



State of Caring 2022

A picture of unpaid caring in Scotland



State of Caring 2022

This report was produced by Carers Scotland and explores the key findings from our latest State of Caring survey. The annual State of Caring has been carried out for over a decade and is the most comprehensive research into the lives of unpaid carers in Scotland.

This report provides an overview of the data from State of Caring 2022 along with the experiences of carers.

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.

The 2022 State of Caring survey was carried out between July and September 2022 and completed by **2,044** unpaid carers across Scotland– the largest sample size in the survey’s history.

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

About respondents

The demographic breakdown of survey respondents is as follows:

- 83% are female, 15% male and 2% chose to self-identify.
- 97% are white Scottish, Irish or other white. Around 3% were from black or minority ethnic communities.
- 91% are heterosexual, 2% gay or lesbian, 2% bisexual, 1% self-described and the remainder preferred not to say.
- A quarter (23%) have a disability as defined under the Equality Act 2010.

- Age of respondents: <18-24 (0.5%), 25-44 (17%), 45-64 (61%), 65-69 (9%), 70-79 (10.5%), 80 or over (2%)
- 5% live in a remote rural or island community, 19% in a rural area, 12% in large village and 64% in an urban area
- 27% also have caring responsibilities for a non-disabled child under 18.
- 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.
- 55% provide care for 50 hours or more each week, 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).
- 72% care for one person, 21% for two people and 7% for 3 or more people.

About the people carers 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.
- 19% of those cared for are under 18, 9% under 25, 37% aged 25-64, 38% aged 65-84 and 21% aged 85 and over.
- 45% of the people cared for have a physical disability, 30% a mental health condition, 23% a learning disability, 22% have autism (22%). 40% have needs from being older/frailty, 21% have dementia, 34% have a long term health condition and 16% a neurological condition, 1% have long COVID and 3% an alcohol or drug addiction. 6.5% have cancer and 2% are receiving palliative/end of life care.

Introduction

A carer is 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 people in Scotland providing such unpaid care. 17% of the female, and 12% of the male, population of Scotland are carers¹.

It would cost an estimated £10.9 billion every year to replace the care they provide. Without unpaid carers it would be impossible to deliver health and social care in Scotland –the system would simply collapse.

However, despite this huge contribution, too many carers experience significant disadvantage to their own lives; often living in poverty, in poorer health and with their opportunities to have a fulfilling life alongside caring curtailed.

There is perhaps no greater example of this than the [cost-of-living crisis. Scotland's unpaid carers](#)² have been among the hardest hit by spiraling household bills, and many are now living a spartan existence, cutting back on essentials like food and heat simply to make ends meet. Many more are living on the margins, struggling to cover their monthly expenses and frightened about what the future holds.

Elsewhere, carers continue to struggle to access the services and support they need to care for themselves and take regular breaks from caring.

This report shines a spotlight on these issues and many more, exploring the biggest challenges facing unpaid carers in Scotland today. It paints a bleak picture, showing the extent to which many are sacrificing their own health, wellbeing, life chances and financial security to provide care.

It gives call to action to better support unpaid carers. For too long, carers have been taken for granted –relied upon and giving so much of themselves but getting so little in return.

This cannot continue. In this report we have set out a range of recommendations – many of whom must be pursued urgently – to support carers practically and financially. They deserve no less.

¹ Scotland's carers: update release, Scottish Government, April 2022

² State of Caring in Scotland 2022: A cost-of-living crisis for unpaid carers in Scotland, Carers Scotland, October 2022

Financial impact of caring

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 decades and is expected to continue to rise to 11% before the end of the year³.

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 poverty⁴.

Many carers already faced higher essential costs because of their caring role. This includes higher energy costs so that their home is warm enough to ensure the person they care for stays well; the cost to power essential equipment such as hoists, oxygen and wheelchairs; additional laundry costs; extra transport costs and special diets to support the nutritional needs of the person they care for.

“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.

“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.”

These pre-existing financial pressures have only been compounded as living costs have shot up so drastically. As this chapter shows, this is leaving too many carers in Scotland without enough money to cover their monthly expenses or afford a decent standard of living.

Carers face growing financial pressures

Unsurprisingly, our 2022 survey findings suggest that the financial pressures facing Scotland’s carer population have worsened significantly since last year. Nearly all carers (91%) said their energy bills had increased, while 89% were spending more on food and

³ Bank of England (October 2020)
<https://www.bankofengland.co.uk/knowledgebank/will-inflation-in-the-uk-keep-rising>

⁴ Joseph Rowntree Foundation. Poverty in the UK 2022.

drink, 73% were spending more on transport, and 22% were spending more on housing costs (eg. rent or mortgage payments).

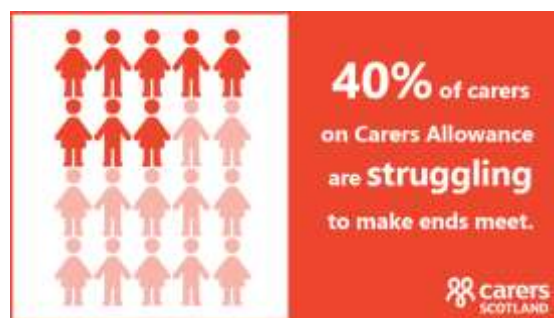
Carers are also spending more of their limited incomes on the cost of care, with 1 in 7 (14%) spending more on care services, nearly a third spending more on supplies such as incontinence pads and 15% spending more on equipment.

All-in-all, 26% of carers told our survey that they were struggling to make ends meet. And, overall, only a third (35%) saying they could afford their bills without struggling financially, which is significantly less than the 59% of carers in State of Caring 2021.

With rising costs, the 2022 State of Caring survey found almost 1 in 5 (16%) struggling to afford the cost of food and a similar proportion struggling to afford to heat their homes.

While few have been unaffected by the cost-of-living crisis, our findings suggest it is having a disproportionate impact on some groups of carers. Firstly, those who are not in paid employment and are receiving Carers Allowance were much more likely to be struggling to make ends meet than carers overall (48% vs 26%), and more likely to be debt because of caring (24% v 16%).

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 2021⁵. Today 40% of these carers are cutting back on food and heating versus 22% just a year ago.



The level of struggle faced by carers on Carer's Allowance is perhaps not surprising. Many carers rely on this benefit as one of the few sources of financial support available – with paid employment difficult if not impossible to fit around the demands of their caring role – but it is amongst the lowest of its kind and the value of weekly payments has fallen far behind current living costs.

Carer's Allowance is currently £69.70 (plus the equivalent of £9.45 per week Carer's Allowance Supplement⁶ for carers in Scotland) for a minimum of 35 hours each week – **worth just £2.26 per hour**.

For the 40% of carers in State of Caring 2022 who care for 90 hours or more each week this is a **miserly 88p per hour**.

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

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

⁵ State of Caring 2021, Carers UK

⁶ Carers Allowance Supplement is paid to carers in receipt of Carer's Allowance Scotland in two 6 monthly lump sum payments of £245.70 each.

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

There is a less generous benefit system for people of working age, with many working age benefits frozen over the years of austerity whilst the State Pension Triple Lock has kept better pace with costs.

“As a family of 5 shopping budget has increased and my gas electricity going up I don’t know the last time I put my heating on. My tax credits have also dropped £100 so I’m living on £150 a week instead of £250 as of this month.”

Giving up paid work to care is a critical factor. Around 600 people give up work every day to take on a caring role⁷ 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.”

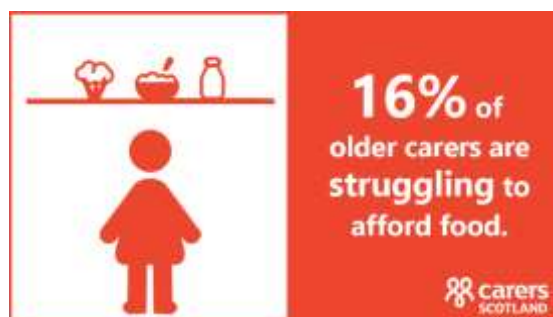
“I will cut back on food to pay my bills. I am determined to continue to work 4 days and to contribute to society but it is exhausting.”

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

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 steadily⁸.

“Fixed deal coming to an end, energy bill due to go up over 100%, food costs for a sensory diet have increased massively. Petrol costs are making it hard to get kids to school (due to ASD eldest can’t cope with public transport)”

However, 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, 16% cannot afford their food bills and just under a quarter (23%) are struggling to make ends meet.



Finally, our findings illustrate that those providing unpaid care while living with a disability of their own (23% of all respondents) are often hit with a double blow.

Disabled people face a higher risk of poverty and have done so for at least the last 20 years⁹. They face the extra costs associated with both disability – estimated to be hundreds of pounds per month on average¹⁰ – and caring at the same time. Given this it is perhaps not surprising that, compared to carers without a disability, disabled carers were more than likely to be struggling to make ends meet (38% vs 26%), to be unable to afford utility bills like electricity or gas (23% vs 16%) and to be struggling to afford the cost of food (38% vs 16%).

⁷ Juggling work and unpaid care A growing issue, Carers UK 2019

⁸ Coram Family and Childcare Survey 2022

⁹ Poverty in the UK, Joseph Rowntree Foundation 2022

¹⁰ Scope (2019). The disability price tag 2019.

"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."

"I am not well enough to take a job and I've been waiting ten months for the DWP to decide whether I'm entitled to any help so I've not got sufficient funds to pay for normal bills let alone pay for the extortionate rises."

Cutting back, borrowing and debt

Worryingly, with few ways to increase their limited incomes, we found that many carers are deploying unsustainable and damaging practices to help them cope with spiraling living costs.

Nearly one in 4 carers (24%) said they were cutting back on essentials like food or heating – double the proportion last year (11%). Small, but notable, numbers said they were using food banks (5%) and falling into housing arrears (3%).



Nearly a fifth (17%) of carers were using their bank account overdraft to help them cope, 29% were using their savings and 17% were using credit cards to get by. These behaviours provide only limited and short-term solutions, leaving many carers with depleted financial resources and greater debt later down the line.

For those carers on the lowest household incomes (of £1,000 per month or less) the picture was even more concerning, with 40%

struggling to make ends meet, 11.5% using foodbanks and 8% falling into housing arrears.

Carers in this group were also more likely to be surviving financially by using their overdraft (22% v 17%), borrowing from friends and family (29% v 14%) and cutting back on food and heat (43% v 24%).

"The only reason I survive is to very carefully manage our benefits which fortunately I am capable of doing. My life reflects that of my gran who was brought up in poverty 100 years ago and who I have to thank for my ability to cope now but I don't know for how much longer"



An energy crisis for carers

Of most concern in State of Caring 2022, are the levels of energy insecurity faced by carers. Whilst the data showed many cutting back on the heating itself, the portion of carers incomes used solely to meet the costs of heating their homes is increasing rapidly. Over a third (35%) of all carers are spending 20% of their income or more on energy, with those on the lowest household incomes (of £1000 per month or less) spending a staggering 50% or more. What is even more worrying is that State of Caring was carried out before the latest price rises in October 2022.

"My fuel bills have doubled. Food has gone up so I eat less, skip meals & ensure my spouse has enough food at mealtimes."

Impact on health and wellbeing

The cost-of-living crisis is causing untold damage to carers financial security but the

impact goes well beyond simply money. Nearly two thirds (64%) of all carers in State of Caring 2022 said that cost of living worries were having a negative impact on their health. Amongst those on the lowest incomes (carers on Carer's Allowance and those households living gross incomes of less than £1000 per month) the impact on health is even more stark. Three quarters of carers (73%) on Carer's Allowance and 84% of carers living on £1,000 per month or less said that money worries were making them ill.

"Not case of "cutting back" simply don't go anywhere, see anyone or do anything."

Throughout the survey, carers described the inescapable stress, anxiety and fear caused by growing living costs, with feelings of hopelessness that their financial situation, and associated mental ill-health, would improve in the time ahead. The impact this was having is palpable.

At the moment I am struggling financially but am not in any debt. At the end of August however, my tax credits and child maintenance comes to an end so I will lose £700 a month. I know then that I will end up being unable to pay bills. I have had a benefits check and am only entitled to £100 a month universal credit when my tax credits stop, so I will still be down £600 a month. I can't move to full time hours at work because I provide care for my daughter but I don't provide enough hours of care to receive carers benefits. The worry over finances is causing me sleepless nights and has left me with suicidal thoughts."

The cost-of-living crisis is making it even harder for many carers to take breaks from caring including spending invaluable time with friends and family and taking part in activity to improve their wellbeing and get the support they need from social care.

Almost half of carers (46%) said they were coping by cutting back on hobbies or leisure activities, and 33% said they were cutting back on seeing friends and family. For many people, caring is a 24/7, all-year-round role, and the opportunity to do things for themselves, spend time with friends and take part in hobbies can be a lifeline that has been cruelly diminished by rising living costs.

"My heating is turned off, and only hot water at present. I'm worried about how this will be impacted as winter arrives. I use minimal electricity. I don't have electrical items on if not being used including the mains to cooker. We don't have hot meals every day. My washing machine is on every day for bedding/clothes Only thing continually on in my home is the fridge. I am already on the lowest tariff for electricity and cannot lower anymore I miss out on meals to accommodate making sure husband has good to coincide with medications. We don't watch TV or have internet provider or home telephone. Mobile essential for links to paying bills, banking as no bank in town! Contacting doctors and keeping in touch with my own family. My husband's is also always charged at his side if I have to go out for essentials. Shopping I work out what I can afford before I leave house and don't deviate from it. I don't use luxury brands and compare receipts for price changes and buy from the reduced section most of the time. I already see the increases in basics in the local retailers. Constant juggling. There is no quality-of-life incentives which doesn't help my husband who has cognitive issues and limited mobility as is. Cost of living increases just makes for more worries. It causes increased loss of communication between each other and have become excluded from social interaction with others."

A more detailed report focusing on cost-of-living **State of Caring in Scotland 2022: A cost of living crisis for unpaid carers**¹¹ was published by Carers Scotland in October 2022. You can find this report on our website at www.carerscotland.org

¹¹ State of Caring in Scotland 2022: A cost-of-living crisis for unpaid carers in Scotland, Carers Scotland, October 2022

Support and services

Carers rely heavily on health and social care services to support them in their caring role, but, with the ongoing pandemic and years of chronic underinvestment, the system is on its knees. This has created care gaps that are usually filled by unpaid carers. Unsurprisingly, we found that many carers are still struggling to access the right care packages when they need them.

Access to care and support

In recent years, Scotland's health and social care system has seen increasing waits to access both assessment and care packages. Whilst the pandemic has been a contributory factor between 2020 and 2022, carers have long told us they struggled to get the support they need.

Whilst there has been a broadly stable picture since 2012 (notwithstanding the need for improvement and investment) rates of both provision of services and waiting times for assessment have fluctuated. Since 2020 these rates have mostly been in decline as a result of the COVID19 pandemic.

The most recent data showed a fall in some local authority areas back to pre-2012 levels but this data does not include the challenges of 2022 with increasing waves of coronavirus, ongoing recruitment challenges and increasing pressure upon the delivery of statutory services.¹²

Inevitably, waits for both assessments and subsequent care packages are putting more strain on unpaid carers.

"Have been awaiting council carers for months. Council and private care services are severely understaffed in this area and have very long waiting lists. Respite beds in care homes are also in extreme demand in this area so our family has not attempted to use this service."

"There has been no help for me. I asked for help for my mum 5 months before residential care - there was none available. I am a single parent going through a tricky divorce. I have to work almost full time to feed and clothe my family. my mum is widowed and an only child. It has been hell."

"We have been waiting for an outcomes focused assessment for my mother for over a year. Although a telephone carers assessment was completed my mother's assessment remains outstanding. As a result, although a service to come and help my mum shower twice a week has been mooted it has never materialized or any other services which might be found to be beneficial. An OT assessment has been completed but we have been waiting for more than 9 months for a banister to be fitted."

"We have been waiting for care at home support and support worker respite support for over a year now. The assessment was completed in August 21 - but no "at home" services have been provided. Our mum has been recently (June) allocated one day of day care per week. Due to the lack of any other respite, and a deterioration in mum's situation, we have asked for this to be extended to two days. Our caring situation has been precarious at times due to the lack of any alternative to us as family carers. Periods of COVID and illness were particularly difficult. We're only looking for two evenings a week to allow some carer respite - but they don't have carers available."

Geography plays a role in access to services, with 23% of carers saying the care and support services available in their area do not meet their needs, and a further 14% saying they had been told there were no care and support services available in their area,

¹² Social Care Eligibility Criteria and Waiting Times, Scotland, 2020–21, Scottish Government, May 2022

increasing to 18% amongst those living in rural or island communities.

Financial struggle also appears to have a significant impact, with almost a third (31%) of carers that reported they were struggling to make ends meet also saying that care services did not meet their needs and 19% saying that they had been told there were no care and support services in their area.

Carers also continue to face an information barrier, with almost a third (32%) saying that they do not know what is available in their area. Again, this is more prevalent in those who are struggling to make ends meet, with almost half (47%) not knowing what is available.

Worryingly, during a cost-of-living crisis, and after nearly 3 years of caring during a pandemic, the cost of care services remains a significant barrier to getting the support they needed with almost 1 in 5 carers (16%) saying care charges are too high. Again, for those carers struggling to make ends meet, over a quarter (27%) said that the costs of care were a barrier.

Service reductions¹³, often reduced or closed during the pandemic, continue to play a significant role in the ongoing lack of support for carers. Many carers continue to report reductions in the care services they previously received, with 27% of carers saying that support from care at home services had reduced, 44% saying that support from day services had reduced and 24% saying that after-school services for disabled children and young people.

Again, carers struggling the most financially faced greater reductions with 4 in 10 (39%) reporting reduction in care at home services,

more than half seeing reduced day services (59%) and 35% saying that after-school services for disabled children and young people.



Even when care packages are delivered, they may not always be appropriate. Too often, services are based around short, task-focused and inflexible appointment times instead of personalised support – with staff running in and out of people’s houses so they can get to their next appointment on time. This fails to meet the needs of the cared-for person and puts even more pressure on unpaid carers.

“My mother did have home carers come in but they only came in twice a day - breakfast and dinner - breakfast carers came in around 11am but my mother is always up around 6am so either myself or her had already done this and she did not want strangers assisting with personal care especially when they were male.”

Getting away from this approach will require the new National Care Service to truly deliver for people of all ages requiring social care and unpaid carers. A new human rights based approach that delivers well-funded, flexible and personalised services and enables people to flourish. It is vital that the co-design of this new approach is embedded not just in the development of legislation but at every stage of design and delivery including in

¹³ We cover reductions in break services in the chapter on assessments

commissioning and in overseeing the work of the proposed new Care Boards.



For many carers, the pandemic is not over and it is simply impossible to “live with COVID”. A significant proportion – some 16% of respondents – continue to tell us that they have concerns about returning to using support services as they are worried that the person they care for will catch COVID19.

In addition, more than a third of carers (34%) said that keeping the person they care for safe when there are less public health measures to reduce COVID19, such as testing, social distancing and mask wearing remains a significant challenge over the next year.

These carers – and the people they care for - have simply been left behind, some caring alone and isolated for nearly three years.

Answers must be found to provide flexible tailored health and care support they need. We must ensure that these carers lives have been substantially improved with notable progress reflected in the results of next year’s survey.

“It was bad enough before COVID but now the fear of bringing back COVID to my son is even more limiting”

Discharge from hospital

Among those carers responding to this year’s survey, many had experienced admissions to

hospital for the person they provide care for – and later, their discharge home again.

With their knowledge of the person’s needs, intimate understanding of the situation at home, and likelihood that they will be playing an integral day-to-day role in the person’s care when they get out of hospital, carers should be treated as expert partners in the discharge planning process.

However, we found disappointing evidence of many being excluded from decision-making, with detrimental effects on the carer and cared-for person.



Nearly two thirds (62%) of carers said that they were not involved in the decisions about discharging the person from hospital. Only 15% of carers said that they felt no pressure to provide care and felt prepared and supported and just a quarter (23%) said that they were provided with the information they needed to care safely and well on discharge.

“Mum discharged December 2020. Discharge shocking. I was given one and a half hours’ notice. No consultation no advice no referrals. Terrifying experience as mum was discharged with a terminal illness. No palliative nurse, no GP follow up, no advice how to manage her. Discharged with urine burns to her groin, ventflon still in situ, dehydrated. No consultation for family and myself re her condition.”

Discharge was often followed by inadequate care being put in place, with less than a fifth (18%) of carers saying they received sufficient

services to protect the health and wellbeing of the person as well as their own health.

“Not well managed. Care package could not be put back into place because of shortage of staff”

“Discharge after spinal impingement. Microdiscectomy performed. Unable to walk post-surgery, only stand. Hospital sorted out carers but released with inadequate medication which took months to sort out and also led to a mental health detention due to too much of one pill being prescribed.”

“My partner was discharged and has had no follow up appointments so far. We have just been abandoned by the NHS and social work and I’m now left caring alone for 3 adults.”

“Still awaiting stairlift after 11 months, still washing at sink, no toilet or shower access as [they are] upstairs - totally discriminated against saying “no” as mum has dementia. Mum is supervised by me 24/7...just left with nothing.”



Worryingly, most carers found that their ability to start or continue caring was not considered during discharge. Less than 1 in 5 (18%) were asked if they were able and willing to provide care and only 12% were offered an Adult Carer Support Plan.

The Carers (Scotland) Act 2016 states that carers must be offered such a plan to consider what support a carer needs in their caring role and to help them to have a life outside caring, including to maintain

employment. It is particularly concerning that carers are experiencing little choice or support in both providing care and over what care they are able to provide. For over a third (37%) this meant that they felt pressured to take time off work to care, creating or exacerbating financial insecurity.



These experiences are an inevitable result of the NHS being under significant pressure to free up hospital beds without increased levels of social care in the community. Therefore, consequently, carers are being asked to take on often impossible caring roles without the support they need – putting even greater pressure on many carers who have gone beyond the point of exhaustion and strain.

“The hospital discharge was poorly managed. I had no Adult Carer Support Plan in place. I knew nothing about the support services available to me. My mum was discharged far too quickly and we were ill prepared for the stress having her living with us after such an illness would have on our family.”

Despite the Carers (Scotland) Act¹⁴ requiring the NHS to inform and involve carers about hospital discharge and guidance¹⁵ that encourages discussions about discharge to start from admission, the evidence from carers shows that too often this is simply ignored.

¹⁴ S28, Carers (Scotland) Act 2016

¹⁵ Involving Carers in Discharge Planning: A practical guide for health and social care practitioners involved in discharge planning from hospital, Health and Social Care Scotland, Scottish Government, 2019

State of Caring 2022 paints a very concerning picture of an overwhelming lack of priority for shared decision-making with carers or consideration of carers as being equal partners in providing care. Unpaid carers are not a resource simply to be taken for granted – to be expected to care but not be consulted, listened to or supported.

Doing so risks poorer outcomes for both the cared-for person and carer alike. Indeed, the effect may be to put even greater strain on services, with carers unable to cope, being burnt out and needing care themselves, or patients having to go back into hospital because the care they received upon discharge failed to meet their needs.

“[The] person [I care for] was readmitted to hospital 2 days later. More respect needs to be given to carers knowledge of persons medical condition rather than being dismissed.”

“It was a shambles. [My] husband was discharged with very low blood count and no explanation given regarding infection he had. 5 weeks later he was back in, seriously ill with sepsis. No advice given and GPs never followed up with anything despite being assured by the hospital consultant that this would happen. Complete breakdown in communication between services and no thought or support for the person who is left caring.”

“Discharged too early, then 2 days later I had to call NHS24 for the same issue resulting in my mum's referral to Hospital @ Home, who, without ANY consultation with me assumed I could move in with her immediately to provide 24hr nursing care (no, I'm not a nurse!) One of their team even assumed I lived with her already! They make a lot of assumptions. I basically had to cancel my entire life for 3 weeks until she was "discharged" from the H@H scheme despite her being in a worse state than ever. They didn't actually help much! One of the worst experiences of my life - I almost had a breakdown. They did mention her going into community hospital for some rehab but didn't do anything to action it. They came to her house every other day to ask the same questions again & again without really progressing. In the end I had no option but to take her to live with me. She's been here 4 months. In that time, I've successfully "got her better". I'm quite sure that the NHS could learn a thing or two from me!”

Carers' health

Caring for someone can be an incredibly demanding role and often with a big impact on a carers' health and wellbeing. Across Scotland, many are caring round-the-clock with little opportunity for a break, constantly worrying or in a state of stress, prioritising the cared-for person's needs above their own and experiencing countless sleepless nights and loneliness – all contributing to physical burnout and mental exhaustion. As this chapter shows, too many carers are missing out on the support they need to look after their own health and wellbeing while providing care.



Physical and mental health

Carers' lives are usually demanding. Day-to-day, they may be responsible for lifting, moving, washing and dressing the person they care for, helping them use the toilet, cooking all their meals and maintaining the home. It is a physically demanding job, especially for those who are caring for a long time or into their older years, when the physicality of a caring role is mixed with the declining health that often comes naturally with aging.

In this context, it is no surprise that almost 1 in 5 (18%) carers reported their physical health to be bad or very bad, rising even further, to 23%, among those who have been caring for

ten years or more, and to 22% among those caring for 35 hours or more a week.



Of particular concern in State of Caring 2022 is the evidence that amongst those carers struggling to make ends meet - often cutting back on food, heat and support - a worrying 32% of carers describe their physical health as bad or very bad.

"As my husband is almost bed bound but able to get up for short spells and thinks he can do more than he is actually able for, I have to be in the house most of the time, except when he has just gone to sleep or a friend comes in to let me out. I suffer from ME and am 84 so I have to rest whenever I get the chance."

"I have carers coming in four times a day. It has reduced the amount of stress and work i have. But because of the years of caring for my wife it has took a toll on my mental and physical side. For example, loss of confidence, fear of going anywhere crowded, bad back and shoulders."

For many carers, the 24/7 nature of their caring role means that regular sleep is unattainable. They may need to be up frequently throughout the night and early hours to help administer medication, check on medical equipment or help the person they're supporting to settle.



Nearly two-thirds of carers (34%) said they were worried about not getting enough sleep, and poor or irregular sleep is linked to a host of health effects – not just exhaustion, but elevated stress, lower immune function and increased risk of cardiovascular disease.¹⁶

A large proportion (27%) of carers reported their mental health as bad or very bad. This again rose for those who are struggling financially to nearly half (48%). Again, this rose to 31% among those caring for 35 hours or more and amongst those who have been carers for 10 years or more.

Carers widely reported the stress, anxiety, depression and impact on their relationships – all driven by their caring role.

Understandably, given the demands of their caring role and the barriers placed upon them – not least cost and concerns about COVID19 – less than 20% said that they are able to benefit from leisure activities to support their mental health.

“I am caring for 3 disabled adults all living in my home. One of my caree’s has not had a support worker for 10 months and it’s having devastating effect on them and myself. I’m exhausted and have lost hope.”

“I care full time unaided for my husband. We are both 78. We have been on a waiting list for 8 months. They are apparently dealing with crisis only and we have had

NO help at all. It is pointless ticking boxes; help is not available here. I cope but am exhausted and my mental health suffers. My husband has advanced dementia and in order to continue caring I need help.”

While it is not a mental health condition itself, loneliness is associated with a heightened risk of mental ill-health – including depression, depressive symptoms¹⁷, stress and anxiety.

Over a quarter of carers (26%) of carers told our survey that they often or always feel lonely and a further 47% said they felt lonely sometimes.

Often this was linked to difficulties getting breaks from caring (see below), the impact of the cost-of-living crisis, which has made the kind of social activities necessary to combat loneliness unaffordable for many carers; and the demands of being a carer, which leaves them with little time to see family and friends.

“I have friends but they are like me in their 50s. None of them are in a caring role for their spouse and I feel so isolated, unappreciated, lonely, unsupported and that life is essentially over for me. I have no family to help and I also am the only person that visits my mum and I bring her out from her residential care to my own home to visit my husband. I am on the go from dawn to dusk and looking after myself is impossible.”

A third of carers (33%) identified support to prevent or reduce loneliness as one of their top needs as a carer, while over 50% said being able to take regular breaks from caring would help them feel less lonely.

“I just want a weekend away twice a year or one night off a month. Surely that’s not too much to ask?”

¹⁶ RSAS and University of Worcester (2016). The experiences, needs and outcomes for carers of people with dementia: Literature review.

¹⁷ Mushtag, R et al (2014). Relationship between loneliness, psychiatric disorders and physical health? A review on the psychological aspects of loneliness. Journal of Clinical and Diagnostic Research, 8 (9).

The importance of breaks from caring

Our findings point to a clear link between access to breaks from caring and better health outcomes among unpaid carers.

While just 37% of all carers said their physical health was good or very good, this rose to 50% among those who had had a break from caring within the last 12 months. Similarly, 27% of carers said their mental health was good or very good, increasing to 38% among those who had had a break within the last year.

Carers reported a host of benefits from taking a break from caring, including the chance to recharge their batteries and do things for themselves.

“My brother comes up from Liverpool when he can to stay with my Dad. Then I can go away for a couple of nights with my husband and stepdaughter. It is lovely to get uninterrupted night’s sleep and to be a family together. Sometimes we go away just me and my husband. It’s very precious time just the two of just as we haven’t had a honeymoon since we wed last October. It recharges my batteries.”

“My sister is able to help and give me a break, this helps me to catch up on sleep and time out which is essential for my mental health.”



Unfortunately, however, these experiences are not universal. Over a third (39%) of carers said they had not had a break within the last 12 months, and many told us about the severe consequences for their health and wellbeing.

“NHS and local council seem to think it is my responsibility to provide care, not theirs. I have not been offered respite or signposted to services despite expressing concern about my own ability to cope and the impact on my own mental health (including suicidal ideation). My employer has made it clear when I have requested unpaid time off that this “cannot be a regular occurrence”. My partner has no other family to help so it falls to me. Taking a break means leaving my partner alone to look after herself and our dog so when I take “breaks” it is for a period of a few hours at most - which I don’t see as a break or respite.”

“I have had one break in the last 18 years”

“I haven’t been further than a visit to the GP centre in 4 and a half years.”

Worryingly, those who are struggling to make ends meet are least likely to have been able to have a break from caring in the last 12 months. More than 50% have had no such break. Older carers are also less likely to have had a break (43%). This raises questions over both availability and cost of the suitable breaks for these carers.

Many carers have long experienced significant challenges to accessing respite, short breaks and day services, but this situation has only deteriorated due to the COVID19 pandemic. Services were severely disrupted when the outbreak began, and many have failed to return to their pre-pandemic capacity over two-and-a-half-years later.

For example, just 9% of carers told our survey that day services had fully re-opened, 3% that care homes for residential breaks had re-opened fully and only 2% said sitting services had fully re-opened.

All these services provide not only critical sources of support and wellbeing for individuals, but also a lifeline for unpaid carers, who have suffered considerably from

the lack of opportunity for regular breaks from their caring role.

“My son has PMLD, and his day centre is still operating on a critical need basis. He gets only one day a week. His life might as well have ended with COVID. I have spoken on radio, tv and tweeted regularly about it but still there is no sign of proper opening. It is heartbreaking to see the effect on my son.”

“Respite centre closed completely we charity running could no longer afford to keep it going. Lost all my help when pandemic hit and still waiting on respite being set back up. Adult child requires round the clock care so it's difficult to get places willing to do some aspects of the care required even though I do it on my own all the time.”

This clearly reflects the evidence from the recent Scottish Government audit of adult day and respite services which showed only 48.7% of services were fully reopened and 38.4% were operating at reduced capacity. More than one in ten of both day services and respite services (11.8% and 14.1% respectively) remained closed.¹⁸

Only 1 in 5 carers (20%) carers have any confidence that these services will return (or continue where they have reopened to some level).

The long delays in fully restarting day services, short breaks and respite – and the varied approaches being taken to this across Scotland – is a source of deep frustration for carers. They look to other aspects of public services and social life that have seemingly returned to pre-pandemic normality and, understandably, feel that they've been taken for granted and forgotten.

Access to these services is a major priority for our carer population. When we asked about

their top needs as a carer, nearly half (46%) identified more breaks or time off from their caring role, while a similar proportion (42%) said more support from the health service/health professionals was most important.

Access to health treatment or assessment

State of Caring 2022 has shown significant issues for carers in accessing both primary and secondary health services.



Primary and community health

Over one in ten carers (13%) told us that they had waited a month or more for an appointment with a GP. Significantly more carers (68%) waited a month or more for dental treatment and 26% had the same wait for an optician.

Carers described frustrations at accessing these services but also the impact these were having on their health and caring role.

“I had a dental appointment in March 2020 which was cancelled due to COVID and haven't been able to get one since. Three of my teeth have crumbled away since the initial date.”

“It has made it a very frustrating process which made me not go when I should go and not follow up on treatment.”

¹⁸ Story: Fewer than 50% of day services fully operational
<https://healthandcare.scot/default.asp?page=story&story=3272&keywords=day-services-disabilities-scotland>

“Having to phone at 8.30 and hang on the phone when I am trying to get the person I care for ready to start the day. Having to wait for someone to call back and that person insisting on speaking to my husband who doesn't always give the answer that's needed or ask the right questions.”

A similar proportion told us that the person they care for had waited this long for GP, dental or optical services in the community. They described how this is impacting on their wellbeing but also how this can make caring more difficult.

“Having a brain tumour my son needs to be seen ASAP, not 1-2 weeks wait. Hospital consultant requests bloods to be done but health centre does not have appointments available.”

“My husband (autistic) was trying to make an appointment with the diabetic podiatrist this morning and, without going into it all, was going round in ever decreasing circles. It was very stressful for him - and for me! He ended up going into a “meltdown” due to everything and, as a consequence, I'm at the end of it all! It is exhausting and damaging to my own health.”

The Scottish Government previously committed to make access to healthcare easier for carers, with more flexible appointments and health checks. This must be expedited to ensure that carers can maintain their own health and, indeed, prevent deterioration.

Specialist health services

State of Caring 2022 has highlighted the scale of the problem of accessing specialist treatment or assessment by a doctor among unpaid carers, with 52% of carers waiting for over six months after referral. Over a third (34%) of these carers have waited for over a year.



Over 67% of carers who were waiting for specialist treatment or assessment said it was negatively impacting their mental or physical health. Some carers told us that this was making their caring role harder, damaging their quality of life and creating a vicious cycle of deteriorating health and wellbeing.

“Stressful as it is a recall for a breast clinic assessment after an initial mammogram and I have family history of breast cancer.”

“I can no longer take my wife out to her hospital appointments as I am waiting for cataract operation.”

“I have just had a telephone consultation with my hip consultant's registrar who says that things are improving but that it may yet be almost 2 years ie. Winter or Spring 2023 before my first of 2 hip replacement ops from when I was first added to the list in May 21.”

“Due to years of stressful caring for my daughter with no support while also juggling work and being a single parent has meant I have had little time or energy to look after myself. I recognised I needed support well over a year ago but am still waiting for any and have now (a couple of months ago) been diagnosed with type 2 diabetes and high cholesterol and high blood pressure. I feel all of these diagnoses could have been avoided if I had just received some support. Even now, with the diagnosis, I am still unable to give myself the time and care I need because all my energy goes into caring for my daughter. I strongly believe that I will die an early death which could have been avoided.”

“Suffering constant pain while waiting is difficult for both carer and the person cared for as unable to care properly.”

"[I am] depressed anxious and pain management with current meds not working, impacts on daily interaction constant pain no further relief available until assessed on then liaison with other hospital/GP on plan of direction. Sleep deprived due to current pain levels. Impacts in my health mindset too."

Carers who are struggling to make ends meet are slightly more likely to have waited 6 months or more (57% v 52%) for such specialist treatment and are a little more likely to say that this wait is affecting their physical or mental health (72% v 67%)

Added to this are concerns over the physical and mental health of the person they care for. Almost half (47%) of carers said that the person they care for had been waiting for 6 months or more for specialist treatment or assessment, with a third (30%) of these waiting a year or more. Two thirds (64%) said that it was affecting the physical or mental health of the person they care for. Lack of access to specialist treatment can only compound the demands of caring.

"My partner has a primary diagnosis of MS and us still waiting for confirmation. It's been weeks and he is eager to know the outcome so we can plan for the future as we have 2 disabled sons living at home."

"I do worry that my husband will not be prioritised due to his age and because other medical departments see the word Alzheimer's and therefore won't see him as a priority. We've waited a long time since our GP referred us on an urgent referral for cardiology. We're still waiting."

"My partner is waiting for a hip replacement, is very disabled physically and is in tremendous pain. This impacts on both his and my quality of life. My Dad is waiting for an MRI and has been told not to drive until he has had it. As he lives in a rural area, this cuts down his independence and increases his dependence on me. We live 80 miles apart."

Also concerning in the context of the cost-of-living crisis, a third of carers (30%) who were waiting for specialist treatment or assessment said it was starting to affect their ability to work – risking their financial resources at a time when many can least afford it. Indeed, nearly a third (31%) of carers waiting for specialist treatment or assessment said they were struggling to make ends meet.

"Waiting on steroid injection in shoulder had to hand in fitness note while waiting as unable to do cleaning job as its exasperating my calcification of tendons in shoulder."

"I have been experiencing pain for over a year now and have already had 2 scans and am now waiting for a general surgery consultation. My work is quite physical at times and I have had to take days off occasionally due to pain (my employer has made allowances in my duties for the pain but due to staff shortages and absences it is not always possible for this to happen). I also do not want to worry the person I care for so I have not told them that I have been having tests etc which is also putting me under some strain."

"Waiting to see a hand specialist as fingers have osteo arthritis and painful. This is affecting my ability to type up reports etc. for work, open cans etc. and carrying hot food as I can't grip them."

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."*¹⁹

It is clear therefore that Government must act to address the challenges of caring and change the future for carers.

¹⁹ Tackling health inequalities in Scotland, Scottish Parliament Health, Social Care and Sport Committee, SP Paper 230, 28 September 2022

Assessment for carers

In Scotland, the Carers (Scotland) Act 2016 gives unpaid carers of any age the right to an assessment. For an adult this is called an Adult Carer Support Plan and, for a young carer, a Young Carer Statement²⁰ (For ease of reading we have used Adult Carer Support Plan throughout this section).

These are carried out by health or social care professionals, sometimes in the voluntary sector (such as by a carers centre worker). They examine a person's situation to discuss their caring role and what support may make their caring role easier.

An Adult Carer Support Plan should cover a range of topics including the carers' health and wellbeing, access to breaks, finances, housing situation and more. It is often a vital first step in identifying carers' needs and connecting them to sources of support, but we found that too many carers are either unaware of their right to an assessment or have been left disillusioned with the process after going through it in the past.

Access to Adult Carer Support Plans

Disappointingly, less than a quarter (21%) of carers told our survey that they had received an Adult Carer Support Plan review or re-assessment during the last 12 months, a small drop compared to 2021, when the proportion was 26%. A small proportion (5%) have requested an assessment but have yet to receive it.

Among those who hadn't had an assessment, review or re-assessment during this time, the single biggest reason was not knowing what

an Adult Carer Support Plan is (51%) – suggesting that too many carers still do not receive information at key points in their journey. It also reinforces the importance of having robust systems in place to identify carers as early as possible, make them aware of their rights and signpost them to the information and support they need.

“Not sure what they are don't think I've ever had one.”

“I was never informed, advised on this, and have never had knowledge that I can benefit of such.”

Equally concerning, one in 7 carers (15%) said they hadn't had an assessment, review or re-assessment because they didn't think it would be beneficial for them.

This is, unfortunately, a long-term trend, with many carers becoming disillusioned at having taken the time to go through the process in the past, only to receive no additional support afterwards due to funding, service and staff shortages.

“The report was undertaken after a long wait. No review has been undertaken. No services have been provided despite recommendations in the report. The report is accurate, but useless as no actions resulted from it.”

“The assessment completed at the Carers Centre was thorough but the conversation with SW that followed was difficult. I had to fight for my right to SDS option 2”

These experiences reinforce the urgency of ensuring that the co-design of the new national care service truly includes ensuring that the needs of carers are not just considered but acted upon. Carers needs greater confidence that there is real benefit to

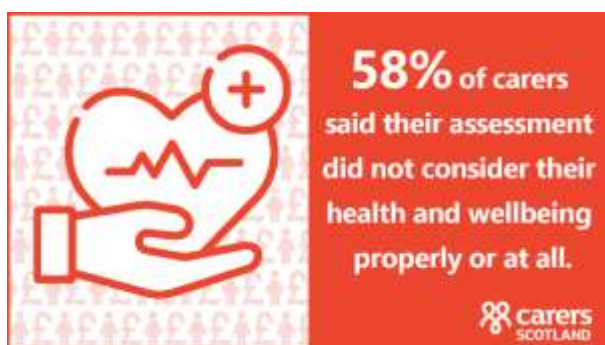
²⁰ For ease of reading we have used Adult Carer Support Plan to refer to both an ACSP and YCS

Adult Carer Support Plans and that flexible, responsive support is delivered to ensure that they can flourish alongside their caring role.

Until that time however the Scottish Government with HSCPs must do more to deliver the support carers need, providing the greatest flexibility possible through self-directed support to ensure that carers do not continue to care alone with little or no help.

Experiences of Adult Carer Support Plans

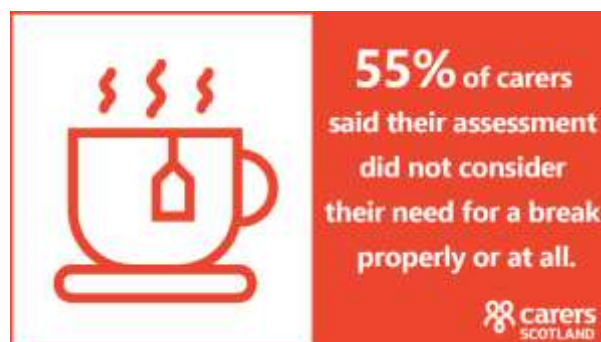
Many carers who had had an Adult Carer Support Plan, review or re-assessment during the last 12 months reported a worryingly poor experience. Time and again, carers reported that the process had not adequately considered or addressed the big challenges impacting on their lives.



More than half of carers (58%) said that the support they needed to look after their own mental and physical health alongside caring was either not considered or insufficiently considered in their Adult Carer Support Plan or reflected in the support they received afterwards.

“They never listen to me or acknowledge the disabilities I have which now make caring physically difficult and painful for me.”

And worse, 55% of carers said their need to have regular breaks from caring was either not considered or insufficiently considered.



“Needs for carer only met due to formal complaint process stage two complaint. [The Council] tried to prevent the use of carers budgets on breaks and gym membership despite health and well-being needs. Legislation was quoted and threat of Ombudsman resulting in their backing down and amending their website to reflect some of the legislation (carers act and SDS).”

Of particular concern in the context of the cost-of-living crisis, just one in five carers (19%) told us that their Adult Carer Support Plan had thoroughly considered the support they need to manage their finances; whilst just 18% said it thoroughly considered the support they need to juggle work with paid employment.

“Because I live with a partner, I did not feel that this plan took my work, my other caring responsibilities etc into consideration as it downgraded the amount of support my daughter was to get post COVID. eg respite reduced.”

The result is that too many carers do not feel their holistic needs are being fully considered in their Adult Carer Support Plan nor does it deliver what they need to continue caring whilst maintaining their own health, wellbeing, employment and more.

It is worth noting, for those carers who had been able to access an Adult Carer Support Plan, many spoke positively of the help from carers centres, reinforcing their important role in supporting carers and as a key partner for future improvement and delivery.

Employment

Around 270,000 people in Scotland juggle paid employment with caring – around 1 in 7 of the working age population. Having the opportunity to work is an important part of life, and one that most of us take for granted. In addition to providing financial stability, it is widely recognised that employment brings wider benefits in terms of a fulfilling career, positive mental health and social interaction.

For carers, work can often represent a lifeline, not only financially, but also as an important part of having a life outside of caring.

A third (32%) of carers in State of Caring 2022 are in paid employment. Of these, 57% are in full time employment or self-employment and 43% are in part-time employment or self-employment.

Most were at the peak age for caring - aged 45-54 (38%) and 55-64 (38%). One in five (27%) also have childcare responsibilities for a non-disabled child and 17% also have a disability themselves.

Barriers to employment

Research in 2019 found that nearly 7% of carers had been forced to give up work to care (nearly 1 in 10 in the 12 months) and a further 5% had reduced their working hours to provide care for someone.

This means that overall, more than 500,000 carers in Scotland have to live with, often long term, consequences of caring impacting on their ability to sustain paid employment.²¹

Understandably, many carers told us that it is impossible to provide hands-on practical and personal care for someone 24/7, manage their

appointments, maintain the home and hold down a full-time job all at the same time.

"I had to retire 13 years early because couldn't cope with caring role and work. This has obviously had significant impact financially due to loss of earnings and vast reduction in pension."

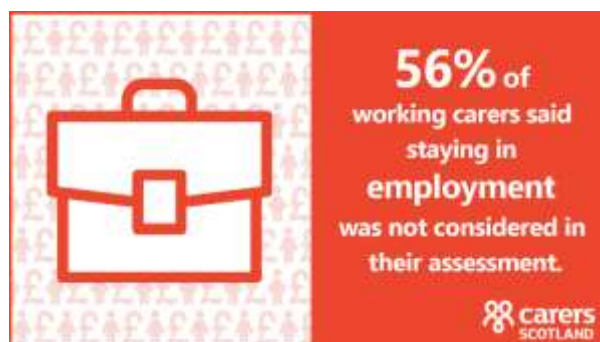
"I did work- but employer was impossible re considering my caring responsibilities- he was horrible, saying awful remarks, so I left. It was my only 5 hour break a week from my caring, but I couldn't continue."

"I am looking for work but I will never be able to go back to senior management which is what I did before I had my son. My earning capacity is seriously diminished as is my entire future."

"Gave up well-paid full-time job to enable me to carry out caring role."

The challenges of balancing work and care are made more difficult by the lack of consideration of these responsibilities in carers assessments.

More than half (56%) of working carers said their need to balance care with their employment was either not considered or considered insufficiently in their Adult Carer Support Plan discussions.



²¹ Carers UK (2019). Juggling work and unpaid care: A growing issue.

Over a third (36%) said that their other responsibilities – either for a child under 18 or caring for someone else – were not considered or insufficiently considered.

Significantly more work is needed to ensure that carers other responsibilities – for work or for children – needs are fully explored and supported in assessments.

The balancing act that carers face has also become even harder due to the disruption to replacement care and social care services caused by the COVID19 pandemic. A third of working carers (36%) said that care services not fully reopening was one of the biggest challenges they faced in the next 12 months. More than one in ten (14%) said that without affordable and accessible alternative care, they'd be at risk of having to reduce their hours or leave their jobs.

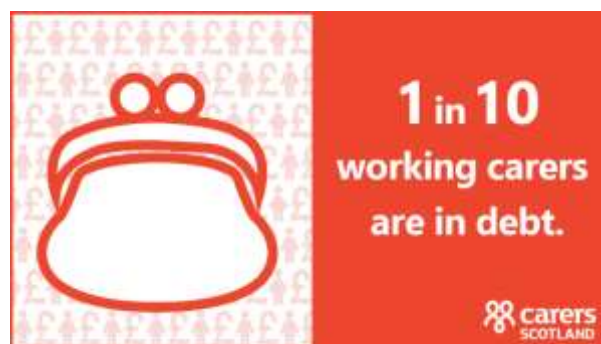
It is also worth noting that some carers in this survey who were in employment before the pandemic were forced to leave because of the risks of the virus to the person they care for. The Scottish Government and employers must find a way to suitably support these carers, including to offer as flexible employment options as possible, such as home and virtual working.

“Not working because COVID is too much of a risk. Gave up part time work to keep the person I care for safe and shielded from COVID.”

Working carers and financial struggle

Carers being forced to withdraw from/stay out of the labour market makes it even harder for them to survive financially, especially considering the low value of carer benefits like Carers Allowance. Unsurprisingly, the proportion of carers who were struggling to make ends meet was much higher among those not working than for carers overall.

However, those in employment are also facing significant financial struggle as the cost-of-living crisis continues to bite. Nearly a quarter of working carers (21%) are struggling to make end needs and a similar proportion (22%) are cutting back on essentials like food and heat just to make ends meet.



With more than one in ten (13%) in debt and two thirds (64%) worried about how they will meet monthly expenses, too many working carers are facing a perfect storm – trying to juggle work and care, often forced into part-time work because of their caring role, with the services they need to support their employment under challenge and their incomes failing to meet ever rising costs.

“[I am] having to stay in 2 jobs to make ends meet [whilst facing] failing health of parent.”

“Parents need lots of support and unable to return to full time work.”

“It’s a struggle for both me and my husband to work. My son is on a reduced timetable for school and childcare can’t meet his needs in breakfast or after school club. We have no family support. My husband is on reduced working hours to pick our children up which reduces our income although we can meet needs at moment we are worried for future when son not in school that someone will need to be with him due to his disability.”

“I did work full time but couldn’t juggle caring on top of that. Do reduced my hours. But every week I say to myself I will have to give up work to do the caring role properly. Then don’t because of the financial

implications. So, feel I am failing at work and at caring. My husband has since reduced his hours too. But nearly impossible to juggle both roles.”

It is also worth noting that a quarter of carers in employment said that they may have to increase working hours to make ends meet. This has profound implications for an already under strain social care system and for the health and wellbeing of these carers. It is therefore important that any financial support for cost of living for carers also supports those who are in employment, many of whom are excluded from Carer’s Allowance because of the limited earnings threshold.

“And losing Carer’s Allowance by trying to make ends meet...NOT HELPFUL. I still do all my caring duties just earn a wee bit more than the pittance carers are allowed to earn. I want to work.”

Working carers health and wellbeing

As well as support within the workplace, it is vital that those carers juggling work and care also have opportunities for breaks and to support their own health and wellbeing.

More than one in 10 (12%) of working carers said their physical health was bad or very bad and nearly a quarter (22%) said the same of their mental health.

Nearly a third (29%) of working carers have waited six months or more for specialist treatment or assessment and 3 in 10 said that this was affecting their ability to work, leaving carers at risk of losing their employment and the vital income it brings. And, with juggling work, care and health appointments for the person they care for, 1 in 10 (11%) had the additional concern of being able to take care of their own health and getting health appointments when they needed them.

Moreover, more than a quarter (29%) of carers haven’t had any break from caring in the last 12 months and 69% have had no access to leisure activities in the last 6 months.



As noted earlier, flexible health appointments that are easily accessible are a necessity for carers and the needs of those in paid employment must be built into planning – not just for health but for wellbeing including breaks. Otherwise, there is a risk that carers will breakdown, losing their employment, health and future financial security.

Experiences of juggling work and care

Those who are juggling work and caring highlighted the multitude of effects that this has – including on their health, wellbeing and more.

When we asked carers about balancing work and care, 74% said that they felt tired at work because of their caring role, and 72% said they were worried about continuing to juggle the two. Carers told us that working and caring at the same time was leaving them increasingly burnt out, struggling with their mental wellbeing and with no time for a break, especially when they’re forced to use their holiday leave to perform caring duties.

“Cared for has so many appointments to juggle around work. Being so burnt out I’m not doing my job properly. Self-esteem suffers. Can’t take part in the social activities outside work increasing isolation.”

“No option for working from home, long hours having to use holidays and flexi time to care for son now out of school, looking now at giving up work as hours don't suit my caring role.”

“Get really tired at times having to go to work after difficult situations which have resulted in little sleep. Trying to support cared for to attend appointments and it not causing issues at work.”

Other carers explained that the demands of their caring role had negatively impacted their career prospects, with 59% saying they had given up opportunities at work because of caring.

The proportion was higher among female carers (61% v 51% of men), possibly reflecting the greater unpaid care burden facing women and the still present, and unjust, expectation that female members of a household will sacrifice their working lives to provide unpaid care.

“Secured part-time work but not in the field I wish to be in. Constantly job searching until appropriate role and working conditions fit my situation. Been job searching since 2018, permanent, work - full time, less travelling.”

“Even though my business is supportive of carers I still feel guilty about taking time off and that I will be judged unfairly - work taken off me, opportunities for progression and inclusion missed because I can't always be always on/100% in work.”

“You need to be available 24/7, 7 days a week, just in case. It's like being on call permanently. Unless the care sector/services are more combined, take more responsibility and reduce being on call. The employment market is going to continue to lose good, experienced people and the taxes/spending that go with it. Unfortunately, mainly female.”



Supporting more carers to better juggle work and caring

We asked carers about the support they need to stay in the labour market and better juggle work with unpaid caring responsibilities. Over 55% said that working from home had enabled them to balance work and caring more effectively – highlighting that what was necessary for the COVID19 pandemic has become an important measure to help carers juggle work and care.

“My employer has been very supportive. Working from home was introduced at start of COVID and is permanent now. Without it my Mum would have been forced into a care home against her wishes.”

Conversely, a similar proportion (55%) of carers told us that returning to the office would make caring more challenging, and 35% said that not being able to work from home would make them consider leaving their job. There was evident worry among many of those carers whose employers were moving back to office-based working, with fears that it would lead to more pressure and exhaustion as they tried to balance work with caring.

“We are going to be asked to be in the office more often, but I have a good balance just now so I would need to look at how I could cope with this.”

“My employer is very supportive but there is a limit to what they can do. Working at home has helped immensely. I am the breadwinner and have 2 young children so reducing my hours or giving up work is not an option as other people rely on me.”

“I’d love to move to a better paid job which reflects my skills and experience. COVID has made that impossible as ppl go back to offices. And many employers still don’t offer flexible/home working.”

It is important to recognise that for other carers, moving back to office-based working would be considered a good thing. Ensuring carers have a choice over how they can work to best suits their needs is key.

“I feel exhausted most of the time because when I’m not at work, I’m caring for my son. However, I appreciate the social aspect of talking with my colleagues as conversations with my son can be limited. It is imperative that I am able to get time off work to support my son when required or when he is ill.”

Elsewhere, just 4% of carers said they had access to affordable and accessible

alternative care, only a third (35%) said they had access to paid carers leave from work, and less than half (48%) said they had been offered flexible working arrangements. All of these measures are important for many carers and, if more widely available, would make it much easier for them to balance work and caring, without having to push themselves to burnout and exhaustion.

Supporting more carers to enter, and stay in, the labour market is not only of benefit to them, but also makes business and economic sense too. Employers face significant costs associated with absence, lost productivity and recruitment whenever their staff’s ability to work is impacted by caring responsibilities.

Across the UK, research²² suggests that that cumulatively, companies could save up to £4.8bn a year in unplanned absences and a further £3.4bn in improved employee retention by adopting flexible working policies to support those with caring responsibilities.

²² Carers UK (2019). Juggling work and unpaid care: A growing issue.

Conclusion and recommendations

This year's State of Caring survey paints a bleak picture of the challenges facing Scotland's unpaid carer population. They have been among the hardest hit by the cost-of-living crisis; are continuing to face major obstacles to accessing the health and social care services they need; are still dealing with the effects of the COVID19 pandemic; and are living with ever-worsening physical and mental health – often running themselves into the ground without regular breaks from caring, proper sleep or the chance to have a life of their own.

Scotland's unpaid carers save the government £10.9bn every year. Without them, the health and social care system – and wider public finances – would collapse. However, far too often, the help and support they get in return for this enormous contribution is either paltry or non-existent.

Carers Scotland have made a range of recommendations for change. The Scottish and UK Governments must prioritise unpaid carers – delivering the reform they need in health and social care, social security, employment rights and beyond. Scotland's unpaid carers deserve nothing less.

To support carers through the cost of living, we are calling for:

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: www.carersuk.org

2. 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 penalised²³. 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.

3. The Scottish Government should provide a Scottish **additional cost of**

²³ A carer whose salary is £1 a week over the threshold would lose up to £3,624 of Carer's Allowance

living payment for carers, for example, by at least doubling December's Carer's Allowance Supplement. The Scottish Government should also seek to extend this cost-of-living payment to the widest group of carers, including those with an underlying entitlement to Carer's Allowance who cannot currently receive Carer's Allowance Supplement.

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 enable 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 over 10% 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.

6. 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.

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. In the interim, Scottish Government must provide nationally agreed guidance to local councils alongside the necessary funding 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 **access to taxi cards** or other such schemes to support transport costs and help those who are more isolated due to concerns over COVID19
 - 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.

To ensure all carers get the support they need, including to take regular breaks from caring and to look after their own health, we are calling for:

10. The Scottish Government should **introduce direct payments or vouchers** for carers to spot purchase non NHS assessments, physiotherapy, counselling and other such similar services. Carers should have access to such occupational support in the same way as health and care employees.
11. The Scottish Government should develop a strategy to enable local areas to **offer health checks** for unpaid carers to identify health concerns or pre-conditions, such as high blood pressure. This should include developing accessible and **flexible appointments for carers**.
12. The Scottish Government with partners in councils and the NHS should **expand social prescribing** including free access to leisure services
13. The Scottish Government should ensure that **updated guidance on Self-**

Directed Support aimed at empowering partnerships to deliver much more flexibility in self-directed support, **is monitored to ensure that it delivers for carers and those they care for**. This should include simplifying administration, the ability to employ close relatives and considering enabling unspent budgets, (which cannot be spent due to lack of services) on other costs that support wellbeing such as breaks and energy costs.

14. The Scottish Government should work with partnerships to **ringfence Carers Act funding** to ensure it is spent on direct unpaid carer support.

15. The Scottish Government should work with local partnerships to ensure their **remobilisation plans** are explicit in describing how provision will be reinstated for planned, regular as well as crisis short breaks, and ensure priority is given to the re-opening of social care services and services which provide breaks from care

16. The Scottish Government should continue to **increase funding to breaks from caring including expanding the availability of non-statutory, flexible approaches to delivering short breaks**, such as those supported through the Short Breaks Fund.

17. In addition to vouchers provided directly to carers, the Scottish Government should provide unpaid carers with access to **tailored, mental health support**, in the same way the registered care workforce has access to this support. For example, this could be delivered through enabling unpaid carers to get access to counselling services by providing funding to

local carer support services. This should include commissioning additional bereavement counselling and support services.

To help more carers to better balance work and unpaid care, we are calling for:

18. The UK Government to **deliver a day one right to flexible working** for all unpaid carers.

19. Building on legislation currently at the House of Commons to offer 5 days unpaid leave, the Scottish Government should include the provision of the following supports for carers in both the Scottish Business Pledge and in requirements for those bidding for contracts from public funds.

- **a minimum 5 days paid carers leave**
- **day one right to flexible working including home working**
- **being a Carer Positive employer**

20. As part of their strategies to support children and parents, the Scottish Government should **develop more affordable and accessible childcare options for unpaid carers**. This should include delivering better options for accessible holiday and after school playschemes for children with disabilities.



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.

www.carerscotland.org

info@carerscotland.org



@CarersScotland



/CarersScotland

© Carers Scotland, November 2022

Carers Scotland is the Scottish nation office of Carers UK. Carers UK is a charity registered in England and Wales (246329) and in Scotland (SC039307) and a company limited by guarantee registered in England and Wales (864097). Registered office 20 Great Dover Street, London SE1 4LX