“UNPAID CARERS ARE NOT UNSUNG HEROES. WE ARE FORGOTTEN, NEGLECTED AND BURNT OUT”

SUMMARY: THE VOICES AND EXPERIENCES OF UNPAID ADULT CARERS FROM ACROSS SCOTLAND.

SEPTEMBER 2023
An unpaid carer is anyone who cares, unpaid, for a friend or family member who, due to illness, disability, a mental health problem or an addiction, cannot cope without their support.

During May and June 2023, Carers Trust conducted a UK-wide survey to better understand unpaid adult carers’ experiences of accessing support. The themes covered in the survey focused around identification, support and services, and rights and entitlements.

In our research, we heard from 3,430 unpaid adult carers across the UK, including 651 living in Scotland. This summary report explores the experiences and needs of unpaid adult carers in Scotland. It includes statistics for the unpaid adult carers living in Scotland in our sample and direct quotes from them.

This summary report tells a story of unpaid carers in Scotland who feel unrecognised, undervalued and are struggling to navigate the complex system of support, which is supposed to be there to help them.

When we asked what support unpaid carers need, they told us:

1. Better support for the person or people they care for
2. A break or respite
3. More money to spend on what they need for their caring role.
KEY FINDINGS FROM RESPONDENTS

23% said they were the sole providers of care and that they didn’t receive help to care from anyone else.

Over half (52%) said that the amount of time they spend caring has increased in the past 12 months.

Only 61% said they got the support they need to be an unpaid carer.

58% said that in the last year they had an adult carer support plan or review of their needs as an unpaid carer. Of those who had not, 44% told us they weren’t offered one, and 29% said they didn’t know they could have one.

Just 30% of respondents said carer’s allowance was enough to make a meaningful difference to them.

Only 36% said carer’s allowance supplement was enough to make a meaningful difference to them.

“Unpaid carers are not unsung heroes. We are forgotten, neglected and burnt out”
“We aren’t unsung heroes. We are forgotten, neglected and burnt out. Who’s caring for us?”

Carers are not being recognised as experts or involved in decision-making and support at the local and system levels. Within our survey, we found:

Only a quarter (25%) of unpaid carers said they could access a break from their caring role whenever needed.

33% disagreed or strongly disagreed that the NHS understands their caring responsibilities and they have received appropriate support. Unpaid carers told us they are not being recognised as experts in the planning and delivery of care for both them and the person they care for.
RECOMMENDATIONS

Recommendations for Scottish Government and local decision makers:

1. **Urgently and sustainably fund health and social care and improve identification of unpaid carers.** We ask that:
   - Scottish Government fully implements the National Carers Strategy Action Plan.
   - Scottish Government transforms, invests and improves social care in Scotland now. In the development of a National Care Service, adequate and sustainable investment is vital to make sure it can be successful in delivering its stated aims.
   - All money to support unpaid carers is **ringfenced**, including Carer’s (Scotland) Act funding.
   - Scottish Government creates a mechanism to ensure the value of locally awarded contracts are amended annually **in line with inflation**, ensuring contracts are sustainable and in line with the cost of delivery.
   - A **legal duty** is introduced so that professionals within the NHS have a responsibility to identify unpaid carers.

2. **Invest in effective community provision for all unpaid carers and ensure the needs of unpaid carers from diverse demographic groups are understood and met.** We ask that:
   - Scottish Government urgently introduces a Right to a Break from Caring and should plan alternative routes for introducing this quicker if there are delays in the development of a National Care Service.
   - Scottish Government introduces a new, dedicated National Outcome on Care to fully value and invest in those experiencing care and all of those who provide it.
   - Local authorities introduce a **single point of contact** for unpaid carers to coordinate the support for the person with care needs.
   - An **intersectional approach** to support and services must be prioritised to ensure support is inclusive and accessible for all unpaid carers.
3. Prioritise support for unpaid carers experiencing financial hardship and improve support for unpaid carers wanting to get into or stay in employment. We ask that:

- Scottish Government delivers, increases the amount and extends the eligibility of **Carer Support Payment** as soon as practical, to ensure more unpaid carers get the financial support they need and deserve. This must include providing financial support for those with underlying entitlement to the benefit.

- All social care charges are scrapped and Scottish Government introduces a specific **Cost of Living Fund** to help unpaid carers experiencing financial hardship.

- Scottish Government introduces a **Minimum Income Guarantee** for all unpaid carers, which is co-developed with unpaid carers and local and national carer organisations.

- More specialist unpaid carer **employability programmes** are commissioned, offering holistic and individually tailored support.

- Local Health and Social Care Partnerships ensure that **dedicated funds within social care** are available to provide replacement care to enable unpaid carers to work or to study.
Urgently and sustainably fund health and social care and improve identification of unpaid carers.

Scottish Government launched a National Carers Strategy for Scotland in December 2022. It is vital that the 89 actions in the Action Plan are fully implemented at pace to guarantee it makes a meaningful difference to the lives of unpaid carers and ensures local carer organisations are better supported to deliver the essential work they do.

Unpaid carers told us they need support now and this cannot wait until the formation of a National Care Service. It is paramount that Scottish Government adequately and sustainably invests in social care now, and in the future, to make sure unpaid carers and people with care needs get the support they need and deserve. We recognise that a National Care Service provides a new opportunity to transform social care support in Scotland and it is essential that unpaid carers and people with care needs are fully involved as equal partners in the planning and design to ensure it can be successful in delivering its aims.

Ringfencing money allocated to support unpaid carers would help to guarantee this investment was spent fully as intended. Providing sufficient ringfenced funding to local carer organisations would help them to remain sustainable and continue to deliver the vital support they do for unpaid carers. Local awarded contracts must also be amended annually in line with inflation to guarantee contract funding remains in line with the cost of delivery. Many local carer organisations report receiving standstill funding for numerous years from their local commissioners, for them this is a real-terms cut to their delivery when inflation rises and costs to run services increases.

A legal duty for professionals within the NHS to identify unpaid carers has the potential for many more unpaid carers to be better identified and ensure they are signposted and receive the support they are entitled to.

The voices and experiences of unpaid adult carers:

“I’ve not met anyone who is a carer that receives enough support. It doesn’t exist.”

“Too many organisations simply signpost you to somewhere else – often they don’t have capacity to actually do anything to help.”

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“Too many organisations simply signpost you to somewhere else – often they don’t have capacity to actually do anything to help.”
We feel isolated, exhausted, all while holding the country together looking after the most vulnerable in society, doing a job that many couldn’t and wouldn’t want to do. Please recognise us and give us recognition.”

“I work full time and fit in caring around my job. There seems to be little available for me. My local carers centre are wonderful though and have been a great support when I have needed them.”

“The NHS do not provide meaningful support to carers as this is left to the local authority and the third sector. The majority of NHS staff I have spoken to have had no training or guidance with respect to the Carers Act and therefore do not know about carers rights in respect to hospital discharge for their loved ones.”

“Support is really difficult to find out about and then difficult to navigate/access with long waiting lists. I feel like there is no safety net for carers.”
Invest in effective community provision for all unpaid carers and ensure the needs of unpaid carers from diverse demographic groups are understood and met.

Unpaid carers have told us they struggle to get breaks from caring. We know that breaks are fundamental for unpaid carers to maintain positive wellbeing. A fully resourced Right to a Break from Caring must be introduced with meaningful consultation and involvement of unpaid carers being essential to guarantee its success. Scottish Government must also consider alternative routes for introducing this Right in full if the development of a National Care Service is delayed to ensure unpaid carers can access this Right as soon as practical.

Scottish Government undertook a National Outcome Review in 2023 and following this review a new National Outcome on Care should be introduced as a priority. A new dedicated National Outcome on Care would help to fully value and invest in those experiencing care and all those who provide it, and would help to ensure this drives action to improve support and community provision for all unpaid carers.

Unpaid carers told us they find engaging with statutory services a complex process and often find themselves continuously needing to provide the same information multiple times and to multiple professionals. If local authorities introduced a single point of contact for unpaid carers to coordinate support, this would help to reduce the burden and complexity for unpaid carers accessing and coordinating services and support for them or the person/people they care for.

An intersectional approach is important to help and ensure all services are personalised and meet the individual needs for all unpaid carers. This approach must include better training for staff and improved collection of good-quality demographic data.

The voices and experiences of unpaid adult carers:

“I’m so frustrated at the lack of support or help in place for my son. I feel I’m failing him but trying everything I can to get help or support for him.”

“You feel as if you are constantly firefighting. Local resources are stretched and you have to fight to be heard.”
“We are doing this because we do not have a choice. We have to get up every day and deal with challenges brought to us and put on a brave face and break down behind closed doors. Losing friendships along the way and social interaction because you are completely exhausted mentally and physically. You do not have the quality time with them as you are having to do all the things that you do.”

“Sometimes it can take a long time to access the support you need, especially respite breaks. It can get to a point where you feel you cannot continue in your caring role unless you get additional support. You can feel trapped and stuck, and unsure where to turn for support. The cared for people don’t have the additional support that they need, and it is nearly impossible to access that support for them.”

“You have to scream and shout to get help and even when things are at their worst, there is still little or no help.”

“My sister and I have had to go hunting to get support for my dad when things got tough, and then discovered the support from health care and local authority is very fragmented. Within the health service different departments did not liaise well, each stating different procedures and disagreeing with each other. In an ideal world there should be one person/service that coordinates support for people with Dementia but that doesn’t happen. It makes a carer’s life much more difficult than it already is. For me that would be the first stage in supporting carers... getting support and treatment right for the person being cared for.”
Prioritise support for unpaid carers experiencing financial hardship and improve support for unpaid carers wanting to get into or stay in employment.

Many unpaid carers voiced that they experienced financial hardship in our survey and removing care charges and introducing a specific Cost of Living Fund would help to alleviate this and help to ensure unpaid carers are not living in poverty. Local Health and Social Care Partnerships should have dedicated funds within social care available to provide replacement care to enable unpaid carers to work or to study and pursue their own aspirations. This investment should be viewed in the same way as investment in childcare.

In the 2021-2022 Programme for Government, Scottish Government made a longer-term commitment to delivering a Minimum Income Guarantee. A Minimum Income Guarantee would ensure everyone in Scotland could have a minimum standard of living and could radically reform financial security in Scotland, narrow inequalities and tackle poverty. Introducing a Minimum Income Guarantee needs to be progressed as soon as practical and meaningfully involve unpaid carers and local and national carer organisations throughout its development to assure its success.

Carer Support Payment is planned to launch in 2024 in Scotland and replace Carer’s Allowance. Scottish Government must increase and extend eligibility to ensure more unpaid carers get the support they need and deserve. A clear timetable for Carer Support Payment setting out further improvements from launch and after case transfer process is complete should be published. Scottish Government should also prioritise extending Carer Support Payment to unpaid carers with underlying entitlement but cannot be paid it because of the “overlapping benefits rule”. Alternatively, a new benefit for those with underlying entitlement to Carer Support Payment should be introduced as soon as practical.

Many unpaid carers highlighted that they wanted to get into or successfully sustain employment, but voiced their struggles in making this a reality for them. More specialist unpaid carer employability programmes should be commissioned, offering holistic and individually tailored support. These programmes should include the input of local carer organisations, employability providers and employers to ensure unpaid carers’ needs are met. Programmes should be evaluated to build the evidence base on ‘what works’ to support unpaid carers to enter and remain in the workplace.
I've been an unpaid carer literally all of my life. I am 35 now. Because of my caring responsibilities I am at a serious disadvantage with regards to the housing market, mortgages, career opportunities and carving out a life of my own that doesn’t involve care. As a long-term carer, I am financially tethered to the people I care for because I cannot work over 15 hours per week lest I lose the Carer’s Allowance; and my caring role consumes 75+ hours of my week anyway. I literally cannot pursue a career path of my choosing, thus, I earn so little, thus, no bank would deign me with a mortgage to buy my own house, thus, I am stuck in council accommodation completely at their mercy.

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The voices and experiences of unpaid adult carers:

“I find the hardest part of being an unpaid carer (for my dad who has Dementia) is juggling my full time work with caring for him. If I could afford to leave my job and concentrate on caring for him, I would do that in a heartbeat. The consideration for this is not just the financial viability short term, but pension/support for me in future years.”

“I've been an unpaid carer literally all of my life. I am 35 now. Because of my caring responsibilities I am at a serious disadvantage with regards to the housing market, mortgages, career opportunities and carving out a life of my own that doesn’t involve care. As a long-term carer, I am financially tethered to the people I care for because I cannot work over 15 hours per week lest I lose the Carer’s Allowance; and my caring role consumes 75+ hours of my week anyway. I literally cannot pursue a career path of my choosing, thus, I earn so little, thus, no bank would deign me with a mortgage to buy my own house, thus, I am stuck in council accommodation completely at their mercy.”

“Unpaid carers are working full time jobs that are often far more demanding than a paid job and usually a lot more hours per week. There is no switching off from a caring role, and more often than not unpaid carers are doing the job alone and unsupported. The stress and toll this takes on a person is insurmountable. The benefits for unpaid carers do not cover the loss of income from having a paid job, and do not cover the emotional toll being an unpaid carer has on a person.”

“Pitiful amount and completely fails to address cliff edge of trying to get into work. Most contracts and pay exceed thresholds. As for pension age carers, just abandoned.”

“I have had to give up work to be able to care for my son's, now they are both adults the responsibility is on me now. The caring responsibility is huge and I worry constantly about what will happen to him.”

“Pensioners should not be penalised for being older and having a pension. They should still receive Carer’s Allowance, they fill an enormous gap caring for others.”

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METHODOLOGY

The survey ran from 12 May to 11 June 2023 and 651 unpaid adult carers aged over 18 years old responded from across Scotland. We promoted the survey via local carer organisations, other charities and external organisations we partner with and on our social media channels.

The survey was anonymous; no identifying data is held about any of the respondents. Unpaid adult carers could choose which questions they did and did not answer and could stop completing the survey at any time.

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

While the survey results are not nationally representative, they are nevertheless intended to provide an invaluable snapshot of unpaid adult carers’ experiences and views across Scotland.
ACKNOWLEDGEMENTS

Our grateful thanks go to:

• The unpaid carers living in Scotland who gave their time to complete our survey.

• Our Lived Experience Advisory Group who worked alongside Carers Trust to design and analyse this survey and for providing critique and challenges to emerging findings and draft reports.

• Carers Trust’s network of local carer organisations who helped us hear from unpaid carers, and who provide invaluable support for unpaid carers’ needs.

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, 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.

This summary report highlights the voices and experiences of unpaid adult carers from across Scotland and makes specific recommendations to improve rights and support for Scottish unpaid carers. You can read the full UK report, which also includes UK wide statistics and recommendations here: https://carers.org/UKAdultCarerSurvey2023

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