



I FEEL LIKE I'VE DISAPPEARED

**AN URGENT CALL TO ACTION
FROM THE UK'S UNPAID CARERS**

November 2022

**CARERS
TRUST**

ACKNOWLEDGEMENTS

Thank you to:

- The 2,675 unpaid carers 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



Over the last few years, I've been caring for my nan with dementia, and this has been a difficult and lonely experience.

Since being diagnosed, she has had so little support from health and social care services. Because of this I've had to drop everything when

she's got to crisis point because there was no other help. And, even though I've worked in health and care for several years, I've struggled to navigate the system to get her the basics.

I know staff working in health and care are doing everything they can, but the impact of years of underfunding on services is undeniable. The UK Government urgently needs to stop things from getting worse and properly fund the health and care system so families don't have to fight so hard.

Caring has also been really tough on me while doing a full-time job. I've often had to drop things at the last minute and being pulled in two directions has made me feel like I'm not good enough. While I'm lucky because I've got a job, caring still puts financial pressure on me because my nan lives so far away and travel has become so expensive. And that is in a context when so many daily costs are going up really drastically.

Caring affects so many elements of my life and many of us don't get any help. I really believe the UK Government needs to urgently step up by taking action and publishing a Carers Strategy. This would make a huge difference to the millions of people who are silently struggling behind closed doors.

Anna Bailey-Bearfield

Unpaid carer

INTRODUCTION: A RED ALERT ISSUE

Successive UK governments have failed to develop a sustainable model for funding social care. As a result, the social care system has come to rely upon **approximately seven million unpaid family carers** who care for sick and disabled family members. The degree to which the social care system has come to rely on unpaid carers is evidenced by the value to the state of this care, now totalling some £132 billion every year.

Tragically, the remarkable support provided by unpaid carers to prop up our creaking health and social care systems has gone unreciprocated. To compile this report, Carers Trust has drawn on the views of 2,675 unpaid carers, many of whom are supported by the UK-wide network of local carer organisations with which Carers Trust works. What we found is that many unpaid carers think they have been ignored by successive UK governments for many years. That lack of reciprocal support from the UK Government, including services and recognition for unpaid carers, is having a catastrophic impact on their physical health and mental wellbeing.

But what our latest research highlights above all else is how ongoing government neglect of unpaid carers, compounded by the worsening cost-of-living crisis, is driving many of them into deeper poverty. This in turn is causing extremely high anxiety levels among unpaid carers about being able to pay bills and put food on the table.

Even before the cost-of-living crisis, Carers Trust was exceptionally worried about unpaid carers' finances and the low prioritisation of 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. This means that the UK Government's prescription of moving people into employment is not open to millions of unpaid carers. The resulting levels of poverty should be seen by the new Prime Minister as a red alert issue.

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.



63%

OF UNPAID CARERS ARE WORRIED ABOUT BEING ABLE TO AFFORD ENERGY BILLS



65%

OF UNPAID CARERS FEEL IGNORED BY THE UK GOVERNMENT



ALMOST HALF

OF UNPAID CARERS ARE WORRIED ABOUT BEING ABLE TO AFFORD FOOD



14%

OF UNPAID CARERS HAVE USED A FOOD BANK



46%

OF UNPAID CARERS TOLD US THEY HAVE NOT HAD AN ASSESSMENT OF THEIR NEEDS AS AN UNPAID CARER IN THE LAST YEAR

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 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 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.
- 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.
- Reviews and introduces reforms to Carer's Allowance during this parliamentary term, so there are expanded eligibility criteria. This would help more unpaid carers get the financial support they need and deserve and help meet unpaid carers' extra costs. Consideration must be given to a minimum income guarantee for all unpaid carers.

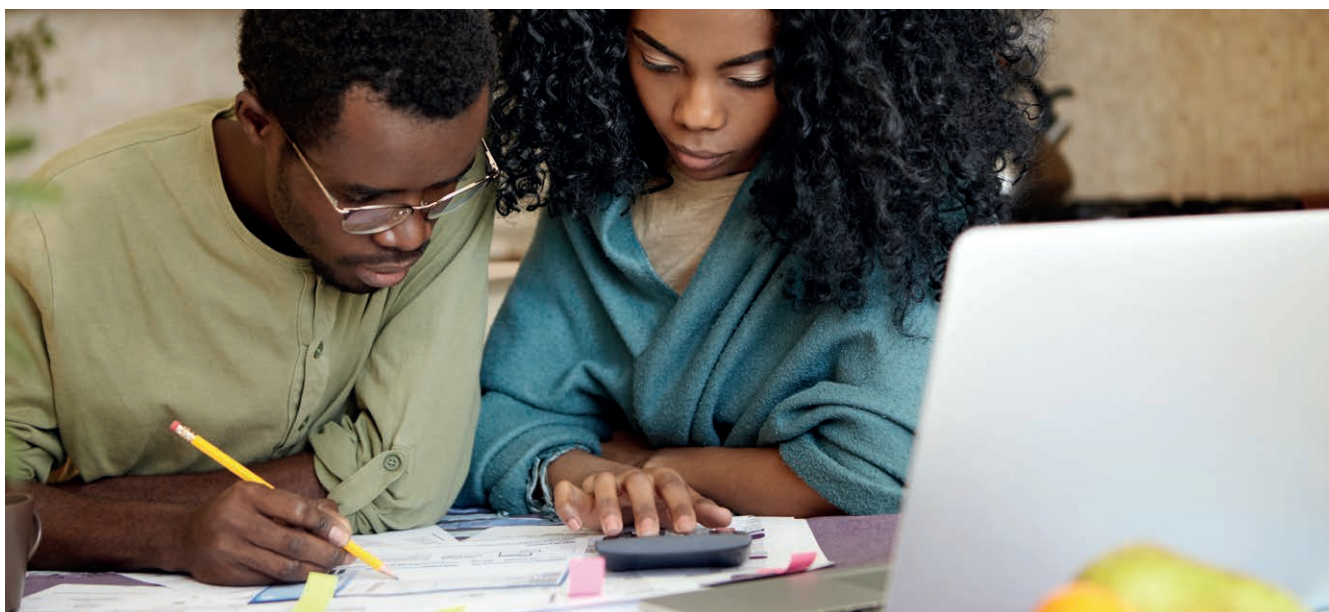


Image credit: Centre for Ageing Better

2. Publishes a UK Strategy for Unpaid Carers. We ask that the UK Government:

- Commits to publishing a UK Strategy for Unpaid Carers by the end of 2023. The introduction of a cross-government strategy and clear ministerial responsibility for unpaid carers has the potential to make a real difference.

3. Urgently and adequately funds health and social care. Given there is cross-party support for developing a sustainable funding solution for adult social care, we ask that the UK 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 and regional health and care partnerships.

To achieve this, the UK 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.

- **Raise the level of funding for carers' personal budgets and ring-fence it, so that carers have adequate funding to meet their assessed needs, including for a break. Stop charging unpaid carers for their own support.** Unpaid carers do not have enough choice about the amount and types of caring they do, due to the huge gaps left by underfunding in health and social care services. Committing to finding a long-lasting and sustainable funding solution for social care would stop unpaid carers being expected to do more and more by default.
- **Ensure funding for local carers services including capacity-building.** This would mean local carers services are funded to provide their expertise as equal partners in developing and shaping local services, such as being at the heart of local integrated care system (ICS) implementation in England.



Image credit: Centre for Ageing Better

WHAT OUR SURVEY FOUND

THE FINANCIAL IMPACT OF CARING:

"I'M TERRIFIED THAT I WON'T BE ABLE TO PAY THE BILLS THIS WINTER."

Our research shows that unpaid carers are experiencing unprecedented financial hardship as a result of their caring role.

Caring means extra costs: the cost of prescriptions and over-the-counter items, adaptations to the home, and repeated transport to and from appointments. Unpaid carers should not have to cover these costs themselves. But, faced with inadequate levels of financial support from the UK Government 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 at £69.70 a week (*at time of writing*), which is lower than other benefits.

Due to the additional costs of caring, 47% of unpaid carers told us they have had to spend their personal savings as a result of their caring role. In addition, a quarter of unpaid carers 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 often have to give up work in order to fulfil their caring responsibilities.

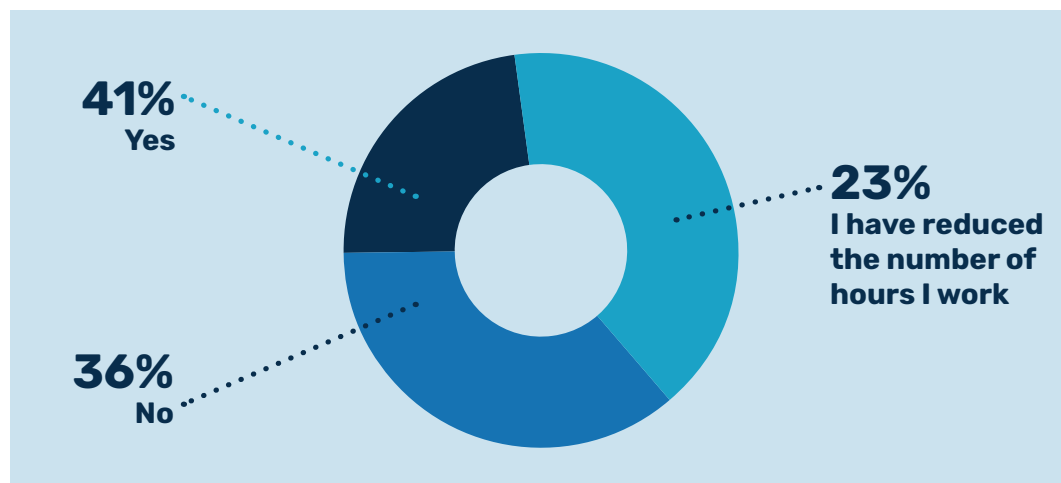


41% of unpaid carers reported they have had to give up a job or paid work as a result of their caring role.

A further 23% 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, 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. 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?

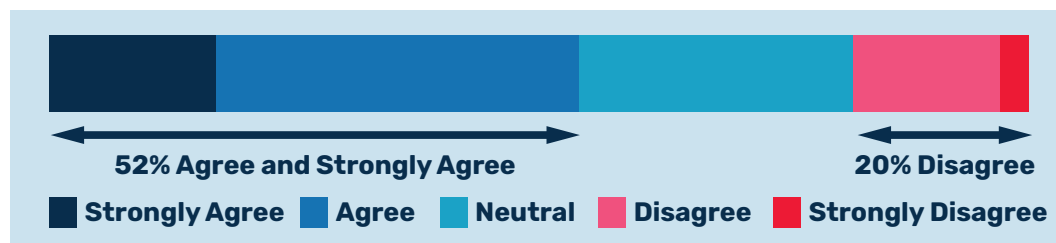


“My mother is 88 with cancer and doesn’t want to go into a home. I gave up my job in education to care for her and then shield her through Covid. I’m financially broke and have many loans to pay back, my house needs repairs and I can’t pay for them. My mental health is struggling every day but my mum needs me so I will stick with it.”

Carer’s Allowance is set at a lower financial rate to other work replacement benefits. This means unpaid carers can face lower levels of financial support in comparison with other groups in receipt of state benefits. 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.

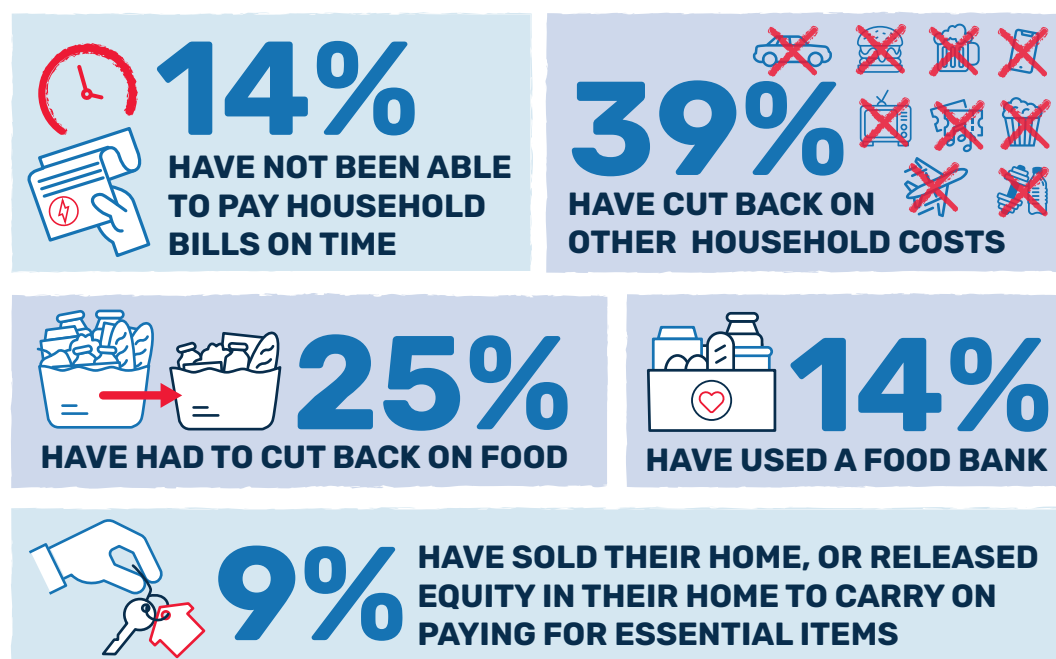
Over half of unpaid carers who responded to our survey are struggling to make ends meet as a result of their caring responsibilities.

Figure 2: To what extent do you agree or disagree with the phrase “I would say I am struggling to make ends meet”?



“We have no option but to make cuts and sacrifices to help support our loved one, this is mainly due to the lack of support, emotionally, physically and financially. I work 45 hours a week, in a good paid job, but between childcare and being a carer I struggle to make ends meet each month, living pay check to pay check.”

Many unpaid carers 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 very worried about covering my disabled son’s costs. His health and general mobility have deteriorated and I need to spend a lot of money trying to make the house more accessible. I also worry about the energy bills as he needs to keep warm in winter.”

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

29% of unpaid carers said they have had to pay for essential items using a credit card.

- 26% have had to borrow money from a friend/relative.
- 18% have taken out a loan.

“I care for my severely disabled adult son 24/7 with no support at all other than my husband. I am unable to work, we have gone into massive debt as my husband can’t earn enough to support three adults plus two kids as well as trying to occasionally be home to give me a hand with caring.”



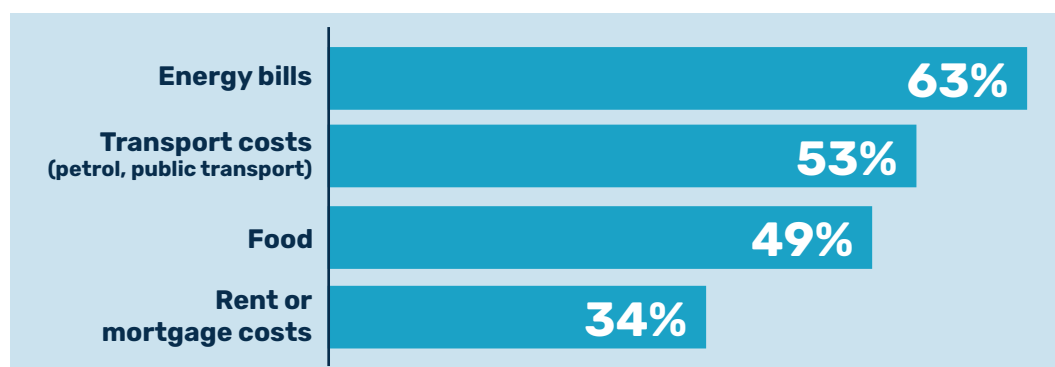
Image credit: Centre for Ageing Better

“My husband works minimum wage and is working 50+ hours overtime a week – which means I have to support two people full time...We have re-mortgaged, have a £7k credit card and are always on overdraft every month.”

With the cost of living rising, the majority of unpaid carers feel worried about how they will cope. Many unpaid carers are concerned they won't be able to afford essential living costs going forward.

- 63% of unpaid carers are worried about being able to afford energy bills.
- Over half are worried about affording transport costs.
- Almost half of unpaid carers are worried about being able to afford food.
- A third are worried about affording rent or mortgage costs.

Figure 3: I am worried about affording the following. Select all that apply.



Compounding this, unpaid carers told us that their caring role also has a wellbeing cost. 43% said they have given up hobbies or interests because of the cost. Unpaid carers described being unable to keep up with friends and family because they don't have the time or energy to socialise. Many said they have little or no time for themselves or to look after their own health and wellbeing. As a result, many unpaid carers said the demands of their caring responsibilities have a detrimental impact on their mental health.

“There is no time/energy left after full-time work, caring, parenting and household chores to maintain contact with friends/wider family or do things for enjoyment. Caring responsibilities are seven days a week.”

“I feel like I've disappeared.”

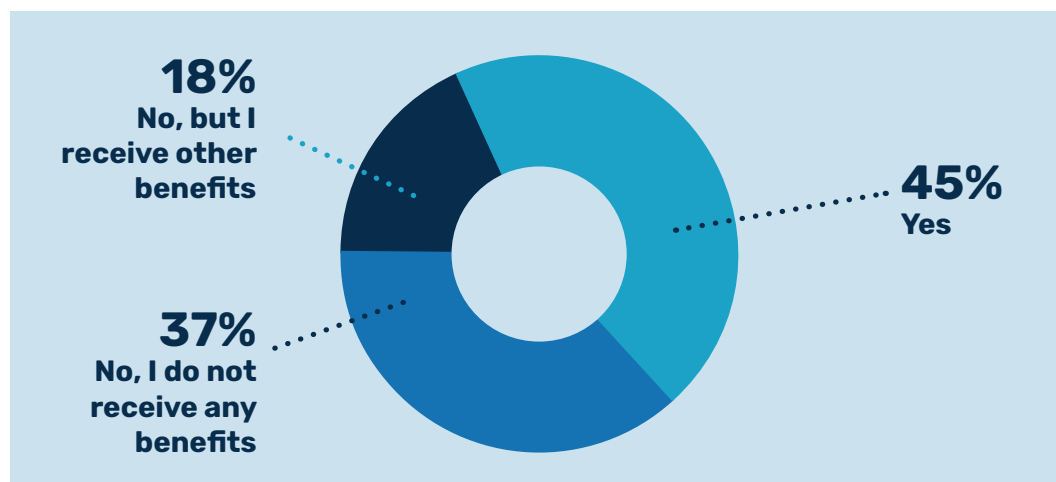
CARER'S ALLOWANCE

Too few 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 work they do or the vital contribution they make to the state. As a result, many feel undervalued, ignored and abandoned.

Over half of unpaid carers surveyed told us they do not receive Carer's Allowance.

This includes 37% of unpaid carers who do not receive Carer's Allowance or any other benefits.

Figure 4: Do you receive Carer's Allowance?



Of those who do receive Carer's Allowance, 47% said the benefits they receive are not enough to meet their needs as an unpaid carer.

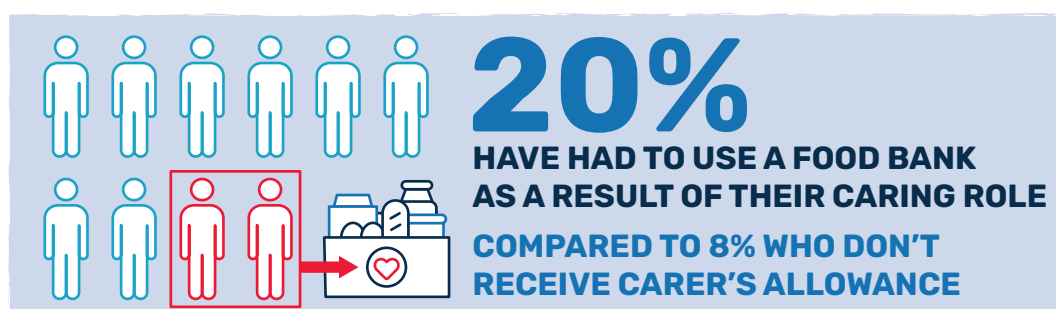
“Carer's Allowance doesn't even come close to covering what we need as a family. Carer's Allowance should be at the same rate as a [paid care support worker] such as those from an agency.”

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.



Image credit: Centre for Ageing Better

UNPAID CARERS RECEIVING CARER'S ALLOWANCE



In our research, unpaid carers identified ways that Carer's Allowance could be improved to better meet their needs. Carer's Allowance must be increased to accurately reflect the cost of caring and the fact that unpaid carers often have to give up work or spend savings to pay for costs associated with caring. The Scottish Government and the Welsh Government have provided unpaid carers with an additional payment beyond the base level of Carer's Allowance, with the Scottish Government committing to ongoing and fuller reform and the Welsh Government providing a one-off payment for 2022.

However, unpaid carers in England and Northern Ireland do not receive this higher level of support. Reforming Carer's Allowance should include ensuring:

- Carer's Allowance rises in line with inflation.
- The level of Carer's Allowance rises, at least to the same level as other benefits such as Jobseeker's Allowance. Unpaid carers and their households should not be penalised, e.g. by Carer's Allowance being taxed, or disability benefits (non-care related) being used by local authorities to go towards the cost of care.
- More unpaid carers become eligible for Carer's Allowance. For example, more unpaid carers should be able to claim whilst doing paid work outside the home, studying or receiving the State Pension.
- Carer's Allowance is not a taxable benefit. It is not a luxury.
- Unpaid carers are able to claim for more than one person that they look after.
- Further consideration given to a financial payment so that unpaid carers receive a minimum income guarantee and are not pushed into poverty by caring. This would depend on the level to which caring has affected an unpaid carer's income.

Crucially, unpaid carers said that Carer's Allowance should reflect the financial and social value to the state of the work that they do.

“I don't feel Carer's Allowance should be means tested but paid on how many hours care you provide despite if you are working or not. It shouldn't affect the [disabled person's] benefits either. After all you are still saving the Government a lot of money by providing care and this should be recognised.”

“Carer's Allowance is a paltry amount for the hours and mental stress involved in being a carer for my husband and son and now my older father as well. Nowhere near enough support financially.”

“Whilst I care for my father for love not money, I have had to reduce my working hours. I think it is very wrong that Carer's Allowance is means tested. I believe the Government could encourage more people to take in an older/disabled family member by making it easier financially, which is far cheaper than care home provision ultimately.”



LACK OF SUPPORT:


"THE SYSTEM IS FAILING FAMILIES"

Despite the critical role that unpaid carers play in our society, many are struggling to get the support they need.


44% of unpaid carers 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.


“Finally, at the age of 24 when the stress of being a young adult carer became too much for me to bear, I was pointed in the direction of [name of local carers service]. This was such an important life-line for me, and has led me to make amazing memories with friends I’ll cherish forever.”



“Being a carer is rewarding, tiring and frustrating at times. Getting the right support at the right time is crucial. Having access to carer support services is vital for unpaid carers – having somewhere and someone to turn to when you have a question, are facing a crisis, or simply want someone to talk to is invaluable.”



“Services such as groups, day care support groups, should be treated as essential services. [Disabled people] rely on these services for mental health like [non-disabled] people rely on a supermarket to survive.”




THE ONGOING IMPACT OF COVID

The pandemic saw unpaid carers facing significant pressures. 59% of unpaid carers 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.

Whilst 52% of respondents said services for unpaid carers have re-opened since Covid, 30% of respondents said that the services they use have only partially re-opened and 11% 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.”



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

“Every service has been affected – GPs, hospitals, 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.

Two fifths (40%) of unpaid carers said they do not feel they have a choice about being an unpaid carer. Over a third (36%) said they don’t have a choice about the type of care that they provide (e.g. emotional support or personal care).

“It’s awful. I love my mum and will never stop caring for her, but that’s because if I leave, the council can’t provide the level of help she needs. It’s never a choice, no one choses this. It’s just something we have to do. I use the words ‘moral obligation’ a lot.”

“We are human and need recognising for the intensive care we provide with no breaks. We do longer shifts than nurses and doctors with no lunch breaks or nights off, yet we are deemed as the bottom of the pecking order in society. We do not choose to be reliant on the state. We do not choose to live this life. We have no choice as the system is failing families.”

“I’m young and I’ve given up having any sort of future to look after a parent as I had no choice. I receive zero support from anyone and no one has any understanding about caring for a loved one.”



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 facing discrimination in the workplace and some have had to leave jobs as a result.

“Unless you do it, no one understands how all-consuming it is and emotionally draining. I am stretched between my sibling, my family and my work. I also have to fight for me or else I would be completely consumed. If it weren’t for flexible working practices and understanding managers, I would not be able to work and care. Caring is expensive.”

“My caring responsibilities as well as my own disability were completely dismissed by every manager, right up to the Chief Executive. In the end, I had to give up the job I loved. It doesn’t make the sacrifices of caring any easier to cope with as I have now lost my income and my sense of identity, on top of the normal married life I had once expected to have.”



Image credit: Centre for Ageing Better

ASSESSMENTS

Access to support services is vital for unpaid carers. However, a high number of unpaid carers have not had an assessment or review of their needs as a carer and are unable to access support as a result.

46% of unpaid carers 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, 68% said they had not been offered one. A further 11% said a professional told them it would not help them get any support.

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.

Even when unpaid carers have assessments and are eligible for support, many find they are unable to access the support they are entitled to. Of those unpaid carers who have had an assessment, 16% do not receive the support they are eligible for. Furthermore, despite being eligible for support, over a quarter do not get a personal budget to pay for their assessed needs.

“I asked for [an assessment] urgently over three months ago and I’m still waiting. I previously asked for one in September 2018 and it never happened.”

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

ATTITUDES TO THE UK GOVERNMENT:

“TAKEN FOR GRANTED, IGNORED AND UNDERVALUED”

It is clear from our research that unpaid carers feel undervalued and abandoned by the UK Government, despite the often unseen but vital contribution they make to our society.

65% of unpaid carers 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.

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

Attitudes towards the UK Government have improved since our last survey which took place during Covid lockdowns. We welcome this and expect this reflects the fact that unpaid carers have better access to support now as some services have reopened. However, it is clear that far too many unpaid carers feel let down and abandoned by the UK Government.

“I care for my daughter, and will do for as long as I am capable, because I love her and she deserves all the support I can provide her with. Carers are such a footnote in the pages of our society, even though every single person could find themselves either becoming one or needing one.”


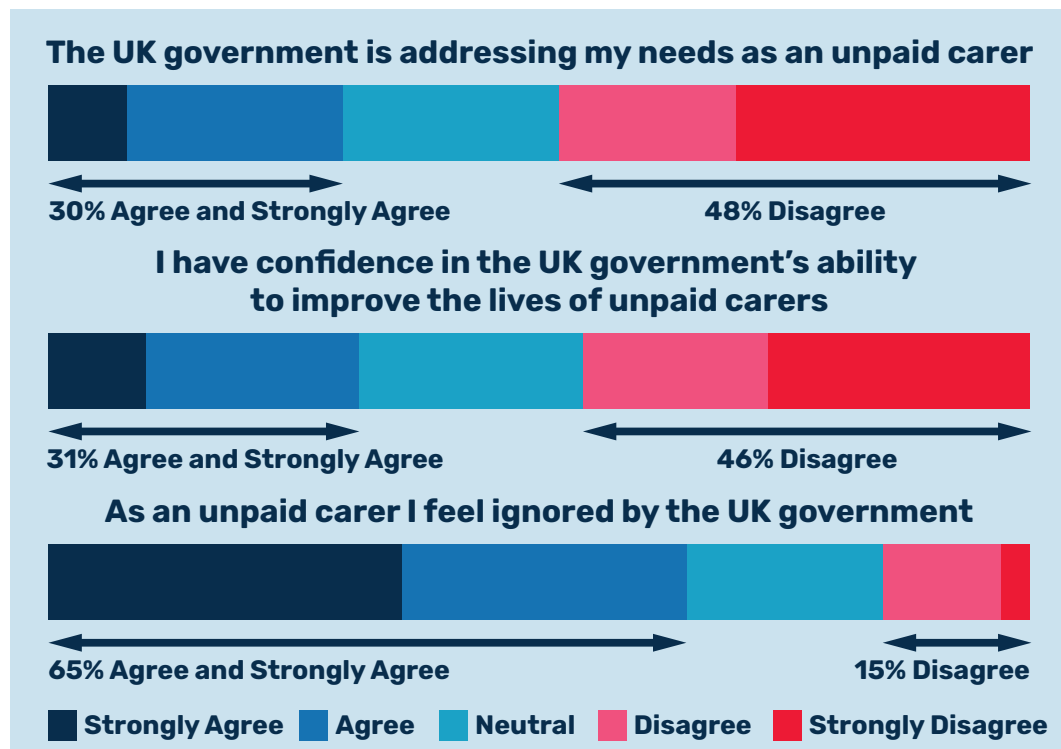


Figure 5: To what extent do you agree with the following statements?



“Carers are part of a wider caring economy. But we are barely mentioned. We provide care that props up the creaking health and social care systems. But there is no investment in us as a workforce. We need that investment in us and our role.”

“I feel taken for granted, ignored and undervalued by society as a whole. This attitude change needs to come from the top.”

WHAT WOULD MAKE A DIFFERENCE?

“TO BE APPRECIATED, RESPECTED AND REWARDED”

It is clear that unpaid carers need more support with the valuable and challenging work they do. When we asked unpaid carers what would make the most difference to them, 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?

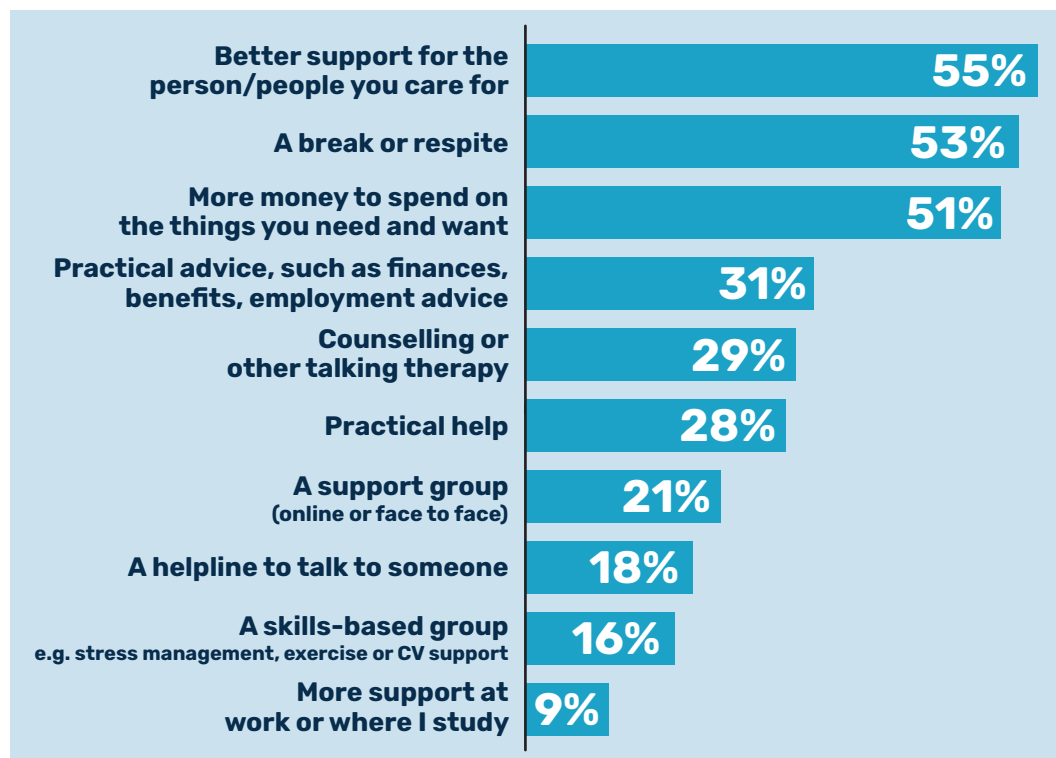




Image credit: Centre for Ageing Better

We asked 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:

“Please [help carers financially] appropriately – I spend more time caring for my child than I ever did working a full-time job. We managed to just about get by in the last few years but the cost-of-living crisis is very much affecting us now.”

“To raise Carer’s Allowance to make us feel valued and help us to make ends meet. I feel they are taking advantage of our good will and love for the people we care for.”

“As a family member I want to be able to support my mum until the end just as I did with my father but it is very tiring and time consuming. Employing a [care worker] to help is a minefield so it is easier not to, therefore I haven’t had a day off since 2019. It is so much cheaper and more peaceful for the [person with care needs] to stay at home but making extra help easier and cheaper would be a boon.”

“Genuine, flexible and remote job opportunities and signposting to routes into such positions – free online training etc.”

“To have some kind of respite care available... I haven’t had a break from caring for my mum for eight years...”



METHODOLOGY

2,675 unpaid carers, aged over 18, completed our survey. Respondents came from across the UK. The survey ran from 22 July to 24 August 2022.

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.

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. It was available in English and Welsh.

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 from 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



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