



PUSHED TO THE EDGE: LIFE FOR UNPAID CARERS IN THE UK

**THE VOICES AND EXPERIENCES OF UNPAID CARERS
A CARERS TRUST REPORT**

**CARERS
TRUST**

ACKNOWLEDGEMENTS

Thank you to:

- The 1, 560 unpaid carers who gave their time to complete our survey.
- The unpaid carers who guide and inform our work.
- The committed and skilled teams across Carers Trust Network Partners and in the wider sector who continue to provide invaluable support to unpaid carers.
- Our partners and colleagues, including in governments across the UK, local authorities, local health boards and trusts, education consortia, research bodies and third sector organisations who supported so many unpaid carers to have their say.

About Carers Trust

Carers Trust is a major charity for, with and about carers. We work to improve support, services and recognition for anyone living with the challenges of caring, unpaid, for a family member or friend who is ill, frail, disabled or has mental health or addiction problems.

We do this with a UK wide network of quality assured independent partners and through the provision of grants to help unpaid carers get the extra help they need to live their own lives. With these locally based Network Partners we are able to support unpaid carers in their homes through the provision of replacement care, and in the community with information, advice, emotional support, hands on practical help and access to much needed breaks. We offer specialist services for unpaid carers of people of all ages and conditions and a range of individually tailored support and group activities.

Our vision is that unpaid carers count and can access the help they need to live their lives.

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FOREWORD

As a long-term unpaid carer, I can testify that unpaid carers are still ignored in public policy discussions of health and social care. During the pandemic, unpaid carers were largely overlooked and forgotten compared to professional health and social care workers.



Why are unpaid carers not entitled to more financial support? Apart from the meagre Carer's Allowance, there is no financial provision for us. Unpaid carers make extraordinary sacrifices while putting our lives on hold, and coping with immense personal challenges physically, emotionally and financially. All we ask in return is that the Government listens to us, and provides the support we need - including acknowledging our contribution with appropriate financial recognition.

We also deserve the same rights and provisions as other benefit recipients who, unlike recipients of Carer's Allowance, are entitled to free prescriptions, eye and dental care and subsidised travel. Such provisions are only fair given the considerable amount of money we save the state by providing unpaid care for family members.

Carers like me need to see our legitimate concerns taken seriously and acted upon. As this report makes clear, carers feel ignored by the Government and brushed off with empty words.

Please prove that you are listening! It is time for real action!

NADIA TAYLOR

Unpaid carer, and Chair of Trustees for Carers Network
(www.carers-network.org.uk)

INTRODUCTION

Carers Trust wants to start this report with a thank you.

Thank you to over 1,500 unpaid carers across the UK who so generously took the time, despite all the responsibilities they face, to share their voices, experiences and thoughts with us.

A 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.

This report draws on the experiences and expertise of these unpaid carers. It helps give voice to unpaid carers who too often are neither seen nor heard by those with the ability to improve their lives and the lives of the people they care for. Throughout the report we have included direct quotes from unpaid carers, which make for powerful reading.

At Carers Trust we strongly believe that unpaid carers need to be recognised and thanked. But as a society we need to offer unpaid carers more than mere thanks.

That's because, in their responses to our survey, unpaid carers could not have been clearer about what they actually need. They don't need empty thank yous from their governments. Nor are they looking for pity or platitudes. And they certainly don't feel the need to be admired, to inspire others or to be told "I don't know how you do it".

Instead, what our survey found is a deeply worrying picture of unpaid carers feeling ignored, let down and left struggling by lack of government support:

- Almost nine in ten (88%) said they don't feel politicians understand unpaid carers like them.
- Over nine in ten unpaid carers feel ignored by government. This goes beyond party politics: More than eight in ten (86%) agreed that "Successive governments have ignored the needs of unpaid carers for a long time".



Many unpaid carers also reported that due to their caring responsibilities they were facing major financial, emotional and practical challenges. These challenges are having a significant impact on unpaid carers' health, wellbeing, relationships and ability to provide the support that is needed.

Shockingly, just 7% of unpaid carers said they received enough support. And even more worryingly, only 1% (just 12 respondents) agreed that government understand unpaid carers.

Unpaid carers need strong leadership from government to ensure a transformational change to their support and circumstances. And they need it urgently. Such change is not unrealistic. Since the pandemic started, we have seen – when needed – that governments can deliver transformational change at pace. The furlough scheme and a mass vaccination programme are examples of this. We now need this level of urgency, pace and innovation to be applied to meeting the needs of unpaid carers.





Most unpaid carers find themselves in this role simply because they care for or love the person they support and are willing to help. Or because they can't see any choice but to provide unpaid care. It can't be right that, in return, they don't get a break, even when that caring reaches over 50 hours a week, every week; that their mental and physical health is compromised; that they have to give up work or education or are pushed into financial hardship and poverty because quite literally they care.

The top three things that unpaid carers told us would make a real difference to their lives are:

1. More money.
2. Better support for the person they care for.
3. A break from providing care.

What also becomes clear from the unpaid carers who have trusted us to speak up on their behalf is that they feel let down by government. To restore this trust and bring about the changes that unpaid carers (and so many people who work in health, social care and beyond) know are needed, we are calling for strong leadership from the highest level of government. Unpaid carers give so much, often at great personal cost, but continue to get so little support in return.

Thank you for taking the time to read this report. But please go beyond reading what unpaid carers tell you. Go beyond listening and take meaningful and lasting action with Carers Trust and unpaid carers to make a lasting difference for unpaid carers.

“ I think getting help takes a lot of effort and time and not every carer is able to fight for the help they need.”

“ A big empty space of no help, trauma, pain, distress and long hours with low quality sleep and rest, and no holiday.”

“ My local council does all they can, and they treat helping carers as a priority. But they have very little money to be allocated, so their ability to help is limited.”

“ I am currently having to think strongly about if I can continue in this role, I need support. I will feel like a failure if I decide it has to end, the guilt about this and utter desperation is affecting my mental health badly.”

RECOMMENDATIONS AND CALLS TO ACTION

The UK governments must develop at pace a strategy and approach which meets the following objectives:

1. Governments across the UK must develop and deliver strategies for transformational and lasting change for unpaid carers, with unpaid carers at the heart of this.

Unpaid carers need to know and trust that their governments are serving them and need to know there is a strategy to help them.

With as many as eight million unpaid carers contributing so much, their role and the support they receive is too important to be left to chance.

That's why we are calling for transformational change across the UK, including:

- A new UK Government Strategy for unpaid carers, which places the needs of unpaid carers at the heart of policymaking across all Westminster government departments. This should address key concerns of unpaid carers including breaks and respite, unpaid carer finances, access to employment, education and training, unpaid carer recognition and involvement in decision making and improving the health and wellbeing of unpaid carers. The continued absence of a strategy for unpaid carers, backed up by strong political leadership, is having a damaging impact on millions of people and on communities across the UK.
- In Wales, the Welsh Government developed a Strategy for Unpaid Carers and Delivery Plan alongside unpaid carers and unpaid carers' organisations in 2021. This is very welcome. We recommend that metrics and measures monitoring the delivery of the strategy be informed by unpaid carers, with the voices of unpaid carers central to informing the Ministerial Advisory Group on Unpaid Carers.

“Emergency measures put into place during the pandemic prove the ability of government to improve people’s lives very quickly if so minded.”

- In Scotland we recommend that the Scottish Government works with national unpaid carer organisations, local unpaid carer organisations, unpaid carers and other key stakeholders on a new Unpaid Carers Strategy.
- In Northern Ireland, we recommend the Northern Ireland Executive develops a new Unpaid Carers Strategy.
- We also recommend that local authorities across the UK develop or update their unpaid carers strategies and action plans, to ensure they are responsive to the evolving needs of unpaid carers and the changed external landscape.

2. Improve the availability of statutory care and support for people with care and support needs of all ages, so that unpaid carers’ caring roles are sustainable and unpaid carers have a real choice.

Government strategies for unpaid carers across the UK must be accompanied by transformational funding for health, social care and education services for people of all ages with care and support needs. Too many carers have seen a lack of day care provision for those they care for, a lack of short break providers and replacement care provision, as well as a paid care workforce shortage. These services can then

improve the way they meet the needs of disabled people and older people, reducing the impact on unpaid carers.

“... the worry of who will care for them when you’re gone and knowing there is nothing out there suitable so you have no choice but to give up your life and keep going until the day you die.”

3. Unpaid carers need access to their own support when they need it. Governments should sustainably fund support for unpaid carers, including regular breaks and respite, and support that means unpaid carers can live a meaningful life alongside caring.

Rights for unpaid carers aren't being fully realised and upheld due to the lack of resources and funding to implement them; in places these rights are beginning to be chipped away at. Funding and resources for other parts of the system impacts unpaid carers: including funding, short break provision, paid care workforce shortages and lack of replacement care options. Proper support will mean unpaid carers feel connected and aren't lonely or isolated, and upholds their rights to wellbeing.

“Central government is continually blaming local authorities as they are responsible in law for the provision of social services. What they ignore is the fact that they have continually underfunded social care in their financial allocation to these local authorities.”

4. Governments across the UK should act to ensure unpaid carers are protected from financial hardship and poverty. Unpaid carers should not be financially worse off because of caring.

To stop more unpaid carers falling into poverty and to meet the extra costs of caring, unpaid carers' finances need to be improved by better access to work, as well as higher levels of eligibility to, and rates of, social security benefits.

Governments across the UK should commit to reforming Carer's Allowance, increasing levels of benefits and to extending benefits to support unpaid carers. At present the system for claiming Carer's Allowance is so restricted that more than half (51%) of unpaid carers responding to our survey question on whether they were able to claim Carer's Allowance said they were not. Government should therefore commit to a full reform of Carer's Allowance, to better support people to care, including those in employment or education. This also includes addressing the 'overlapping benefit rule' that disadvantages unpaid carers on state pension.

The UK government should model options for improving and extending Carer's Allowance so that it's in line with other benefits. Options should include Carer's Allowance increasing to at least the same level as Jobseeker's Allowance. Unpaid carers should not be financially

penalised or have to use their own income or savings to meet the costs of caring. Charging carers for their own support should stop. The Care Act 2014 (which applies to England) makes it clear that an unpaid carer must not be charged for support for the person they care for, such as replacement care to give the unpaid carer a break, as this is regarded as a service to the latter.

“ I had to give up my career to fulfil my caring duties. Carer's Allowance does not compensate for the vast reduction in wage and we struggle financially.”



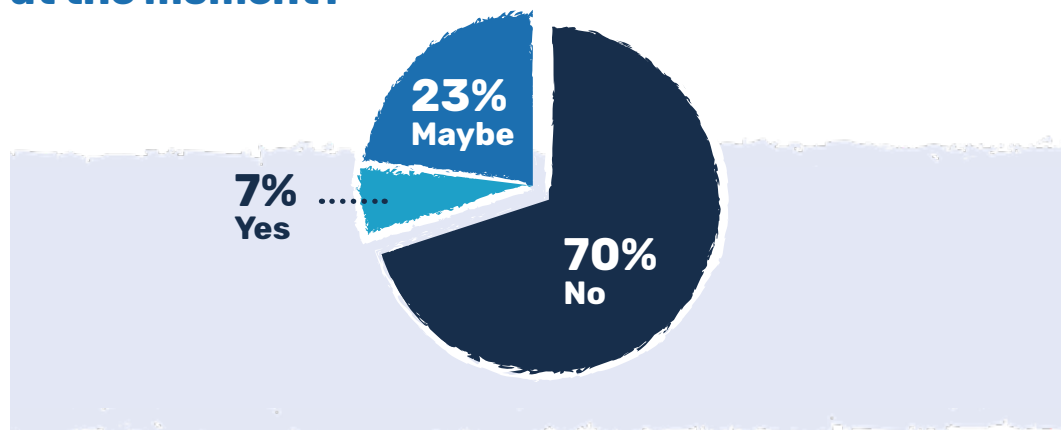
SUPPORT FOR UNPAID CARERS

Based on what unpaid carers told us, we've divided this report into three main sections:

- 1) Support for unpaid carers.
- 2) Finances.
- 3) Support for the person with care and support needs.

Only 7% of unpaid carers told us that they received enough support

Figure 1: Do you receive enough support as a carer at the moment?



When support works well, it's clear what an impact this can have:

“ I switched to a new employer at this time last year and have been astounded by the support I have been given in my caring role. My manager is brilliant and understanding of the pressures in caring for my son. This was not the case before and I would have to use my annual leave to take care of the needs of my son.”

“Huge, I have a very responsible full-time job, without that support I would not be able to continue working. If that were to be the case our finances would be negative, and I fear we would fall into debt and all the other horrible things that happen when you lose financial security and independence.”

It's vital that employers consider the support they can give to working carers, just as they do for working parents. The proposed (at time of writing) introduction of unpaid carers' leave is a good start, but it must be paid so that working carers aren't further financially penalised for being a working carer.

Local carers support, and paid care support workers can also make a huge difference:

“ [Name of local carers charity] provides a lot of helpful caring workshops and always responds immediately when requests are made.”

“ The difference is without the support I could not look after my wife in our home.”

“ Makes everything possible and I am very lucky to receive support.”

This is the kind of unpaid carers support local authorities should prioritise, making a clear case for additional and appropriate levels of funding for social care from national and UK governments.

The impact of not having enough support is huge on unpaid carers:

“ I feel incredibly trapped, isolated and alone. I have severe mental health issues of my own to deal with and virtually no support for myself. I have no friends or family which can help as they don't live locally and the mental health services and respite services in my area are beyond dire. My husband gets incredible medical support for his condition, yet I'm expected to provide 24-hour care 365 days a year alone.”

“ Hard. I don't really get a break, I don't get a chance to do things I want to do. I can't afford to do fun activities that I really enjoy that have such a positive impact on my mental wellbeing. I don't get Carer's Allowance as I don't do enough hours, yet I can't find a job that is either flexible and understanding or because they don't want a carer. It's hard.”

“ Feels like we've been abandoned by the NHS and the council.”

“It is completely exhausting and draining and living with the worry about my mum that I care for but also the impact that the time it takes for me to care for my mum has on my children and my husband and our family unit. I never feel able to relax or rest. When I am with my mum I am worried about the impact on my children and when I am with my husband and children I am constantly worried about my mum.”

“Hopeless. Constantly stressed and exhausted trying to balance full-time work and caring responsibilities, and honestly buckling (mentally) under the emotional blackmail (guilt-tripping) of the ... parent I care for.”

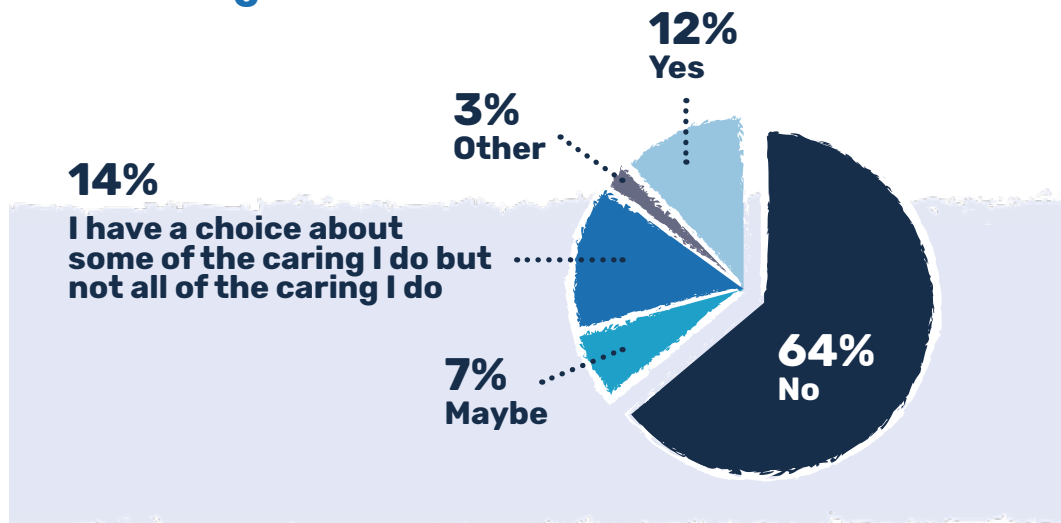
“I was doing the work of a full acute mental health team and I asked for help as I felt suicidal ... and my emails were ignored.”

This includes a lack of flexible commissioned support available outside of weekday working hours:

“There is a huge gap in what is available for those of us who care for our spouse, work and are parents. Everything is either in the workday, during school runs. There is no financial help because you are working and so you're stuck in a cycle – need to work to find money for food, bills etc, need to fund adaptations, need to be a parent and also exhausted.”

Far too many unpaid carers (64%) felt they had no choice about being a carer:

Figure 2: Do you feel like you have enough choice about being a carer?



“ I am my parents’ carer and attend their medical appointments. Whenever something crops up that requires managing eg wound care, it’s assumed that I will take care of it. I don’t recall ever being offered alternative options, eg district nurse/home visits.”

“ ... over the last two years, other things have gone wrong which have forced me into a carer’s role. She is my wife and I love her, there is no other option. But there was no choice involved.”

Health and social care services are under-resourced and underfunded, leading them to reduce choices for unpaid carers, as well as choice and control for disabled people and older people:

“Choice is a tricky term. I could choose not to do so much as a carer and get agencies in, but I know that my mother would be very unhappy and not able to live as fulfilled a life as she does. So, while the choice is technically there, it is not a choice I feel able to make at this stage. Is that actually choice? I don't feel I have choice. It is complex.”

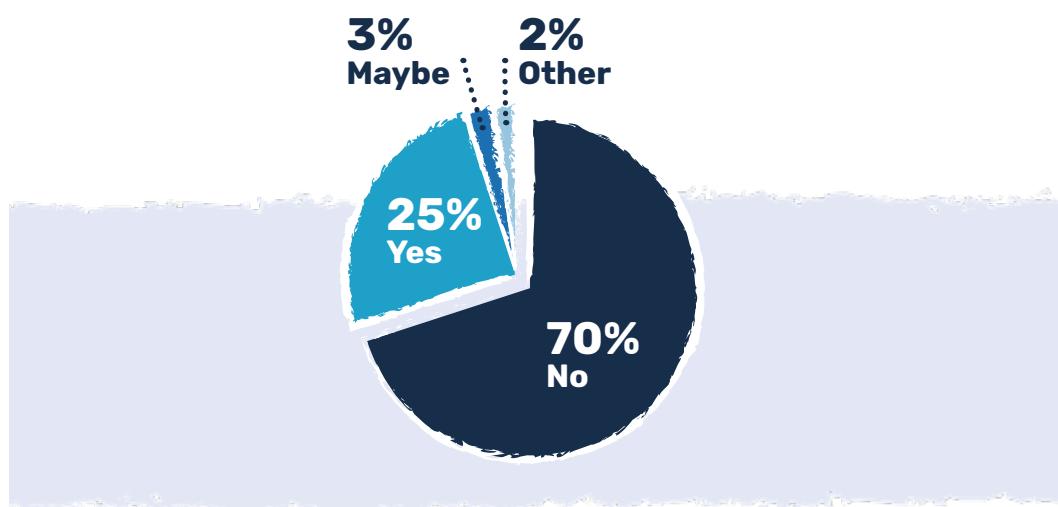
“Social services just assumed I would do it. Neither [they] ... or the health service asked me and they put a lot of pressure on me to say I'd buckle down to it.”

“I feel like I was cornered into becoming a carer because the support services in place were withdrawn very quickly and we were told the alternatives were a private care company or nursing home, neither of which my mother wanted. Her wishes were entirely disregarded.”

It's vital that quality social care is available so that unpaid carers can make the choices that are right for them.

Carers Trust has high levels of concern about unpaid carers' needs assessments as local authorities have been very stretched in the pandemic. This has led to a very high number (70%) of unpaid carers not having assessments/support plans or re-assessments/reviews of their needs:

Figure 3: In the last year, have you had an assessment, or re-assessment, of your needs as a carer?



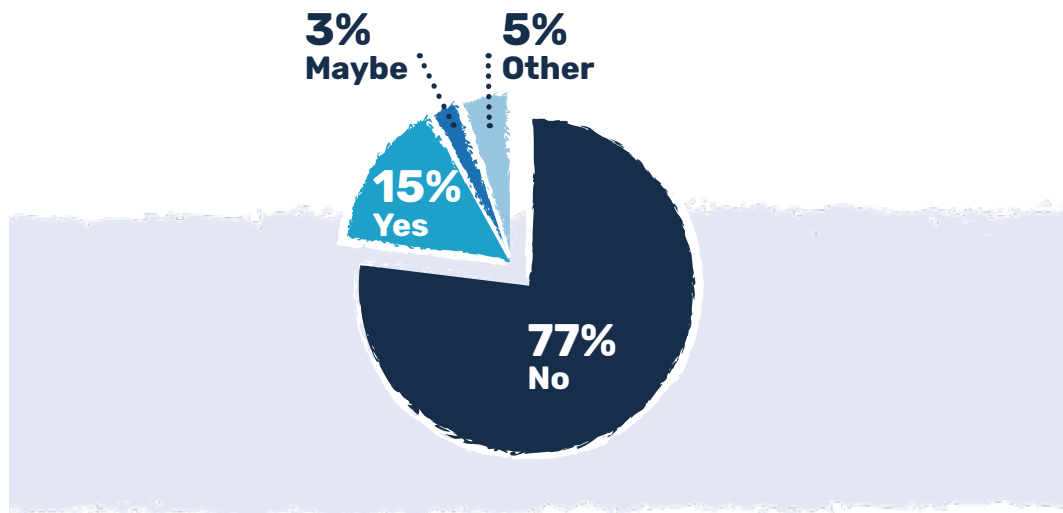
The top three reasons for not having an assessment were:

- 1) I wasn't offered one.
- 2) No one told me I could get one.
- 3) I've had one in the past, but no one has been in touch to offer another one.

Because of a lack of funding and resources, not enough unpaid carers are getting the support they need.

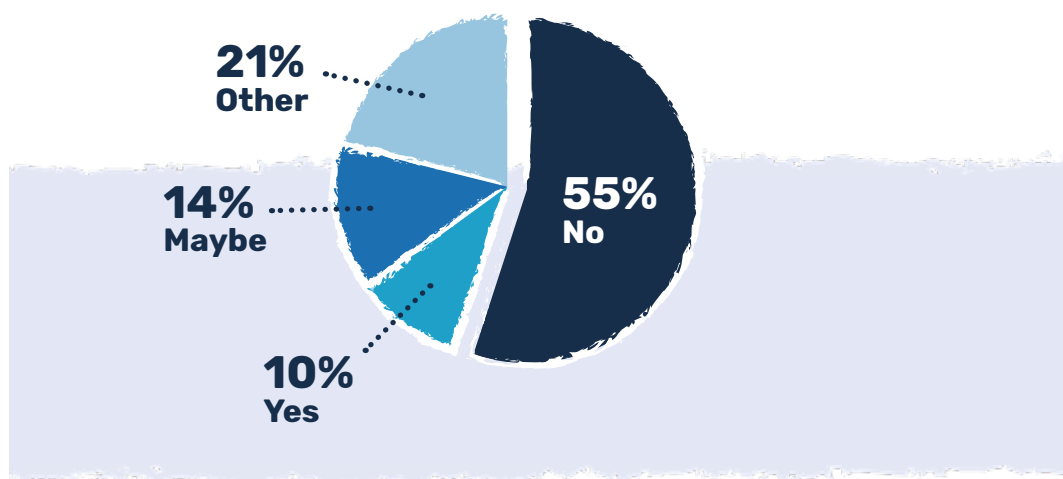
Despite being assessed as needing support, 77% of unpaid carers are not getting a personal budget to pay for support that will meet their assessed eligible needs.

Figure 4: Did you get a personal budget to pay for your assessed needs as a carer?



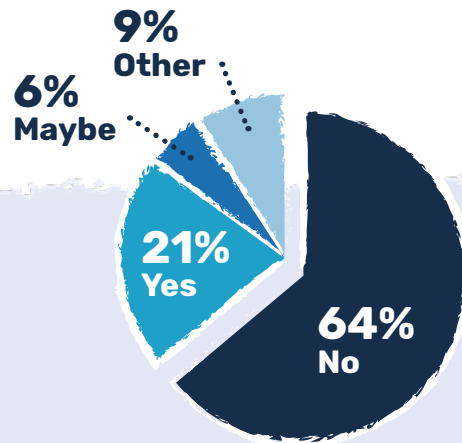
Or when they do, this either doesn't meet their needs (55%),

Figure 5: If you get a budget, is this enough for your assessed needs as a carer?



Or support may not be available due to a lack of paid care support workers (64%).

Figure 6: Have you been told that you won't be able to get all the support you're entitled to?



“ Assessments are as rare as hen’s teeth in my area, and just as useful when they are completed. I do not have confidence that an assessment would be particularly helpful. I feel it would be a process I would go through, after which someone would tick the box to say it had been done and that would be it!”

“ I did not know that the needs of unpaid carers are ever considered.”

“ We had an assessment just before lockdown in 2020 and the person was in touch a few months later to check how we were but we’ve heard nothing since and not been made aware we could have a re-assessment either.”

“ The present system of eligibility criteria is such that you have to be at breaking point before you can receive support. Support should be person centred and not financially driven. The only support I receive is from the third sector.”

FINANCES

Carer's Allowance

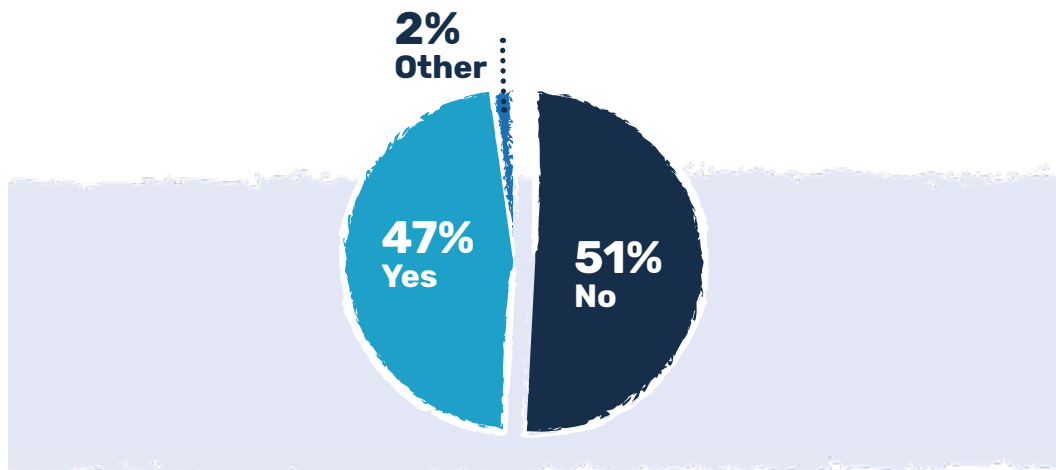
Carer's Allowance is a hugely important benefit to unpaid carers, and one with a lot of symbolism as well. However, not enough unpaid carers are eligible for, or entitled to, it. Those that are eligible say that it isn't enough money. It is a factor in driving many unpaid carers into levels of financial hardship. Unpaid carers have some great ideas and feedback to help improve it. We should move towards a more equitable system where more unpaid carers are entitled to it. As Carer's Allowance can often act as a passport or qualifier to other benefits, this would also improve access to other services and benefits for many unpaid carers. All unpaid carers in the UK should receive the same amount.

Devolution of carer benefits in Scotland means the Scottish Government has been empowered to award unpaid carers an additional Carer's Allowance Supplement beyond the base level of Carer's Allowance. However, unpaid carers' financial needs are not met to this higher level in England and Wales.

Carer's Allowance should be fully reformed to not only stop unpaid carers experiencing poverty but to also recognise the immense contribution unpaid carers across the UK provide to people with care and support needs. Carer's Allowance should also reflect the huge value to the state of the work undertaken by unpaid carers. The level of Carer's Allowance should rise, recognising both the extra costs of caring, and the consequent loss of earnings or need to use savings. The eligibility criteria for Carer's Allowance needs to be overhauled. For example, being able to claim Carer's Allowance while studying, working, or receiving a pension, would also be both symbolic, but also practically helpful. Carer's Allowance is not a luxury and should stop being a taxable benefit. If implemented, these recommendations would all represent success factors that would help break down financial barriers for unpaid carers and tackle unpaid carer poverty.

Just under half of unpaid carers who responded to our survey told us that they receive Carer's Allowance.

Figure 7: Do you get Carer's Allowance?



“ It doesn't go very far. I don't buy new clothes and Christmas presents are unaffordable.”

“ Carer's Allowance needs to carry on after a person becomes pension age as they do not stop being a carer.”

“ It isn't enough and if you care for more than one person you get nothing to support you financially for the second person.”

“ I appreciate the extra top up from the Scottish Government.”

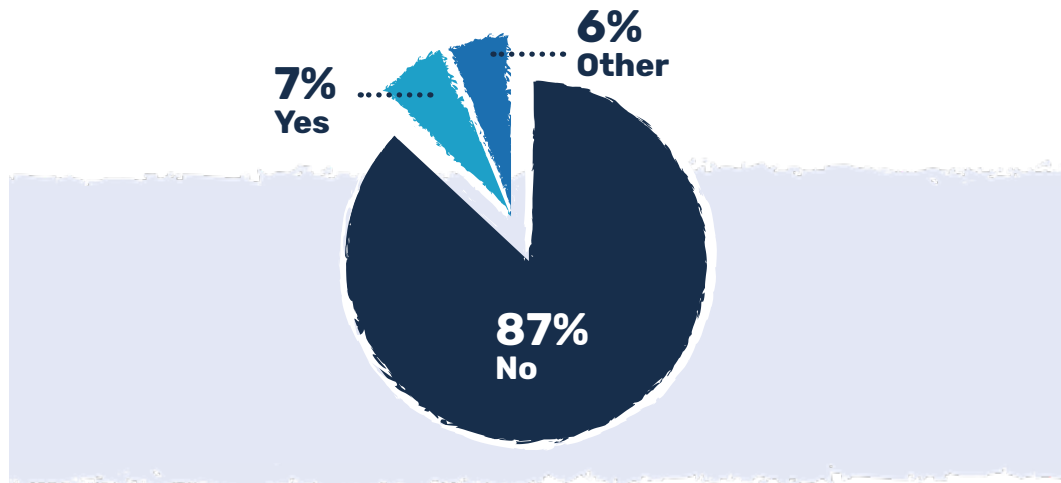
“ ... pointless applying for and getting it as it's taxed £ for £.”

“ Carer's allowance should not be taxed. The amount you are allowed to earn and hours you are allowed to study when in receipt of the benefit should be increased.”

“ Make it more accessible for all unpaid carers no matter if you do five hours a week or ten hours a week or 30.”

Of those who receive Carer's Allowance, 87% told us it wasn't enough to meet their needs as an unpaid carer.

Figure 8: If you do [get Carer's Allowance], is it enough to meet your needs as a carer?



“We are on the brink of a financial crisis which would involve us losing our home.”

Many unpaid carers aren't able to seek work which would help their financial position:

“I feel that it needs to be increased. Full-time carers have no options to be able to make any extra money.”

“It's stolen back off me by Universal Credit ... if I could work I'd be able to earn £150 extra!”

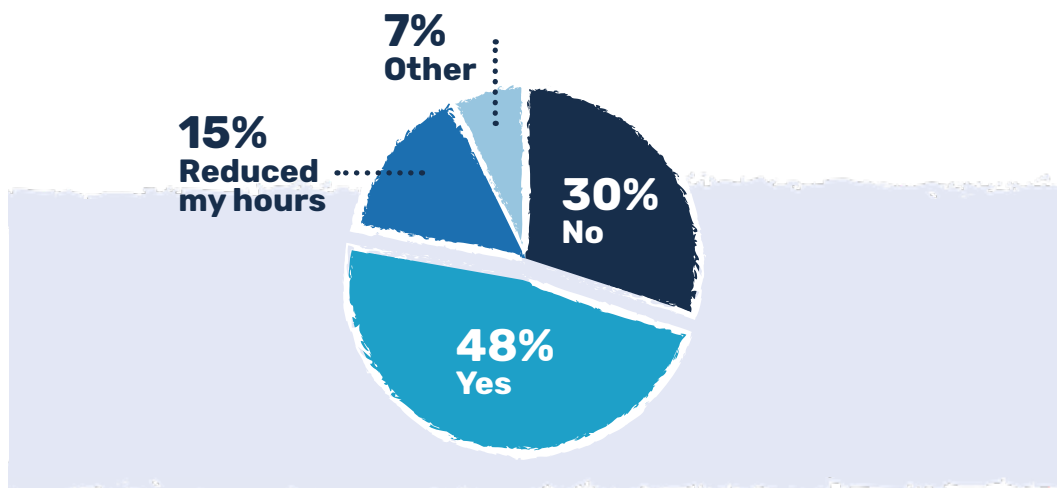
“ ... had to give up my well-paid career so Carer’s Allowance does not match the income in any way to what I had to give up to care for my children. We have had to make many adjustments to our lifestyle to manage on the reduced income.”

“ It is an insult to consider it a “payment” or taxable income, it is at best a token of recognition, at worst it’s a harsh insult.”

Employment

Almost half (48%) of unpaid carers reported that they had to give up work or study to care, and a further 15% had to reduce their hours:

Figure 9: Have you had to give up work or study because of your caring role?



Financial difficulties

Perhaps the most worrying finding of all from our survey is the huge financial sacrifices unpaid carers are routinely having to make as a result of their caring role. In multiple written responses from unpaid carers, it was impossible to miss the acute sense of betrayal felt by so many. They feel they have kept their side of the bargain – never more so than in the pandemic when they took on extra caring responsibilities. But they feel that, as a result of increasing responsibilities that are not matched through extra financial support, they are being pushed inexorably towards financial hardship and sacrifice.

We asked unpaid carers what they'd had to do to manage financially due to being a carer. Their three top answers were:

- 1) Give up my hobbies or interests.
- 2) Use my personal savings.
- 3) Pay for things that are essential for my caring role or that make things easier (such as buying pre-prepared food or taking taxis).

51%

had to give up on hobbies or personal interests.



49%

had to use personal savings.



45%

had to use their money to pay for things that are essential for their caring role.



42%

had to cut back on other household expenditure.



31%

had to cut
back on food.



27%

had to borrow
money from
a friend.



24%

had to use a
credit card
to pay for
everyday items.



22%

had not been able
to pay household
bills on time.



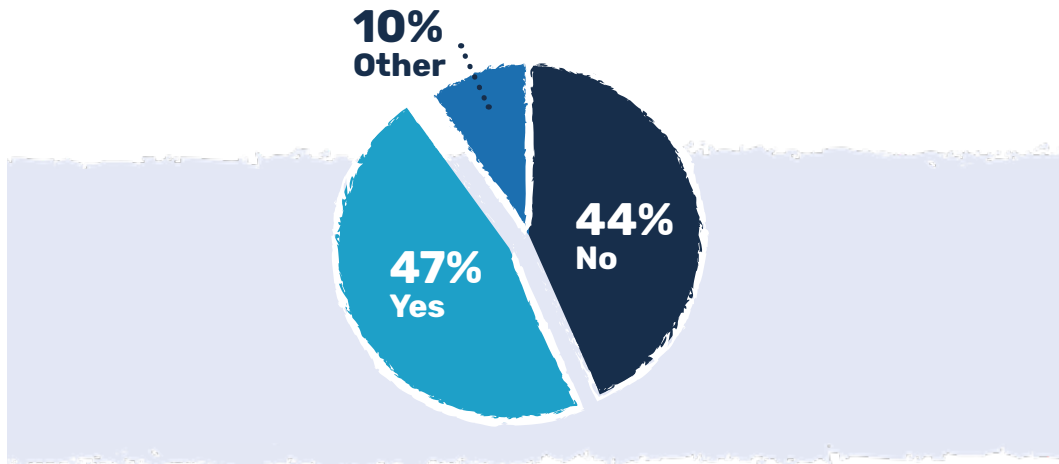
Not being able to afford hobbies clearly shows that unpaid carers struggle to do something for themselves when they do have a break, assuming they can get one. This clearly shows the extra costs of caring on wellbeing.

“ Drive myself into the ground trying not to spend money. Exhausted trying to live. No joy. I haven't smiled in years.”

“ There are many hidden costs, such as buying clothes that your child will not wear due to sensory issues once she has worn them once and then realised that the item is itchy, too tight, doesn't feel right; take away food as you have not had time to cook or are simply too tired; taking taxis as your child cannot use public transport; cost of parking, petrol and hospital stays for numerous appointments. Cost of hotels to stay the night before at hospitals that are not local to you because of the complex needs your child has cannot be treated at a local hospital, numerous car journeys to and from school because they could not manage the whole day ... replacing broken beds, buying sensory toys and equipment which always cost so much more, the list goes on and on ...”

47% of unpaid carers described themselves as struggling to make ends meet:

Figure 10: Would you describe yourself as struggling to make ends meet?



“It will soon get to the point where we cut back on everything to self fund the adaptations. We already don’t have the heating on unless absolutely necessary.”

“Once our savings have gone then I’ll be really worried.”

“We are on the brink of losing our family home due to me having to give up work and now having only one incoming salary.”

“We have just enough money to manage the basics but not much else. Can’t save any money as none spare.”

SUPPORT FOR PEOPLE WITH CARE AND SUPPORT NEEDS

Carers Trust strives to ensure that unpaid carers' needs are considered as much as those with care and support needs. Equality of needs is an important principle in legislation that protects and promotes the rights of both unpaid carers and those with care and support needs.

Given that unpaid carers told us that support for the person they care for was one of their top three things needed, we have focused one of our recommendations on what funding and resources the health, social care and education sectors need, as well as how they can work to ensure that unpaid carers are not being unfairly expected to provide support.

Much of this is down to a failure to provide sufficient resources, as well as not enough being done to involve unpaid carers as expert partners when making decisions about care packages.

“Have the vital support back that the day centres bring. They gave carers the opportunity to do shopping, rest, meet with friends and the chance to do something for themselves.”

“My partner is a veteran with complex conditions but I'm regularly told no support worker would be able to cope with his care, so I'm left to shoulder his care alone 24/7.”

“ Social work expect me to manage five waking night shifts with my husband and be able to support him through the day too. They refuse to give me more night care. I am 78.”

“ More support for the person I care for would mean emotional and physical benefit for me as a carer. As it stands my needs are bottom of the pile, sadly.”

“ At times I get overwhelmed and don't know who, as in a professional body, can I turn to. Constantly in contact with doctors and going round in circles.”



WHAT CONCERNS CARERS ABOUT THE FUTURE?

We asked unpaid carers: What worries or concerns you most about the New Year and/or the next six months as a carer?

“The fact that we may need to sell our family home (that has already been suitably adapted for our severely disabled son) and move to a smaller property (with three children) that is unlikely to meet the needs of my disabled child. We cannot afford birthdays/Christmas or family holidays at all.”

“Being able to care for my mother but also the needs of my children too. My mother is immunosuppressed and so I am continually having to make choices regarding her health and trying to not expose her to germs but then I have to leave my children when they need me most. This breaks my heart.”

“That my own medical issues are going to get worse and I won't be able to rest enough to be able to provide the full-time care that I do and have done for the past 21 years.”

“ I feel like I don't know how much longer I can cope for, the thought that this is all I have to look forward to for the next six months or years to come is depressing.”

A sense of anger, despair and abandonment ran through far too many unpaid carers' responses to our survey. Unpaid carers do so much to prop up our stretched health and social care services. But this deep commitment from them is in no way reflected in the support they receive in return, and this is unfair.

In the coming year and beyond, governments across the UK must take urgent action and make long-term commitments to transform the lives and situations of unpaid carers.



MESSAGES FOR THE PRIME MINISTER, CHANCELLOR AND FIRST MINISTERS

We asked unpaid carers: If you could tell the most important decision makers in your country (the Prime Minister, Chancellor or First Minister), one thing that would make a difference for you as a carer, what would it be?

“All anybody wants is to enjoy their life. Being a carer is extremely demanding, can be thankless, tiring, and is constant, until the person dies.”

“... wish they [the government] could live an unpaid carer's life for one week.”

“Ask the PM and the Health Minister to spend a week as an unpaid carer. Government are ignorant of the obstacles we face in our caring roles.”

“Junior doctors had the sympathy of the nation for having to be on call for 72 hours without a break. Carers are on call 24/7/365 for decades without one minute of training or any back-up.”

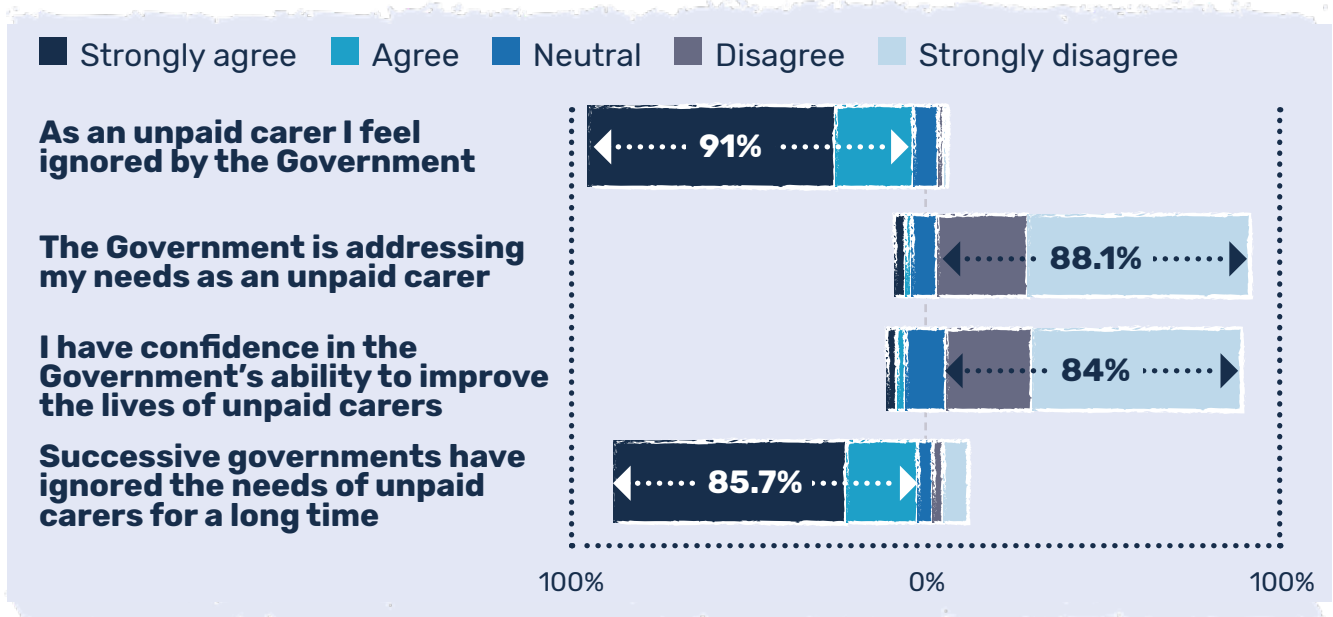
“Accept that responsibility for care of my sibling is a state responsibility and that care provided by unpaid carers should be a bonus and not fundamental to the care and safety of the vulnerable person.”

“It is all well and good having various Acts which mean carers and the people they care for are supposed to get full needs assessments etc, but if there are no resources to follow through then it is all just words on paper.”

“The issues of unpaid carers need to be addressed now not in 2023 and beyond. Supposed support in 2–3 years’ time is not good enough for people caring now.”

It cannot be acceptable that unpaid carers feel ignored by government, don't feel their needs are being addressed or that they have little if any confidence the government has the ability to improve their lives.

Figure 11: Do you agree or disagree with the following statements?



METHODOLOGY

To obtain the qualitative and quantitative data used in this report, we asked unpaid carers from across the UK to complete a survey.

1,560 unpaid carers, aged over 18, completed the survey on our invitation. The survey was anonymous, and no identifying data is held about any of these unpaid carers.

Unpaid carers 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.

Survey completion was voluntary, and no unpaid carers received any reward or remuneration from Carers Trust to complete the survey. Unpaid carers were able to choose which questions they did and did not answer, including any free text, and to stop completing the survey at any time. An email address was provided for any questions. We signposted all participants to support, for any unpaid carers for whom completing the survey brought up any difficult feelings, and/or unpaid carers who realised they might need, or be entitled to, support and services.

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.



For our fieldwork, we collected responses via Microsoft Forms from 4 November to 6 December 2021. The survey had 60 questions of various types including radio buttons, free text, Likert scales. It was available in English and Welsh.

While the survey results haven't been weighted by demographics and so are not necessarily nationally representative, it is nevertheless intended to provide an invaluable snapshot of unpaid carers' experiences and views from across the UK.

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