

# National Carer Organisations response to: Social Justice and Social Security Committee call for views on the Carer's Allowance Supplement (Scotland) Bill

# Introduction

The National Carer Organisations welcome the opportunity to respond to this call for evidence. We are very supportive of the intention to provide an additional amount in the December Carer's Allowance Supplement payment and of the power to bring forward additional payments in future. The Committee has, of course, a key role to play in scrutinising this and any future additional payments as does the Scottish Commission on Social Security (SCoSS).

From the outset, it is vital that the Bill progresses and payments are not delayed. As we will go on to outline, unpaid carers very much appreciate the support of Carer's Allowance Supplement and many believe this is a good way to recognise the huge contribution of unpaid carers during COVID-19, and indeed their contribution to Scottish society each and every day.

However, the majority of Scotland's 1.1 million unpaid carers will not benefit. This does not mean that we should not move forward promptly with increasing the payment to those that do, but rather than this is an important juncture to lay out the disadvantage faced by unpaid carers during COVID-19 and in their everyday lives and take the opportunity to set out some initial ideas on how the Scottish Government can seek to mitigate these alongside potential opportunities for the Committee to examine how we can begin to address these in the short, medium and long term.

# Carers' Survey

In evidencing our response to the Bill, the National Carer Organisations undertook a short survey with unpaid carers where we asked their views on the Bill. We have attached the full responses in Appendix 1. 633 unpaid carers responded to the survey of whom 70% are unpaid carers in receipt of Carer's Allowance with the remaining 30% ineligible for the benefit.

#### Views on increasing the December payment of Carer's Allowance Supplement

Overall, 93.1% were in favour of the proposal to pay an increased amount of the supplement. Unsurprisingly, a higher proportion (97.5%) of those in receipt of Carer's Allowance, who would receive the supplement, were in favour. However, amongst unpaid carers not in receipt of Carer's Allowance or the supplement, high levels (82.9%) were in favour.

Unpaid carers talked about the difference Carer's Allowance Supplement has made to them already but also what difference this double payment will make to them financially and, importantly, in recognising the

significant extra care that they have provided during the pandemic (and continue to do so). With large numbers of unpaid carers taking on more care<sup>12</sup> during the pandemic, this is an important recognition.

""My carers allowance is just about covering my outgoings. The supplement will mean I will be able to pay some things, like replacing my broken laptop and be able to send gifts to my kids which would be really difficult otherwise. It sounds like luxuries but it makes the winter look bearable. It really helps my morale to think it will be there later in the year."

"You don't have spare cash when on benefits, the carers allowance supplement is like winning the lottery."

"A thank you to the Scottish Government for acknowledging carers and trying to help with the only way they can at the moment."

"Carer's Supplement makes a massive difference, even to make you feel appreciated when unable to work due to child's needs."

"After having to give up my semi-professional career 2 years ago to look after my son the drop in my finances has been huge and debilitating! An increase in payments is very much needed."

# Views on whether this is the best way to support carers with the challenges of COVID-19

The majority of unpaid carers (67.7%) surveyed felt that a double payment of Carer's Allowance Supplement is the best way to support them during the pandemic. However, this represented 77% of those who were receiving the supplement but saw a far smaller proportion (47%) of those *not* receiving the supplement agree with this view. Some pointed out that only some unpaid carers, around 10%, of the total unpaid carer population are eligible for Carer's Allowance Supplement:

"Every penny directly paid to unpaid carers is welcome but only 10% of carers are eligible, the stipulations that you cannot be a full-time student and the earnings limit preclude so many people who often work in excess of a 50 hours a week on top of their other commitments not just because of love but because they have no choice as social care SDS assessments can take years, yes years."

"Another unfair proposal by the Scottish Government. How many pensioners care for loved ones without any support and not entitled to benefits, living on basic pension and the majority in fuel poverty. The costs of caring include heating, adjustments to home, beds/mattresses, transport, special diets and incontinence products just as basic requirements, if not assessed for social care, carers have to meet costs themselves as well as toll on own health. The majority of elderly carers, are not entitled to carers allowance and miss out. A great proportion of Scottish unpaid carers are the elderly."

"Carers who have previously applied or received carers allowance but due to the underlying claim/overlapping benefit rule we lose out on the supplement others get. Surely something can be put in place so we don't miss out in these circumstances."

Caring Behind Closed Doors, Carers UK/Carers Scotland, October 2020 https://www.carersuk.org/images/News and campaigns/Caring Behind Closed Doors Oct20.pdf

 $<sup>^1</sup>$  87% of carers reported that they are providing more care and 8 in 10 said the care needs had increased.

<sup>&</sup>lt;sup>2</sup> 90% of carers are providing more care. The person(s) I care for needs have intensified 46%<sup>2</sup>

However, whilst many unpaid carers are in agreement that this is the best way to support unpaid carers with the challenges faced as a result of COVID-19, a significant minority, almost a third, were not in agreement or were unsure.

Some carers went on to note that they believed that this should become a permanent increase.

"Actually, it should be doubled permanently, if the government had to pay for outside agencies to do the work of carers it would cost a lot more. Carers are completely undervalued and forgotten about."

"As much as a double payment this year will be welcomed - there should be more support long term. I firmly believe the supplement is a great idea but not enough long term."

Funding has been made available by the Scottish Government to, for example, deliver flexible grants to help unpaid carers and young carers have time out from caring or to support their wellbeing, to support the work of carers centres/services and for online mental health measures. And of course, in June last year a similar double payment of Carer's Allowance Supplement was made.

We welcome this support but many unpaid carers remain isolated and exhausted by the demands placed upon them. The pandemic has had a massive impact on unpaid carers. As mentioned earlier, research by Carers Scotland<sup>3</sup> found that 87% of unpaid carers were providing more care and this was further evidenced by a recent report<sup>4</sup> from Carers Trust Scotland who found 90% of unpaid carers were providing more care. Not only have unpaid carers been providing more care, but the care they have provided has been more demanding with 8 in 10 saying the care needs of the person they care for have increased.

This increase in care and levels of care provided has continued throughout the pandemic, placing significant demands on unpaid carers' physical and mental health, finances and employment. For example, 29% of unpaid carers in *Caring Behind Closed Doors*<sup>5</sup> said that they were struggling to make ends meet and 7% had had to give up work to care. In research published during Carers Week, 71% of unpaid carers in Scotland reported not being able to take a break during the pandemic. Over three quarters (77%) reporting feeling exhausted and worn out, with 7 in 10 (72%) saying that their mental health had got worse because of a lack of breaks and 72% of unpaid carers said their physical health had deteriorated.

A survey of young carers and young adult carers by Carers Trust Scotland<sup>6</sup> highlighted the impact of the pandemic. To focus on young adult carers in the survey (who would be within the age range for this supplement) 63.6% said that they were providing at least 10 hours more care per week. Nearly 20% of these young adult carers reported an increase of 30 hours or more in the amount of time they spend caring per week and almost 15% said they are now spending over 90 hours a week caring for a family member or friend. The impact on their wellbeing because of the pandemic is stark, with 68% saying their mental health is worse, 76% saying they are more stressed and 73% feeling less connected. 85% are worried about the future.

<sup>&</sup>lt;sup>3</sup> Caring Behind Closed Doors, Carers UK/Carers Scotland, October 2020 https://www.carersuk.org/images/News\_and\_campaigns/Caring\_Behind\_Closed\_Doors\_Oct20.pdf

<sup>&</sup>lt;sup>4</sup> Covid-19 in Scotland: The impact on unpaid carers and carer service support workers, Carers Trust Scotland, July 2021 <a href="https://carers.org/downloads/scotland-pdfs/covid-19-in-scotland.pdf">https://carers.org/downloads/scotland-pdfs/covid-19-in-scotland.pdf</a>

<sup>&</sup>lt;sup>5</sup> Caring Behind Closed Doors, Carers UK/Carers Scotland, October 2020 https://www.carersuk.org/images/News\_and\_campaigns/Caring\_Behind\_Closed\_Doors\_Oct20.pdf

<sup>&</sup>lt;sup>6</sup> 2020 Vision: Hear Me, See Me, Support Me and don't Forget Me, Carers Trust Scotland 2020 https://carers.org/young-carer-and-young-adult-carer-coronavirus-research/our-survey-on-the-impact-of-coronavirus-on-young-carers-and-young-adult-carers-in-scotland

# Further views on the Bill

We do not have further views on the Bill itself but rather wish to set out thoughts on what both the Scottish Parliament and Government can do to ensure that unpaid carers are not further disadvantaged.

# Moving forward

#### A COVID-19 recovery plan for unpaid carers

We set out the impact to make the Committee aware of just how damaging the pandemic has been to unpaid carers. It has stretched unpaid carers to limit and beyond (and continues to do so) and has exacerbated existing impacts and inequalities. It will take much work across all policy areas – care, education, health, social security, employability and more - to even begin to restore unpaid carers to what was a low starting base of wellbeing. Whilst we know that the Scottish Government is making efforts to ensure that there is such a cross cutting view of the needs of unpaid carers which started before the pandemic<sup>7</sup>. The National Carer Organisations believe that the Scottish Government needs to develop a COVID-19 recovery action plan specifically for unpaid carers, built with unpaid carers, alongside a similar action plan for young carers.

This would be a positive starting point and a strong statement of Scotland's commitment to ensuring that unpaid carers are supported and rewarded for a role that is vital to the wellbeing of our society. There is an opportunity within this to identify "quick wins" that will help unpaid carers recover, even as the pandemic continues, to build on this important additional Carer's Allowance Supplement. Within the survey report appended, unpaid carers set out some ideas of things that could help them now.

We would also note that whilst the easing of COVID restrictions has felt a welcome relief to many, for a significant minority of the country, it has brought increased anxiety and a return to informal shielding. With the numbers of individuals caring reaching 1.1 million over the pandemic, this will impact on many unpaid carers and the people they care for.

There is a need for any COVID-19 recovery plan to recognise that for as long as COVID remains at high levels, despite the success of the vaccination programme, many individuals remain at higher risk and thus they and their unpaid carers will require support financially, practically and with employment as we go forward. Without knowing what the pandemic holds for us, this may be required consistently and/or in response to the particular variants in circulation and their impacts.

Alongside this, moving into the Autumn and Winter period, unpaid carers are concerned about a resurgence of COVID19 pressures on NHS and social care, which may lead to further reductions in care packages leading to more demands on carers. How is this going to be addressed in any remobilization plans?

#### Scottish Carer's Assistance and other financial support

Within our survey of unpaid carers for this Bill, unpaid carers made some specific suggestions as we move forward to deliver Scottish Carer's Assistance. This includes expanding eligibility, increasing the level of the benefit, recognising those unpaid carers with more than one caring role and providing support for those who are not currently eligible.

This reflects the National Carer Organisations Manifesto for Carers and Young Carers<sup>8</sup> (ref developed from the views of unpaid carers). This calls for a full reform of Carer's Allowance, in order to support unpaid carers better, including those in employment or education. The new benefit should recognise that caring impacts on

<sup>&</sup>lt;sup>7</sup> https://consult.gov.scot/health-and-social-care/carers-strategic-policy-statement/

<sup>&</sup>lt;sup>8</sup> https://www.carersuk.org/scotland/policy/manifesto-2021

health, employment etc at 20 hours per week or more and it should seek to address the overlapping benefit rule that disadvantages unpaid carers receiving other entitlements, such as State Pension.

"Remove the rule that if you work and earn over a certain amount you can't claim carers allowance. I work so excluded from claiming. My child's needs don't magically disappear because I work. As soon as I leave work, I deliver care to a child with complex physical disabilities and rather unstable diabetes day and overnight. Having more than one child it's easy to compare the additional support that is required when disabilities are present. Of course, I do it because as a parent that's what you do however it is all consuming and expensive to manage. I genuinely believe that should be recognised and supported and may keep more parents in the situation in work which would not only benefit them and their family but society as a whole."

"I wish students could claim carers allowance. I am a student nurse. Yes, I get a bursary but it does not cover the care I need to pay for, for my autistic daughter."

"I think it ought to be given to pensionable age carers because caring gets harder with age as do cared for people's disabilities. I see how my mum has no choice but to neglect herself. She doesn't get to spend time with her grandchildren like normal granny's - she is taking care of my dad 24/7. And in the time, she has cared for him he has progressively got more disabled and more difficult to manage while she has aged and grown frail and thin. She will be worked to death looking after him. And it won't be long. She is only 66."

"Most carers are also on benefits; your standard carers allowance is subtracted from the benefit leaving no financial difference for the job you do. Carers need to be properly recognised and paid a living wage equivalently."

For those unpaid carers who are not eligible, there is an opportunity to develop, for example, a Carers Recognition Payment with the supplement providing a model for delivery.

Finally, a small proportion of unpaid carers responding to our survey raised the issue of having no access to benefits or cannot access Carer's Allowance due to residency conditions. This can occur, for example, where an individual or the person they care for has not been habitually resident in Scotland for a sufficient time or is subject to certain immigration controls. The unpaid carer quoted below provides an example of this.

"They should consider the unpaid carers, who are not eligible for Carer's Allowance, due to the fact, that the disabled person they care for (in my case-24-hour care, by myself -no respite- for my adult severely disabled son), has No Recourse to Public Funds (NRPF). Hence, he has no disability award letter. Albeit the unpaid carer is a British citizen, and the cared for is here legally, I struggle every day to put food on our table, and keep our utilities on. Both my son and myself had COVID. I still had to care for him despite having COVID, I had no choice and no money. Carer's Allowance along with a supplement would have allowed me to bring someone in to help us. We are both still suffering from the effects of having COVID."

Other examples include where someone has returned to Scotland to provide care to an elderly parent. They may not be entitled to Carer's Allowance, despite saving the public purse considerable amounts of money by providing care until they have been resident for a period of time. The Scottish Government and Scottish Parliament should consider measures to address these issues.

Scottish Carer's Assistance should be a passport to other supports. The unpaid carer below makes the suggestion of free dental treatment and we are aware the Scottish Government plans to expand eligibility, beginning with young people. We would suggest that there is an opportunity to include unpaid carers in the

early tranches of expansion. Furthermore, unpaid carers have also highlighted examples where help could be provided such as council tax reductions, free glasses and leisure access and concessionary travel.

"Free dental included with Carer's Allowance. It's so expensive and would help us stay healthy in order to ensure we are at our best to fulfil our caring role."

# Conclusion

In conclusion, we welcome the Bill and the proposal to provide a double Carer's Allowance Supplement in December and we hope the Committee will support this and enable it to be paid on time. We invite the Committee to consider in its work programme how it can best support carers in the short, medium and long term. The National Carer Organisations would be happy to offer to help support Committee members to meet and engage directly with unpaid carers as part of this work.

10 August 2021 Fiona Collie

Policy & Public Affairs Manager, Carers Scotland on behalf of the National Carer Organisations

#### Contacts:

- Fiona Collie, Carers Scotland: fiona.collie@carerscotland.org
- Claire Cairns, Coalition of Carers in Scotland: coalition@carersnet.org
- Kate Hogarth, Shared Care Scotland: <u>kate.hogarth@sharedcarescotland.com</u>
- Suzanne Munday, MECOPP: suzanne@mecopp.org.uk
- Paul Traynor, Carers Trust Scotland: ptraynor@carers.org

The National Carer Organisations are Carers Scotland, Carers Trust Scotland, the Coalition of Carers in Scotland, Crossroads Caring Scotland, MECOPP, Shared Care Scotland, and the Scottish Young Carers Services Alliance.

Together we have a shared vision that all Scotland's unpaid carers will feel valued, included and supported as equal partners in the provision of care. The NCOs aim to achieve this through the representation of unpaid carers and giving them a voice at a national level.

We believe we can deliver more for unpaid carers by working together to share our knowledge and experience, and by focusing our collective efforts on achieving improvements in areas of policy and practice that are of greatest concern to unpaid carers.

# **Carer responses to the Carer's Allowance Supplement Bill**

# 1. Background - what we did

We put together a short survey about the Bill for unpaid carers to respond to. We asked unpaid carers whether an increase in Carer's Allowance Supplement in December was a good idea and also whether there were other ways in which the Scottish Government could have supported unpaid carers during the pandemic. We also allowed space in the survey for unpaid carers to feed back any other comment that they wanted to share about the Carer's Allowance Supplement Bill.

The survey was live between 27 July – 2 August 2021 and received 633 responses from unpaid carers. Out of those 633 carers, 70% were unpaid carers who receive Carer's Allowance and the remaining 30% were unpaid carers who were not eligible for Carer's Allowance.

# 2. Findings – what we found

Do carers agree with the proposal to double the carers allowance supplement payment in December?

We asked unpaid carers whether they agreed with the proposal to double the Carer's Allowance Supplement payment in December.

Overall, 93.1% of all unpaid carers who responded to the survey agreed with the proposal to double the Carer's Allowance Supplement in December. 2.1% said that they didn't agree with the proposals, and 4.9% were unsure.

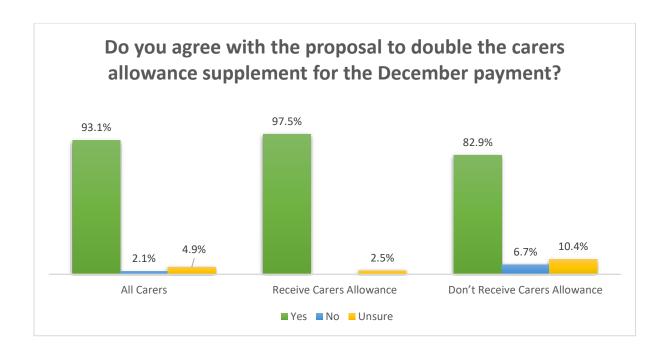
If we break this figure down by unpaid carers who get Carer's Allowance vs unpaid carers who don't get Carer's Allowance then we find that:

#### Out of the carers who receive carers allowance

- 97.5% said yes, they agree with the proposal
- 2.5% said they were unsure about the proposal
- None of the carers disagreed with the proposal

## Out of the carers who did not receive carers allowance:

- 82.9% said yes, they agree with the proposal
- 10.4% said they were unsure about the proposal
- 6.7% said that they disagreed with the proposal



#### Feedback from Carers who receive Carer's Allowance

Those in receipt of Carer's Allowance were more likely to support the proposal to double Carer's Allowance Supplement payment in December and were very much grateful for the additional financial support, as reflected in the comments:

- A great help
- A thank you to the Scottish Government for acknowledging Carers and trying to help with the only way they can at the moment.
- Anything we get is a bonus it goes towards making life a bit easier.
- Carer's Supplement makes a massive difference, even to make you feel appreciated when unable to work due to child's needs.
- Carers allowance supplement has help both me and my son financially during covid a lot especially since I've had to spend more money on getting things to do at home to keep him entertained without this, I wouldn't have been able to do this
- CAS is a valuable token of gesture towards Unpaid Carers
- Had to buy extra things to keep myself and kids busy during lockdown, so the extra money will help areatly
- You don't have spare cash when on benefits, the carers allowance supplement is like winning the lottery
- This extra money is a godsend when you have two registered disabled children in your family, it can pay for extra days out, clothing and sadly bills
- My carers allowance is just about covering my outgoings. The supplement will mean I will be able to
  pay some things, like replacing my broken laptop and be able to send gifts to my kids which would be
  really difficult otherwise. It sounds like luxuries but it makes the winter look bearable. It really helps
  my moral to think it will be there later in the year.

Those in receipt of Carer's Allowance also shared some additional thoughts about the proposal to increase the December Carer's Allowance Supplement payment. There were some common themes which we have summarised here:

# There should be a permanent increase in carer's allowance/carer's allowance supplement

- A welcome payment to support carers. Maybe spread it out to 4 extra payments over the year.
- Actually, it should be doubled permanently, if the government had to pay for outside agencies to do the work of Carers it would cost a lot more. Carers are completely undervalued and forgotten about
- As much as a double payment this year will be welcomed there should be more support long term. I firmly believe the supplement is a great idea but not enough long term.
- At the moment we receive around £67 per week. Caring for someone for 40+ hours per week is so much less than minimum wage which is the law but we are not classed as working just caring
- After having to give up my semi-professional career 2 years ago to look after my son the drop in my finances has been huge and debilitating! An increase in payments is very much needed.
- Carer's allowance is a big help to family finances. If it were to be raised it would be wonderful.
- Carers Allowance should always be Double every month us Carers are not paid enough for the caring roll
  we do for loved ones is 24/7 we don't get a day off or go home for the weekend it's mentally and
  physically exhausting
- Carer's allowance should fall within the same level as the national living wage.

# Carer's allowance needs reforming

- Carer's allowance should be assessed on the level of care given i.e. someone who provides a high level of care (i.e. personal care, moving and handling and assistance to eat etc) 24hrs a day is paid the same as someone who does a much lower level of care etc.
- I appreciate the extra little help this gives me although I feel carers allowance should be more and you should be able to get it for more than one person as I was looking after both my parents who have dementia and other illnesses for years and was only getting paid it for dad until his death last year then I had to reapply for to be mums Carer even though I'd looked after them both for over ten years
- Yes. I do not agree that the amount of carers allowance is deducted from universal credit payment. Not my fault I can't work as I need to be home for my son.
- You can't go over 128-pound a with carers allowance it's not fair especially if you have a small pension very low income to try and live on, we don't want to be paid thousands just to manage better government should know the cap 128 a week should be higher than it is just now why should we struggle and worry if we might go over the amount not realistic should be considered also.
- What about multiple carers. I care for my son (child), daughter (18 yrs) & my mother who are all disabled. Being a multiple carer seems to be ignored in terms of all support.
- That all unpaid Carers get the payment and that the UC/CA distinction is removed in order to do so. I think DWP would need to provide more information in order to make that work.
- I'm an unpaid carer for my adult son. Next year, I will perform exactly the same care for him as I did last year. Next year I will not receive careers allowance as I receive my pension. Attendance allowance doesn't help or situation. When will this anomaly be rectified?

# There should be recognition for all carers (regardless of whether they receive carers allowance or not)

- All Carers deserve to be recognised paid or unpaid as unpaid carers give up their time to care for their loved ones as they don't want to see them struggle. Myself I am a paid carer looking after my disable wife with spina bifida, during this time it has been challenging along with my own mental health, my health during this has affected me emotionally to the point at times I feel like what's the point on living. All carers paid or unpaid deserve to be recognised
- It's a great idea. Carers who work over the allowance or who study should also get the supplement.
- It should be offered to all registered carers. I receive carers allowance for looking after my son. My partner works but receives carers element on uc too for being a carer to our other son but no carers supplement because he has to work as well as being a fulltime carer to our kids to be able to support our family.

# **Better support for carers**

- Extra Regular support would be nice, too. A one-off double payment isn't exactly much for carers who often get forgotten about
- Free dental included with carers allowance. It's so expensive and would help us stay healthy in order to ensure we are at our best to fulfil our caring role
- It's good that we are recognised but it doesn't make up the impact of damage caused over that time I have 3 disabled children and an adult with disability at home, I am the main person for all of them, I've had to stop working and claim carers. It's not recognised what I've lost as a person to be a carer. Not just financially but all over impact.

#### Feedback from carers who do not receive Carer's Allowance

Comments from those who **do not receive Carer's Allowance** reflected (not surprisingly) the need to consider unpaid carers who are unable to claim Carer's Allowance due to the earning threshold, student status, or because they are in receipt of a state pension or other income related benefits. We have summarised the comments from unpaid carers who don't receive Carer's Allowance - many of these mirrored the same concerns and issues raised by carers who receive Carer's Allowance:

## Increase the amount of carer's allowance and carer's allowance supplement

- Increase the amount paid to unpaid carers permanently by a higher amount. Identify when people need more than one carer and make a second carer eligible for carers allowance too.
- It's a gesture, not a permanent solution to a growing problem. Carer's allowance should be higher and carers should be allowed to claim it regardless of their other income.
- Carer's allowance is woefully low and the supplement is a welcome addition although a better monthly rate would be preferable

# Additional financial/practical support should be available to carers who are unable to claim carers allowance

- I think every unpaid carer should get something not only those who receive carers Allowance. It's unfair to those of us who also work and provide many hours of care to our loved ones.
- Not all people qualify for a carers allowance but still need help with bills and expenses

- What about parent carers that do not meet the criteria to claim carers allowance?
- Unpaid carers often work- (usual low paid employment) then go home to caring role no financial support for them. If u care regardless of circumstance you should receive financial support if you wish to claim it. Real support is needed not tokenism A Bill should make a lasting difference for all. Better ways to spend money- even the carers centres can't offer much support due to cuts Sort yourselves out instead of pretending to care about carers actually offer real life improvements for people
- How can someone with "no recourse to public funds" as part of their visa conditions access ANY help?
- Hi I'm not against help but let's help with the Carers who don't qualify because they work, they still have to care for loved ones so really, they should be awarded CA as well it would be a lot more expensive if they had to put loved ones in care homes please help all Carers not just some Thanks
- I think the whole system requires reviewed and updated. As a mum and a nurse and a Carer to an ash daughter and elderly father with dementia. I do not meet the criteria for any financial supports. The carers Assessment is not fit for purpose when I had mine done it was patronising and unsuitable for anyone who works as anything offered was during this time.
- They should consider the unpaid Carers, who are not eligible for Carer's allowance, due to the fact, that the disabled person they care for (in my case-24-hour care, by myself -no respite- for my adult severely disabled son), has No Recourse to Public Funds (NRPF). Hence, he has no disability award letter. Albeit the unpaid carer is a British citizen, and the cared for is here legally. I struggle every day to put food on our table, and keep our utilities on. Both my son and myself had Covid, I still had to care for him despite having covid, I had no choice and no money. Carers Allowance along with a supplement would have allowed me to bring someone in to help us. We are both still suffering from the effects of having Covid.

# Expand the eligibility criteria for carers allowance so more carers are able to claim

- Also needs to be recognition that parents who work are still carers and can often have to combine work with significant care duties-but they are not entitled to carers allowance.
- Remove the Rule that if you work and earn over a certain amount you can't claim carers allowance. I work so excluded from claiming. My child's needs don't magically disappear because I work. As soon as I leave work I delivery care to a child with complex physical disabilities and rather unstable diabetes day and overnight. Having more than one child it's easy to compare the additional support that is required when disabilities are present. Of course, I do it because as a parent that's what you do however it is all consuming and expensive to manage. I genuinely believe that should be recognised and supported and may keep more parents in the situation in work which would not only benefit them and their family but society as a whole.
- Not all unpaid carers get the allowance for example I am a full-time student and don't qualify
- Increase weekly amount Carer can earn before not being eligible to claim it a whole group of carers are
  missing out on the payment as they have to work but still care for someone when not working, I find it
  hard that just because you have to work & are not able to claim carers allowance you are being
  penalised, yet again, you are still caring for someone though for every hour you are not working.
- I wish students could claim carers allowance. I am a student nurse, yes, I get a bursary but it does not cover the care I need to pay for, for my autistic daughter.
- Only thing i would say is carers allowance should be based on circumstances just because I work i don't get it but i also care for my son at work because he works with me for that reason
- Just like Pip. Carer's allowance should not be means tested.
- Carers Allowance should be in line with Job seekers allowance and the limit to paid work should be raised to enable more people to be eligible. Many people provide substantial care and still work full time.
- Parents of severely disabled children/adults who work are being penalised because they work during school hours/day centre hours meaning they are not entitled to carers allowance or this supplement
- I think it ought to be given to pensionable age carers because caring gets harder with age as do cared for people's disabilities. I see how my mum has no choice but to neglect herself. She doesn't get to spend time with her grandchildren like normal granny's she is taking care of my dad 24/7. And in the time, she

has cared for him he has progressively got more disabled and more difficult to manage while she has aged and grown frail and thin. She will be worked to death looking after him. And it won't be long. She is only 66.

• We have 4 children who all have additional needs. 3 claim dla or pip at a rate that would allow us to claim carers. However, as we both work, we cannot claim

# Do carers agree that the double payment in December is the best way to support carers during the pandemic?

We also asked unpaid carers whether the extra Carer's Allowance Supplement payment in December was the best way to support unpaid carers with the extra challenges they faced during the pandemic.

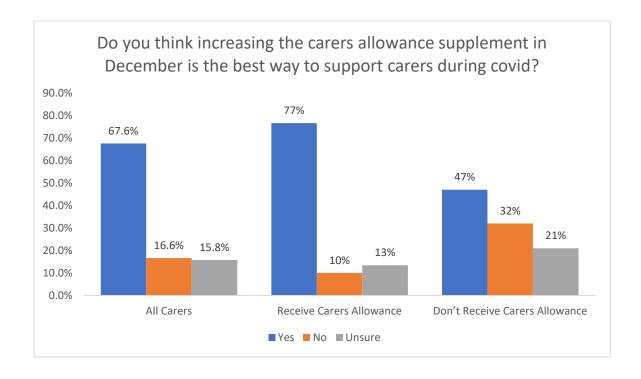
Overall, 67.6% of the unpaid carers who responded to the survey said that yes, increasing Carer's Allowance Supplement in December was the best way to support unpaid carers during the pandemic. 16.6% said that they didn't think that this was the best way to support unpaid carers during the pandemic, and 15.8% were unsure if this was the best way to support unpaid carers during the pandemic.

#### Out of the carers who received carers allowance

- 77% said yes, increasing the carers allowance supplement was the best way to support carers during the pandemic
- 10% said that no, this wasn't the best way to support carers during the pandemic.
- 13% said they were unsure whether this was the best way to support carers during the pandemic

## Out of the carers who did not receive carers allowance:

- 47% said yes, increasing the carers allowance supplement was the best way to support carers during the pandemic
- 32% said that no, this wasn't the best way to support carers during the pandemic.
- 21% said they were unsure whether this was the best way to support carers during the pandemic



We asked unpaid carers for ideas on how the Scottish Government could better support unpaid carers during the pandemic (other than double the Carer's Allowance Supplement payment in December). The responses did not vary much between unpaid carers who receive Carer's Allowance and those who don't. So, we have summarised the **responses from all unpaid carers** into a number of key recurring themes.

## Increase the carers allowance/carers allowance supplement permanently

- Upping the weekly money and it not affect other benefits
- To increase the amount of carers allowance as a lot of people have to give up jobs to care and this affects the household income and saves the government a lot of money because they don't then have to provide day care for those people
- They could increase the amount of Carers Allowance weekly, and then stop the Universal Credit taking more out of people's payments for it.
- The cost of living has gone up dramatically so maybe it should be increased to allow us to live better rather than watching every penny 18-year-olds get more money on jobseekers that we do and if you own your own house the struggle is real
- Substantially increase CA permanently. Our household income decreased by two thirds when husband became ill and I his carer. We would both prefer to still be working full time. I provide 24-hour care thus saving the LA the cost of a nursing care placement. I do not feel valued at all.
- Increase carer's allowance it's the lowest benefit. We are fobbed off with 'You choose not to work... this is not a substitute for work' by the UK government. Come on Scotland prove you value of real work caring and raise the rate of carers allowance to reflect the real hours we work every week with no time off, on call 24 hours a day.
- I'm a carer for an 83yr old parent with chronic heart failure almost blind and deaf and he's disabled. I am unable to work because of this. There's only 1 wage comes in to our house and we sometimes get universal credit every other month. We are up to our eyes in debt and are robbing peter to pay Paul. There are no other benefits we can apply for. Carers allowance weekly just isn't fair I worked my whole life. £67 .60 does not even meet my family shopping bill, I have a 12 Yr old son whose missed out on so much because I'm caring for his grandfather.

# Changes to carers allowance

- Most carers are also on Benefits, your standard carers allowance is subtracted from the benefit leaving no financial difference for the job you do. Carers need to be properly recognised and paid a living wage equivalently.
- Help every week not just twice a year. I personally do over 70 hours a week looking after 2 people with very complex needs and one needs manual handling which I have to do on my own. I struggle with finding time to spend with my own family as am always at my cares home do everything from personal care to housework to gardening also all meds etc on my own. Last holiday I had was in 2019 when I had a week with my family before that it was 8 years since a holiday. My health is getting worse as I am so exhausted and in constant pain with sore back and shoulder. Help would be nice and pay that represents what I actually do. If you look after 2 people full time you should be paid for looking after both the people not just one.
- Get rid of the earnings limit for carers allowance
- Every penny directly paid to unpaid carers is welcome but only 10% of carers are eligible, the stipulations that you cannot be a full-time student and the earnings limit preclude so many people who often work in excess of a 50 hours a week on top of their other commitments not just because of love but because they have no choice as social care SDS assessments can take years, yes years.
- I'm entitled to carers allowance but due to being esa I don't get paid it I get a top up on my esa but I think I should still be entitled to the extra payments

- I've got to work part time financially and because of this I lose out in carers allowance even though I still care full time for my son
- Even those who have to work as well as be a carer should be allowed some payment regardless of earnings. Then they might not need to work such long hours, or can pay someone to do something for or with the cared person.
- Another unfair proposal by the Scottish Government. How many pensioners care for loved ones without
  any support and not entitled to benefits, living on basic pension and the majority in fuel poverty. The
  costs of caring include heating, adjustments to home, beds/mattresses, transport, special diets and
  incontinence products just as basic requirements, if not assessed for social care, carers have to meet
  costs themselves as well as toll on own health. The majority of elderly carers, are not entitled to carers
  allowance and miss out. A great proportion of Scottish unpaid carers are the elderly.
- Carers who have previously applied or received carers allowance but due to the underlying claim/overlapping benefit rule we lose out on the supplement others get. Surely something can be put in place so we don't miss out in these circumstances.
- All carers should get carers allowance Regardless of earnings just like DLA & PIP. I earn 5 more than 128 and lose out on carers allowance and the supplement. My daughter suffers because of this. She has a lifetime disability.
- Whole carers allowance should be updated. For instance, I do not get because I receive a widowed
  parent's allowance. However, if my husband had divorced me and paid same amount in child payments
  as the widow's allowance, I'd be eligible to receive the carers allowance for my disabled son. Scandalous
  that his death instead of a choice prevents us receiving much needed help!

# Remove barriers to employment for unpaid carers

• Carer's allowance is greatly appreciated, however, why not look at removing barriers to work so we don't have to rely on benefits. We need after school club/breakfast club provision for disabled young people in special schools, guaranteed holiday club type activities in school holidays, decent day care for our adults with disabilities. All this would allow carers to compete in the market place for jobs alongside non carers. This would mean we would have decent pensions and financial provision for our old age and therefore be less reliant on benefits when we are older and in better position to care for our young people. Of course, we must respect that for some carers work is not an option due to the extent of their caring obligations where they have to support their child in hospital stays, appointments, administering medication during the night, etc. And they should be getting better respite and relevant person-centred support too.

#### **Practical support for carers**

- We need more support from Carers Centres & not based on a postcode lottery. We need proper care plans for carers.
- Vouchers
- There has been no support from anyone the money is a huge help but the reality is unless critical i.e. will die zero care or carer support and this needs addressed beyond a payment that will offer a small relief for a few weeks.
- Support groups, opening centres where carers can go to relax
- Support the provision of more opportunities in the community
- Support carers with emotional and mental health. Been confined for so long and getting no help will impact massively on carers
- Offer more contact support to unpaid carers also, money doesn't always help everyone, some people just need extra support.
- More support (emotional & practical) as well as financial help

- Further funding for respite. Funding childcare aimed at special need children. Having a grant system for goods or items that the government could purchase at cost that is available to anyone with an underlying entitlement to Caters allowance regardless of they receive it.
- Free bus pass it's ok to say u can travel as a companion but the person I care for was isolating cost me a lot in fares
- Extra money does not stop burnout & exhaustion in unpaid carers, better support in social care does.
   Local Authorities have not even complied with COVID 19 Guidance of Self-Directed Support for flexibility usage of budgets, instead they have clawed them back. Many unpaid carers also have no Adult Carers Support Plans in their own right either, with the choice of the 4 options of Self-Directed Support to meet their practical needs.
- carers who don't normally qualify for carers to receive some kind of gratuity payment as they also have been through covid

## Better support for the person they are caring for

- Some carers have had to decrease working hours as adult services haven't fully opened or are not starting new referrals. This means that social work budgets are not being used but carers income has decreased in order to provide full time care. It's a great start but surely there could be a compromise with funding.
- Restarting activities, support groups and especially CAMHS waiting times
- More money should be going to respite, after school clubs etc to provide time out for carers rather than money which I imagine I'll probably spend on kids Christmas which while obviously helps me out probably not what its intended for.
- Increase budgets to social care so parent Carers can actually get the support they need. My local area
  has 2.5 OTs within the children with disabilities team to deal with all the disabled children and families.
  It is not good enough
- Getting NHS clinics back up and running and also social care services such as social support & respite
  plus looking at how to help children who have regressed their skills due to the lack of support during
  Covid
- Close the accountability gap. Ensure councils put adequate services and support in place for disabled people
- Whilst the money is a huge help financially the best way to support unpaid carers is to stop reducing the services the person, they care for requires. This has the biggest impact on a carer.
- We need respite i.e., Daycentre which we've heard in Aberdeen are not opening again. Unpaid carers are at breaking point and are not being listened to what they need to help loved ones and our caring role. I am begging the Scottish government to rethink about the changes that's being made and listen and act on what unpaid carers are saying. We have rights and so has our loved ones. Anyone caring for someone with Dementia knows how hard things can be they need stimulation and being in with people like them. A sitting service is not what most carers want although we keep getting told that's what we asked for. Every other unpaid Carer I have spoken to in groups I attend do not want sitting service we are all in the same agreement we need places where we know our loved ones are safe and enjoying themselves, we get some well-earned respite. Most carers will appreciate a bit of extra money but priority has to be respite.
- Unpaid carers need a break. No respite or day care for 18mths. our physical and mental health is shocking. Money is good but action of respite would be better

Shubhanna Hussain-Ahmed Coalition of Carers in Scotland on behalf National Carer Organisation shubhanna@carersnet.org