

'We are eating one meal a day and will not put the heating on the house'

State of Caring in Scotland 2022 A cost-of-living crisis for unpaid carers in Scotland

October 2022



About this report

This report was produced by Carers Scotland. It draws from State of Caring 2022, a UK wide survey carried out by Carers UK and Carers Scotland.

2,044 current carers living in Scotland responded to the survey. A demographic breakdown of respondents is on page 13.

We have interspersed this report with the voices of carers. We thank them for telling their stories and sharing their concerns.

Who are unpaid carers?

An unpaid family member, partner or friend who helps a person with daily activities who wouldn't be able to manage if they didn't have help. This could be someone who is seriously ill, disabled or who needs extra help as they grow older. There are approximately 800,000 adults in Scotland providing such unpaid care. It would cost an estimated £10.9 billion every year to replace the care they provide.

Introduction

We are living through an unprecedented time, with the cost of energy, food, fuel, and basic commodities all rising at the same time. The inflation rate is at its highest level in over 40 years¹ – and is due to increase to 13% by the end of the year.² Unpaid carers have been among the groups hardest hit by the cost-of-living crisis in Scotland. Even before the current challenges with cost of living, carers were more likely to be in



poverty than people without a caring role. According to the Joseph Rowntree Foundation, 44% of working age adults who are providing unpaid care for more than 35 hours a week are in poverty³.

The Department of Work and Pension's Family Resources Survey found that 1 in 5 households in receipt of Carers Allowance reported living in food insecurity – nearly three times the rate of the general population⁴.

Many carers already faced higher essential costs because of their caring role. This includes, but is not limited to:

- higher energy costs so that their home is warm enough to ensure the person they care for stays well
- essential equipment that requires power such as hoists, oxygen and wheelchairs
- additional laundry costs as a consequence of incontinence
- extra transport costs to support a person to and from health appointments
- special diets to support the nutritional needs of the person they care for.

 ¹ https://www.theguardian.com/business/2022/jun/22/ukinflation-rises-to-91-its-highest-rate-in-40-years
² https://www.ft.com/content/571dbb52-971f-49e5-9159-3bc73b497742

³ Joseph Rowntree Foundation. Poverty in the UK 2022.

⁴ Table 9.7 Household food security data tables, Family Resources Survey 2020-21, DWP.

"We need the heating on for S, otherwise he becomes ill with chest infections. We also have to pay for his oxygen condenser electricity and then claim it back but it's a 3-month delay. its cost is about £15 per week. it runs 24/7."

"It's horrendous! J is a 71-year-old disabled man who needs heating constantly which I can't afford to do."

"My daughter is on a very fixed diet due to sensory issues so I am unable to cut costs of food for her. She has circulation issues and needs heating on to keep her warm or her chronic pain gets worse so I am unable to cut energy costs. We don't have access to a bus service so going out requires car or taxi, and 15-minute drive to my parents or £15 taxi each way means I can't cut fuel costs. I am so worried about how I can possibly keep this going as the costs keep increasing when there is very little I can do to make savings."

The financial pressures faced by carers have only increased as the costs of life essentials – food, heating, a roof over their head – have increased.

These 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 limited incomes from the social security system leaves many carers in a precarious situation. Beyond giving up care, they have few if any options to increase their incomes and financial security.

"My earnings are not far over the limit to be able to claim Carer's Allowance so I have never been able to claim, even though I have had to drastically reduce my working hours over the years."

Struggling to make ends meet

Across all age groups, carers report struggling to make ends meet, cutting back and being greatly worried about living costs and how they will manage in the future.

With rising costs, the 2022 State of Caring survey found more than a quarter of all carers (26%) are struggling to make ends meet, almost 1 in 5 (16%) struggling to afford the cost of food and a similar proportion struggling to afford to heat their homes.

Nearly 40% of carers who said that they are struggling to make ends meet said that they cannot afford essential costs, 49% are struggling to afford the cost of food and 37% are in debt as a consequence of caring. 8 in 10 are worried about whether they can manage in the future.

The number of carers cutting back on essentials has almost doubled since State of Caring 2021.⁵



40% of carers on Carers Allowance are **Struggling** to make ends meet.

& carers

⁵ State of Caring 2021, Carers UK

Carers on low incomes

The average wage in Scotland in 2021 was £26,007⁶, or just over £2,100 per month. More than half (52%) of carers in State of Caring 2022 do not even have a household income anywhere near this level and indeed, around 1 in 7 (15%) have a gross monthly household income of £1000 or less.

For carers on Carer's Allowance and/or with a household income of £1000 per month or less, the picture is a particularly troubling one with 40% struggling to make ends meet, and almost over a quarter saying they are struggling to afford the cost of food (28%).

The levels of carers in receipt of Carer's Allowance who are cutting back on essentials such as food and heat has almost doubled since the State of Caring 2021⁷. Today 40% of these carers are cutting back on food and heating versus 22% just a year ago.

"I sold my jewelry to pay for the oil tank this year."



Working age carers

Working age carers are more likely to be struggling financially than carers of State Pension age

⁶ Earnings in Scotland 2021, SPiCE 2022

Carers aged 25-34 are considerably less likely to be able to afford utility bills. Over a quarter (29%) of carers in this age group said they were unaffordable versus 11% of those aged 65-69.

Working age carers are more likely to be in debt because of caring. An average of 29% of those of working age versus 5% of those aged 65+ are in debt.

Of all age groups, those aged 18-24 are most likely (80% of respondents) to report that they are struggling to make ends meet.

"I am worried that due to reducing my hours at work I'm not paying as much into my pension. So may have to work longer as can't afford retirement."

There may be a number of factors which influence the higher rates of financial struggle for those of working age.

Firstly, the benefit system for working age people is less generous: not least the low rate of Carer's Allowance at just £69.70 a week. Even with the welcome top up of £245.40 every 6 months from Carer's Allowance Supplement, this equates to only £79.15 each week.

Many carers of working age were excluded from extra cost of living support payments whereas older carers on low incomes received extra support.

Housing costs may also be a factor. Facing a struggle to afford rent or mortgage costs is higher amongst younger carers (25-34 (16%), 35-44 (8%) versus less than 1% of those aged 65 and over.

⁷ State of Caring 2021, Carers UK

Giving up paid work to care is a critical factor. Around 600 people give up work every day to take on a caring role⁸ as they cannot juggle work and caring. Carers also reduce hours and take lower paid but more flexible jobs simply to be able to juggle work with the demands of caring.

"I went bankrupt and had property repossessed when I became a full-time carer to my severely disabled husband."

Finally, within this survey, 27% of carers also said that they had parental responsibilities for a non-disabled child under 18, which may reflect the fact that the cost of childcare, alongside all other household costs (outwith the 1140 hours funded early years provision) continues to rise steadily⁹.

"Due to taking a job that pays less but allows me to be at home in evenings and weekends has reduced our monthly income. But as my daughter needs me around as much as possible, she has autism and dyscalculia so needs support with communicating and understanding my brother also has a learning disability a head injury and cortical basal degeneration, so combine the two with my being a wife mum of three and finances become really tight. I am not entitled to Carers Allowance."

Older Carers

It is important to say that, despite the higher levels of financial insecurity amongst working age carers, older carers also face significant challenges. State of Caring 2022 reports that 15% cannot afford their energy bills and 16% cannot afford their food bills. Two thirds are extremely worried about how they will manage financially and 23% are struggling to make ends meet.

Slightly more older carers said they were spending more on their energy bills (93% v 91% for all carers), on supplies such as incontinence products (37% v 29%), housing costs (25% v 22%) and lateral flow tests (11.5% v 9%).



Carers in paid employment

Even for those with some form of income beyond social security, the picture is bleak. Just under a third (32%) of respondents were in paid employment or self-employed.

Of these, one in five said that they were struggling to make ends meet and 1 in 10 were struggling to afford the cost of food. Almost a quarter were cutting back on essentials such as heat and food. Almost two thirds (64%) were worried about whether they can manage financially in the future.

Many employed carers had household incomes below the Scottish earning average with 29% having a gross household income below £2,000 per month and 11% below £1000 per month.

 $^{^{\}rm 8}$ Juggling work and unpaid care A growing issue, Carers UK 2019

⁹ Coram Family and Childcare Survey 2022

One in five work part time, reflecting the fact that many carers have to reduce their hours to juggle work with their caring role.

Only 14% receive Carer's Allowance or the Universal Credit Carer Element alongside their earnings from employment. This low level of support from social security, reflects the challenging and complex benefits system, where carers can earn only 13.5 hours at the national living wage (£132 per week maximum) before losing their entitlement to Carer's Allowance.

"I can't work due to my son's disabilities. My partner is on a low wage he has to change job to be with us more to support our son and I don't know how we can financially make it through the year. Every aspect of our lives is impacted. Even the fuel to get him to work is unaffordable. I'm full of anxiety and can't see a light at the end of the tunnel. I will be a carer for the rest of my life but have no savings and no way of earning to help meet rising costs."

Disabled Carers

Just under a quarter (23%) of carers who took part in State of Caring 2022 have a disability as defined under the Equality Act 2010.

Disabled people face a higher risk of poverty and have done so for at least the last 20 years¹⁰. Working age disabled people are twice as likely to live in poverty than those who do not have a disability.

Given this, it is perhaps not surprising that carers with a disability were more likely to be struggling to make ends meet (38%) than the average carer responding to the survey and significantly more likely to be struggling to afford the costs of food (38% v 16% all carers) and of energy bills (23% v 16% all carers).

"I am also disabled as well as caring for my son. I struggle to work and spend a lot of time sick but I must still care for my son. We live on north coast of Scotland and I won't be able to buy more heating oil when tank runs out. I need to bath my son every day."

Rising Costs

Unsurprisingly, almost all carers (91%) said they were spending more on energy and heating costs. Carers report high levels of energy insecurity, spending significant proportions of their income on the energy.

In Scotland, fuel poverty is measured by two criteria:

- to maintain a "satisfactory heating regime" costs must be more than 10% of household net income after deducting housing costs and;
- the remaining household net income after the payment of fuel costs and any benefits received for a care need or disability (if any) and the household's childcare costs (if any) must also be insufficient to maintain an acceptable standard of living for the household.

Overall, over a third (35%) of carers in State of Caring 2022 are spending 20% of their income or more on energy. 16% are spending 30% or more.

¹⁰ Poverty in the UK, Joseph Rowntree Foundation 2022



35% of carers in State of Caring 2022 are spending 20% of their income or more on energy. Those on the lowest incomes are facing even greater challenge with 47% of carers on Carer's Allowance spending 20% of their income or more on energy. Over a third (37%) of older carers are spending at least 20% of their income on energy.

Some groups of carers are spending even greater amounts of their incomes on heating. A third of carers who are struggling to make ends meet are spending 30% on fuel and almost one in five (19%) of carers with gross household income of less than £1,000 per month are spending 50% or more of their income on energy.

The proportion of carers' limited incomes being spent on energy is extremely concerning. It is even more concerning that this will be a deteriorating picture. State of Caring 2022 was carried out before the latest rises in October 2022



19% of carers with an income of less than £1,000 per month are spending 50% or more of their income on energy. & carers SCOTLAND However, across **every** part of their lives, carers talked of having to spend more from their limited incomes.

Spending more on:

- 89% spending more on food and drink
- 73% spending more on transport
- 22% spending more on housing costs
- 59% spending more on cleaning products
- 47% spending more on consumer goods such as clothes and household items

Moreover, for carers the cost of their caring role has also increased.

- 14% spending more on care services
- 29% spending more on supplies related to care such as incontinence pads
- 15% spending more on equipment

Carers also continue to bear the financial cost for keeping the person they care for safe from COVID19. 29% are spending more on items such as PPE, hand sanitizer and masks and asymptomatic lateral flow tests.

Cutting Back

Carers talked about the ways they were trying to meet the extra costs they faced.

Almost quarter (24%) of carers were cutting back on essentials like food and heating.



Carers also told us about borrowing, using savings and falling into arrears but also cutting back on costs associated with their informal and formal support systems and the things that help support both their wellbeing and the wellbeing of the person they care for.

"I cannot afford quality time with my terminally ill son ie. days out, lunches, cinema etc."

"The only thing my son enjoys is fast food but we can't afford it anymore."

Carers who said that they were "struggling to make ends meet" were around twice as likely to have to cut back, fall into arrears, or rely on borrowing or savings compared to those carers who said that they were "not struggling". *(Figures for carers struggling to make ends meet are indicated in red).*

Cutting back

- 24% cutting back on essentials (54%)
- 4.43% are using foodbanks (11.5%)
- 48% are cutting back on hobbies/leisure activities (75%)
- 51% cutting back on luxuries (75%)

"Sitting without heating on as too afraid to burn it. Cutting back on my monthly food shop using cheaper washing up liquids, soap. Not being able to treat my son to one outing per month totally devastating at times plus extremely low moods."



54% of carers who are struggling to make ends meet are cutting back on food and heat. % carers

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

Falling into arrears

- 7% energy utility bills (17%)
- 3% rent or mortgage payments (8%)

"We are on the verge of losing our home. Our home will be repossessed as my husband, our only source of income has lost his job. Our home is adapted for our severely disabled son and I am ill with worry thinking of the accommodation we could possibly be housed in."

Borrowing and savings

- 17% using bank account overdraft (34%)
- 29% using savings (41%)
- 17% using credit cards (35%)
- 4% bank loan (8%)
- 2% pay day loans (4%)
- 14% borrowing from friends and family (33%)

"I have to live off of borrowed money during the summer because I don't have the time to work due to my caring responsibilities. It is insane that I am not entitled to Carer's Allowance because I am a student. Neither of these cancel out the other one, despite what the means-tested Carer's Allowance dictates."

Reducing support

- 33% are cutting back on seeing friends and family (62%)
- 6% cutting back on support services which help with caring (13%)

Unexpected Expenses

State of Caring 2022 also explored whether carers have any ability to plan for an unexpected but necessary expense of £850.

An example may be replacing a washer/dryer – an essential item for carers particularly those that have large amounts of bedding or clothing to be washed and dried on a daily basis because of incontinence.

Very few carers had the means to absorb such an expense. Nearly half (48%) of carers said they could not meet such a cost and, amongst carers in receipt of Carer's Allowance, over two thirds (67%) said this would be impossible.

Over half (53%) of carers in receipt of Pension Credit and almost 8 in 10 (79%) of those with a household income of \pounds 1,000 or less said they could not afford such an expense.

Effects on Physical and Mental Health

The cost-of-living crisis is causing significant damage to carers financial security but the impact goes well beyond simply money.

Nearly two thirds (64%) of carers in State of Caring 2022 told us that cost-of-living

worries were causing a negative impact on their physical and mental health.

For those on lower incomes, this impact was even greater, with 73% of carers on Carer's Allowance and 84% of carers with a household income of £1,000 or less a month saying that the cost of living was having a negative impact on their health.

Recently, the Scottish Parliament's Health, Social Care and Sport Committee clearly identified that *"caring is a social determinant of health inequalities"* and that there was *"strong evidence of the interconnection between levels of poverty and levels of health inequality and the severe negative impact poverty has on health and wellbeing outcomes."*¹¹

Our main State of Caring 2022 report speaks to the wider challenges of being a carer in Scotland in 2022. This includes more detailed analysis of the health and wellbeing impacts of caring and the impact of carers of delays to and accessibility of treatment.

However, the combination of the long understood negative health impacts of caring and the significant poverty that many carers are facing - exacerbated by the cost-of-living crisis means this must be considered a significant public health priority.

The costs of doing nothing will leave more carers in poor health, financially insecure and continuing to face unacceptable choices of heating or eating. The risks of both carers and care breaking down are high.

¹¹ Tackling health inequalities in Scotland, Scottish Parliament Health, Social Care and Sport Committee, SP Paper 230, 28 September 2022

"We are eating one meal a day and will not put the heating on the house is damp. We have asked GP for support with grant applications for insulation but they said there was nothing they could do. Now taking inhalers and all suffering ill health from mould and lack of access to physical recreations..."

"It is a big worry as i have no idea how I am going to manage the food and energy increases that are occurring and getting worse so I cannot plan and it is affecting my mental health which is already fragile."

"I am so worried about the increase cost of living that I get panic attacks, I can't sleep, I feel nauseous when I look at my bank balance. I honestly don't know what to do if it gets worse - what else can I cut back on? Eat less? Turn the power off? Stop taking my son anywhere? It's absolutely terrifying and nobody in power seems to care at all."

Carers priorities for assistance

We asked carers what could help support them financially. Carers could choose more than one option.

Their top priority was an increase in the value of carers' benefits (42%) closely followed by an increasing in the Carer's Allowance earnings threshold (33%) and a one-off cost of living payment (32%).

A quarter of carers (24%) said that improved support and guidance to help them navigate the benefits system would help.

More than one in ten (13%) said some form of other financial help such as a hardship grant would help support them and a similar proportion (13%) highlighted the need to reduce care charges.

Conclusion

Poverty amongst carers is a growing crisis, which is being exacerbated by the current cost of living crisis, which is threatening to get worse. Many carers are being forced to cut back on the very basics of life, and essential supports for caring – impacting on their health and wellbeing, financial security, employment and ability to provide care.

Action is necessary now by both the Scottish and UK Governments as well as from local councils, health and social care partnerships and the NHS to support carers through the cost-of-living crisis. There also, needs to be a long-term plan delivered by Governments that aspires to value and support carers effectively and prevent lifelong poverty and financial insecurity.

Recommendations

1. Carers UK, is making the case to the UK Government for a range of measures to help carers.

This includes uprating all benefits including Carer's Allowance and the Carer's Element of Universal Credit by inflation (ideally before next April to support people to survive the winter months) and providing a top up payment for all carers with an entitlement to Carer's Allowance.

The UK Government should also review pension rules with initiatives to bring carers up to similar pension levels as non-carers including creating a mechanism by which carers are able to receive their state pension up to five years early. The full recommendations can be found at: <u>www.carersuk.org</u> In partnership with the UK Government, the Scottish Government should seek to increase the earnings limit for Carer's Allowance. At a UK level, Carers UK are calling for this to be set at 21 hours a week at National Living Wage (£199.50 at 2022/23 rates), to allow working carers to make up the difference in their incomes and outgoings.

Unpaid carers need the option to make ends meet during these unprecedented times, without being penalised¹². Carers Allowance has no taper, so carers going over their earnings limit of 13.5 hours a week at NLW, even by a small amount, will lose all of their entitlement to Carer's Allowance.

- The Scottish Government should provide a Scottish additional cost of living payment for carers, for example, by increasing December's Carer's Allowance Supplement. (As an example, in Wales, carers can receive a one-off £200 fuel support payment). The Scottish Government should also seek to extend this cost-of-living payment to carers with an underlying entitlement to Carer's Allowance.
- 4. The Scottish Government should introduce dedicated help with energy costs for households with a severely disabled person. At a minimum this should include identifying those people with the highest costs related to their conditions eg. hospital and hospice at home services, home oxygen, electric hoists and beds etc. and develop a financial support

scheme to cover these additional costs.

These costs if not alleviated will increase the likelihood of greater and more costly intervention including hospital admission to provide safe heating levels or to equipment usage.

5. The Scottish Government should commit to uprating devolved benefits by current inflation. We welcome the earlier uprating of some devolved benefits by 6% earlier this year. It recognised inflation at that time but inflation continues to climb and is expected to reach 13% by the end of the year, we do not believe that vulnerable people on low incomes can wait until April to have an increase to their benefits, without serious consequences to their health and wellbeing.

The Scottish Government should provide an interim payment to devolved benefits that matches inflation and commit to uprating devolved benefits in 2023/24 rates by a similar proportion.

 As part of the delivery of the replacement for Carer's Allowance – Scottish Carer's Assistance – the Scottish Government should actively review eligibility criteria and implement changes to ensure that it adequately values and supports carers including supporting carers more effectively to juggle work and care.

 $^{^{12}}$ A carer whose salary is £1 a week over the threshold would lose up to £3,624 of Carer's Allowance

Older carers also face significant financial challenge and are currently not eligible for Carer's Allowance. Therefore, the Scottish Government should increase the pace of work to develop an additional payment for longer term carers who are of State Pension Age.

- 7. With carers in State of Caring cutting back on vital care services because of cost, the Scottish Government should seek to remove care charging at pace but in the interim set a framework, national directions and provide the necessary funding to local councils to ensure that all local partnerships provide disability related expenditure reductions to take account of increased energy and inflationary costs.
- 8. Carer poverty is not new. It is being exacerbated considerably by the current cost of living crisis, and carers were *already* more likely to be in poverty. The impact of caring on incomes can be lifelong and continue long after caring has ended, leaving carers in dire straits with reduced state and occupational pensions.

The Scottish Government should commit to developing a national Carer Poverty action plan with clear measurable actions to support carers' financial security in the longer term. This has been identified by the Scottish Parliament Health, Social Care and Sport Committee's Tackling Health Inequalities report, as an important element in reducing the health inequalities amongst carers – without a plan, caring will continue to cause financial insecurity and damage to health.

- 9. The Scottish Government should work with local councils, health and social care partnerships and the NHS to consider what they can introduce locally to support carers incomes and their health and wellbeing. This includes:
 - Extending the Scottish Welfare Fund to include unpaid carers experiencing hardship.
 - Expanding social prescribing of free leisure access
 - Expanding access to taxi cards or other such schemes to support transport costs and help those who are more isolated due to concerns over COVID
 - Providing income maximisation services (or have an active referral system to these) across all services including in acute hospitals, primary care and community.
 - Expanding access to adult carer support plans, in particular offering them to all carers during the hospital discharge process.
 - Developing a more coordinated approach across health, social care and local council services to refer carers to third and community support including, in particular food support and fuel vouchers.

State of Caring 2022 Carer Profiles

Respondents who answered the demographic questions in State of Caring 2022. There were 2,044 responses in Scotland.

Where carers can pick more than one option eg. disability or condition of the person they care for these will not total 100%.

Gender: 83% are female, 15% male and 2% chose to self-identify.

Ethnicity: 97% are white Scottish, Irish or other white. Around 3% were from black or minority ethnic communities.

Sexuality: 91% are heterosexual, 2% gay or lesbian, 2% bisexual, 1% self-described and the remainder preferred not to say.

Disability: A quarter (23%) have a disability as defined 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.

Age: <18-24 (0.5%), 25-44 (17%), 45-64 (61%), 65-69 (9%), 70-79 (10.5%), 80 or over (2%)

Other caring responsibilities: 27% also have caring responsibilities for a non-disabled child under 18.

Length of time they have been a carer:

32% have cared for 15 years or more, 14% for 10-14 years, 23% for 5-9 years, 20% for 2-4 years, 8% for 1-2 years and 3% for less than a year. **Caring hours per week**: 55% care for 50 hours or more, 14% for 35-44 hours, 11% for 20-34 hours and 20% for less than 20 hours. (Note, 40% of those caring 50 hours or more are caring for 90 hours plus each week).

Number of people cared for: 72% care for one person, 21% for two people and 7% for 3 or more people.

Who do they care for? 38% care for a parent/in law, 38% for a son or daughter/in law, 30% for a spouse/partner, 11% for another relative and 1% for a friend or neighbour.

Cared for person's age: Under 18 (19%), under 25 (9%), 25-64 (37%), 65-84 (38%) and 85 and over (21%),

Condition/Disability of the person they

care for: physical disability (45%), mental health condition (30%), learning disability (23%), autism (22%), needs from being older/frailty (40%), dementia (21%), long term health condition (34%), neurological condition (16%), cancer (6.5%), sensory impairment (13%), alcohol or drug addiction (3%), multiple conditions (20%), palliative/end of life (2%) and long COVID (1%).

Where do carers live?

Remote rural or island community (5%), rural (19%), large village (12%), urban (64%)





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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