A FEW HOURS A WEEK TO CALL MY OWN

Unpaid carers’ call to action for the UK Government to urgently reform social care

November 2020
A CALL TO ACTION ABOUT SOCIAL CARE FROM THE UK’S UNPAID CARERS

The debate about the funding of future social care reform hasn’t sufficiently focused on unpaid carers to date. While the funding of care and support for older people and disabled people has an impact on unpaid carers, carers need support that is for them as carers.

While this report is not about the pandemic and carers, it is of course sited in a time when this is a huge added pressure, so naturally it has come up in carers’ answers.

Social care funding for carers was already in crisis before the pandemic. Demands on carers have increased due to the pandemic, with no added social care support, and in many cases, a reduction. In September 2020, Carers Trust asked unpaid carers what needs to be in place to support them in their caring role, and how social care should and could support unpaid carers more effectively. Despite all the growing pressures they face, caring during a pandemic, as well as the usual demands of their caring role, 2,078 unpaid carers generously found the time to share their experiences with us.

We also invited them to send a message to the Prime Minister or Chancellor.

This is what they told us.

Unpaid carers are clear that what they need is:

• Some time for themselves, away from their caring role
• Support for their own mental health and emotional wellbeing
• Help with their finances, so that being a carer doesn’t impact negatively on their current and future financial situation
• Real choices about whether to stop or reduce paid work
• Responsive services that meet unpaid carers’ needs
• Health, social care and education services that meet the needs of the person they care for, so that unpaid carers can have more of the relationship they want to with the person they care for.

Unpaid carers are pleased and proud to support the person, or people, they care for. In most cases, they care because they want to, and because they love the person they care for. All they ask for in return is the support they need to be able to care, without a lasting impact on their physical health, mental health and finances.

We’ve all faced serious challenges during the pandemic. However, social care funding reform and better support for unpaid carers pre-dates the pandemic and must be urgently prioritised by Government.

“
I have looked after my husband for nearly 10 years at no cost to the country. I am on call 24 hours a day, 7 days a week, 52 weeks of the year. Surely at 72 I am entitled to a few hours a week to call my own.

A shockingly low proportion of unpaid carers (only 12%) said that they receive enough support.
RECOMMENDATIONS AND CALLS TO ACTION

**Recommendation 1:** Carers Trust calls on the UK Government to form, at pace, a plan to move towards sufficient, secure and sustainable social care funding reform for the long-term. This social care funding must measurably benefit and reach carers in their own right, separately from the people they care for.

**Recommendation 2:** This plan must move away from annual settlements, which do not allow local or devolved governments to plan resources effectively. Local authorities are doing their best with what they have, but do not have sufficient funding to be able to support unpaid carers properly.

**Recommendation 3:** Social care funding reform was a key election promise, and so Carers Trust call on the government to implement this before the next General Election in 2024.

**Recommendation 4:** In England, funding reform must run alongside an extension to a Carers Action Plan.

Unpaid carers are being negatively impacted by the current funding shortfall in social care in multiple ways. Reform of the social care funding system needs to ensure that it solves the following issues:

- Unpaid carers having to provide more and more care to people with care and support needs, because of the shortfall of good quality social care for disabled people and older people. This puts unpaid carers’ health (mental and physical) and wellbeing (including financial) at risk.

- As well as providing more care, and despite having rights to their own assessment and support, not enough unpaid carers are identified or assessed for their own needs, which means they are going without the support they need, further putting their own health and wellbeing at risk.

- When support is made available to an unpaid carer from a local authority, because of funding constraints, it is often a one-off payment which does not consider the individual needs of the unpaid carer. Unpaid carers are not getting the breaks or respite they need from their caring role leading many to be near or at crisis point.

- Local carer services are seeing the effects of the hard choices their local authorities are having to make – seeing their local authority contracts reduced, or a de facto cut – being asked to provide more services for the same amount. Some have closed or merged. This means fewer services for unpaid carers.

- Services who provide regulated care are also seeing these contracts being reduced in value, putting that service at risk and causing uncertainty for the organisation, and the unpaid carers and disabled people and older people they support.

- The development of two-tier services as those who can afford are increasingly becoming self-funders of their own care, where it is available.
Becoming an unpaid carer should always be a choice, and unpaid carers should always have a choice about how much care they want to give, and what kind of care they want to give.

It's not just about how we fund social care. It's about what we do with it. It's important that unpaid carers receive preventative services, the right advice and information at the right time, as well as funded carer breaks and respite.

Carers Trust urges you to listen to unpaid carers’ voices and join us to take action to fix the crisis in social care funding so that we can address the pressures unpaid carers face every day. Together, we will ensure that unpaid carers get the right support, at the right time, in the right place.

Please write to us policy@carers.org. Please write to your MP. Ask them to work to provide a lasting social care funding solution that works for unpaid carers. Ask them to write to the Prime Minister and the Chancellor so that the people who make the most important decisions know that unpaid carers matter.

You can’t help but hear unpaid carers’ voices as you read this report. You may be an unpaid carer yourself. You may need the support of an unpaid carer. Amidst unpaid carers’ anger, frustration and stress, they have hope. Hope that their stories make a difference to getting real and long-lasting support for unpaid carers.

Let’s make a difference for unpaid carers together.
**WHAT LIFE IS LIKE BEING AN UNPAID CARER**

**Time spent caring**

Unpaid carers spend a high proportion of their time caring.

### 64% of unpaid carers spend more than 50 hours a week

To put that into context, a 9-5 working week is 35 hours, so caring for more than 50 hours is the equivalent of one and a half extra working weeks. Every week.

The 2011 census asked unpaid carers the same question. In 2011, 23% of unpaid carers said that they care for more than 50 hours a week.

**This means that for some unpaid carers, the number of hours of care has almost tripled.**

The more hours an unpaid carer spends caring, the more likely they are to face poorer health (physical and mental) outcomes, to need to leave work, and to see their long-term financial situation deteriorate.

### Time spent caring

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<thead>
<tr>
<th>Carers Trust 2020 survey</th>
<th>2011 census</th>
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<tr>
<td>1-19 hours</td>
<td>14%</td>
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<tr>
<td>20-49 hours</td>
<td>22%</td>
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<td>50+ hours</td>
<td>64%</td>
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“I'm exhausted. Really exhausted. I don’t think I can face 6 more months like the last 6 months. I really feel like ... carers [have] been abandoned.”
While the amount of social care support for carers and those they care for was not acceptable pre-pandemic, it’s clear that the two issues combined have had dramatic implications for carers. Unpaid carers told us that the time they spend caring has dramatically increased in the last six months. This is for a variety of reasons:

- Services for the person with care and support needs (day centres, additional education support) may have stopped or reduced.
- Operations and healthcare have stopped or reduced.
- The way we live has changed. A disabled person or older person who might previously have been able to live a much more independent life, may be unable to do so because of being clinically extremely vulnerable, “lockdowns”, social distancing, or an inability to spend longer food shopping.
- Any of us can become an unpaid carer at any time. Many people will have found themselves becoming unpaid carers to people living with the effects of Long-Covid.
- For unpaid carers of people with mental health problems, the person they care for may have seen their mental health problems develop or worsen during the pandemic.

Two-thirds of unpaid carers have seen the amount of time spent caring increased in the last 6 months (66%).

Of unpaid carers who said that, on average, the time they spent caring has increased per week, it increased by this much:

- **25%** by 6-10 hours
- **60%** by more than 10 hours
- **16%** by more than 40 hours
Caring and work

Good work (work where the conditions are good) is good for us – it can give us a sense of purpose, for some it brings social connections and status, and of course it pays our bills and helps us save for the future.

"I get direct payments that cover the hours my son isn’t at college which allows me as a single parent to carry on working. I cannot stress how important it is for me to continue to be able to work."

There is more to do for all employers until all unpaid carers who want to can balance work and care.

**Carers Trust would like all employers to offer, as a minimum, five days of paid carers’ leave, ideally more.**

We also want employers to offer flexible working so that more unpaid carers can combine work and care.

54% of unpaid carers have given up, or reduced, paid work because of caring responsibilities

39% of unpaid carers are caring full time; 34% are in work or education

Given the numbers of hours many unpaid carers are caring for, it’s not hard to see why some unpaid carers have to give up work or can’t balance work and care.

"I currently work but am having to give up work because I can’t afford to care and work anymore - it’s ruining my health. This will leave our finances in a mess, but I don’t have a choice."

Unpaid carers may also face additional barriers to work. A high proportion of the unpaid carers who answered our survey identified as having a disability (the Equality Act 2010 - applies to England, Scotland and Wales - defines disability as “a physical or mental impairment … [that] has a substantial and long-term adverse effect on … [a person’s] ability to carry out normal day-to-day activities.”).

Around two fifths of unpaid carers who responded are also disabled (41%), almost double that of the wider population at 21% (source: Scope). This suggests unpaid carers are considerably more likely to be disabled than the wider population.

While many disabled people are perfectly able to work – some may need the right support and reasonable adjustments to be in place – employers also need to be able to support unpaid carers who may also have a disability.
Messages for the Prime Minister

Fixing social care was a Conservative Party manifesto promise; the Prime Minister declared on his entry to Downing Street that he would fix social care. While the pandemic has been a huge national challenge, unpaid carers were waiting for social care to be fixed before the pandemic, and they are still waiting now.

Unpaid carers’ messages are powerful, but they are all constructive and show a clear path.

Unpaid carers’ messages fell into themes (shown in the visual below), three emerged as the most important for unpaid carers:

1. Money / finances / the cost of being an unpaid carer
2. Better practical support / more support / investment in social care
3. Better recognition of unpaid carers
Building on the messages to the Prime Minister, we asked unpaid carers what support they need, whether they are getting enough support, the difference support makes, and what worries them most about the next six months. Unpaid carers’ key asks overall for our future system are described in the next section.

**MONEY/FINANCES/THE COST OF BEING A CARER**

“Would you work 50 plus hours a week for £67.25, with no lunch or tea breaks, with no social life? Then please understand how worthless I feel.”

“Recognise the value of what unpaid carers do for this country and how much we save the Government and local authorities - show us a bit of financial appreciation for that, rather than punishing us through the Universal Credit system and its savage deductions of “unearned income”. It’s costing me £130 a month out of my benefits to be a home-based carer. How is that fair?”

“Increase Carer’s Allowance. people give up their jobs/lifestyles to care for others, which allows a lot of elderly/disabled people to not go into care that is funded by the government.”

“I am just as worthy of a salary/wage as you. I work 24hrs a day, 7 days a week, no holidays, always on call. The work I do is highly specialised and personalised medical, financial, emotional support and care for a vulnerable person.”

“Please recognise just how much carers contribute to this country and fix the no Carer’s Allowance if claiming State Pension anomaly, as a lot of carers are over pension age.”

“Improve the Carer’s Allowance and also let it become a not means tested benefit. I find very upsetting that Universal Credit takes money off because I do get Carer’s Allowance.”

“Proper amount of Carer’s Allowance to be paid to carers. £269 IS A JOKE. Being a carer for a family member is not a choice most people want to take but they do and without financial help for them so they can pay bills and have a break is degrading.”

**RESPITE / BETTER PRACTICAL SUPPORT / MORE SUPPORT / INVESTMENT IN SOCIAL CARE**

“Proper support and advice from social worker and proper funding for their future needs without having to mortgage my retirement.”

“Being well informed about what support is available. A wide range of support which is easier to attain than having to be on waiting lists.”

“Support for carers who are looking after family members unpaid are important and need support themselves. It’s incredibly stressful and you need to do better.”

“More support for those who are disabled and living alone.”

“Ensure that local authority care services and care charities are well funded, well-staffed and well organised, so that when help is required it is made available in an efficient manner.”

“That when my husband needs care from the social services as he has dementia we would have the same support as cancer victims.”
“The respect and recognition that my caring role deserves. My ability to care for my son as intensely as I do has kept him out of hospital numerous times, saving vital NHS funds. I’d like to see more support when needed for carers, both emotional and practical.”

“Treat us with respect and acknowledge how much money we save you by doing what we do!”

“Value all carers properly - actions not patronising words is what is needed.”

“Please recognise us as to be as important as the NHS. We save the government millions each year and yet we are never ‘honoured’ like front line staff.”

“To recognise carers and hear their voice.”

**What support do unpaid carers need?**

We asked unpaid carers to select – from a selection of options – what support would make the most difference to them. The top three choices are:

- **Better support for the person/people I care for (60%)**
- **A break or respite (59%)**
- **More money to support me as an unpaid carer (56%)**

![Support Options](chart.png)
We then asked unpaid carers what three things would make the most difference to their lives.

- The most common choice that would make the most difference is “more services and support for the person/people I care for” similarly to the previous question.
  - 34% selected this as the most important and 64% putting this in their top 3.

- The second most common choice that would make the most difference is “Better mental health and emotional wellbeing” unlike the previous question.
  - 21% selected this as the most important and 58% putting this in their top 3.

- The third most common choice that would make the most difference is “enough money to cover my day to day living costs” similarly mirroring the previous question.
  - 15% selected this as the most important and 40% putting this in their top 3.

- The fourth most common choice that would make the most difference is “Better social life, more time to see my friends and the things that I enjoy.”
  - 7% selected this as the most important and 39% putting this in their top 3.
Are unpaid carers getting enough support?

We asked unpaid carers if they are currently receiving enough support.

A shockingly low proportion of unpaid carers (only 12%) said that they receive enough support.

64% of unpaid carers said unequivocally that they did not receive enough support, and a further 24% said they were unsure if they received enough support.

WHAT DIFFERENCE DOES SUPPORT MAKE?

The 12% who said they did receive enough support were asked what difference this support made to their life as an unpaid carer.

“As we are CHC [Continuing Health Care] funded we get help so that I can have respite. But as I only get Carer’s Allowance and have had to give up my job it’s not enough to really do much.”

“It allowed me to talk to people who understand. The respite care for my husband gave me the break I badly needed, but it took a long time and seemed hard to get. I buy other support such as aromatherapy massage which helps my stress levels and I pay for a [care worker] to come in to check on husband once a week so I can go out for longer.”

“Having a break is key for my mental well-being.”

“Makes it so I can have the confidence to work part time.”

“The support is important. To feel that I’m not the only one who is feeling frustrated, annoyed, guilty. To be given solutions to think about and how I can implement these in my daily life.”

The right support for unpaid carers means that their health and wellbeing isn’t adversely impacted, that they can make decisions about the amount and type of caring they want to do, that they have time for themselves to do the things they enjoy, and to undertake their choice (or not) of work, study or volunteering.
WHY DO UNPAID CARERS THINK THEY DON’T GET ENOUGH SUPPORT?

Unpaid carers have rights to an assessment of their own needs, and to support if the assessment shows this is needed. They may be eligible for the flu vaccine. Unpaid carers also have rights to ask for other things like flexible working, or to apply for benefits such as Carer’s Allowance. Yet unpaid carers don’t feel they get enough support. Why is this? The lack of sustainable social care funding in the system plays a big part, coupled with low levels of state benefits for unpaid carers.

“As a full-time student/carer I am unable to apply for Carer’s Allowance which often is a criteria requirement to access further support.”

“The carers role is hugely undervalued and underpaid for the jobs that that are done... And the small amount of £67 goes nowhere, especially in this climate. A carer’s role does not stop at 5pm, the jobs to do are always there, and if broken down the £67 doesn’t even cover the National Minimum Wage for an adult. If a carer was to be paid for 30 hours at £8 per hour that would come to £240 ... significantly higher than £67. The financial worries only add to the stressful process of caring for someone.”

“I am caring for my wife with no practical help (since Covid 19) from anyone and no respite. This is a 24/7 caring role.”

“Coronavirus rules exclude a section of the support workers, so it literally means we are housebound.”

“There is no respite care relief in my borough, and I have personal responsibility for [the person with care needs] 24 hours a day seven days a week.”

“There’s nothing for me. Services seem to operate on a weekday, I would have to use my annual leave. I don’t feel like anyone gets what it’s like to support someone with mental health issues, people just tell me to “take care” or “look after myself”.”

“I don’t receive any support apart from receiving Carer’s Allowance. Nobody would even be aware that I was a carer unless I told them. I’d like it if there was a recognised scheme that acknowledges the role of an unpaid carer, similar to the way NHS and emergency services have.”

“Since Covid 19 pandemic I didn’t get support at all.”

“All our respite stopped during lockdown, we have just been told that we may get a few days in January. That will be 12 months without, we need time when we are not responsible for our disabled daughters care.”

Restrictions in the eligibility criteria for Carer’s Allowance are problematic for some unpaid carers - some other services for unpaid carers, or in the wider community, may have a criteria in place of being a recipient of Carer’s Allowance e.g. access to the flu vaccine. Not being able to receive Carer’s Allowance at the same time as other benefits, or to work or study, is hugely symbolic to some unpaid carers. Many unpaid carers face financial difficulty and extra costs, and the level of Carer’s Allowance feels low, particularly when compared to other benefits. As benefits are a devolved issue, unpaid carers in Scotland receive a Carer’s Allowance Supplement. Better funded social care support would also mean that unpaid carers don’t have to spend their small Carer’s Allowance on things that they need as an unpaid carer, or to top up what the person they care for needs.
WHAT WORRIES OR CONCERNS UNPAID CARERS MOST ABOUT THE NEXT SIX MONTHS?

Unpaid carers painted a highly concerning picture of loneliness, stress, financial concerns and poverty, impossible choices, and constant juggling. It is not acceptable that they are left feeling like this.

“Money. I currently work but am having to give up work because I can’t afford to care and work anymore - it’s ruining my health. This will leave our finances in a mess, but I don’t have a choice.”

“Deterioration of my Dad and balancing that with my part time job and university course.”

“Having to give up my job and not having enough money to support us as a young family with children. Working is taking its toll on us all but quitting would mean we are financially worse off and we need that extra income.”

“My mental health breaking completely, and what would happen to my daughter if it did.”

“Another lockdown and no access to Covid safe Support. I’m on my own with this.”

“That we are left behind. We haven’t been hardly anywhere since March. People have been living their own lives which is fine but we aren’t living ours. We are existing only as the risks to us are too great. So we feel left behind. We can’t see this changing.”

“My health isn’t that good so I worry about my child and where to go for help and information.”

“Everything. Death, being able to cope, the crushing loneliness and poverty.”
THANK YOU

- The 2,078 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 our Network Partners and in the wider sector who continue to provide invaluable support
- Our partners and colleagues in government, arm’s length bodies, local authorities, local health boards and trusts, education consortia, research bodies and third sector organisations who supported so many carers to have their say

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