

State of Caring 2023

“I’ve got no money at all”:

The financial impact of caring in Scotland

October 2023



About this research

This report, produced by Carers Scotland, explores the key findings from the State of Caring Scotland survey 2023 on the financial impact of unpaid caring.

Carers Scotland's annual State of Caring survey has been undertaken for over a decade and is Scotland's most comprehensive research into the lives and experiences of unpaid carers. This year's survey was carried out between June and August 2023 and completed by 1,771 unpaid carers in Scotland.

We have interspersed this report with the voices of carers. These are highlighted in red, and we thank those quoted and everyone who took part for telling their stories and sharing their concerns.

Note: Not all respondents completed every question in the survey, and some questions offer the ability to select more than one option.

About unpaid carers

An unpaid carer is a family member, partner, friend or neighbour who helps a person with daily activities that they would not be able to manage if they did not have help. This could be a partner, family member or friend who has a long term or terminal illness, someone who is disabled, has a mental health condition, is affected by addiction or who needs extra help as they grow older. There are approximately 800,000 people in Scotland providing such unpaid care¹. It would cost an estimated £13.1 billion² every year to replace the care they provide.

Carers in State of Caring 2023

The demographic breakdown of carers responding to State of Caring 2023 is as follows:

- 81% of respondents are female, 18% male with the remaining 1% preferring to self-identify as either non-binary or transgender.
- 3% are aged 18-34, 13% are aged 35-44, 25% are aged 45-54, 36% are aged 55-64, and 23% are aged 65+.
- 29% have a disability³.
- 98% of respondents are white Scottish, Irish or other white; 2% of respondents are black, Asian or minority ethnic.
- 92% of respondents are heterosexual, 4% are gay, lesbian or bisexual, the remainder preferred not to say or skipped this question.
- 45% are in some form of employment and 24% are retired.
- 20% also have parental responsibility for a non-disabled child under 18.
- 3% have been caring for less than 1 year, 25% for 1-4 years, 25% for 5-9 years, 27% for 10-20 years and 20% for more than 20 years.
- 19% provide 1-19 hours of care per week, 10% provide 20-34 hours of care pre week, 15% for 35-49 hours and 14% for 50-89 hours, 42% provide 90 or more hours of care per week.

¹ Scotland's Carers update release, Scottish Government 2022

² National Care Service Financial Memorandum, Scottish Parliament 2022

³ As described under the Equality Act 2010: this defines a disabled person as someone who has a physical or mental impairment which has a substantial and long-term adverse effect on their ability to carry out normal day to day activities

- 71% care for one person, 21% care for two people, 6% care for three people and 2% care for four or more people.

The people carers care for

Carers responding to State of Caring 2023 provided information about who they care for and the conditions or disabilities that affect them.

- 35% are caring for a parent/parent-in-law, 34% were caring for a spouse or partner, 38% for a son/daughter/in-law), 11% for another relative and 3% for someone else e.g. a friend or neighbour.
- 18% care for someone aged under 18, 22% for someone aged 18-34 years, 30% for someone aged 35-64 and 58% for someone 65 or over.
- Respondents were caring for people with a range of health conditions and/or disabilities:
 - 90% said that the person(s) they care for has a long-term health condition or illness such as arthritis, diabetes, kidney disease.
 - 34% a mental health condition.
 - 29% autism, ADHD or another neurodiversity.
 - 26% a physical disability.
 - 25% needs that arise from being older.
 - 24% a neurological condition such as multiple sclerosis.
 - 24% dementia.
 - 22% a learning disability.
 - 18% a sensory impairment.
 - 4% alcohol or substance misuse.

Thanks

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

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Introduction

Last year, in State of Caring 2022, Carers Scotland laid out the financial, physical and emotional toll that the emerging cost-of-living crisis, was having on unpaid carers. This closely followed the worst effects of the pandemic resulting in a devastating impact on a significant number of Scotland's unpaid carers.

This year brings no better news for carers, particularly those who were already struggling to make ends meet. Our 2023 report shows that poverty and financial insecurity has grown yet again, as the cost-of-living crisis has got worse and more damaging to households.

The poverty rate for carers remains higher than for those without a caring role – 29% compared with 20% (an increase from 24% in the previous year)⁴. The rate is higher still for those of working age and those in receipt of certain benefits. For example, the poverty rate for those in receipt of Carer's Allowance is now 34%⁵.

It is not surprising therefore that the DWP's Family Resources Survey found that one in five (21%) households in receipt of Carer's Allowance reported living in food insecurity – nearly three times the rate of the general population⁶.

And as nearly six in ten people live in families where someone is disabled, households are often additionally disadvantaged, facing extra costs over and above their non-disabled peers. These extra costs include, for example, additional costs of heating for someone who has limited mobility, specialist diets for those with digestive or swallowing problems, the additional cost of accessible transport and costs such as care services, products and equipment.

Many of these costs have been subject to significant inflationary increases, making even the basics of everyday life unaffordable for many households.

These financial struggles are exacerbated by carers often having to give up paid work or reduce their working hours to provide care. Reduced incomes from paid work and the limited monetary value of social security benefits leaves many carers in a precarious situation. Limitations in the availability and flexibility of social care to allow paid work leaves carers with few, if any, options to increase their incomes and financial security.

It is clear from the results of State of Caring 2023 set out in this report that substantial numbers of unpaid carers are struggling and can see no respite from the current financial storm. Governments and public authorities must act to give unpaid carers hope of a brighter future.

⁴ Joseph Rowntree Foundation. Poverty in the UK 2023.

⁵ Ibid.

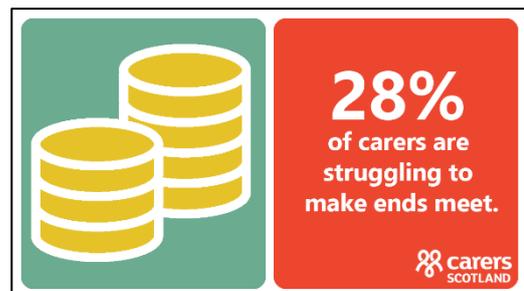
⁶ Department for Work & Pensions (DWP), released 23 March 2023, GOV.UK website, statistical release, Family Resources Survey: financial year 2021 to 2022.

Carers are living with devastating hardship

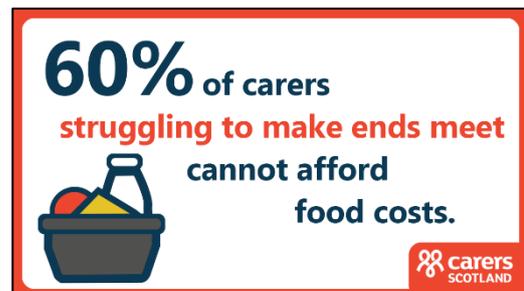


Across all age groups and caring situations, carers report struggling to make ends meet, cutting back on essentials and facing great worry about living costs and how they will manage in the future.

With costs that continue to rise, our 2023 State of Caring survey found more than a quarter of all carers **(28%) are struggling to make ends meet** – an increase of 2 percentage points since 2022. One in five **(21%) are struggling to afford the cost of food** and **16% are struggling to afford to heat their homes**.



More than one in four **(41%) of carers who said that they are struggling to make ends meet said that they cannot afford utility costs** such as heating and **60% say they are struggling to afford the cost of food**.

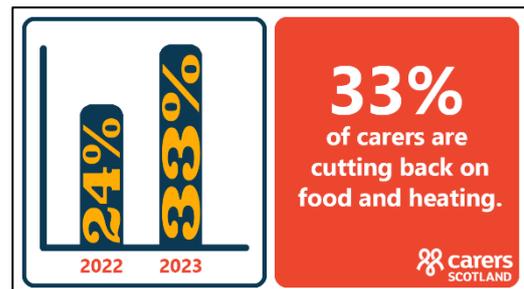


Both food and fuel poverty have increased since 2022. Food poverty rates are significant, growing by 11% since 2022 – undoubtedly driven by the high levels of food price inflation witnessed over the last year.

- *“I haven't got money for food at all, I only have money for some bills.”*

37% of carers that reported they were struggling to make ends meet are also in debt as a consequence of caring and more than one in fifteen (15%) **cannot afford rent or mortgage payments because of financial strain. Eight in 10 are worried about whether they can manage financially in the future.**

The number of carers who tell us they have been forced to cut back on essentials such as heating and food has increased from just under a quarter (24%) in 2022 to 33% in 2023. This is a staggering increase of 38% in just one year.



Of even greater concern is the level of carers who say they are struggling to make ends meet who have to cut back on essentials such as food and heating, with more than two thirds (68%) saying that they have done so.

- *“We were cold over most of the winter being forced not to use gas central heating for more than a couple of hours a day and relied instead on hot water bottles. It was very uncomfortable for us. We took showers at the local pool to save using hot water.”*

Yet, being forced to cut back is only part of the picture. More than half (54%) of all carers reported in the State of Caring survey that they have had to use their savings – nearly double that of 2022 (29%) and of the carers that reported they were struggling to make ends meet more than two third (67%) told us they had relied on their savings.

Given the level of struggle carers are facing, it is unsurprising that two thirds (66%) say they are worried about their ability to plan and save for the future.

Their worries are well founded as the need for carers to use savings to get by simply stores up more poverty for the future, often after their caring role is over.

- *“[I am] using my retirement savings.”*

Debt and borrowing amongst carers continue to grow. The use of credit cards to get by has doubled since 2022 (34% v 17%) and a quarter of carers (24%) are using bank overdrafts to get by. For carers that reported that they were struggling to make ends meet, nearly half (44%) of them are using credit cards and 41% their bank overdraft.

- *“Savings were used in 2018, credit cards are at their limits paying for childcare, have repayment plans (or am about to arrange repayment plans), mortgage deal ends in less than a year and I expect to struggle.*

Can't afford to eat meat anymore, it is just too expensive. We cook from scratch because of food allergies but the increases in basic items have hit us very hard.”

Carers on low incomes

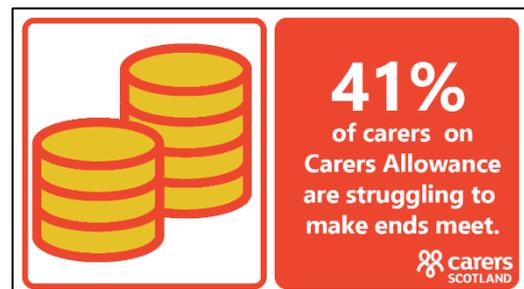
For carers on low incomes and income replacement benefits the picture continues to be particularly troubling.

We know from the most recent Family Resources Survey that nearly a third of carers (**31%**) receiving Carer's Allowance have a net weekly income of under **£200**, with one in five (**23%**) having less than **£150** a week to live on.⁷

The average wage in Scotland is £528 per week and someone working 35 hours at the real living wage (£10.90 per hour) would earn £381.50 per week.⁸ Yet for carers in Scotland, the main benefit – Carer's Allowance (with an extra Carers Allowance Supplement in Scotland) – is worth an equivalent of just £87.15 per week.⁹

Therefore, despite contributing at least 35 hours a week of care but often much more including 24/7 care in some cases, many unpaid carers relying on Carer's Allowance continue to live on devastatingly low levels of income in the face of rapidly rising prices.

State of Caring 2023 shows that levels of financial difficulty continue to be high with **41% of carers in receipt of Carer's Allowance saying they are struggling to make ends meet**, and nearly a quarter (22%) saying they are struggling to afford the cost of food and a similar proportion (23%) struggling to afford the cost of utilities.



The number of carers in receipt of Carer's Allowance responding to the State of Caring survey who are cutting back on essentials such as food and heat as more than doubled since 2021¹⁰. Today 44% of these carers are cutting back on food and heating versus 40% in 2022 and 22% just two years ago.

- *“We can only afford to heat one room. This means our already very restricted life has shrunk even more. It's cold and damp in Scotland for 9 months of the year so this is dismal.”*

⁷ Department for Work & Pensions (DWP), released 23 March 2023, GOV.UK website, statistical release, Family Resources Survey: financial year 2021 to 2022.

⁸ Office for National Statistics. (2022, October 26). Employee earnings in the UK: 2022.

⁹ Carers in Scotland in receipt of Carer's Allowance (worth £76.75 a week) also receive a twice per year lump sum called Carer's Allowance Supplement (worth £541 per annum). Taken together this delivers an annual income of £4532 (equivalent to £87.15 per week)

¹⁰ State of Caring 2021, Carers UK

Again, debt is prevalent with 33% of those carers using credit cards and 26% their bank overdraft to get by.

But Carer's Allowance itself is not the only indicator of poverty and financial struggle. More than half (52%) of carers in receipt of any 'carer element'¹¹ in income replacement benefits (but not receiving Carer's Allowance) told us they were struggling to make ends meet.

Note: a carer element is our shorthand for extra amounts used in the calculation of certain income benefits to reflect caring responsibilities. This is primarily within income support, universal credit and pension credit.

A shocking **40% of these carers are struggling to afford the cost of food** and nearly a third (30%) the cost of energy. More than half (52%) are cutting back on essentials to make ends meet and one in six (16%) are using foodbanks.

- *“Living on Universal Credit is extremely difficult, particularly as I previously earned upwards of £45,000. I am good at managing money but I have been forced to use foodbanks and to cut back on essentials like toiletries and cleaning products in order to survive.”*

These carers are currently excluded from receiving the Carer's Allowance Supplement worth £541 in 2023/24 which, although not of huge value, would still help with crucial bills such as heating. Current plans for the new Carer Support Payment, which will replace Carer's Allowance in Scotland, will not address this.

- *“I have been extremely cold all winter. It saps my energy for caring and makes it harder to look after myself and my cared for person.”*

Parent Carers

The Scottish Government's Child Poverty plans¹² indicates that support of children in households affected by disability and poverty are a priority. Given this priority, it is concerning that many of those caring for a child or young person under 18 that responded to the State of Caring survey reported high levels of financial insecurity.

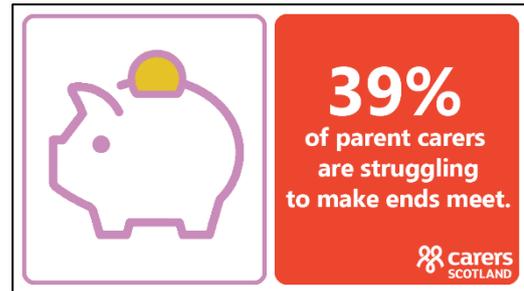
A third (**34%**) of **parent carers of a disabled child under 18 reported they were struggling to make ends meet**, and a worrying 27% cannot afford the cost of food. One in five (20%) are in debt as a result of caring and nearly one in five (18%) cannot afford the costs to heat their home.

- *“There are activities I take my disabled children to where I could pay to join in but I can't afford it. I've leisure and sports. Carers often don't count for discounted prices whereas jobseekers and disabled people etc. do.”*

¹¹ Carer Element in Universal Credit, Carer Premium in Income Support, Carer Addition in Pension Credit

¹² Best Start, Bright Futures: tackling child poverty delivery plan 2022 to 2026, Scottish Government

The level of hardship for parents caring for an adult son or daughter is also high. Over a third (**39%**) of these parent carers reported **struggling to make ends meet**, with 30% unable to afford the cost of food, 22% the cost of heat and a quarter being in debt (23%).



These carers face continued care costs which are not reflected in support available via the social security system.

- *“Fuel costs for large wheelchair vehicle are crippling. It is very hard when all the children's benefits stop as your 'child' is still living with you and eating and needing as much support so nothing changes. Your earning power decreases as they are always there and charities to apply for help are non-existent. Councils are very poor at recognising the massive costs associated with PMLD and insist on a one size fits all client contribution.”*

It is also important to recognise that carers who also have parental responsibility for a non-disabled child under 18 face similar struggles.

A third of carers (**33%**) with responsibilities for a non-disabled child under 18 reported **struggling to make ends meet**. A quarter (25%) are struggling to afford the cost of food and one in five (20%) cannot afford utility bills or are in debt.

This shows a clear need for further work on developing financial support for carers who are caring for both a non-disabled child and someone with a disability.

More care, more struggle

The results of State of Caring 2023 show a clear link between the intensity of care, i.e. hours of care, duration of care, numbers of people being cared for, and financial struggle.

A third of carers (**33%**) caring **35 hours a week or more reported struggling to make ends meet**. This was more than double than those caring for 34 hours or less (16%) or caring for less than 20 hours (15%).



Furthermore, **40% of those caring for three people and 38% of those caring for four or more people reported struggling to make ends meet**.

Carers who have been caring for 10 years or greater are more than twice as likely to report that they are struggling to make ends meet (36%) than those that have been caring for less than 5 years (17%).

We know that caring impacts upon the ability to remain in paid employment.

Half (50%) of carers are in employment compared to 59% of non-carers, and carers are significantly less likely to be in full time work (34% versus 57% for non-carers) and more likely to be in part-time employment (16% v 12%).¹³

Evidence also suggests carers who care for 20 hours or more a week are 22% less likely to be in paid employment than non-carers.¹⁴ With less opportunity to increase earnings to provide financial stability, it is perhaps not surprising therefore that carers with large or long caring responsibilities have struggle to make ends meet.

And, for those that are caring for children and parents at the same time, sometimes known as 'sandwich carers' there is little recognition in the social security system of the demands of multiple and/or long-term caring responsibilities.

- *“We were cold over most of the winter being forced not to use gas central heating for more than a couple of hours a day and relied instead on hot water bottles. It was very uncomfortable for us. We took showers at the local pool to save using hot water.”*

As part of developing a new devolved Carer Support Payment, which will replace Carer's Allowance, the Scottish Government has proposed the development of a Carers Additional Person Payment to recognise multiple caring roles.

However, it is clear that further work is needed to protect the financial security of those with long term, multiple or highly intense caring roles.

¹³ Informal Carers, House of Commons Briefing, 2 June 2023

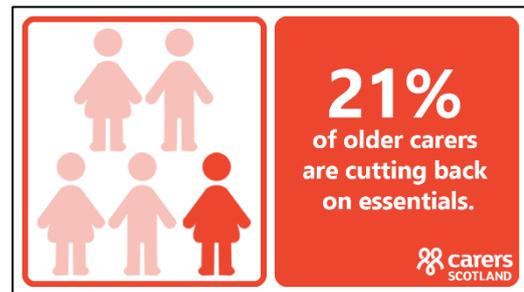
¹⁴ Caring for carers The lives of family carers in the UK Kathryn Petrie James Kirkup, Social Market Foundation, 2018

Working age carers versus older carers

Working age carers under 65 are more likely (33%) to report struggling to make ends meet than those 65 and over (13%).

- *“I am leaving my lighting off and worry for winter again. Makes the home atmosphere very morbid. My husband stays in bedroom rather than moving to living room on days.”*

However, whilst older carers are less likely to report struggling to make ends meet than those of working age, nearly one in ten are struggling to afford the cost of food and one in five (21%) are cutting back on essentials like food and heating to make ends meet. Nearly (42%) say that they are finding it more difficult to manage financially due to the cost of living.



- *“Keeping heating off as gas bill has been too high £182 one month so now, we sit with blankets if it's cold as our state pension is not enough to pay huge utility bills.”*
- *“My husband is housebound/palliative so we don't go out to spend money.”*

Carers with a disability

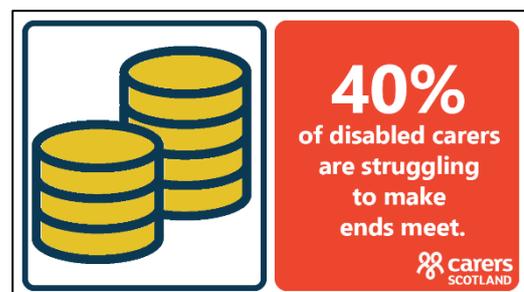
One in five (20%) of carers responding to State of Caring 2023 also have a disability or long-term condition under the Equality Act 2010.

Research shows that the poverty rate for people who live in families where someone is disabled is 28%, which is 9% higher than those who live in families where no one is disabled. Just under half of all households in poverty have someone who is disabled.¹⁵

Carers with a disability therefore face additional risks of being in poverty. State of Caring 2023 found rising levels of carers with a disability who are struggling financially.

Four in 10 (40%) carers with a disability reported struggling to make ends meet compared to 38% in 2022.

One in four (25%) reported that they cannot afford their energy bills and nearly a third (31%) are struggling to afford the cost of food. Four in 10 (41%) have cut back on food or other essentials, one in ten (10%) have been forced to use a foodbank to get by. Cutting back and using foodbanks has not been enough for some leading to increased



¹⁵ Joseph Rowntree Foundation. Poverty in the UK 2023.

debts on necessities. One in ten (9%) say that they have fallen into arrears with housing costs and one in five (18%) with utility bills.

Twenty one percent of disabled carers have high levels of debt as a result of caring. They are also most likely to say (at 11%) that they are struggling to afford the cost of care.

All this means that disabled carers have continued to cut back to try and make ends meet, with three quarters (**77%**) **saying they are finding it more and more difficult to manage financially**. 68% are worried about the costs of living and whether they can manage financially in the future.

- *“Starving isolation depression”*

Worryingly, because of the challenges they face in making ends meet and despite their own disabilities, nearly one in ten (8%) have cut back on support services which help with caring.

Carers in paid employment

Paid employment does not protect carers from poverty.

Nearly a quarter (**23%**) of carers in paid employment reported struggling to make ends meet, with more than one in ten (**11%**) unable to meet all their energy costs and one in six (16%) struggling to afford the cost of food. 30% are having to cut back on essentials such as food and heating, and more than one in ten (12%) are in debt because of their caring responsibilities.



- *“I am working day and night, 4 part time jobs which fit around the care for my son. He is getting far less attention from me. I need to pay the bills and stay out of debt. I never get a day off I have no sick pay so can't be ill. Worry worry worry. Work work work.”*
- *“I have had to take sick leave from my part time job because of a huge increase in my caring role. I have a very understanding employer however they are unable to pay me any more sick pay after this month and my employer will be reviewing my employment.”*

Carers' incomes are cut to the bone

Some households said that they had received support through the UK Government's cost-of-living support programme.

For example, 28% had received the £650 low-income cost of living payment and 18% had received the £300 pensioner cost of living payment and others had received some support through the Scottish Government (28%) and a third (37%) have received the £150 discount from their energy supplier.

However, it is clear that many carers have not received any support and for many the support they received has not been enough.

Significant numbers of carers **(64%) reported that it is becoming harder and harder to manage financially because** of cost-of-living increases. Three quarters of those carers on Carer's Allowance (71%) and nearly all (98%) of those who said that they are struggling to make ends reported that it is becoming harder to manage financially.

- *"I have been unable to do adaptations to house and have no flooring following a flood as can't afford to replace."*

Throughout this report we have highlighted rising levels of debt, increased borrowing and arrears.

- *"I have been unable to do adaptations to house and have no flooring following a flood as can't afford to replace."*

As well as traditional means of borrowing such as credit cards and overdrafts, more carers (16%) are borrowing from friends and family. For those on Carer's Allowance, a quarter (26%) have resorted to this, rising to 39% for those carers who said they were struggling to make ends meet.

And, without adequate income and no realistic option of increasing it, one in six **(16%) carers reported they cannot cut back any further**. For those in receipt of Carer's Allowance this rises to nearly a third (30%).

- *"I can't repair my roof which needs replacing"*
- *"I have no overdraft or credit card - if I need more money, I have to sell things."*

However, given the increasing costs of utilities and rent/mortgage payments, greater problems may arise for carers.

In 2022, 17% of carers who reported in the State of Caring survey they were struggling to make ends meet said they were in arrears with utilities and 8% were in arrears with their rent or mortgage.

However, in 2023, this has increased significantly. More than a quarter **(26%) of those struggling to make ends meet are now reporting being in arrears with utilities**.

Worryingly the level of housing arrears for rent or mortgage has rocketed for all carers who responded to this survey, and not just those who reported struggling to make ends meet, with one in six (16%) telling us they are in arrears.



Homelessness is a very real prospect for carers and the disabled and older people they care for. This is something that the Scottish Government, housing providers and local authorities must not ignore.

- *“Terrified of losing my house due to mortgage increases.”*
- *“Our mortgage payments have increased by £500 and I am unsure where we will be able to find the additional funds. I need to cut back on my hours at work because of my caring responsibilities and we are not entitled to any additional benefits to help.”*

Financially isolated

But it is not just the ‘essentials’ that carers are having to reduce. Nearly half of all carers **(46%) have cut back on seeing friends and family**; who can be valuable support when caring.

The majority of those that reported struggling to make ends meet (79%) as well as nearly two thirds (63%) of those on Carer’s Allowance have cut back on hobbies and leisure activities.

Caring can often lead to isolation and, as such, cutting back on activities like seeing friends and family, hobbies and leisure activities only adds to this isolation.¹⁶

- *“Can no longer afford the little treats that made life bearable. Now I have finances to add to my huge list of worries.”*

Luxuries are often a long-forgotten thing for the majority (81%) of those carers that reported struggling to make ends meet.

- *“Habits of a lifetime have changed, e.g., a daily newspaper has been cut.”*

The link between poverty and poorer health outcomes is well evidenced. People living in the poorest two-fifths of households are almost 8 times as likely to report poor health as the richest fifth.¹⁷

Having access to a sufficient income enables people to not only have the security of the basics of life such as a warm home and sufficient food but reduces the stress and worry that lack of income brings. It also allows access to activities that sustain and improve health such as social, leisure and educational opportunities¹⁸ as well as vital breaks from caring.

- *“With ASD [autism spectrum disorder] and routines it is hard to change shopping and activities for my cared for person so I have had to give up all mine to keep my person feeling safe and secure. I was also mid change from income support to UC for the first cost of living payment and the week of eligibility was the week I had no entitlement.”*

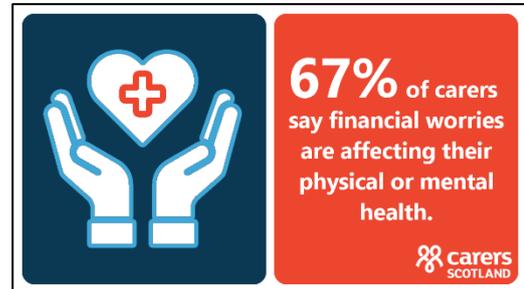
¹⁶ Carers are seven times as likely to be lonely as the general population. Carers UK (2015) Alone and Caring

¹⁷ Leave no one behind: The state of health and health inequalities in Scotland, the Health Foundation. January 2023 <https://doi.org/10.37829/HF-2023-HL01>

¹⁸ How does money influence health? by Michaela Benzeval et al, Joseph Rowntree Foundation, 2014

Even before the cost-of-living crisis, carers were already more likely to be in poor health than non-carers. Those with the heaviest caring responsibilities were twice as likely to be in poor health¹⁹.

It is therefore of no surprise that two thirds of all respondents (67%), including 78% of disabled carers, three quarters (74%) of carers on Carer's Allowance – and a shocking 95% of those reporting struggling to make ends meet say that the financial challenges they face is impacting their mental and physical health.



¹⁹ Census 2011

Caring costs

Local councils can charge for some services provided to disabled and older people. Examples of services include community alarms, non-personal care services provided at home for the person they care for, equipment and in some cases replacement care to enable them to take a break from caring.

Carers may also have to “buy-in” services not provided by local councils such as meals, cleaning, housework as well as additional home care services.

Whilst rising numbers of carers responding to State of Caring are struggling to make ends meet and cutting back as a consequence, too many are also finding the cost of care unaffordable.

Nearly one in ten (9%) of those on Carer’s Allowance and 7% of all respondents reported struggling to afford the cost of care, with a similar proportion having to cut back on care services to make ends meet.

However, alongside this, many carers are being asked to fund the costs of care from their own limited funds.

We asked respondents to State of Caring 2023 if they had expenditure on a range of services and other assistance for the person they care for and to support caring. We also asked how these costs were paid for, whether it was by the cared for person, publicly funded or by carers meeting these costs out of their own pockets.

The information in the following paragraphs refers to the percentages of respondents who said there was such expenditure **and** the percentage of carers who were meeting these costs from their own, often limited, incomes.

Equipment and care services

One in four (**43%**) respondents said that there was expenditure on equipment such as **hoists and grab rails for the person they care for**. Nearly half (46%) of those carers had to pay the cost for this equipment themselves.

A similar proportion of **respondents (43%) reported that there was spending on technology to support care and safety** such as alarms, sensors or remote monitoring. Again, nearly half (48%) of these carers were having to pay the cost for this out of their own pockets.

A quarter (**26%**) of respondents said there was expenditure on **practical support** for the person they care for such as care workers and 14% of respondents reported expenditure on

day care or care home services. One in ten (10%) of these carers were paying for the costs of care at home themselves and one in seven (14%) for day care/care home services.

- *“Day centre costs are greater than pension and attendance allowance, giving up work if they are cancelled would also become a financial burden.”*

Transport

Although Motability vehicles are often funded through disability benefits, for those that require adaptations to their vehicles there can be additional costs to the disabled person. One in seven respondents (14%) reported that there was expenditure on Motability vehicles with nearly a quarter (23%) of these carers meeting this cost themselves.

Two thirds of respondents (66%) said they had expenditure on transport costs (fuel or taxis), with the majority (82%) of these carers saying they were paying the cost of this themselves.

- *“There have been appointments that I have been unable to take my cared for people to because I couldn't afford the fuel for the car.”*

Support for parents

One in twenty (4%) of respondents said there was expenditure on specialised childcare for a disabled child. More than half (53%) of these carers had paid the cost of this themselves.

- *“Tons of stress, and more concerned about future. I am a new dad and finding it very difficult to cope up with all the needs of the household.”*

Other costs

To help manage both caring and family life, carers also have to spend their own funds on a range of supports such as cleaning and meal delivery.

Of those who had such expenditure, 50% paid for the cost of cleaning and 41% paid for meal delivery out of their own pockets, rather than receiving financial support from statutory sources, such as social care.

- *“Food prices. We have to buy specific foods for allergy and autism. Many places also do not count carers as being entitled to discount or concessions and I never understood why this is. I have to paid full entry price to many places where students and unemployed etc are entitled to a concessions rate. I feel I need this and therefore often cannot to go and do things I would like to. Carer's Allowance is my only income. I do not have a job.”*

One in five carers (20%) said they were receiving support to help them cope with their caring role e.g. therapy or counselling and thus had expenditure in this area. Unfortunately, the vast majority (82%) said they had to pay for this themselves rather than being provided or funded from the NHS/health and social care partnerships.

Incontinence poverty

The NHS estimates that between 3 and 6 million people in the UK have some degree of urinary incontinence, with major faecal incontinence affecting around 1.4% of the population. More than half of women will be affected by urinary incontinence at some point in their lives and 10% of men over 65.²⁰

Bladder & Bowel UK has found that more and more people are unable to afford the essential products to manage incontinence. Its research has found that this can lead to a lower quality of life for individuals and their families, as well as other physical and mental health problems.

Within State of Caring 2023, four in ten (41%) respondents said that there was expenditure on incontinence products in their household. Of these carers, more than a third (39%) were paying for this themselves and 42% were funded by the cared-for person. Only 19% said that these products were funded by the NHS, with few having access to continence services.

Worryingly, 38% of carers who are spending their own money on incontinence products are, at the same time, cutting back on essentials like food and heating and 37% are struggling to make ends meet. For households where the disabled or older person pays, nearly a third are cutting back on essentials.

The Scottish Parliament has a proud record in passing legislation to tackle the inequality of period poverty that many women and girls faced. It was recognised as a key element of ensuring dignity. **Incontinence poverty must be seen in the same light.**

How much extra are carers spending?

The cost of caring is high. For those who said they had expenditure on the cost of care and caring, over a third (37%) of carers spent up to £100 per month extra on care support, 16% between £100 and £250 and nearly one in ten (9%) between £250 and £500.



Parents (whether caring for a disabled child or for an adult, but with a non-disabled child under 18) are likely to spend more on care support. Nearly one in seven (15%) were spending between £250 and £500 and 4% were spending between £500 and £750 each month; likely reflecting the significant costs of childcare.

Across all groups, carers are finding it harder and harder to afford the cost of care including care services, transport, equipment, technology, products. Over a third (39%) of all respondents, half of disabled carers and two thirds (68%) of those reporting that they were struggling to make ends meet said they are finding it more difficult to afford these costs.

²⁰ <https://www.allaboutincontinence.co.uk/incontinence-statistics>

And, a large proportion of respondents – from 68% for all carers rising to 97% of those carers reporting that they were struggling to make ends meet – are extremely worried about the extra increases brought about by the cost-of-living crisis.

Given the experiences throughout this report of carers cutting back on just about everything from food and heat to seeing friends and family, it is not unexpected that carers are extremely worried about their financial future.

But it is quite simply unforgivable, given the huge contribution they make to Scotland, that carers' financial security has been allowed to be so compromised; leaving too many in poverty and despair.

Lack of information

Section 3 of the Social Security (Scotland) Act 2018 places a general duty on Scottish ministers to promote take-up of devolved social security including carer and disability benefits.

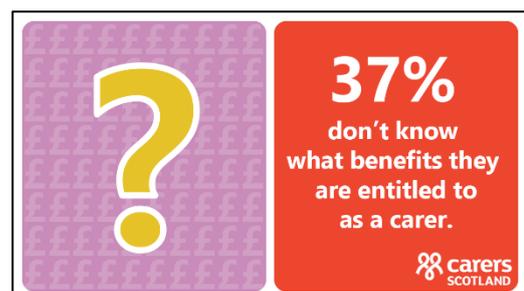
Furthermore, the Carers (Scotland) Act 2016 requires local authorities to have an information and advice service for carers to provide information and advice on, amongst other things, income maximisation.

Both pieces of legislation recognise the critical importance of information, awareness and income maximisation to ensuring that people have access to the greatest financial support available.

However – and worryingly – more than one in five (**22%**) respondents said that they did **not know where to go for help with their finances**.

There was also a general lack of awareness of benefits entitlement with over a third (37%) saying they did not know what they were entitled to as a carer.

Finally, a quarter (27%) did not know where to go for help with their energy bills.



For those who reported that they were struggling to make ends meet, this lack of knowledge was greater with four in 10 saying they did not know where to go for help with finances (41%) or for help with energy bills (42%). A similar proportion (40%) do not know the benefits they are entitled to as a carer.

Whilst there has been significant work nationally and locally, not least in local carers centres, it is clear that for too many carers information has simply not reached them effectively.

Given that the Scottish Government notes the importance of communication and delivering information in the right way in the right place, more work must be done to close the information gap for carers.

- *“I hate being constantly worried about being permanently overdrawn, skint unable to go anywhere and I am very pro-active at helping myself.*

I just get fed up having to turn down offers to go for a coffee days out social events so folk have stopped asking and nobody understands how demoralising it is being permanently broke.

I'm not in arrears with my gas, electric, phone, council tax, TV license, insurance but I have absolutely no life insurance, the cat hasn't had her immunisations or health checks in three years. I cannot afford any work done in the house and everything that I used to enjoy doing I can no longer afford to do, going to the cinema, theatre, live shows, going to NTS properties, days out, walking groups, going for coffee and cake.

I have sold everything that I can but will never go to a food bank, warm space, take food parcels etc, my pride won't allow me.

Every single penny of my savings are gone and the bank won't loan me money because I have no way of paying it back.

On the very very rare occasions I have to borrow money from my friends I get moaned at and made to feel even more humiliated and desperate than ever. They offer then make me feel bad for asking and I would soonest go without.”

Conclusion



As increased cost of living continues to bite, carers are amongst those most significantly affected. In 2022, carers in State of Caring told us of their plight of cutting back the very basics of life, and essential supports for caring and its impact on their lives.

In 2023 this picture has deteriorated further with more carers living in poverty, facing higher costs and cutting back even more. Carers face impossible choices not just of heating, eating or keeping a roof over their head but of sustaining care services and the support they provide.

Action is urgently needed by both Scottish and UK Governments as well as from local councils, health and social care partnerships and the NHS to support carers. We need a long-term plan that seeks to both reduce and prevent carer poverty. With nearly 1000 people starting or ending caring every day and two thirds of us becoming carers at some point in our life – it is not just about today's carers but about every one of us when (not if) we take on a caring role.

Recommendations

1. With Winter fast approaching, the Scottish Government should seek to provide **hardship funding** for unpaid carers during Winter 2023/24 made available through Carers Centres and local councils.
2. The Scottish Government should work with organisations across the sector and **introduce dedicated help for the additional cost faced by households with a severely disabled person**. At a minimum this should include identifying those people with the highest costs related to their conditions e.g. home oxygen/dialysis, additional laundry because of incontinence, electric care equipment or those receiving hospital and hospice at home services.

The Scottish Parliament's Social Justice & Social Security Committee should undertake an inquiry into these additional costs and longer-term actions to address these.

3. The Scottish Government should commit to **uprating all devolved benefits by inflation**.
4. The Scottish Government and Social Security Scotland should undertake a **public awareness campaign** to ensure that those carers receiving only reserved benefits are aware of potential devolved social security entitlements and be provided with some support to ensure that their incomes are maximised.
5. We welcome the planned extension of the replacement for Carer's Allowance – **Carer Support Payment** – to those in full-time education which will be delivered for new claims initially in pilot areas and then throughout Scotland in 2024. However, the Scottish Government should set out a clear timetable for introduction of substantive changes including to the earnings threshold, support for those caring for more than one person and payment when the person who is being cared for enters hospital or dies.

This timetable should include a timeline to develop a payment for those with an underlying entitlement (who cannot be paid Carer's Allowance or the Carer Support Payment) including older carers.

6. The Scottish Government should work with the Department of Work and Pensions to extend **Carers Allowance Supplement** to those with an underlying entitlement.
7. The Scottish Government has committed to **remove care charging** as part of the development of the national care service. These charges should be removed immediately.
8. The Scottish Government should **review its plans for childcare and early years and tackling child poverty** to ensure that they provide appropriate financial and practical support for parent carers.

9. We welcome the recent commitment in the Scottish Government's Programme for Government to progress a minimum income guarantee (MIG) for carers which would be an important component in any plan to tackle and prevent carer poverty.

The Scottish Government should ensure that the MIG, carers benefits, and a range of work to reduce costs forms part of a measurable plan to reduce carer poverty including action on costs such as extending concessionary travel and dental treatment to carers.

10. MSPs across all parties should work together to introduce policies and legislation to **tackle incontinence poverty**.

11. The Scottish Government should work with local councils, health and social care partnerships, the NHS and third sector partners to consider what they can introduce locally to support carers incomes and their health and wellbeing. This includes:

- Providing **income maximisation and advice on fuel and food support** services across all public services including in acute hospitals, primary care and in the community.
- Providing **additional financial assistance to carers centres** to support their capacity.
- Seeking to expand social prescribing of **free leisure access**.
- Expanding **access to taxi cards** and other forms of demand responsive transport to support transport costs.

12. Both Scottish and UK Governments should work to ensure that carers can remain in employment and are better able to juggle work and caring

The UK Government should:

- Ensure that the **Carer's Leave Act 2023** (which gives carers up to one week of unpaid leave from work per year) and new flexible working rights are brought in by April 2024, with robust awareness and implementation.
- Carers Scotland and Carers UK want to see Government hold a longer-term vision about carers juggling work and care, including the **introduction of two weeks paid Carer's Leave and a longer period of unpaid leave**.
- Deliver a **short strategic review** and implement changes that better support carers to juggle work and care within the benefits system.
- Provide a dedicated Work Allowance for carers in receipt of Universal Credit, thus enabling more carers to keep their paid work and to return to work alongside their caring role.

The Scottish Government and MSPs across all parties should seek to **further promote the Carer Positive scheme**, supporting employers to become more carer friendly.

13. 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 Carer Positive** and move towards becoming carer-friendly and support employees who are unpaid carers.

14. The UK Government should review pension rules for unpaid carers with implementation of initiatives to bring 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 unpaid 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/Carer Support Payment to ensure that they continue to contribute to additional pensions.



Carers Scotland is Scotland's membership charity for unpaid carers. We work to represent and support the approximately 800,000 people in Scotland who provide unpaid care for ill, older or disabled family members or friends – fighting for increased recognition and support for all carers and to ensure they have a voice in the issues that affect them.

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