they needed more financial support



69%

of working carers said affordable, accessible and reliable replacement care for the person they care for would help them juggle work and care



Table 8: Costs of care that carers need more financial support with.

Costs of care	% of carers who responded
Support to help cope with my caring role (eg therapy and counselling)	45%
Transport costs (eg fuel costs or taxis)	30%
A cleaner	27%
Practical support from care workers coming in to help	22%
Technology like alarms, sensors or remote monitoring to help with caring	18%
Incontinence products	18%
A Motability vehicle	17%
Equipment in the home of the person I care for (eg hoists, grab rails)	17%
Use of a day centre or care home	13%
A meal delivery service	11%
Specialist childcare for a disabled child	8%



20% of carers who were caring for a child said they needed support with specialist childcare for a disabled child.

Carers in receipt of social security benefits were even more likely to need support with the costs of care. For example, 50% of carers in receipt of Universal Credit with Carer Element, and 39% of carers in receipt of Carer's Allowance need more help with transport costs, compared to 30% of all carers.

Some carers said that it was utility bills that they needed help with, due to the extra costs involved in having the heating on for the person they cared for, powering equipment such as hoists, or doing extra washing due to incontinence.

“Gas and electricity costs are astronomical and no help with how much equipment having to be on adds to the bills, even though it is life saving medical equipment.”

“I am buying numerous items such as incontinence pads, I wash sheets and clothes every day so spend more on my water meter which is charged at full rate.”

“The extra is costs for energy bills and water, being fulltime at home with people with extra sensory needs uses 3 – 4 times more electricity, gas and water and I don't receive anything to help with the extra costs.”

“As my wife is immobile and cannot stand or walk without her [paid] carer's help, she feels the cold greatly and I therefore keep the house warm throughout the 24 hours. This causes our heating bills to soar.”

Other caring costs that carers said they needed support with that were not mentioned in the above list included cleaning products; leisure activities to support the wellbeing of the person they cared for; specialist food; toiletries to help with allergies or skin conditions; childcare costs for a non-disabled child to allow time for respite; a gardener or handymen; phone and internet costs which were higher due to making calls to support services; legal fees; parking costs; and medication not available through the NHS.

“My partner finds a lot of solace in going to cafes several times a day, but this is becoming extremely expensive but I am do not want to cut back on this if I can help it as it is the thing that gives her most enjoyment at the moment.”

“Need help with the garden so that lawns are mowed and paths kept accessible.”

“My partner has a low immune system and therefore the house needs to be sterile. Cleaning products are expensive.”

“With autism things get destroyed frequently (chewing through clothes and bedding etc) and they both rely on technology to regulate so if an iPad breaks I need to replace it straight away.”

Some carers also mentioned opportunity costs, such as the loss of income when they'd had to reduce their working hours.

“Reducing hours at work – so loss of present and future income (and impact on pensions).”

“Loss of earnings is never acknowledged as a cost of caring and more importance should be attached to this. My household is approximately £25,000 a year worse off because I have been unable to return to work.”

Some carers said that they had had to pay for adaptations to their home which could be expensive. Others said that they wanted to move to more suitable housing but couldn't afford to.

“We have had to spend all our savings trying to make our home suitable for the needs of the 3 disabled adults plus child living here.”

“We had to spend a significant amount of money to adapt our home to be suitable for my daughter. The council helped with a little bit of the money but we had to remortgage to afford it, all while on one income.”

“Have had some adaptations to home for daughter with M.E. but these now need updating and we would prefer to move to more accessible accommodation but no chance of affording it.”

Support with the cost of care

Carers were not always aware what support might be available to help them pay for essentials. 30% said they didn't know what support is available to help them with electricity and gas bills, and 30% said they didn't know what support is available to help them with transport costs. This suggests that carers need more information and advice about how they can find out if they are eligible for financial support, and how they might be able to reduce energy bills.

Some carers said that that financial support they had previously been given was no longer sufficient to cover the costs. Others said that they were unable to use financial support like Direct Payments due to lack of available services.

“Although my son has a personal budget, it is no longer adequate for his needs. I pay all his bills and as his level of disability increases, they increase too.”

“It's not the cost that's the problem, it's the availability of services.”

“The cost isn't the problem, the problem is lack of access, we can't get paid people in, they're not interested in what we need.”



Social security system

40% of carers who completed the survey are in receipt of Carer's Allowance and 14% are in receipt of Universal Credit with Carer Element.

We asked carers in receipt of social security benefits how the process of claiming benefits could be improved. The main way in which carers said the process could be improved was having more information and advice about what benefits they are entitled to (67%). This was followed by being informed by the Government if there is other support they are entitled to with caring (64%).

Some carers suggested that there should be a 'one stop shop' for advice with claiming financial benefits; others said that information should be provided when a condition is first diagnosed.

“I do not know what benefits I am entitled to and do not have the time to spend ringing different departments to find out what financial support I would be entitled to.”

“When diagnoses are given very little help is given in what your entitlement is and can take years before you find out.”

“Need a unified person-led system when first diagnosed. At the moment there is too many leaflets, people and orgs and it's a minefield. You end up giving up. There should be one place with all the info.”

57% of carers said they would like more support with understanding the rules around claiming specific benefits.

“I think information is very difficult to access. When you enquire there seems to be a misconception you know how the system works. There seems to be a lot of “sign posting” which would be good if you actually reached someone who helps.”

“How are we to know what the thresholds are if we claim too much and who to inform of change of circumstances to avoid overpayments?”

“[Need] online calculators to keep track of earnings vs carers allowance limits.”

67%



needed more information and advice about what benefits they're entitled to



51% said they would like better communication with the Government when claiming benefits. Some carers said it could take a long time to speak to someone on the phone. Others said they would like a more compassionate service.

“More understanding of the difficulties a carer can have providing information with short deadlines, and the difficulties involved trying to get a disabled person to a compulsory in person appointment.”

“It would be a great help if long waits on telephone calls made to government departments such as DWP could be shortened.”

“Not being treated like criminal or benefit fraudster every time I have to deal with DWP about any of the benefits I receive.”

“[Need] kind, compassionate, well-trained people in the system. We have been left traumatised by the pip process in particular.”

42% of carers said it would be helpful to submit a claim for multiple benefits at the same time. Many carers said that information should be shared across departments so they didn't need to submit separate claims.

“Better information sharing between Attendance Allowance office and Carers Allowance office so that same info doesn't have to be given to each separately by phone!”

“Upon application for one benefit, have the system linked so you automatically get any qualifying benefits without having to apply separately. One form for multiple applications.”

“I spend hours reporting my earnings. To various sources and by lots of different means (uc, carers allowance, hmrc) all use different systems, some online some by phone some by paper. Long waiting times on the phone and no central sharing.”

“[Need] a one stop shop for all benefits.”

This is what carers ask for but it's impossible to deliver.

Table 9: What support carers would like to improve the process of claiming benefits.

Support needed	% of carers who responded
More information and advice about what benefits I am entitled to	67%
Being informed by the Government if there is other support I am entitled to (e.g. Government officials telling carers they can register as a carer with their GP)	64%
More support with understanding the rules around claiming specific benefits	57%
Better means of communicating with the Government when claiming benefits (eg having an online chat function; being able to contact Government officials by email as well as phone)	51%
Quicker processing of claims by the Government so I know if my application has been successful sooner	46%
Being able to submit a claim for multiple benefits at the same time	42%
Being notified by Government sooner if there is an issue or delay with my application (eg if I have unintentionally gone over the earnings limit for Carer's Allowance)	35%
Being able to view my benefit status and payment history online	35%
More information and advice given to me if my claim is unsuccessful or delayed	32%
None of the above	9%



In addition to the response options above, many carers said they would like a reduction in the amount of administration involved.

“ Making the process less complicated. Although I receive carers allowance and my daughter gets ADP [Adult Disability Payment], the process for claiming council tax reduction is so complicated I have not bothered doing it.”

“ Collecting the information, bank balances, savings amounts, etc, is such a burden. These may seem like trivial tasks but in a digital only world these tasks are so challenging I always find the next most urgent job to do. I spend my time fighting fires and I don't have time for this especially when it's unlikely to result in a successful claim.”

“ Making the process less draining. This is about me rather than the people I care for, but as a recent example I didn't complete my PIP claim because it was just too much and I didn't have the energy.”

“ The forms take forever to fill in so are a) a barrier to claiming and b) a barrier to updating. It would be good if this could be simplified- eg more on line and being able to just adjust say one or two boxes of something changes.”

In particular, some carers said it was tiring to continually resubmit claims when the condition of the person they cared for was not going to change.

“ My partner's medical conditions won't ever improve and can only get worse. Having to fill in a 30 or 40 page detailed claim form, even if it is only every 3 years or so, seems futile and depressing. Futile, because they have all the information of his many health conditions from previous claims.”

“ Not having to prove disability for DLA/PIP for my daughter every few years. She has Down's Syndrome and is autistic. She will not “get better” and having to prove her level of disability again and again is both hard work and depressing.”

“ With progressive or terminal conditions where the prognosis tends to be the same, surely we could be spared a 30 page claim form for attendance allowance.”

We also asked former carers what financial support might have been helpful when they were caring. 43% said they would have liked more information and advice about what benefits they are entitled to, and 31% said they would have liked better means of communicating with the Government when claiming benefits.

“ So much is hidden from carers and it is only word of mouth that reveals some of the help available.”

“ The DWP made me feel like a criminal but also made it difficult to contact them.”

Carer's Allowance amount

90% of carers in receipt of Carer's Allowance said that this benefit was not sufficient.

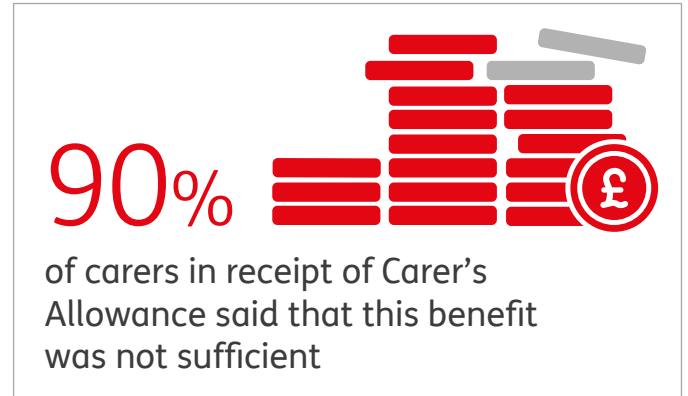
- “ Although the Carer's Allowance is welcome, in reality it doesn't stretch very far.”
- “ Providing 35 hours support for this amount is not a liveable amount/sustainable for a prolonged period.”
- “ Trying to survive on £81.90 per week is very hard.”

Many carers had had to give up paid employment in order to care and were struggling with the loss of this income – they felt that Carer's Allowance should be increased to cover this.

- “ If, like me, you have had to give up a full time position to care for a loved one, the drop in salary is enormous. We have had to reduce our living standards and I seldom socialise as I can't afford to pay someone to look after him.”
- “ If someone has given up work to be a carer then how on earth are they meant to survive on that? It doesn't even cover a weekly shop for a family.”
- “ Our family lost my 50k salary as I had to become a carer and this was the only replacement. I've been unable to work at all around care for my other child not being viable with childcare and lack of specialist provision. We are hard pressed and were formerly comfortable”

Many carers said that the Allowance was not sufficient to cover the increased cost of living, and that they struggled to afford essentials.

- “ It does not meet the cost of living needs and therefore it is a case of going without basic essentials and food, fuel.”
- “ It has not kept pace with inflation or the recent hike in cost of living. I incur additional costs in petrol and maintaining a car which is an essential, given the limited mobility of the person for whom I provide care.”
- “ I ended up draining all my savings and in debt. Cost of living is higher for carers (e.g. having to run a car and reliance on more expensive food due to time and resource constraints) yet we are expected to live on less.”



Many carers said that Carer's Allowance had a negative impact on their health and wellbeing, because they felt it demonstrated how undervalued they were.

- “ There is no difference in the care provided at home by a family member, compared to that provided by someone paid to do it. So why then are carers disrespected by receiving so little, for a service that they are saving the government billions on!”
- “ The amount of work done for such a small amount. You can't afford to buy anything but work harder than those with a real job. It is soul destroying being told that it's not a real job and that you are unemployed.”
- “ I provide over 90 hours of care per week, meaning I'm supported with less than £1 an hour for my caring role. I provide too much care to be able to work, so I'm stuck on benefits with no pride. I feel isolated, forgotten, unappreciated and taken for granted.”



A significant proportion of carers said they would like to be paid the minimum wage for caring. Some carers said they felt they were working just as hard as paid carers, but for no reward.

“ I provide over 90 hours of care per week and am unable to get a paid job. I save the government thousands upon thousands of pounds by providing full time care, yet I’m plunged into poverty for it. If I worked as a paid carer, my hours would be capped, I’d be entitled to rest periods, I would have workers’ rights, I’d have annual leave, I’d be given mandatory training and I would be paid at least national minimum wage. Right now, I get paid less than £1 an hour, which would be illegal if I were employed.”

“ It is very little for such a difficult job. Yes it is a job. She may be my mother but it was not my aim in life to be doing this. At least minimum wage if not more should be paid.”

“ The Carers Allowance should be set more in line with the minimum wage (use average working hours as a guide) so that carers can have a better standard of living. With a better standard of living we would make less calls on other services for health and wellbeing. I’m not sure how any government thinks that people can survive on what is paid to a carer, which is less than unemployment benefit.”

“ Caring full time like I do is equivalent to having a full time job. No full time caring job would pay only £81.90 a week. The amount we get does not reflect our role and how it prevents us being available for employment”

42% of former carers said that an increase in the value of carers benefits such as Carer’s Allowance would have been helpful when they were caring, and 36% said they would have liked a wider eligibility criteria for Carer’s Allowance so that those in receipt of a pension can access it.

“ [Need] allowance for those who take early retirement in order to care and get a lump sum as part of their pension. Due to this lump sum we couldn’t apply for means tested benefits. I took a considerable hit on my pension when I retired to care full time.”

Carer’s Allowance and employment

75% of carers in paid employment said that a change to the eligibility criteria for Carer’s Allowance, allowing them to work more hours or take on higher paid work, would be helpful in allowing them to juggle work and care.

Many carers who had claimed Carer’s Allowance while in paid employment said they had experienced challenges when doing so. 62% of carers who had experienced challenges said they had been unable to work more hours or take on higher paid work due to the earnings threshold for Carer’s Allowance. Some carers said this had a negative impact on their finances or their career development. Others said it caused them stress, as they were worried about exceeding the limit and losing the benefit.

“ [Carer’s Allowance] nowhere near covers the number of hours I care for my daughter per week. I have to top it up by working but I’m trapped by the earnings cap. I can only work on a flexible, zero hours basis but can’t take extra hours if offered on an ad hoc basis for fear of losing my Carers Allowance.”

“ The earnings threshold is way too low. It needs to change. You try to claw your way out of poverty but are hindered/pushed back at every turn. All of it just adds to the already stressful situation you are trying to manage and cope with.”

“ I work in a primary school. I am unable to undertake further training because my boss will pay me for this and I will exceed the limit for earnings. I cannot further my career and do continued personal development unless I tell my boss I will attend for free.”

“ I’m so frightened at losing my carers allowance that I only work to cover holidays and only one day a week so I don’t break the rules. The fear is the biggest thing and causes severe anxiety.”

41% of carers who had experienced issues when claiming Carer’s Allowance while in paid employment said they had given up work due to the earnings threshold in Carer’s Allowance.

“ My wages at my previous employment went up but that took me over the limit and I was unable to cut my hours down any more...I left work.”

“ I took on a lowly paid shop job for 1.5 days a week, but had to give it up. The wage was within the earnings threshold but it quickly became clear they expected extra hours from me to cover annual leave and sickness. Working those hours would mean losing my Carers Allowance, so I'd effectively be working longer hours but losing money. I was in an impossible situation.”

“ I miss working. I have worked nearly 45 years and to have to give it up a) to care full time and b) to be concerned that any earnings would automatically cancel any benefit is offensive. Trying to balance work and home is difficult at the best of times but with caring it is impossible. Some real compassion and common sense to consider what is a reasonable threshold needs to be considered.”

20% of carers who had experienced issues when combining paid employment with claiming Carer's Allowance said they had unintentionally exceeded the earnings threshold for Carer's Allowance and had to repay overpayments.

“ I earned £1 too much for 19 weeks and have to pay all the Carer's Allowance from that time. I ended up using credit cards to cope. I've had to give up carers allowance to get another job to cope financially. My husband is 70 and on state pension. This is crippling us mentally and physically.”

“ I have apparently gone over the earnings threshold by pennies on occasions and I am currently paying back nearly £3000.”

“ During Covid-19 I was working and caring. Over four months I was over paid £4. This was due to changing wages through furlough. I was made to feel like a criminal. The accountant and my boss contacted carers allowance and explained what had happened. I had to pay nearly £400 back and was terrified about getting a criminal record. I became very depressed over the stress of this. So horrendous.”

Communication with the DWP was also an issue – 40% of carers who had experienced issues when they were in paid employment while claiming Carer's Allowance said they had found it difficult to communicate with the DWP about earnings, such as experiencing delays or being unable to get through. Some carers also said that DWP had not acted on information they had provided, or that they had lost access to the benefit with no explanation.

“ I had to decline annual pay rises to keep my earning under the limit as they pay rise was minimum and I would have been worse off by losing the carers allowance. One employer paid me a bonus and I wasn't aware and carers allowance stopped immediately without communication and I had to wait and numerous letters to get reinstated.”

“ My earnings was increasing and I phoned the DWP and gave them all the information 3 times. They continued to pay me carers allowance for 8 weeks. I was getting very upset thinking about the debt I was getting myself into because they kept paying me.”



41%



of carers who had experienced issues whilst in paid employment and claiming Carer's Allowance said they had given up work due to the earnings threshold

Some carers wanted a more straightforward process for reporting earnings.

“ I think it’s a good idea to be able to inform one department and all other departments get updated. Universal credit is easy because you can do it through the journal but pip and others you have to spend hours on hold waiting to speak to someone.”

“ I have to send in my wage slips and letters throughout the year to show when I am entitled to carers allowance as I have variable wages due to being on a zero hours contract with both remote part time jobs and only being paid when I work. I would like to see an online system that I can use to upload information and prevent the need to call and write in and print documents off all the time.”

“ I fell foul of the earnings limit unwittingly...The rules are confusing - it’s difficult to get a straight answer. I kept meticulous records and still got it wrong.”

17% said they didn’t know how to notify the DWP about a change in circumstances, such as a change in income. Some carers said they didn’t want to claim the Allowance because the rules were so complicated that they struggled to understand.

“ I’ve never considered Carer’s Allowance due to being baffled by the entire process.”

“ I will never claim Carer’s Allowance as it’s very complicated. Too many rules.”

“ Too confusing so gave up trying to claim.”

“ I haven’t bothered even applying for Carer’s Allowance because it’s too complicated to work out how many hours I work over a year due to the nature of my job & being self employed.”

Table 10: Issues carers had experienced while claiming Carer’s Allowance and being in paid employment.

Issues carers had experienced	% of carers who responded
Being unable to work more hours or take on higher paid work due to the earnings threshold for Carer's Allowance	62%
Giving up work due to the earnings threshold for Carer's Allowance	41%
Finding it difficult to communicate with the DWP about earnings (eg experiencing delays or being unable to get through)	40%
Unintentionally exceeding the earnings threshold for Carer's Allowance and having to repay ‘overpayments’	20%
Not knowing how to notify the DWP about a change in circumstances (eg a change in income, or employment situation) which might affect Carer's Allowance	17%

39% of former carers said they would have liked a wider eligibility criteria for Carer’s Allowance so that carers can earn more money and work extra hours if they would like to do so.

“ I had to juggle work – and had to reduce my hours by 40% – whilst also caring for my son 24/7 without support. I couldn’t claim any benefits, so I was in effect earning less and having to pay for more (food, electricity, etc).”

Conclusion

The rise in the cost of living in recent years has had a huge impact on unpaid carers. Increased food prices and the higher cost of energy are having a lasting impact on carers' ability to manage. We are seeing carers take increasingly drastic measures in order to cope with their difficult financial situation, from skipping meals to wearing layers and layers of clothing because they cannot turn the heating on.

The proportion of carers cutting back on seeing their family and friends has almost doubled in the last 2 years. This lack of contact, combined with what is already a challenging and often isolating role, will undoubtedly be contributing to worse mental health and wellbeing of unpaid carers.

We have heard from the new Government that growth is their number one priority and that there is a long-term ambition to get an 80% employment rate, meaning an extra 2 million more people in work. We cannot get there without better supporting unpaid carers. Up to 600 unpaid carers leave work every single day in order to provide unpaid care.

While not every carer will be in a position to take part in paid work, for those who can, a number of significant barriers exist. The earnings limit in Carer's Allowance is a key barrier.

This report has shed more light on the consequences of the earnings limit for those carers who have tried to combine paid work whilst claiming Carer's Allowance. Many carers in this position felt they could have increased their hours or received higher pay, many cited the earnings limit as a reason for leaving paid work altogether, whilst 1 in 5 said that they received an overpayment of Carer's Allowance which then had to be paid back.

Those who cannot combine paid work with unpaid care should be well supported to continue to provide vital care. Their unpaid care should also be recognised and seen as work rather than being classed as 'economic inactivity'. The vital work of unpaid carers would cost £162bn every year in England and Wales alone, if it had to be replaced.



The solution needed from the Government has to be two-fold. We need a better social security system which properly supports unpaid carers to do what they need to do, particularly in instances where they are not able to work and are caring intensely. However, for many carers, removing barriers to work and improving workplace rights and support to re-enter the jobs market will be crucial to lifting carers out of financial hardship and allowing them to benefit from keeping hold of their jobs.

Finally, we cannot support unpaid carers to stay in work without an affordable, reliable and good quality social care system. This is a pre-requisite for many carers juggling paid work and unpaid care. A new better social care system is urgently needed to underpin the Government's ambition to get more people back into work.

Recommendations

The UK Government should:

- Begin a review of the current support provided to unpaid carers through the social security system, including setting objectives for carers' social security benefits as well as timescales and options for change. The review should particularly investigate interactions between benefits in the current system to understand how they affect individual entitlements.
- Increase the level of Carer's Allowance by at least £11.10 a week in England, Wales and Northern Ireland (at 2024/25 rates) to match the effective rate in Scotland.
- Immediately increase the value of Carer Element, Carer Premium and Carer Addition by £11.10 per week, to lift at least 30,000 people out of poverty and 40,000 out of deep poverty.
- Increase the Carer's Allowance earnings limit to 21 hours at National Living Wage (£240.42/ week) and peg it to National Living Wage increases so carers' ability to earn is not eroded over time.
- Prevent the accumulation of Carer's Allowance overpayments, by writing off past substantial overpayments where carers could have been notified sooner and bringing forward options and timescales to introducing a taper to earnings similar to other benefits.
- Improve the process for claiming Carer's Allowance to make it less complicated for claimants by modernising delivery, increasing staffing and improving staff training, improving information sharing between DWP departments, and improving carers' understanding of eligibility rules.
- Reform the eligibility rules for Carer's Allowance, such as removing the 21-hour study rule, whereby someone is not allowed to claim Carer's Allowance and be in full time education of more than 21 hour a week.
- Commit to introducing a National Carers Strategy, including carrying out a consultation with stakeholders and carers.
- Introduce a new statutory right to paid Carer's Leave to support more people to balance employment and unpaid care and remain in work.
- Develop the plan for the National Care Service and deliver much-needed funding to help stabilise social care, to better support unpaid carers' wellbeing and enable some carers to continue with or return to paid work.
- Provide additional financial support to carers of State Pension age, including a new non-means-tested payment. There should also be a review of pension rules for carers, with implementation of initiatives to get carers up to similar pension levels as non-carers.
- Review and expand the eligibility criteria for Winter Fuel Payments, including unpaid carers on the list of recipients as well as households with disabilities.



This is the first of a series of reports based on data from State of Caring 2024



Across the UK today 5.8 million people are carers – supporting a loved one who is older, disabled or seriously ill.

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

We're here to make life better for carers.

Carers UK 20 Great Dover Street, London, SE1 4LX

T 020 7378 4999 | E info@carersuk.org



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