

# State of Caring 2023

A health and social care crisis for unpaid carers in Scotland

*'I just do not have time to look after myself'*

November 2023



# About this research

This report, produced by Carers Scotland, explores the key findings from the State of Caring Scotland survey 2023 on the health of carers and the support they receive from local authorities, health and social care partnerships and the NHS.

Carers Scotland's annual State of Caring survey has been undertaken for over a decade and is Scotland's most comprehensive research into the lives and experiences of unpaid carers. This year's survey was carried out between June and August 2023 and completed by 1,771 unpaid carers in Scotland. We have interspersed this report with the voices of carers. These are highlighted in red, and we thank those quoted for sharing their experiences.

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

## About unpaid carers

An unpaid carer is a family member, partner, friend or neighbour who helps a person with daily activities that they would not be able to manage if they did not have help. This could be a partner, family member or friend who has a long term or terminal illness, someone who is disabled, has a mental health condition, is affected by addiction or who needs extra help as they grow older. There are approximately 800,000 people in Scotland providing such unpaid care<sup>1</sup>. It would cost an estimated £13.1 billion<sup>2</sup> every year to replace the care they provide.

## Carers in State of Caring 2023

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

- 81% of respondents are female, 18% male with the remaining 1% preferring to self-identify as either non-binary or transgender.
- 3% are aged 18-34, 13% are aged 35-44, 25% are aged 45-54, 36% are aged 55-64, and 23% are aged 65+.
- 29% have a disability<sup>3</sup>
- 98% of respondents are white Scottish, Irish or other white; 2% of respondents are black, Asian or minority ethnic.

<sup>1</sup> Scotland's Carers update release, Scottish Government 2022

<sup>2</sup> National Care Service Financial Memorandum, Scottish Parliament 2022

<sup>3</sup> As described under the Equality Act 2019: 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

- 92% of respondents are heterosexual, 4% are gay, lesbian or bisexual, the remainder preferred not to say or skipped this question.
- 45% are in some form of employment and 24% are retired.
- 20% also have parental responsibility for a non-disabled child under 18.
- 3% have been caring for less than 1 year, 25% for 1-4 years, 25% for 5-9 years, 27% for 10-20 years and 20% for more than 20 years.
- 19% provide 1-19 hours of care per week, 10% provide 20-34 hours of care pre week, 15% for 35-49 hours and 14% for 50-89 hours, 42% provide 90 or more hours of care per week.
- 71% care for one person, 21% care for two people, 6% care for three people and 2% care for four or more people.

## The people carers care for

Carers responding to State of Caring 2023 provided information about who they care for and the conditions the person(s) live with:

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

## Thanks

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

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# Introduction

Last year, in State of Caring 2022, Carers Scotland provided a snapshot of the lives of unpaid carers in Scotland, setting out the toll that providing care was having upon their lives, finances, employment, health and wellbeing. Battered by the cost-of-living crisis and living with the ongoing effects of the pandemic, carers were breaking.

Last month Carers Scotland published [\*“State of Caring 2023: the financial impact of caring in Scotland”\*](#)<sup>4</sup> which brought no better news for carers, particularly those who were already struggling to make ends meet. Poverty and financial insecurity had grown yet again, as the cost-of-living crisis extended and continued its damage to carer households.

In this report, *“State of Caring 2023: A health and social care crisis for unpaid carers in Scotland”* we show the ongoing struggle that carers face to access the services and support they need to provide care and to care for themselves including to take regular breaks from caring.

We do not shy away from using the term “health and social care crisis” in this report.

Despite their huge contribution to the Scottish economy, to our communities and to the lives of the people they care for, carers are facing deteriorating physical and mental health, loneliness and isolation with too many driven to despair and denied access to the very supports they need to maintain a healthy life.

**This cannot continue.**

In this report we set out a range of recommendations, not just for Government but for local councils, health and social care partnerships and NHS Boards across Scotland.

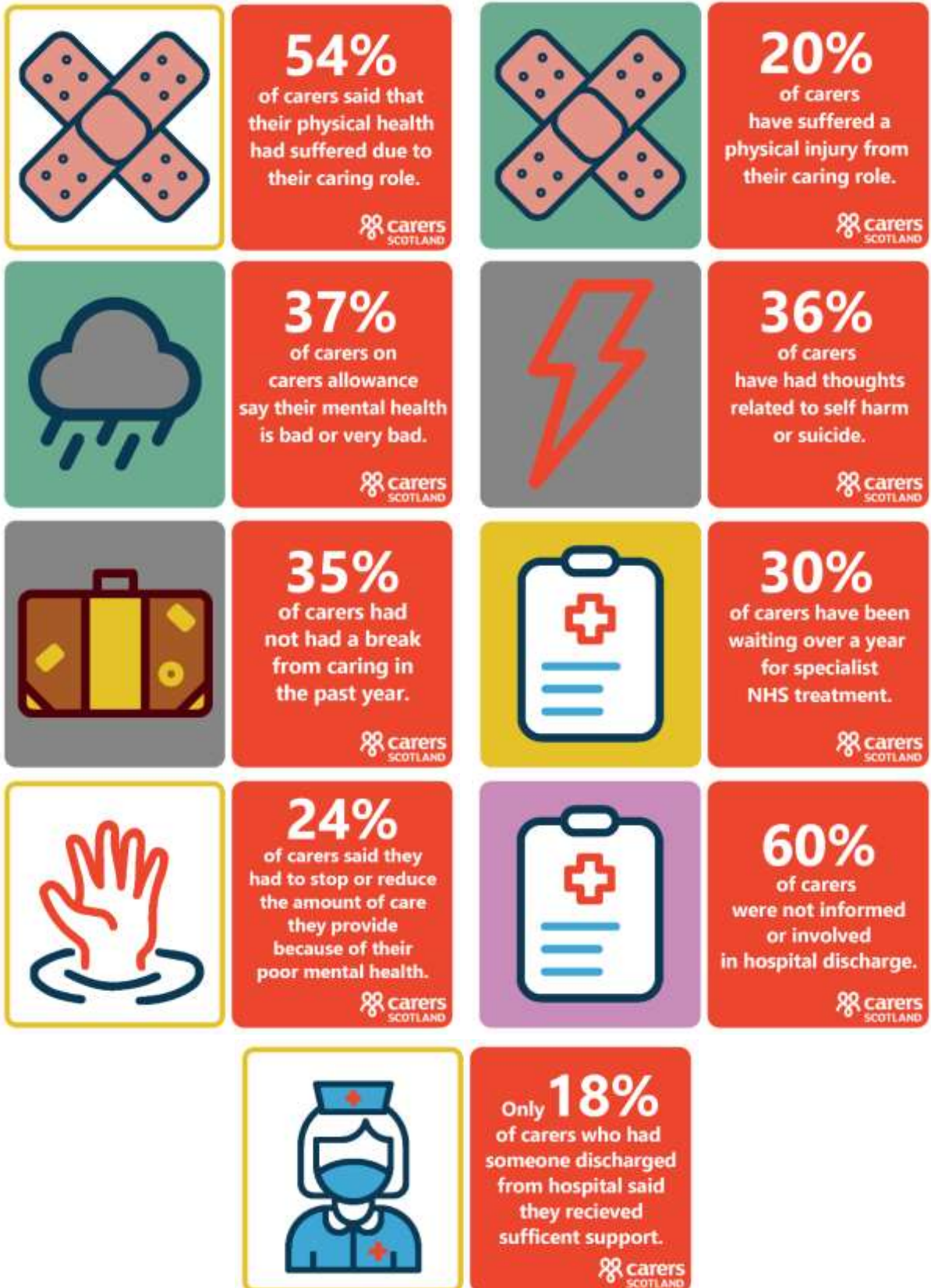
**Action is needed, urgently.**

**Carers simply cannot wait.**

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<sup>4</sup> Find this report at: [www.carersuk.org/reports/state-of-caring-in-scotland-the-financial-impact-of-caring-in-2023/](http://www.carersuk.org/reports/state-of-caring-in-scotland-the-financial-impact-of-caring-in-2023/)

# Key Findings



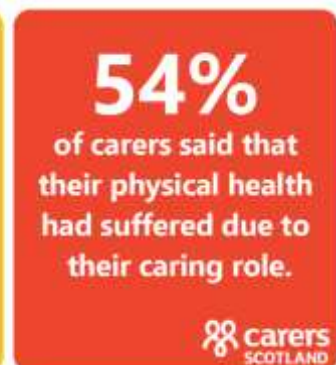


## Carers health

Providing care for someone has is a highly challenging responsibility, frequently affecting the physical and mental health of those who are providing care. Throughout Scotland, unpaid carers provide high levels of care, seldom having the chance to take a break from caring. They grapple with constant anxiety, stress, and the consistent prioritisation of the person they are caring for, often resulting in numerous sleepless nights and feelings of isolation. These factors collectively contribute to physical fatigue and emotional exhaustion.

It is clear from the results of State of Caring 2023 that a significant number of those who provide care are not receiving the necessary support to attend to their own health and wellbeing alongside their caring responsibilities.

We asked carers if caring had an impact on their health and wellbeing. In this context, it is no surprise that **more than half (54%) said that their physical health had suffered** because of their caring role, with **one in 5 (20%) suffering a physical injury** from caring



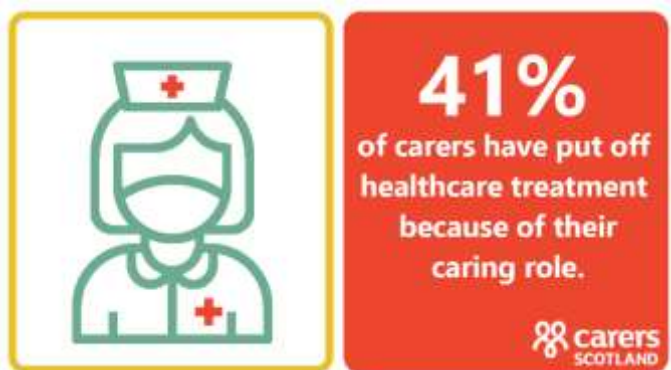
and two thirds (69%) saying that they struggled to get a good night's sleep.

**Nearly four fifths (79%) of carers said that the main challenge they would face over the coming year would be the impact of caring on their physical and/or mental health.**

*"I constantly have lack of sleep; I assist with care during the night but unable to catch up during the day due to other chores. I am constantly tired and depression kicks in which I try to hide from my family display all's fine approach"*

Of particular concern in the findings of State of Caring 2023 is the number of carers who have put off healthcare treatment because of their caring role.

**Four in 10 (41%) carers have put off healthcare treatment**, with more than two fifths of carers (46%) who care for 35 hours or more a week said that they had put off such care. This increases to 50% of carers with a disability.



These findings are reinforced by comments from carers themselves, further illustrating the impact caring is having on their ability to care for their own health.

*"I have cancelled a hospital appointment twice as I had no one to assist me after an anaesthetic"*

*"I have been told I may have a tumour and need operation, got no offer of any assistance from social work - have no idea what will happen if I am not able to manage."*

As well as having to put off treatment because of the demands of caring, **nearly a third of carers (30%) have been waiting over a year for NHS specialist treatment** and 18% have waited for more than six months.



This can be compounded by the person they are caring for also having to wait for specialist treatment - 28% of carers reported that the person they were caring for had



been waiting over a year for specialist treatment and 16% for more than 6 months. This can add to the physical and mental demands of caring and thus the impact on carers own health.

## Mental Health

A large proportion of carers also reported that their caring responsibilities impacted negatively on their mental health. **More than a quarter of carers (28%) said their mental health was bad or very bad.**

This impact on mental health was particularly prevalent amongst carers in receipt of Carers Allowance. **Over one third (37%) of carers on Carer's Allowance described their mental health as either bad or very bad.** This may be because those in receipt of Carers Allowance were particularly at risk of struggling to making ends meet financially and were more likely to be cutting back on essential items such as food and heating, which could explain the significant impact their the mental health.



*"My mental health has rapidly deteriorated in the last year. I am in a very poor place."*

*"I am permanently stressed depressed  
And just feel completely hopeless and feel like  
I'm serving a prison sentence for committing no crime."*

Carers went on to share in detail the impact of caring on their mental health. **The majority (88%) had difficulty sleeping or increased tiredness, continuous low mood (85%) and feelings of hopelessness (82%).**

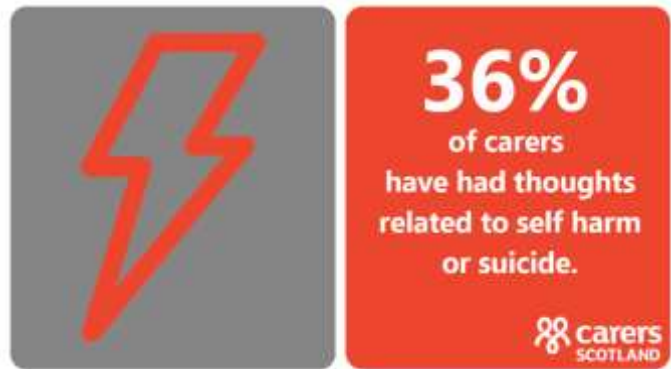
Three quarters (79%) experienced an inability to switch off from worrying about caring and similar proportions experienced irritability and mood swings (77%), low self-esteem (76%) and regularly feeling tearful (71%).



*"Tearful & very emotional, trying hard to accept how my life has changed since my caring role began in July 2021"*

**Of significant concern is that over a third (36%) said that they had thoughts related to self-harm or suicide.**

We share below just a few quotes from carers – there are many more, equally distressing that set out the devastation that caring can cause to mental health.



*"Would like to walk into sea, to float away, but know I can't because there'd be no-one to step in to support dad."*

*"It will only end when I die, but knowing my luck there will be reincarnation and it will be worse next time"*

*"My anti-depressants were increased recently and though my mood has been less suicidal my weight has gone up - a known side effect of the tablets - Venlafaxine - this in turn makes me feel physically and mentally worse. I have no confidence in myself and look and feel a right mess. I exist I don't really live and the only thing that keeps me alive is my cat. She will be 14 next month and if anything happens to her, I cannot see any reason to go on."*

Although a third (31%) of carers responding to this survey are receiving some form of NHS support for their mental health, and 17% are getting emotional support from their local carers centre, **over a third (35%) indicated that they are not receiving any mental health support at all.**



A quarter of carers (25%) said that accessing counselling, therapy or a listening support service which would improve their health and wellbeing.

However, too many carers are struggling on unsupported. We asked carers why they might not be seeking help with their mental health and the results revealed some stark findings.

**Half (50%) of carers said that they were simply too busy with the demands and responsibilities of their caring role.**

*"No time to go"*

*"I just feel stuck and not able to make decisions about my happiness as it always comes back to my caring responsibilities."*

However, delays in NHS appointments have a critical role, with a quarter (25%) of carers saying that this was the reason they had not accessed mental health support.

*"I am on four different waiting lists and have been for a year"*



Worryingly, the stigma around mental health seems to still play a role in carers who are not accessing mental health support as **more than one quarter (26%) said they do not feel comfortable talking about their mental health.** In addition to this, one in five (20%) said they were too embarrassed to speak about their mental health.

Overall, it is clear, too many carers are missing out on the support they need to look after their own health and wellbeing while providing care. This is directly influencing many carers capacity to care.

**More than a quarter of carers (24%) said they had to stop or reduce the amount of care they provided because of their poor mental health**, with family or social care having to take over in 12% of these cases.



Shockingly, **almost three quarters (72%) said they had to continue providing care even though they felt they were at breaking point.**

In addition to having an influence on their capacity to care, it is also having an impact on carers' ability to earn; vital in these times of financial strain. Around one fifth (18%) said that they had to leave a job or reduce working hours because of poor mental health caused by their caring role.

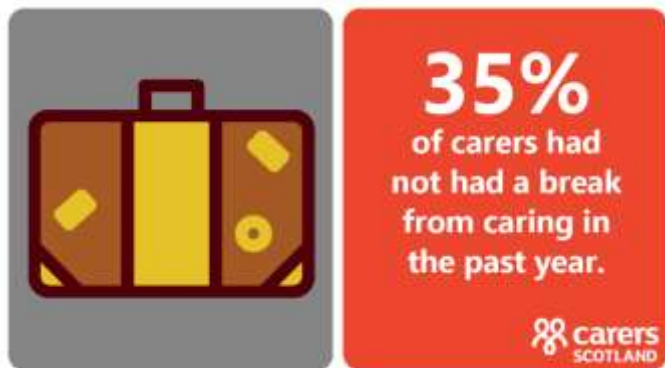




## The important role of breaks from caring

More than half (58%) of carers said taking a break from caring was critical to maintaining both their physical and mental health and there is a clear link between access to breaks from caring and better health outcomes amongst unpaid carers.

However, **just over a third of carers (35%) in State of Caring 2023 told us that they had not had any break from caring in the past year**, often saying that it is just too difficult to get the breaks they desperately need.



For those who have had a break only one in 10 (11%) were able to receive this break with support from social care services, with the greatest majority relying on friends and family to have any sort of break from their caring responsibilities.

Some groups of carers are struggling most to take a break. Duration of care and hours spent caring have a clear impact and our evidence also suggests that the cost-of-living crisis and financial insecurity plays a significant part in the ability (or not) to take a break from caring.

More than half (51%) of carers who told us that they are struggling to make ends meet and 42% of carers on any carer benefit have not had a break. And 40% of those caring 35 hours a week or for 10 years or more have not had a break in the last year. Worryingly, almost half (49%) of carers with a disability also told us they have not had a break.



*"I don't feel I am able to take the time to prioritise anything for myself. I would love to be able to take a paid break without feeling guilty and for this to be on a regular basis as any other person doing a job would expect."*

*"Cannot get respite from my role despite being entitled to it."*

*"If you were guaranteed paid respite breaks throughout the year to look forward to and plan things around it would relieve so much pressure"*

*"I'd like to go away with my husband occasionally but we're unable to leave our son alone overnight"*

*"It feels rare that I get to commit time to doing things just for me, without worrying about fulfilling my caring role or being interrupted."*

*My husband has Vascular Dementia so I would dearly love to have regular breaks from caring. His personality has changed completely towards me, but only me, so its very draining to live with 24/7.*



## Social connections and loneliness

Carers continue to tell us that their caring responsibilities bring loneliness and isolation. **Over a quarter (29%) said that they always or often feel lonely**, with a further 59% saying that they sometimes feel this way. However, the level of loneliness is far higher for some groups, with a further 59% saying that they sometimes feel this way. However, the level of loneliness is far higher for some groups.

**Carers who told us that they are struggling to make ends meet financially were almost twice as likely to be always or often lonely (50%)** and 39% of carers who are on Carer's Allowance say they are always or often lonely. This suggests that there is a link between a carer's financial wellbeing and loneliness and isolation, for example, many carers have reported that they have cut back on social activities because of increased costs. And, 40% of carers with a disability also reported always or often feeling lonely, suggesting that carers with a disability face greater barriers in supporting their mental health and wellbeing.



**Carers who are struggling to make ends meet are twice as likely to always or often be lonely.**



**Loneliness directly affects carers' health and wellbeing with 49% of all carers, 54% of carers with a disability, and 57% of carers on Carer's Allowance or struggling to make ends meet saying loneliness was affecting their health.**

Nearly a third of carers (21%) said that they needed support to prevent or reduce their social isolation and loneliness with one in 4 (23%) saying they need more help with maintaining and building relationships with others; relationships that have been limited or lost because of their caring responsibilities.

Having a life outside caring and being able to have opportunities to build and sustain connections with others is critical for carers' health and wellbeing.

Carers stated clearly in response to the survey that having time, and money, to spend time with friends and family helps sustain and improve their health and wellbeing. More than two thirds (68%) of carers that responded emphasised this was important. This was particularly prevalent in responses from older carers (65 and over) where three quarters (75%) said that spending time with friends improved their health and wellbeing.



However, as the "State of Caring 2023: the financial impact of caring in Scotland" report sets out carer poverty and the cost-of-living crisis reduces this option significantly for too many with **nearly half (46%) of all carers having cut back on seeing friends and family simply to make ends meet.** This leaves carers isolated without valuable support.

*"I haven't been able to spend time with friends for 3 years now, since I became a carer. At the moment I don't have enough money to live on so can't afford breaks, to pursue hobbies or follow interests. I also can't leave my partner overnight when he is vulnerable which is a lot of the time."*

*"I would like to meet up with friends I have known for 70 years but can't leave my husband for any length of time. Someone to step in & allow me to go away for a day would be wonderful."*



Many carers also told us about the importance of hobbies and interests. **57% said that engaging in hobbies and interests would improve their health and wellbeing.**

*"I don't have time to paint, which is a lifelong hobby."*

Others talked about how the chance to have education or training opportunities would help their health and wellbeing (17%) as well as the ability to be in paid employment (32%) giving opportunities for the future and much needed financial security.

Healthy activities were also important to carers. **58% said that being more physically active would help their health and wellbeing and being able to eat a balanced diet (42%) both limited by time and money.**

*"I would like to be able to go out walking or swimming more but can't leave my husband for very long."*

*"Would like more exercise, to join a class"*

Finally, and perhaps most importantly, carers said that having **good quality care services** for the person they care for (45%), getting a **break from caring** (58%) and **being valued as a carer** (54%) were critical to improving their health and wellbeing.

*"I don't prioritise my health and wellbeing as there is nothing in place to allow me to have a break. I would like to have a hobby again and to have friends."*





## Support and Social Care

Unpaid carers save Scotland £12.8 billion<sup>5</sup> per year in social care costs yet, **just a third (38%) of carers are receiving support in their caring role from formal social care services.**



Indeed, most (44%) support received by unpaid carers responding to this survey is informal from friends, family or neighbours. Around a third of carers (37%) reported receiving some help from a local carers' organisation, a local charity or community organisation (10%) or from a faith organisation or place of worship (3%).

Of those who were receiving social care services, 57% were satisfied with the quality of care provided. Nearly half (48%) said that they felt that they would be listened to if they raised concerns about the quality of care provided.

*"Alanmart Day Centre are truly outstanding. My mum attends for two afternoons per week. They treat her with dignity, kindness and love. They offer her mental stimulation and a place to socialise. They help foster her sense of place in the world as a person with dementia. She also receives four daily visits from Nightingale Care, funded by the council. The carers are all very competent and a few have formed a close bond with my mum."*

<sup>5</sup> [Scottish Government, National Care Service Financial Memorandum Para 7.2](#)

However, only just over a **third (36%)** said that they felt they could rely on social care services and a similar proportion (**37%**) said that care support did not meet their needs or those of the person they care for. Around a third (30%) said that social care was not consistent (ie. provided by the same staff at regular times).

*“Care workers as individuals try very hard but are overstretched. Changes in personnel are unsatisfactory for an individual with dementia who relies on familiarity and routine. Also requires me to be more active in care giving as staff are unfamiliar with home and routine.”*

*“Service, especially day centre, is not as good as pre Covid. There are fewer services available now as well and everything comes down to cost, not the needs/what’s best for the cared for person.”*

*“Lack of services. No care staff. Lack of community amenities. Poor accessibility. Left to fend for yourself. Have self-directed support budget and had no support with implementing it.”*

*“Can’t find a PA for my caree as no applicants on rural area.”*

*“I’ve become disabled and struggling to cope with both of our separate needs. No staff in the Highlands to help and no support.”*

We asked carers what assistance from local councils and health and social care partnerships could better support them in managing their caring responsibilities. **Nearly half (47%)** said that councils needed to better recognise their needs as a carer and deliver increased choice (41%), better quality (37%) and more affordable (25%) services for the person they care for.

Caring responsibilities can have a significant impact on carers’ ability to maintain employment. Carers are less likely to work full-time work<sup>6</sup> (34% v 47%) and more likely to be in part-time work (16% v 12%) than non-carers<sup>7</sup>. And, given the stresses and strains that can

<sup>7</sup> Family Resources Survey 2021/22

result from balancing work and caring, it is unsurprising that 1 in 6 carers give up work or reduce their hours to care<sup>8</sup>. **Therefore, it is of significant concern that one in five (19%) carers in State of Caring 2023 said that they needed better support from social care to return to or maintain paid employment.**

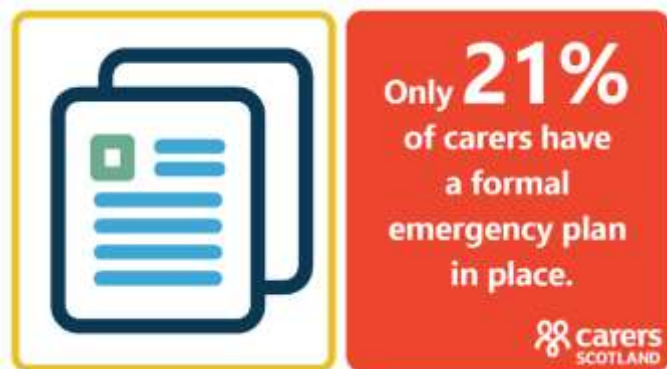
In State of Caring 2022, carers set out a range of services that had been reduced and had not returned to pre-pandemic levels (27% were facing reduced care at home services, 44% reduced day services and 24% reduced after school services for disabled children). In 2023, there has been little improvement, with four in ten (42%) carers say that support services were still not operating at full capacity or had not reopened and that this is one of the biggest challenges they face.

## Planning for Emergencies

The Carers (Scotland) Act 2016 sets out that carers should be supported to develop an emergency plan as part of their Adult Carer Support Plans (ACSP) and Young Carers Statements (YCS). An emergency plan is a written record of the arrangements that are in place for the cared for person if the carer has an emergency eg. if they go into hospital or are unwell and unable to care.

However, it is clear that despite the Act, there is insufficient awareness of emergency plans amongst carers. **A quarter (22%) of carers had never considered planning for an emergency and a similar proportion (29%) were not sure how to plan for an emergency** – and would like more support with this.

Even amongst those carers who have planned for an emergency, **only one in five (21%) have a formal emergency plan in place**, although a larger proportion (41%) have more informal plans in place; identifying people who might be able to provide care in their absence.



For those who have planned, only one in twelve (8%) have let social work services and just 3% their GP (or the GP of the person they care for) know what should happen if they are unable to provide care and support in an emergency.

<sup>8</sup> Employers for Carers, Carers UK

There is a worrying gap between the intention of the Carers (Scotland) Act and its implementation. Carers should be enabled to plan for emergencies and processes to ensure that relevant professionals involved in care are both aware of a carer's emergency plan and be ready to step in should a carer require support.

*"We were in a crisis emergency. A car accident put me in hospital. Despite this we were give zero assistance to help care for my child. He missed school due to me being unable to drive as I was physically housebound. Social Work, school and Connecting Carers charity all let us down. My son was left unable to care for himself. It was a dreadful time which has left me traumatised over the lack of care."*

*"I have power of attorneys in place for my parents and myself, more needs done to support all over the age of 18 getting POAs in place as a routine."*

*"I did try to plan for my total knee op. Social work agreed to increase the budget for time to recover. Support provider knew I needed support. They knew it was coming. But in the end, I got NOTHING from them. I was told that they didn't have anyone to help, because most workers had been transferred to supported living during the pandemic. I was asked on the Friday if I could go in the following Wednesday. OK, I get that was a bit short notice, but since the team leader did the rota, she knew I was going in, she could have juggled things. As it was, my husband had to take time off work, my daughter, who was on maternity leave had to help out and my youngest son was coming in from his work (support worker), to help out. My daughter texted the team leader that I was out of surgery and how it went. A year later, were still waiting for her to reply."*

*"I have tried to plan but I don't have relatives or friends who can help. Social services can't help until an actual crisis arises."*

## Information and technology to support carers

Every day, nearly 1000 people start caring<sup>9</sup>. This is often a time of uncertainty, managing sudden or progressive disability, illness or frailty of a partner, family member or friend and getting the right information at the right time is critical. This criticality of information was recognised in the Carers (Scotland) Act 2016, with local authorities required to provide information and advice services for carers.

We asked carers where they would go for information about caring and support. The largest proportion would rely on the voluntary sector – a local carer organisation (50%), a national carers charity like Carers Scotland (14%) or a charity specialising in a particular illness, condition or age group such as Age Scotland, MS Society Scotland (15%). Friends, family and other carers (19%) and the internet (42%) are also vital sources of information.

The public sector remains critical with one in five (21%) saying they would ask their GP or other health professional, 16% social work services, 5% their local pharmacy and 6% their local council.

However, **one in 10 (11%) carers said they did not know where to go for information**, so it is clear that more remains to be done to ensure that the ever-changing population of carers can access the information they need in a way that suits their needs.



Carers continually tell us of their frustrations at having to tell their story again and again to health and social care services in order to access even minimum levels of support. As part of the consultation on the National Care Service, the majority of carers (86%) surveyed at Carers Parliament in 2021 were in favour of a new electronic health and social care record which has been proposed, believing it could help to share information and be identified as an unpaid carer. This support was reinforced by carers in this year's State of Caring with **two thirds (63%) saying that they would like systems in which information about them or the person they care for is shared across services, so they do not have to repeat themselves.**

Systems are in place to record caring on GP records; however, this is not necessarily consistent. Therefore, carers also identified the need for any system to be able to identify

<sup>9</sup> Analysis from University of Sheffield, Centre for Care from the UK Household Longitudinal Survey (UKHLS), also known as Understanding Society, using data from 2010-2020. The sample includes all people who participated in the survey in any of those years. Carer churn from 2011 onwards, requiring the use of the data from 2010.

them as carers on the record of the person they care for (71%) and on their own patient record (69%). More than half (52%) of carers said they would like digital access to their own health and social care records and a similar proportion (54%) suggested that there should be an extra feature on such a record where they could identify themselves as an unpaid carer.

Six in 10 (60%) carers said that they would like digital access to the patient and care records of the person they care for. Whilst this approach would need safeguards and consent, there are opportunities for this approach to support simplicity and flow of information from carers to professionals in improving the care and support of the person being cared for.

Technology also offers other opportunities to make carers lives easier and to support improved health and wellbeing of both carers and those they care for.

**A third (35%) of carers said that they would like access to technology to support care** such as remote monitoring (such as motion sensors, fall detectors), a quarter (25%) to technology to support vital signs monitoring (such as blood pressure, blood glucose, heart rate) and 23% to apps that help pain or mood management. A third (33%) said they would like to be able to access online support groups and activities for carers.

## Carers as healthcare providers

**More than three quarters (77%) of carers told us of the significant and varied health care tasks they provide to support the health of the person they care for.** Recent calculations from the Scottish Government<sup>10</sup> estimate that providing these types of tasks save the health services £320 million each year.



These responsibilities can range from monitoring the mental health and wellbeing of the person they care for (68%), monitoring blood pressure or blood sugar (18%), dressing wounds (16%) and hoisting (9%) through to complex health support such as supporting home dialysis or devices that provides oxygen or continuous positive airway pressure (CPAP)<sup>11</sup> (6%), tube feeding (2%), giving injections (12%) and making decisions about whether or not to give emergency or specialist medication (24%).

<sup>10</sup> National Care Service Financial Memorandum

<sup>11</sup> A CPAP (continuous positive airway pressure) machine is used in the treatment of sleep apnoea. This device delivers continuous pressurized air through tubing into a mask that you wear while you sleep.

*"Luckily, I am a trained nurse. Although the older I get, the harder it is, but my husband would refuse help anyway."*

*"I assist my wife in setting up her Parkinson's medication pump and her colostomy bag."*

*"Have had to adjust diabetic support/care due to symptoms of dementia."*

Many carers talked about how they had little choice but to provide such support due to lack of local primary and community health options for the person they care for, with **four in 10 (41%) saying they needed more support from the NHS or healthcare professionals.**

*"Due to the lack of NHS support (eg. GPs being a primary problem), I just get on with dressing wounds for the person I care for. This includes buying wound dressings (Quite expensive at times) and cleaning/applying dressings. At times I have contacted the person I care for GP practice to seek advice/help, I get a response of "go to hospital". I don't mind doing these tasks for the person I care for. The point is, even when help/support is needed from the NHS it's not there. A message of "go to hospital" is not needed and not wanted - it doesn't warrant going to hospital, also, most crucially the person I care for would absolutely not be able to manage sitting in a hospital waiting for hours on end. So, I get by doing what I need to do to ensure the person I care for has a clean wound."*

*"I didn't have a choice taking on monitoring my Mum's mental health and wellbeing - she lives alone and has attempted to take her own life previously. I am mental health first aid trained through my career path however, it is very different when it is your own family there is a lot more emotion attached to decision making."*

*"No choice as two insulin dependent sons one with progressive neurological disorder and one registers as partially sighted."*



Although some carers spoke of the support and training they had received to carry out such tasks, others felt that this type of training was too limited and, for some, non-existent.

*"We had extensive support and training from health re: the current medication, delivered subcutaneously via a pump, and still have support from specialist nurses."*

*"I received some training for taking blood pressure though not that confident. It's a huge responsibility to monitor emergency medication. As a carer, you just have to do what you can."*

*"I have had training to use both the ceiling tack hoist and sling that we have and the mobile hoist. I am having to pack and dress a pressure sore for my cared for and I have had no official guidance or training on doing so. We visit the nurse twice weekly and show a photo of how the wound is looking and get supplies. My cared for is not able to get on the bed at the nurse so in the whole time that the pressure sore has been there (approx. 6 months) no health professional has seen the wound in person only in photos."*

*"I feel out of my depth with supporting mental health and how to help, with no training."*

*"Given rescue medication (syringe) to use for epilepsy. Given a brief talk but no real training or any understanding of stress this causes me to make decision on when to use this for partner."*

## Medication

As well as a range of health support, many carers also support the medication of the person they care for carrying out a range of tasks from collecting (69%) and/or ordering (68%) medication (68%), sorting into correct doses (39%) and checking and prompting someone to take medication (67%). However, **nearly half (48%) administer medication and nearly a third (30%) check for contraindications or allergies with other medications.**

Whilst over a third (34%) of respondents had asked for and received help with ordering and collecting repeat prescriptions from their pharmacy, less have been able to access advice on how to take a medicine safely (20%), administering medications (19%) or dealing with devices such as inhalers (11%). **Just under a third (31%) said that they had received help with treating minor health concerns but almost one in 10 (9%) would like more help with this.**

## Keeping safe from COVID19

In 2022, 16% of respondents told us that they had concerns about returning to support services as they were worried that the person, they care for would catch COVID19, with over a third (34%) saying that keeping the person they care for safe (when there are less public health measures to reduce COVID19) would be a significant challenge over the next year.

**This year, these concerns remain for too many, with a quarter (26%) of carers telling us that keeping the person they care for safe from COVID19 would be a significant challenge in the coming year.**

*"I have a reduced immune system, which not only affects my choice of wise social events, it also restricts the things to which I can take my husband"*





## Carers and support from the NHS

Carers are an important support in helping the people they care for to have the best experience from the health services they receive. State of Caring 2023 asked carers about their experience of the NHS as a carer and what might improve this. This covers a wide range of areas from hospital admission and discharge, attending appointments and future developments such as virtual wards.

### Hospital Appointments

The support that carers provide in helping the person they care for in their appointments with health professionals cannot be underestimated. Significant proportions of carers in State of Caring support the people they care for to attend hospital appointments. This can range from booking appointments, arranging transport and attending with the person.

Nearly all the carers responding to the survey (92%) reported that they have supported someone to attend at least one appointment in the last 12 months, with 25% helping someone attend five or more appointments. Indeed, **over a quarter (29%) have supported someone to attend 10 or more appointments in the last 12 months.**



## Hospital Admission

We asked carers whether the person they care for had attended accident and emergency (A&E) in the last 12 months and their experience of this admission.

**A third of carers (34%) reported that they had attended A&E.** Of these, a third (34%) had waited 30 minutes or less for an ambulance, 25% for between one to two hours and 29% for between two to six hours. **One in eight (12%) waited eight hours or more for an ambulance to arrive.**

Half of carers (50%) who had attended A&E said that handover between ambulance and A&E staff had taken 30 minutes or less, but a quarter (26%) had waited between one to two hours, 19% between two to six hours and **5% eight hours or more.**

Waits for initial examination by a doctor or nurse took less than 30 minutes for almost a quarter (23%) of carers, between one to two hours for a third (33%) and similar percentage for between two to six hours. **For 9% waits for this initial assessment took eight hours or more.**



## Hospital Discharge

State of Caring 2022 showed a significant lack of involvement in hospital discharge. Disappointingly, this year's report shows **no improvement**.

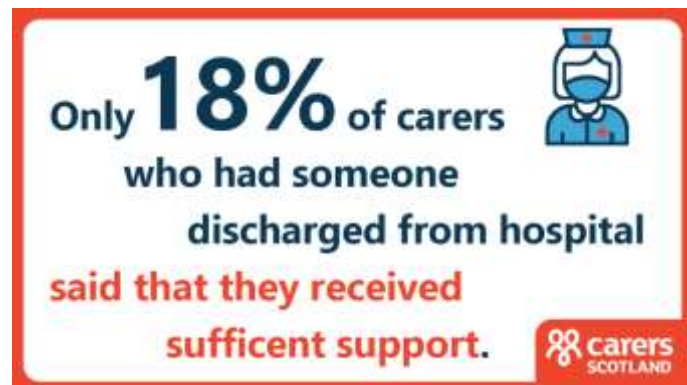
Of those who had someone discharged from hospital, **60% were not informed and involved in decisions about this discharge**.

Worryingly, **only 20% were asked about their willingness or ability to provide care and just 18% said that they received sufficient support** to protect the health and wellbeing of the person they cared for as well as their own health.

**Only 20% received an Adult Carer Support Plan.**

The Carers (Scotland) Act 2016 places a duty on NHS boards to involve and inform carers in discharge of the person they care for. As such, it gives carers a right to be involved and promotes the importance of ensuring that carers have access to support. Thus this lack of progress by health services in effectively involving and supporting carers as part of discharge processes is deeply concerning, **and in need of urgent action**.

*"Admitted with same complaint – delirium and infection. Very little information. Drs not available. Information given on discharge summary on occasion incorrect – missed medications resulting in missed doses of cardiac medicine at home as informed on letter discontinued. Phone calls to GP practice who are very supportive resulting in phone calls to hospital. Human error medication missed on admission although list of medication and blister pack given to nurse. GP recommended medication immediately and chemist delivered."*



*"He was discharged in the same state he went in with. No formal assessment was carried out nor the family asked how things were at home."*

*“Mum was discharged and I voiced my concerns on her getting home after having a serious infection. I had to keep emphasising that it was an infection on her tooth and was still in a lot of pain even although on antibiotics which the hospital were guessing the infection was until a junior dr listened to me and got a community dentist out as mum’s tooth was badly infected and needed urgent removal that day and they still discharged her back home to missing her carer so she had missed her medication so I had to come up to attend to my mum. It was an absolute shambles.”*

There is also a worrying variance for some groups of carers. For carers with a disability, just a third (33%) reported being involved in decisions about discharge and **only 14% were asked about their ability and willingness to provide care**. Only 12% said that they received sufficient support to protect the health and wellbeing of the person they care for as well as their own health. **Given these carers already have disabilities or health conditions that affect their day to day lives, it is striking that healthcare professionals, instead of providing additional consideration for their need to manage care alongside these, instead appear to offer even less support.**



Only **14%** of disabled carers were asked about their ability or willingness to provide care.

 carers  
SCOTLAND

*“Being able to continue as I have a disability and my condition will get worse”*

Older carers are more likely to be asked about their ability and willingness to provide care (30%) and to be provided with sufficient support to protect their health and wellbeing and those of the person they care for (31%). **However, given that the prevalence and incidence of most health conditions rises with increasing age<sup>12</sup>, it is concerning that large numbers of older carers in State of Caring 2023 are being neither asked about their ability to care nor provided with sufficient support to protect their health and wellbeing.**

Carers in the early stages of their caring journey also face additional barriers to support. Just one in 10 (9%) said that they were asked about their willingness or ability to provide care and a similar proportion – just 9% were offered an Adult Carer Support Plan.

The lack of involvement of carers in hospital discharge planning and failure to listen to carers and provide them with sufficient support can have significant consequences for both carers

<sup>12</sup> Scottish Public Health Observatory

and those they care for, with carers telling us about hospital readmissions and further deterioration of the person they care for.

*"We have had more than 20 admissions since January"*

*"She was discharged but a stomach bug came 8 hours later and she fall going to the toilet in the middle of the night, and fractured her neck"*

*"Went to hospital on Monday, discharged that day and readmitted by the Saturday."*

## Virtual Wards/Hospital at Home

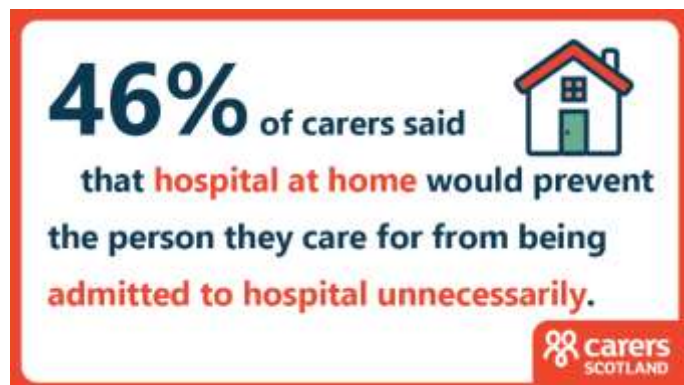
A virtual ward is services a *"time-limited service enabling people who have an acute condition or exacerbation of a chronic condition requiring hospital-level care to receive this care in the place they call home, either as an alternative to hospital admission or by facilitating an earlier discharge from hospital."* This enables multidisciplinary healthcare teams and remote monitoring to support someone to stay at home rather than being admitted to hospital.

The Scottish Government has been keen to expand these virtual wards which are better known as *Hospital at Home*.

However, such home based hospital level care is not yet widely available in all NHS areas in Scotland. Indeed, only 4% of respondents to State of Caring 2023 said that the person they care for had received care through a virtual ward/Hospital at Home.

However, we asked all respondents - with or without experience of receiving care from a virtual ward - what they saw as potential benefits and drawbacks of such an approach. **Nearly half (46%) of respondents said that it could prevent the person they care for being admitted to hospital unnecessarily, a third**

**(33%) that it could allow them as a carer to provide more personalised care and 55% that the environment would be more comfortable.** However, it is important to note that carers have concerns that this will increase the demands of their caring role. More than half (54%) felt that virtual wards/hospital at home would involve them providing more care.



## Conclusion

The findings in this report paint a stark picture of carers buckling under the strain of propping up a health and social care system that is under severe pressure. This pressure in the delivery of public sector services has meant that carers have been left to carry a growing burden of significant care – where social care cannot provide a service, it is unpaid carers who are expected to step in, where the NHS needs a “bed” it is carers who are left to support discharge.

At the same time, carers physical and mental health continues to deteriorate, often significantly whilst they have little time, money or energy to be able to maintain their own health and wellbeing.

Rightly, the Government has recognised the need to bring down NHS waiting lists and improve access to health services, including crucial mental health services. However, dedicated funding and planning is urgently needed to ensure that carers can access the health services they need and support for caring from social care services to prevent the shocking levels of poor health they are experiencing.

**Quite simply, action is needed, and it is needed now.**

## Recommendations

To ensure all carers get the support they need to look after their own health:

1. The Scottish Government should develop and introduce a **Carers Health Plan**, recognising that unpaid care is a social determinant of health, and setting out how they will in the short, medium and long term not only maintain and improve the health of unpaid carers and young carers but prevent long term health inequalities.
2. Support for mental health is of significant concern and the Scottish Government should **fund dedicated, tailored mental health support for unpaid carers**, including providing funding to local carers centres, disability and condition specific organisations and palliative care organisations to enable them to commission mental health support for those they support. This should include support for anticipatory grief, bereavement counselling and specific mental health support for young carers.



3. The Scottish Government should **fast track unpaid carers to support to maintain their health whilst caring**. This could include: introducing direct payments or vouchers for carers to spot purchase non-NHS assessments, physiotherapy, counselling and other such services. Carers should have access to occupational support in the same way as health and care employees.
4. To ensure that carers are able to look after their own health, the Scottish Government should progress at pace actions within the National Carers Strategy to **deliver flexible health appointments for carers, including providing replacement care for appointments**.
5. Local health and social care partnerships and NHS Boards should develop their own local plans to **deliver regular health checks for unpaid carers** to identify health concerns or pre-conditions, such as high blood pressure and diabetes.
6. Local councils should seek to develop **concessionary or free access to leisure services** within their areas not just to carers in receipt of Carer's Allowance but expanding to include all carers and young carers. This could include working with local carers centres and GP practices to develop social prescribing of leisure access.
7. The Scottish Government should work with NHS Boards to ensure their **plans for reducing waiting lists set out how they will consider the unique and individual needs of unpaid carers**, including prioritising carers for healthcare support that will support their ability to care.
8. Prior to the introduction of a right to a break from caring in the National Care Service, the Scottish Government should commit to:
  - **increase funding year-on-year for short breaks** delivered by the voluntary sector, including through the:
    - Time to Live fund administered by Shared Care Scotland and local carers services.
    - Take a Break Scotland fund for families with disabled children and young people administered by Family Fund.
  - **increase funding year-on-year to health and social care partnerships and local councils for a range of breaks** from caring and ensure that this funding is protected within their budgets.
  - **work to expand availability of short breaks services** across Scotland to ensure that when the right to a break is introduced, there are sufficient and varied services for carers to choose from

9. The Scottish Government should work with local councils, health and social care partnerships and NHS Boards to **improve knowledge of carers rights amongst staff** who come into contact with them and **ensuring that carers can access support** when it is needed by:
- **improving access to Adult Carer Support Plans**, in particular ensuring that they are offered as standard to all carers during the hospital discharge process.
  - **improving referral routes between services for Adult Carer Support Plans and Young Carer Statements** to ensure that carers and young carers are able to have access an assessment and services promptly.
  - **encouraging greater and more consistent use of flexibility within self-directed support** to empower and better support unpaid carers and those they care for. This should include simplifying administration, promoting 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.
  - **improving uptake of emergency planning (and anticipatory planning)** within both Adult Carer Support Plans/Young Carer Statements and in care planning.
10. To improve both the visibility and value of care, the Scottish Government should introduce add **a new dedicated national outcome** on care to fully values and invests in those experiencing care and those providing it.
11. The Scottish Government should **work with partners to develop a more coordinated approach** across health, social care and local council services to refer carers to third sector and community support including, in particular food support and fuel vouchers, vital to protecting health and wellbeing.



**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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