



# I SEE NO LIGHT AT THE END OF THE TUNNEL



**AN URGENT CALL TO ACTION FROM  
SCOTLAND'S UNPAID CARERS**

November 2022

**CARERS  
TRUST**  
  
**SCOTLAND**

# ACKNOWLEDGEMENTS

## Thank you to:

- The 531 unpaid carers in Scotland who took the time to tell us what they think and need.
- Carers Trust's network of local carer organisations, and our other partners, who advised us, helped us hear from unpaid carers and who provide the invaluable support unpaid carers need.
- Carers Trust's report team.

# ABOUT CARERS TRUST

Carers Trust works to transform the lives of unpaid carers. It partners with its UK-wide network of local carer organisations to provide funding and support, deliver innovative and evidence-based programmes and raise awareness and influence policy. Carers Trust's vision is that unpaid carers are heard and valued, with access to support, advice and resources to enable them to live fulfilled lives.

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# UNPAID CARER FOREWORD



**Can you be doubly invisible? That is how we feel, invisible as unpaid carers and invisible as carers of an autistic/neurodivergent daughter (38 years old). There are thousands of others in a similar position.**

Our daughter finds adding two numbers under ten a challenge; can read and write; fine motor coordination is weak e.g. using sellotape, scissors, a sharp knife and threading a needle is almost impossible. However, her biggest challenge is ADHD which means planning and organising are exhausting as her thoughts are racing and attention is lost. Most of our time is spent setting up and implementing the weekly timetable, accompanying her to appointments, banking, form-filling (e.g. bus pass), being her gym buddy, demonstrating how to clean, sorting out IT problems, returning parcels for online purchases, planning meals, shopping, convoy driving and providing back-up when things go wrong. There are no close friends to share the day with or make phone calls with, we are her social life. We never stop thinking about the next day, week, or years as she cannot live independently. Our daughter is aware of this and our inevitable death frightens her.

We have had specialist advice and help but generally it is not adequate or appropriate. One comment that sticks in my mind from an employment coach about my daughter was, *"She looks fine to me"*. What were they expecting blue spots, horns, multi digits? I don't blame them, as understanding the complexities of neurodiversity took us over 30 years. We have become distanced from friends and family, as they don't see the difficulties either and think we should be firmer.

Financial support and the treatment of unpaid carers urgently needs to be reformed and improved. When I was employed, my salary was above the earnings threshold to get Carer's Allowance and now I am retired, I am not eligible either. But even if I had a million pounds of benefits, I would not be able to spend it as the support required is not available.

There are lots of warm words and hand wringing but remarkably little action after over 20 years of a Scottish Government. We have numerous strategies, policies, frameworks, mapping exercises, consultations but little implementation.

**Susan Chambers**

Unpaid carer

# INTRODUCTION: A RED ALERT ISSUE

Unpaid carers give up so much to support the person they care for, and ask for very little in return. Our latest research, drawing on the views of 531 unpaid carers in Scotland, finds that many unpaid carers face serious emotional, financial and practical challenges as a result of the support they provide. Yet many unpaid carers are left struggling without enough support from the state, at a cost to their finances, their employment and their health. There is a lack of an adequate and reciprocal offer of support, services and recognition, which is having a catastrophic impact on the physical health and mental wellbeing of unpaid carers.

Even before the cost-of-living crisis, Carers Trust was exceptionally worried about unpaid carers' finances and the support available for a group of people who are the unseen cornerstone of our health and social care system. Many unpaid carers face additional costs associated with their caring role, such as higher energy bills, transport costs and the costs of specialised equipment. Crucially, many cannot look to employment as a route out of poverty due to the lack of replacement care on offer. Given the results from our latest research, we now know support for unpaid carers needs to be a matter of the utmost concern for decision makers.

Carers Trust has written this report for decision-makers on behalf of the unpaid carers who took the time to share their messages with us. These are their voices. And our message is that a solution desperately needs to be found so that unpaid carers get the support they need. Unpaid carers are not asking to live in the lap of luxury or saying they do not want to work – they are having to “choose” whether to eat or not, to turn the heating on or not, leave their jobs, and are compromising their own health and wellbeing. Given all the other things they have to do, worrying about eating and heating should not be something unpaid carers need to think about.

In our research, we heard from 2,675 unpaid carers across the UK, including 531 living in Scotland, many of whom are supported by the UK-wide network of local carer organisations with which Carers Trust works. This report is a deep dive into the experiences and needs of unpaid carers in Scotland. It includes statistics for the unpaid carers living in Scotland in our sample and direct quotes from them. Our findings for unpaid carers in Scotland are broadly in line with unpaid carers from the UK as a whole and we have drawn out differences where relevant.

## Key findings from unpaid carers in Scotland:



**74%** (ALMOST THREE QUARTERS)  
ARE WORRIED ABOUT BEING ABLE  
TO AFFORD ENERGY BILLS



**69%** (OVER TWO THIRDS)  
FEEL IGNORED BY THE UK GOVERNMENT

**58%** (OVER HALF)  
FEEL IGNORED BY THE SCOTTISH  
GOVERNMENT



**46%**  
ARE STRUGGLING TO MAKE ENDS MEET AS A  
RESULT OF THEIR CARING RESPONSIBILITIES



**12%**  
OF UNPAID CARERS HAVE USED A FOOD BANK



**55%** (OVER HALF)  
TOLD US THAT THEY HAVE NOT HAD AN  
ASSESSMENT OF THEIR NEEDS AS A CARER  
IN THE LAST YEAR

The Scottish Government and the UK Government urgently needs to find solutions which meet the three most important issues for unpaid carers:

- 1. BETTER SUPPORT FOR THE PERSON/PEOPLE THEY CARE FOR.**
- 2. A BREAK OR RESPITE.**
- 3. MORE MONEY.**



# RECOMMENDATIONS

**Our top three recommendations are that the Scottish Government and the UK Government:**

## **1. Prioritises support for unpaid carers due to the extra costs of caring, with urgent access to financial support during the cost-of-living crisis and beyond. We ask that the:**

- Scottish Government makes double payments of Carer's Allowance Supplement to recognise the additional costs associated with caring and help unpaid carers to pay their rising bills during the cost-of-living crisis.
- Scottish Government introduces and extends eligibility of Scottish Carer's Assistance as soon as practical, to help more unpaid carers get the financial support they need and deserve.
- Scottish Government introduces a Minimum Income Guarantee for all unpaid carers. It is vital that the experiences and voices of unpaid carers are central in future policy planning.
- UK Government increases Carer's Allowance immediately and at a minimum raises it in line with inflation if unpaid carers are not to be plunged into greater poverty.
- UK Government urgently makes unpaid carers a priority group for a 2022 winter package of support, so they do not go hungry or cold due to the cost-of-living crisis.



Image credit: Centre for Ageing Better

## 2. Commit to fully resourcing the forthcoming Scotland Strategy for Unpaid Carers

- The Scottish Government to commit to fully funding and implementing the forthcoming Scotland Strategy for Unpaid Carers. The introduction of this cross-government strategy must make clear who is responsible for implementation and present clear actions that can be delivered at pace which have the potential to make a real difference to the lives of unpaid carers.

## 3. Urgently and adequately fund health and social care. We ask that the Scottish Government ensures a social care funding solution that means:

- a) Local carers services have adequate funding, including those who provide home care services.
- b) Unpaid carers and disabled people are properly supported in their homes, in their communities and in their workplaces.
- c) Local carers services and unpaid carers themselves have the capacity to engage as valued expert partners in local health and social care partnerships.

To achieve this, the Scottish Government should:

- **Raise the level of funding for local carers support and ring-fence it.** Most local authorities work well with their local carers services and good commissioning reduces unmet need. The overall ever-diminishing pot of funding means that local authorities are in too many cases having to make impossible decisions about what they can and cannot fund, which compromises carers services and unpaid carers.
- **Ensure funding impacts on wages.** Lack of funding means that pay is too low for paid care support workers who provide replacement care, including personal care. This contributes to difficulties in recruiting and retaining staff. This in turn leads to a lack of both quality and quantity of paid care support workers available to support unpaid carers, older people and disabled people. Committing to finding a long-lasting and sustainable funding solution would stop unpaid carers being expected to do more and more by default.

- **Co-design the National Care Service in Scotland with unpaid carers and disabled people.** The introduction of a National Care Service provides a new opportunity to transform and improve social care support in Scotland and it is vital that unpaid carers and people who use services are fully involved as equal partners in the planning and design. The Scottish Government must adequately and sustainably fund the National Care Service in Scotland so that it can be successful in delivering its stated aims.
- **Urgently introduce a Right to a Break from Caring.** This must be fully resourced and a range of short break services must be available that meets the varied needs of unpaid carers to ensure this right is implemented and upheld.
- **Ensure funding for local carers services includes capacity-building.** This would mean local carers services are funded to provide their expertise as equal partners in developing and shaping local services.



Image credit: Centre for Ageing Better

# WHAT OUR SURVEY FOUND

## THE FINANCIAL IMPACT OF CARING:

***“IT’S CRUSHING TO NOT EVEN BE ABLE TO AFFORD THE MOST BASICS IN LIFE DUE TO BEING AN UNPAID CARER.”***

**Our research shows that unpaid carers in Scotland, like those across the UK, are struggling financially as a result of their caring role.**

Caring can be very expensive, from the cost of adaptations to the home, to transport to and from appointments. Unpaid carers should not have to cover these costs themselves. But, faced with inadequate financial support from governments, both for themselves and the person they care for, they often do. Unpaid carers face extra costs of caring, and many experience loss of income from leaving work, or reducing their hours. Carer’s Allowance is not an adequate income replacement.

Echoing findings from the full UK sample, 46% of unpaid carers in Scotland told us they have had to spend their personal savings as a result of their caring role. In addition, over a quarter of unpaid carers in Scotland told us they have had to pay for items that are essential for their caring role or that make things easier.

On top of paying for the costs of caring, unpaid carers in Scotland often have to give up work in order to fulfil their caring responsibilities.

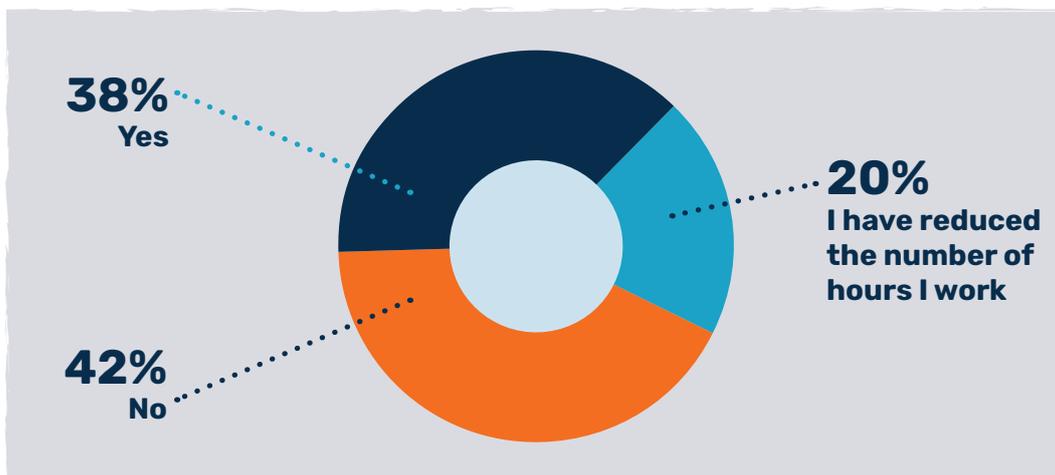


**38% of unpaid carers in Scotland reported that they have had to give up a job or paid work as a result of their caring role.**

A further 20% have had to reduce the number of hours they work.

Unpaid carers who leave employment to care face the dual impact of a reduction in income and receiving state benefits lower than most paid positions, whilst also covering the additional costs associated with caring. Our research shows that unpaid carers who have had to give up paid work are more likely to be struggling financially. Our findings from across the UK show that 59% of unpaid carers who have had to give up paid work as a result of caring are struggling to make ends meet, compared to 37% who have not had to give up work.

**Figure 1: Have you had to give up a job or paid work because of your caring role? (Data for unpaid carers living in Scotland).**

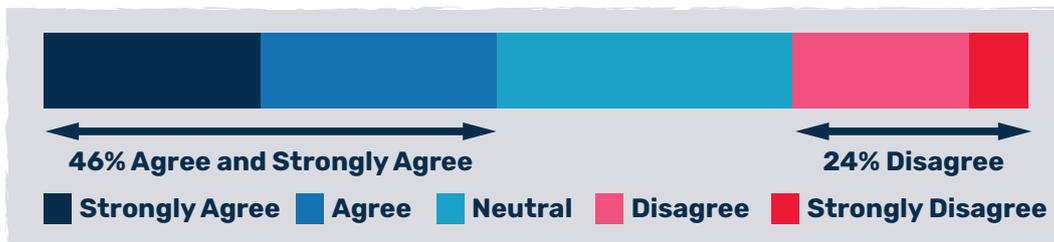


**“I had a good job with a good wage but I had to resign in 2017 at the age of 59 due to the enormous pressure I was under trying to juggle everything i.e. look after my elderly parents... and my husband who has Asperger’s”** *Unpaid carer from Scotland*

Unpaid carers are significantly disadvantaged with high costs and low levels of financial support, leaving many struggling to get by and worried about what the future holds for them.

**46% of unpaid carers in Scotland are struggling to make ends meet as a result of their caring responsibilities.**

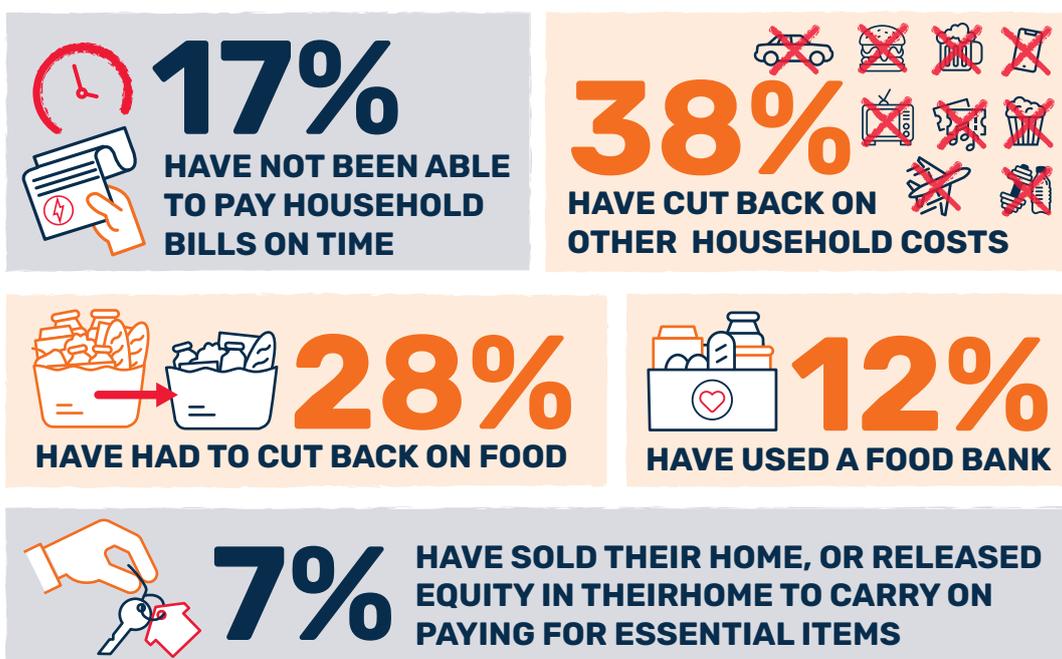
Figure 2: To what extent do you agree or disagree with the phrase "I would say I am struggling to make ends meet"? (Data for unpaid carers living in Scotland).



**“ I receive absolutely NO financial assistance whatsoever. I am constantly struggling financially. It is really depressing. I feel trapped.”**

**“ My mum and I are living in poverty in a cost-of-living crisis, this situation just isn't right.”**

Many unpaid carers in Scotland told us they are unable to afford essentials like food and energy:



**“All general bills are a worry. It’s crushing to not even be able to afford the most basics in life due to being an unpaid carer.”**

**“I am retired so no longer qualify for Carer’s Allowance - seriously worried about heating costs going forward. Need to maintain a higher temperature due to heart failure.”**

In addition, many unpaid carers have been forced to take on debt to afford essential costs.

**27% of unpaid carers in Scotland said they have had to pay for essential items using a credit card.**

- 1 in 4 have had to borrow money from a friend/relative.
- 17% have taken out a loan.

**“Feeling overwhelmed after 23 years of caring, I see no light at the end of the tunnel, as I get older, I worry about what will happen to my son, what will happen to me, to have no life and be grateful for every penny thrown my way.”**

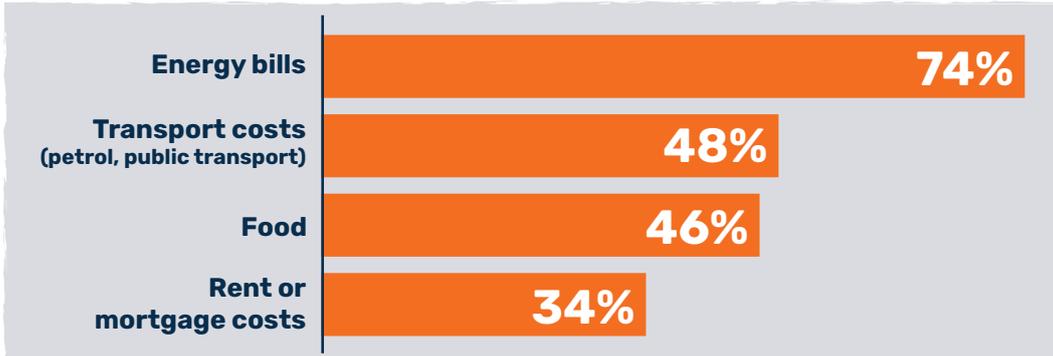


Image credit: Centre for Ageing Better

With the cost of living rising, the majority of unpaid carers in Scotland feel worried about how they will afford essential living expenses going forward.

**74% are worried about being able to afford energy bills.**

**Figure 3: I am worried about affording the following. Select all that apply. (Data for unpaid carers living in Scotland).**



On top of all this, unpaid carers told us that their caring role also takes a toll on wellbeing. 45% of unpaid carers in Scotland said they have given up hobbies or interests because of the cost. Unpaid carers said they lacked the time and energy to keep up with friends and family or look after their own wellbeing. As a result, many unpaid carers said the demands of their caring responsibilities have a detrimental impact on their mental health.



## CARER'S ALLOWANCE

Across the UK, not enough unpaid carers are eligible for Carer's Allowance. And those who do receive it, say it is not enough money to cover the cost of caring. This is a key factor pushing unpaid carers into financial hardship. Unpaid carers feel that Carer's Allowance does not adequately reflect the difficult unpaid work they do or the vital contribution they make to society. As a result, many feel undervalued, ignored and abandoned.

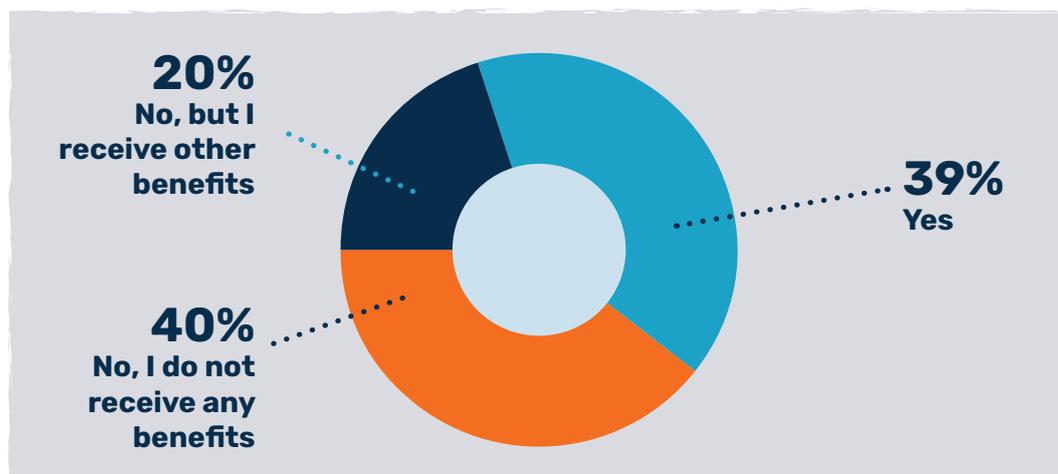
The Scottish Government currently provides unpaid carers with an additional payment beyond the base level of Carer's Allowance, called Carer's Allowance Supplement. A small number of unpaid carers stated that this supplement has made a difference to them. However, the majority feel they still do not get enough financial support. Over half of unpaid carers surveyed told us they do not receive Carer's Allowance.

**61% of unpaid carers in Scotland told us they do not receive Carer's Allowance.**

This includes 40% of Scottish unpaid carers who do not receive Carer's Allowance or any other benefits.

**“The Scottish Carer's Supplement has made a huge difference.”**

**Figure 4: Do you receive Carer's Allowance?**  
(Data for unpaid carers living in Scotland).



**Of those who do receive Carer's Allowance in Scotland, 56% said Carer's Allowance is not enough to meet their needs as an unpaid carer.**

**“While I'm grateful for getting Carer's Allowance and the carer's element on UC (Universal Credit), Carer's Allowance is really not enough to rely on...and it's taken off my UC payment so my carer's element is given to me but instantly taken away... So I'm having to lose so much which makes it even harder to be able to afford even good food for myself and my family and to be able to cook for my parents.”**

Carer's Allowance should prevent unpaid carers experiencing poverty as a result of their caring role. However, our research shows that unpaid carers who receive Carer's Allowance are more likely to be experiencing financial hardship. 58% of unpaid carers receiving Carer's Allowance said they are struggling to make ends meet, compared to 38% of those who don't receive Carer's Allowance.

In our research, unpaid carers identified ways that Carer's Allowance could be improved to better meet their needs, including increasing the amount and making more people eligible.

**“I don't meet criteria for Carer's Allowance since mum is in a home and my sister's needs are sporadic. Right now I'm totally on my knees and utterly at the end of the rope, with zero support.”**

**“I think Carer's Allowance should not be means tested, if you have a caring role, you should receive it regardless of what you earn from a job.”**

In early 2022, the Scottish Government launched a consultation on Scottish Carer's Assistance – to replace Carer's Allowance. The consultation sought views on several proposals for the future of carer benefits in Scotland, including extending the eligibility criteria so that more unpaid carers would be able to receive Scottish Carer's Assistance and extending run on periods when the benefit usually stops, such as after the death of the cared for person. The consultation

also sought views on future proposals for Carer's Allowance Supplement, as well as about the introduction of an additional payment for those who care for more than one disabled person. The Scottish Government also asked for views on how they could better support people who would not qualify for Scottish Carer's Assistance because they have an overlapping benefit, such as the State Pension.

In 2023 the Scottish Government will begin transferring Carer's Allowance to Scotland and set up Scottish Carer's Assistance, this is estimated to take around 18 months. Changes to the benefit won't take place until Scottish Carer's Allowance is launched and the process of transferring people currently receiving Carer's Allowance to Scottish Carer's Assistance is complete.



## LACK OF SUPPORT:

***“IT HAS HAD A DETRIMENTAL EFFECT ON MY MENTAL HEALTH AND WELLBEING”***

**Our research found that many unpaid carers are struggling to get the support they need, despite the critical role they play in our society.**

**51% of unpaid carers in Scotland told us they do not receive enough support to be a carer.**

Support services are vital to unpaid carers, whether they provide respite, emotional support, financial support or care for the person they look after.

**“Services such as groups, day care support groups, should be treated as essential services. People with disabilities rely on these services for mental health like able bodied people rely on a supermarket to survive.”**



## THE ONGOING IMPACT OF COVID

The pandemic put a lot of pressure on unpaid carers. In line with findings for the UK, 65% of unpaid carers in Scotland told us they spent more time caring during lockdowns and restrictions as a result of closure of local services. In many places, services have not fully re-opened since Covid lockdowns and unpaid carers are still providing more support at home as a result. 36% of Scottish unpaid carers said the services they use have only partially re-opened and 12% said they have not reopened at all.

Services were already stretched before Covid and unpaid carers told us the situation is worse now. The services that unpaid carers desperately need are under-resourced, leading to waiting lists and reduced provision.

**“Services were already stretched before, following Covid these have been substantially reduced and more focused on self-care.”**

**“Many services are continuing with the ‘virtual’ meeting, consultation, phone access. I find this unsatisfactory. I like to see a ‘real’ person! Also as an old carer with hearing loss, the ‘virtual’ scene is unmanageable. Reduced services are also still being excused ‘because of covid’, ‘staff absence’!”**

Not having access to enough support is hugely detrimental to unpaid carers.

**“Every service has been affected – GPs, hospital, pharmacy deliveries, drop-in centres. I’m grateful some are there but nothing is the same. It has had a detrimental effect on my mental health and wellbeing and both of my parents for whom I care for.”**

While many unpaid carers care because they want to, others feel they do not have a choice about the caring they do. This is usually due to the inadequate or insufficient support from statutory services available for the person they care for.

Over half (53%) of unpaid carers in Scotland said they do not feel they have a choice about being an unpaid carer. 47% of unpaid carers in Scotland say they don't have a choice about the type of care they provide (e.g. emotional support or personal care).

**“Carers do not necessarily choose to be carers. The role is usually thrust upon them due to the assumption that one will look after family members.”**

**“We do it because we love our partner but we don't have a choice, as if we don't do it, who will?”**



Image credit: Centre for Ageing Better

## EMPLOYERS

Having a supportive employer makes a huge difference to unpaid carers who work. However, unpaid carers in our research described a lack of support from their employers and some have had to leave jobs as a result.

**“Please make it mandatory for employers to have ‘carer’s support’ plans and packages as part of their HR offering. I have this at my work and it makes a huge difference.”**

**“I used to work full time, but my dad’s health declined just before lockdown, and I had to resign and go back to another job on a zero hours contract, to allow for flexibility when my dad needed to get to appointments and took ill.”**



Image credit: Centre for Ageing Better

## ADULT CARER SUPPORT PLANS

Access to support services is vital for unpaid carers. However, a high number of unpaid carers in Scotland have not had an Adult Carer Support Plan or review of their needs in the last year and are unable to access support as a result. This is in line with our findings for the UK as a whole.

**55% of unpaid carers in Scotland told us they have not had an assessment of their needs as a carer in the last year.**

Of those unpaid carers who hadn't had an assessment in the last year, 75% said they had not been offered one.

Access to assessments seems to have improved since our last survey which took place during Covid lockdowns. However, we are still concerned that not enough unpaid carers are having their needs assessed as local authorities are overstretched and Adult Carer Support Plans are not being prioritised.

Even when unpaid carers have Adult Carer Support Plans and are eligible for support, many find they are unable to access the support they are entitled to. Of those unpaid carers in Scotland who have had an assessment, 19% do not receive the support they are eligible for.

**“ [I was] assessed in March as significant needs - nothing happened since, I can only assume it's due to shortages at social work.”**



# ATTITUDES TO THE SCOTTISH GOVERNMENT AND THE UK GOVERNMENT:

***“DON'T UNDERSTAND OR CARE ABOUT THE NEEDS OF CARERS”***

**It is clear from our research that Scottish unpaid carers feel undervalued and ignored by governments, despite the incredibly valuable contribution they make to our society. This attitude is echoed in unpaid carers across the UK.**

**69% of unpaid carers in Scotland feel ignored by the UK Government.**

Many unpaid carers don't feel the UK Government is addressing their needs and don't have confidence in the UK Government to improve their situation. In general, Scottish unpaid carers feel more negatively about the UK Government than unpaid carers across the UK.

- 65% of unpaid carers in Scotland said they do not feel understood by politicians (compared to 56% of unpaid carers in the UK).
- 57% of unpaid carers in Scotland said they don't have confidence in the UK Government's ability to improve the lives of unpaid carers (compared to 46% in the UK).
- 59% of unpaid carers in Scotland don't feel the UK Government is addressing their needs as an unpaid carer (compared to 48% in the UK).

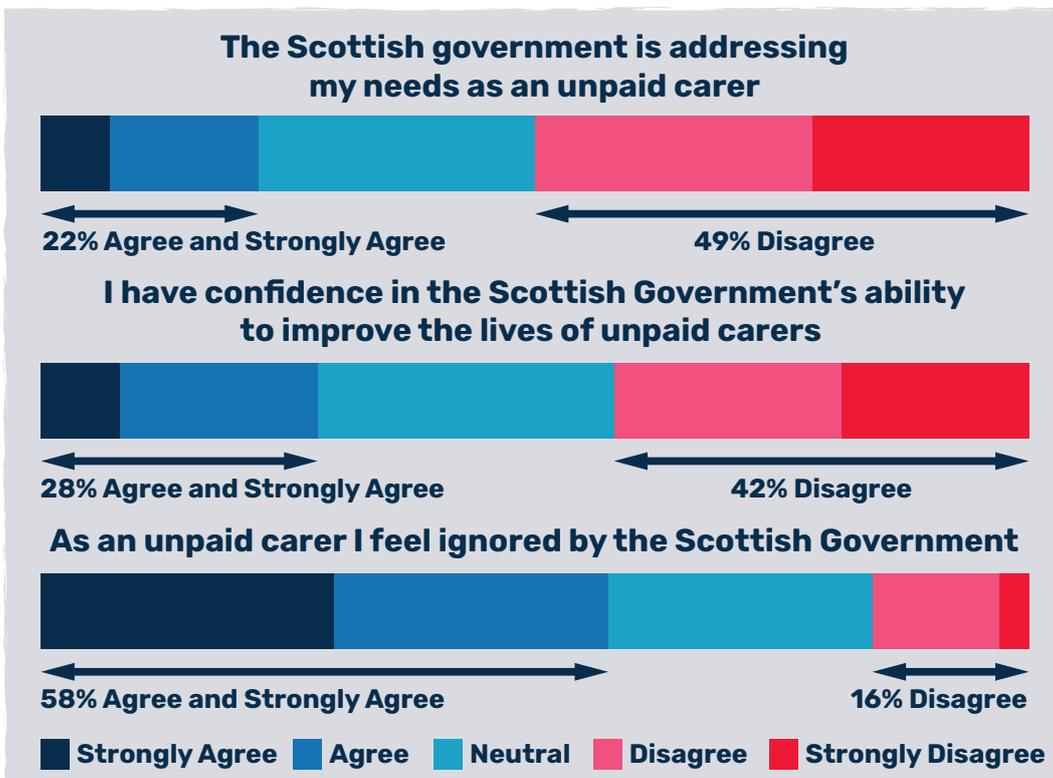
**“ I honestly believe that senior politicians in the UK don't understand or care about the needs of carers. They come from a privileged elite that rarely have had to concern themselves with the dirty reality of caring. Without doubt they will have had family members who have demands, but this is a role that they can afford to give to someone else.”**

Scottish unpaid carers feel more positive about the Scottish Government than the UK Government. However, unpaid carers still feel that the Scottish Government needs to do more to support them.

**58% of unpaid carers in Scotland feel ignored by the Scottish Government.**

- 42% of Scottish unpaid carers said they don't have confidence in the Scottish Government's ability to improve the lives of unpaid carers.
- 49% don't feel the Scottish Government is addressing their needs as an unpaid carer.

**Figure 5: To what extent do you agree with the following statements?  
(Data for unpaid carers living in Scotland).**



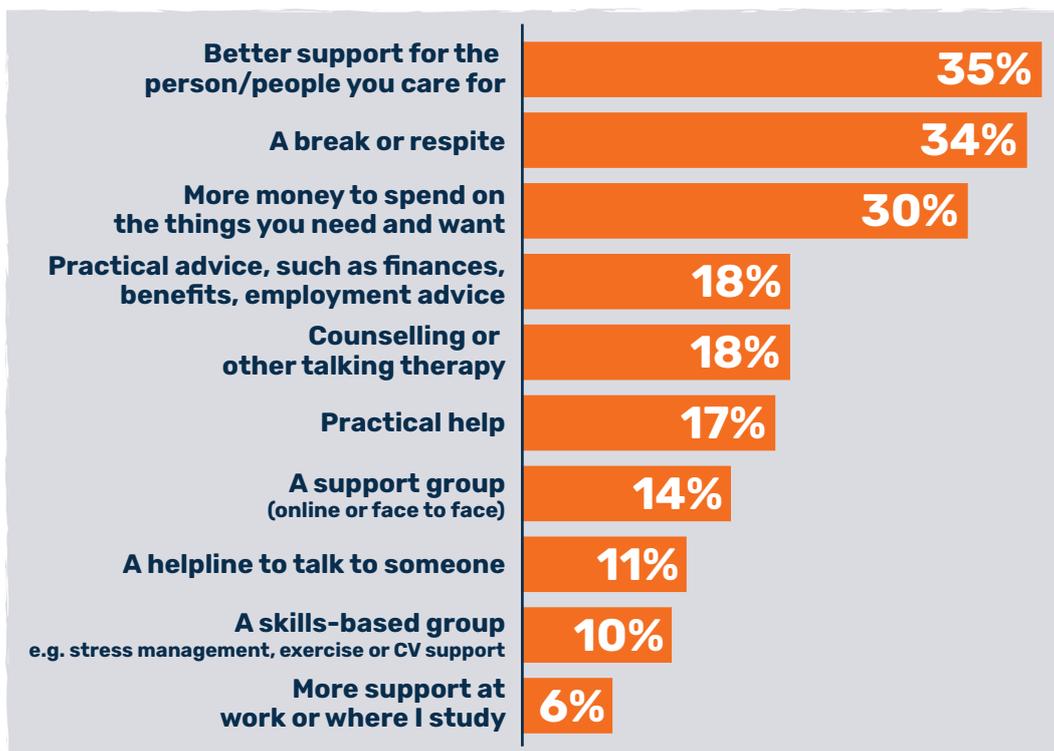
# WHAT WOULD MAKE A DIFFERENCE?

***“NOT WAITING TILL SITUATION IS CRISIS LEVEL”***

It is clear that unpaid carers need more support with the valuable and challenging unpaid work they do. When we asked unpaid carers in Scotland what would make the most difference to them, their answers reflected those given across the UK. The top three answers they gave were:

- 1. BETTER SUPPORT FOR THE PERSON/PEOPLE THEY CARE FOR.**
- 2. A BREAK OR RESPITE.**
- 3. MORE MONEY.**

Figure 6: What support would make the most difference to you as an unpaid carer? (Data for unpaid carers living in Scotland).





We asked Scottish unpaid carers to tell us one thing senior politicians could do to make a difference to them as an unpaid carer. Here is what they told us:

**“If I could find a respite service to fully meet my adult son’s needs, my husband and I could spend some time together, have a break, go on holiday knowing he was being fully supported.”**

**“Access to staff and appointments for my daughter - not waiting till situation is crisis level.”**

**“Acknowledge the informal support that unpaid carers continue to provide across the country.”**

**“I would say better financial support would be the most important thing among many that I would raise with politicians. Caring is an exhausting role that saves the state massively, plus it is better for the cared for person to be looked after by a family member that understands them and their way of communicating for a better outcome.”**

# METHODOLOGY

**2,675 unpaid carers from across the UK, aged over 18, completed our survey. 531 respondents said they lived in Scotland. This is the sample we refer to throughout this report as 'Scottish unpaid carers' or 'unpaid carers from Scotland'.**

We promoted the survey via Carers Trust Network Partners, other charities and external organisations we work in partnership with, and on our social media channels. The survey ran from 22 July to 24 August 2022.

Respondents self-identified as unpaid carers aged over 18 before completing the survey; a short definition of an unpaid carer was provided in the introductory text of the survey.

We ran quality assurance checks on the data to check for invalid responses.

Unpaid carers were able to choose which questions they did and did not answer and to stop completing the survey at any time. An email address was provided for any questions. We signposted all participants to support, in case completing the survey brought up difficult feelings or respondents realised that they might need or be entitled to support and services.

Our survey contained 44 questions of various types including Likert scales, radio buttons and free text.

While the survey results haven't been weighted by demographics and so are not necessarily nationally representative, they provide a valuable snapshot of unpaid carers' experiences and views in Scotland and across the UK.

The research was designed to follow on from research we conducted in November and December 2021 entitled 'Pushed to the Edge: Life for Unpaid Carers in the UK'. You can find that report here:

[www.carers.org/pushed-to-the-edge](http://www.carers.org/pushed-to-the-edge)

# CARERS TRUST

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