

# Scottish Carers Assistance Consultation

## Response from the National Carer Organisations



The value of unpaid care is estimated at £10.9 billion a year<sup>1</sup> in Scotland, which equates to £43million a day. The health and social care system could not function without the contribution made by unpaid carers. However, this comes at a personal cost, as caring often has a significant impact on both carers' health and wellbeing and also on their financial security.

Despite this, for decades Carer's Allowance was the lowest income replacement benefit in the UK and was only recently raised to the same level as Job Seekers Allowance through an additional supplement financed by the Scottish Government. It is still one of the most complex social security benefits, with unfair eligibility criteria which excludes many carers from claiming it.

Carers and carer organisations have been campaigning for many years for the reform of Carer's Allowance, including changes to eligibility and an increase in payments.

We welcome the Scottish Government's plans to replace Carer's Allowance with Scottish Carer's Assistance. The proposals set out in the consultation papers have been broadly welcomed, particularly some of the changes to the eligibility criteria which are long overdue.

However, carers have criticised the pace of change and also voiced their concerns that the proposals do not go far enough. 24% of carers are already in poverty<sup>2</sup>. Added to this, we are facing a cost of living crisis which will have a disproportionate impact on carers. The proposals set out by the government in their consultation will only deliver a modest rise in income for some carers, which will not offset the rising cost of living, nor will it lift carers out of poverty.

### How we engaged carers in the consultation

The National Carer Organisations have been engaging unpaid carers in conversations about social security benefits, including Carers Allowance, for over a decade. We are pleased that many of the proposals within this consultation paper were proposed by carers who have been campaigned on them for many years.

In more recent times carer representatives and the National Carer Organisations have been involved in various advisory and stakeholder groups which have played a key role in developments around the transfer and reform of social security benefits in Scotland, including carer and disability benefits. We have therefore drawn on this body of evidence and expertise in developing this response.

In addition, during this consultation period we have engaged carers through focus/discussion groups, through an online survey and by using Facebook polling on specific questions. We have also promoted the consultation through our networks and social media platforms to encourage carers to submit a responses on an individual basis. By using this range of options, carers have

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<sup>1</sup> Unseen and Undervalued, Carers UK 2020

<sup>2</sup> UK Poverty 2022: Trends in poverty" Joseph Rowntree Foundation

been able to select their preferred method of engagement, according to the amount of time they have had available to them, from a few hours to 5 minutes.

The online survey we hosted received 180 responses.

We posted 9 Facebook Polls, with the number of responses for each question ranging from 108 to 250. In total, we had 1,503 responses to the questions we posted, with some carers responding to multiple questions.

Finally, we held two engagement events which allowed for more in-depth discussion. One was a meeting of Rural and Island Carer Support Workers and the other was a Carers Summit, which was attended by 60 carers.

All of this evidence and lived experience has helped to shape and inform our submission.

## **Section 1: Scottish Carer's Assistance from launch**

### **Question 1: Please give us your views on how Scottish Carer's Assistance services could be designed to suit carers' needs**

Carers have often talked about their dissatisfaction with the current social security system, which is perceived as being impersonal and at times punitive. One of the key changes carers are seeking from Social Security Scotland, is an enabling and needs-led approach and being able to interact with a system that treats them with dignity and respect at all times and recognises the huge contribution they make to our society through the provision of their unpaid labour.

Carers are supportive of the human rights approach set out by Social Security, with the development of both the Social Security Principles and the Charter and are hopeful that these foundations will translate to a more positive and empowering experience for claimants. They expressed the need for a system where the process is transparent, timescales are prompt and set out in advance and claimants are provided with information and support at all stages, where required.

In order to respond to carers needs effectively, the system must be accessible, non-bureaucratic and it should provide a choice of options for how carers interact and communicate with services. For example, some carers would prefer to interact online, while others would prefer communication by telephone or face-to-face.

For carers with additional communication support needs, whether this be little or no literacy in English, a requirement for braille or to address digital exclusion, we urge that the proposed changes be considered within the current review of the Public Sector Equality Duty and specifically, the addition of a requirement to implement inclusive communication.

This is particularly important as BME carers consistently report difficulties with understanding and navigating the current system.

As previously stated, choice of interaction methods with the benefits system must be actively promoted to ensure communication difficulties are not a barrier to uptake. This must include access to 'real time' interpretation services.

In relation to the current application process for Carers Allowance, we asked carers '*How easy/difficult is the carers allowance application process*'

We received 119 responses to this question:

- 97% - found the Carers Allowance application process fairly easy
- 3% - I found the Carers Allowance application process fairly difficult

It is important to note that this was an online poll, so this will have produced a bias against people who are digitally excluded, including many older people. As one respondent commented '*I found this process quite easy but then I am computer literate. Most people who try to claim aren't*' Echoing this, a 2018 survey by Citizen's Advice Scotland found that amongst respondents aged between 65 – 79 years of age, only 25% used the internet often, 46% never used the internet, 18% had difficulty using a computer and 16% could not use one at all.

Another respondent noted that the application process was more difficult and involved for those in employment, who had to provide additional evidence: '*I was working at the time and had to get an accountant to fill out part of it for wasn't even getting a profit from the job. Seemed the extra effort and cost was pointless*'

We would also highlight the difficulties experienced by carers who work fluctuating hours and the difficulties in resolving this with the current system.

For particular groups of carers, access to an account for payment of social security benefits cannot be assumed. Where this is an identified gap, information and sign-posting should be provided to the individual to enable this to be addressed.

**Question 2: Please give us your views on support that Scottish Carer's Assistance could link to that would be helpful for carers.**

Many carers receive support from local money advice services and from their local Carers Centres to apply for social security benefits. Historically Carer's Allowance has been an underclaimed benefit, in some cases due to the impact on the benefits of the cared-for person, but also due to the lack of awareness amongst many groups of hidden carers. It is important that there is continued investment in local carers centres and other third sector organisations who can identify carers and support them to maximise their income.

Connecting carers to their local carer support services will also align well with objectives to ensure that carers have access to wider supports. This includes being offered an Adult Carer Support Plan, emotional support, referral for social care services, breaks from caring, and to other forms of financial support, such as short break grants and in some cases hardship funds.

In addition, it is our view that Scottish Carer's Assistance should become a passport to other supports. We would suggest that eligibility for free dental treatment, free glasses and support for travel to hospital could be expanded to include unpaid carers. Furthermore, carers have also highlighted examples where help could be provided such as council tax reductions, subsidised fuel

costs, leisure access, concessionary travel and subsidised broadband. One example worthy of consideration would be to prioritise carers as a distinct group with Scottish Government initiatives to address the digital divide such as Connecting Scotland.

For 'hidden' carers, consideration should also be given to their preferred or only means of accessing information and support to access social security benefits. For example, their may be a reliance on or preference to approach BME or LGTBI organisations rather than a local carer centre.

**Question 3: Do you agree or disagree with the proposed residency criteria for Scottish Carer's Assistance?**

Mostly Agree

**Question 4: Please write the reason why you agree or disagree with the proposed residency criteria for Scottish Carer's Assistance, or any other information you want to share on this question.**

In our previous engagement with carers relating to Carers Allowance Supplement, a small number of carers raised the issue of having no access to 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 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. Additional measures should be considered to address these issues.

As a minimum, we support the proposal to bring the residency rules for Scottish Carers Assistance in line with those of people claiming disability benefits by reducing the residency criteria to 26 weeks.

**Question 5: Please give us your views on the 'past presence test' which should be used for Scottish Carer's Assistance.**

We support the proposal to remove any past presence test for Scottish Carer's Assistance where the cared-for person is awarded support under the special rules. During our consultation we heard from several carer support workers who knew of carers who had returned home to care for a relative who was terminally ill. In these circumstances they often had to leave employment and in some cases they chose to re-locate permanently to Scotland. Given their contribution in providing end of

life care and the financial savings to health and social care services, we believe they should be financially supported during this time through access to Scottish Carers Assistance

Another area of concern which was raised by two of our member organisations who support carers living in Dumfries and Galloway and the Scottish Borders, is the process for carers claiming Scottish Carers Assistance when they move from another area of the UK to live and care for someone in Scotland. We believe it is essential that there is no delay in them receiving the benefit, particularly where they are already caring for an individual and receiving Carers Allowance through the DWP. This was a scenario which carers centre staff in both local authority areas, bordering England, had encountered before.

In these situations it would be important to ensure that the carer did not experience a loss of income which might prevent them from moving to Scotland to provide care for an individual, as this could be detrimental to both the carer and the person requiring carer and would place additional strain on social and healthcare services.

**Question 6: Do you agree or disagree with the proposed re-determination timescales for Scottish Carer's Assistance?**

Mostly Agree

**Question 7: Please write the reason why you agree or disagree with the proposed re-determination timescales for Scottish Carer's Assistance, or any other information you want to share on this question.**

We agree with the proposed timescale for submitting a re-determination and also agree that this period should be extended where there is a good reason. We can envisage several situations where a carer might face circumstances culminating in a delay to their submission, including carer illness or breakdown, illness or increasing care needs of the cared for person, or challenges with getting an appointment or attending an appointment with an advice or support organisations.

Again, we raise the additional difficulties for carers and/or the cared for person who experience digital exclusion and who rely on support workers to assist them in informing Social Security Scotland or the DWP of any changes to their circumstances.

We welcome the Scottish Government empathy and their understanding of the complexity of people's lives, which reflects Social Security Scotland's core principles of dignity fairness and respect.

However, we do not agree with timescale for decision making in relation to re-determination. We feel that 56 days is too long. There will be circumstances where a carer has had to take on a caring situation in an emergency and may have no income during this period. As well as causing personal hardship, this could potentially have an impact on their ability to care. For example, if they do not live with the person they care for and are unable to afford transport and fuel costs. We have heard from one carers centre that they have had to provide emergency funding in situation such as this and have funded this through donations.

**Question 8: Do you agree or disagree with the proposals on when payments of Scottish Carer's Assistance should be suspended?**

Agree

**Question 9: Please write the reason why you agree or disagree with the proposals on when payments of Scottish Carer's Assistance should be suspended, or any other information you want to share on this question.**

We welcome this proposal. Suspending payments of Carer's Allowance when the cared-for person's benefits are suspended is unfair and causes unnecessary stress and hardship to carers. In most circumstances the carer will continue to provide care during this period of suspension, so they are unlikely to have an alternative source of income and are being penalised for actions which are not their own

We are also aware of many examples where the DWP has suspended the benefits of disabled people without due cause and without compassion. For example, where someone has a mental health breakdown and is unable to attend appointments. During periods such as this, it is not unusual for a person's caring role to actually increase.

**Question 10: Please give us your views on what should happen to payments of Scottish Carer's Assistance when a cared for person's qualifying benefit is suspended.**

We agree that this should only happen in exceptional circumstances. We also agree that carers should be able to challenge a decision and payments should not stop until a decision is reached. It is also our view that carers should be able to access advice and support to enable them to challenge a decision.

**Question 11: Do you agree or disagree with the proposals for when an award of Scottish Carer's Assistance should be set to £0?**

Mostly Agree

**Question 12: Please write the reason why you agree or disagree with the proposals for when an award of Scottish Carer's Assistance should be set to £0, or any other information you want to share on this question.**

This proposal was broadly supported and was felt to have several benefits, including providing more financial security for carers who would otherwise have their benefit suspended or ended, sometimes on a regular basis. It would remove the stress of having to go through the claims process again and it would mean more carers would be able to combine work and care.

As part of our survey we asked carers *'Do you agree or disagree with the proposal to look at a 'run on' after a carer earns over the earnings limit in future?'*

We received 179 responses to this question with the majority of carers agreeing with the proposal.

Agree	78%
Disagree	2%
Unsure	20%

A significant number of carers expressed the view that there should be no earnings limit, provided the carer can combine work and caring and they are able to care for at least 35 hours a week.

Responses included:

- *'Regardless of your income a carer should be rewarded, a carer is a carer regardless of earnings, look at the bigger picture!'*
- *'All carers should receive this regardless of how much they earn.'*
- *'My husband works part time and cares for me. Unfortunately, he earns more than the cap, and therefore is not eligible to apply for a carers allowance which I feel is extremely unfair.'*
- *'Every carer should receive a form of payment for their caring role, not to be restricted by the amount of payment they receive from their paid work. As long as they are caring for 35 hours, they should receive the money.'*
- *'Personally I think even if I work a 40 hour week you can still care for a person 35 hours. So I think there should be no cap in working as you will also be contributing to tax and NI.'*

Carers also expressed the view that the government should be actively supporting measures to assist carers in being able to combine work and caring, as it is not only a positive financial outcome for the carer, but it also supports the economy. It was felt that this would remove one of the barriers to carers being able to return to work or sustain employment.

- *'This seems to be a very practical proposal. Earning for the future is always a good thing. Caring comes to an end sometime, but nobody knows when'*
- *'Being in that very situation many years ago when all benefits ended due to earning £5 over the limit. Losing heart to have that job. That other valued place in society running along with the caring role'*

Carers have also highlighted that the loss of Carers Allowance due to the earnings threshold has an emotional impact, describing it as detracting from a recognition of their identity and the contribution they continue to make to civil society as a carer.

Several carers referenced the increased cost of living which has a disproportionate impact on disabled people and carers, resulting in pressure on families to both reduce costs and generate more income. Being able to claim Carers Assistance while earning more income through employment was thought to be an option for some, although others pointed out that this would add additional responsibility onto carers who were already under strain:

- *'Just because someone earns more than the minimum doesn't mean they can suddenly afford all the extra costs involved in caring for someone.'*
- *'Have you tried to work/ do care duties, bring up children and keep house? It's exhausting and something has to give as a human being before ill health affects the carer. Forced into working extra to pay increasing energy bills but collapsed from exhaustion after a week.'*
- *'Carer's allowance should be paid regardless of income. We are struggling financially and emotionally to juggle me working with my caring role. We took on a mortgage when our children were young with the view of me working full time. I never believed I would have to work 2 days to support my daughter. She wouldn't cope with us selling our house and giving up our home but what are we to do? We feel so unsupported'*

- *‘Yes, there was no mention whatsoever of unpaid carers who receive carers credit which is a non-monetary benefit. I personally am just over the threshold for carers allowance and claim carers credit but feel disadvantaged about the bonus every 6 months as I and many more in the same situation who are single parents are carrying on with extra expenses. It doesn’t actually pay us to work these days but we do for our mental health’*

For many carers, their situation requires greater flexibility than is afforded by the current social security system. This included carers who have an unpredictable and fluctuating caring role, requiring the need for more flexible working patterns and carers whose employment was irregular or seasonal. It was felt that this proposal would go some way to mitigating these challenges.

- *‘Cared for persons health can change week to week which may mean some carers aren’t able to earn that regular income every week.’*
- *‘I think consideration also needs to be given to the self-employed who often can get different amounts each month and so an average must be taken across the year rather than the week. For example, when I have school holidays I can’t do any self-employment or bank work at all whereas when they’re at school I can make up those hours of work but then I don’t because it would leave me earning over the threshold’*
- *‘It is a reassuring to have this, the cared for person could deteriorate when the carer goes to work and things might rapidly change’*
- *‘Self employed and work from home carers are penalised unfairly by income limits. Why must my work contract because of an arbitrary limit when I care and work simultaneously. The system is set up for outdated work patterns.’*

Others felt that the proposals do not go far enough with one carer commenting it was ‘An inadequate change but better than nothing’

**Question 13: Do you agree or disagree with the proposal to pay Scottish Carer’s Assistance to carers when the person they are caring for is receiving short-term assistance?**

Agree

**Question 14: Please write the reason why you agree or disagree with the proposals to pay Scottish Carer’s Assistance to carers when the person they are caring for is receiving short-term assistance, or any other information you want to share on this question.**

We agree with this proposal, as we stated previously, carers should not be financially disadvantaged, or left with no income while challenging a decision, or when the person they care for is challenging a decision.

Carers are already on low incomes, many of them live in poverty and they may not have any financial resources to fall back on. The “UK Poverty 2022: Trends in poverty” published by the Joseph Rowntree Foundation found that carers are more likely to live in poverty than those without caring responsibilities: 24% compared with 21%. Carers of working age are even more likely to be in poverty. Working age carers and those who care for more hours have the highest poverty rates. 44% of working age adults caring for 35 hours or more a week are in poverty, with those caring between 20-34 hours at 26%.



As stated before, removing their benefit may have impact on their ability to continue to care, which would leave the people they care for in an extremely vulnerable position

**Question 15: Please give us any other views you want to share on the proposals for Scottish Carer's Assistance when it is first launch**

It will be essential to have a co-ordinated approach to communications, involving key stakeholders during this first phase when Scottish Carer's Assistance is launched. In particular:

- current claimants of Carer's Allowance will require reassurance that they do not have to apply for Scottish Carer's Assistance, as this is a concern which has regularly been raised.
- carers who are currently claiming the carer's element of Universal Credit need advice and practical support to understand whether claiming Scottish Carer's Assistance will enable them to be better off

In addition, it is likely that expectations will be raised, as people may expect that with the launch of the new benefit there will be significant changes to the rate of payment and eligibility criteria, reflecting the proposals set out in this consultation.

It will therefore be important to be transparent about the timescales and pace of change and what the process for new applications will be.

The National Carer Organisations and local carers centres should be recognised as key partners in this process, as they are able to disseminate information to carers through their networks using a variety of communication methods

Again, we reference the need to ensure that all communications and publicity surrounding the proposed changes should take full account of the need to ensure inclusive communications and messaging. We strongly advocate that an inclusive communications strategy be developed at the earliest possible opportunity and organisations who support individuals with additional communication needs be involved at the outset. Furthermore, inclusive publicity campaigns should be undertaken on an annual basis as reinforcement of messaging is vital to reaching hidden carers.

## **Section 2: Extra Money for Carers in Scotland**

### **Carers Allowance Supplement**

**Question 16: Do you agree or disagree that Carer's Allowance Supplement should be paid alongside carers' regular payments of Scottish Carer's Assistance in future?**

Disagree. Whilst we can see that there are administrative benefits and savings in combining Carer's Allowance Supplement alongside Scottish Carer's Assistance, 80% of carers responding to our survey and polls said that they wished it to be continued as a lump sum every 6 months. The national carer organisations recommend that both options are available to carers, to enable individuals to choose which best suits their circumstances.

**Question 17: Please write the reason why you agree or disagree that Carer's Allowance Supplement should be paid alongside carers' regular payments of Scottish Carer's Assistance in future, or any other information you want to share on this question.**

Carers were clear of the benefit of the lump sum and concern that a regular payment would simply be subsumed into household bills:

- *"I enjoy getting that wee lump sum and I can treat myself to something... gives you a wee boost and something to look forward to."*
- *"Helpful around the holidays when extra spending is 'expected'"*

**Question 18: Please give us any other views you want to share on the proposals for Carer's Allowance Supplement.**

No

### Carers Additional Person Payment

**Question 19/20: Do you agree or disagree with the proposed eligibility criteria for Carer's Additional Person Payment?**

Carers responding to our survey were strongly in favour of paying an additional payment to people who are caring for more than one person, with 79% in favour.

They were, however, less sure of the proposed eligibility criteria. Just over half of respondents to our survey and polls (53%) were in favour but a significant proportion – a third (33%) were unsure.

**Question 20: Please write the reason why you agree or disagree with the proposed eligibility criteria for Carer's Additional Person Payment, or any other information you want to share on this question.**

Carers noted that they felt it was unfair that those with an underlying entitlement would not receive the payment, no matter how many people they were caring for.

- *"Carers over pension age can also be caring for more than one person, but would be not receive CAPP as proposed. Recognising the role of the carer, regardless of their age/SCA eligibility, would address this."*
- *"SCA or if they are still on CA, or if they have underlying entitlement. Lots of people don't claim Carers Allowance as it is deducted from other benefits anyway."*

The national carer organisations reflect the views of carers that those who are caring for more than one person should receive an additional payment for each person they care for. However, the national carer organisations believe that the Scottish Government should explore mechanisms to make this payment to those with an underlying entitlement or who are claiming the carer element of Universal Credit.

**Question 21: Do you agree or disagree with the proposed payment frequency for Carer's Additional Person Payment?**

Agree

**Question 22: Please write the reason why you agree or disagree with the proposed payment frequency for Carer's Additional Person Payment, or any other information you want to share on this question.**

N/A

**Question 23: Do you agree or disagree with the proposal to target Carer's Additional Person Payment to carers who are getting payments of Scottish Carer's Assistance?**

Agree and disagree

**Question 24: Please write the reason why you agree or disagree with the proposal to target Carer's Additional Person Payment to carers who are getting payments of Scottish Carer's Assistance, or any other information you want to share on this question.**

As noted above, whilst we welcome the proposals to introduce an additional payment for people caring for more than one person, we believe that the Scottish Government should explore mechanisms to make this payment to those with an underlying entitlement or who are claiming the carer element of Universal Credit.

**Question 25: Please give us any other views you want to share about the proposed Carer's Additional Person Payment.**

62% of respondents were in favour of the level suggested at £10 per week per additional person cared for. However, whilst welcoming the proposal for an additional payment, many carers in our survey felt the level was much too low.

- *“£10 a week for constant care is an insult to the people who care round the clock if this was unemployment that would be per hour not week!! Already we are being disregarded there should be no cap it should be equal for all it's a disgrace I don't get any help for caring for more than one child as my workload is x3 all day everyday.”*
- *“£10 is a bit of an insult.... Should be full care allowance for each person you care for.”*
- *“I have two daughters I care for. I get carers allowance for one. The service provider gets paid more in a shift for one daughter than I get paid a full week. It's wrong. They should be living their life independently but rely on me and others for everything.”*
- *“I care for 2 full time. It is a 24/7 job for both which only impacts more and more on my own health. The thought is appreciated but I agree with the other comments. It's not enough but it's a gesture anyway. What should really be addressed is carers payments being treated as an overlapping benefit, that really needs to be stopped.”*

We therefore recommend further consideration of the payment level suggested. There are two potential options to consider in the interim:

1. To align it with the rate paid for the Scottish Child Payment, uprating at the same time and introducing measures to assess its impact on carer poverty.
2. To provide carers caring for more than one person with an extra payment of Scottish Carer's Assistance itself.

### Section 3: Changes to Scottish Carer's Assistance

**Question 26: Do you agree or disagree with the proposed future change to allow carers in full-time education to get Scottish Carer's Assistance?**

Agree

**Question 27: Please write the reason why you agree or disagree with the proposed future change to allow carers in full-time education to get Scottish Carer's Assistance, or any other information you want to share on this question.**

Agree: The National Carer Organisations support the proposal to allow unpaid carers in full-time education to be eligible for Scottish Carer's Assistance and believe this should be introduced for the launch of Scottish Carer's Assistance.

We have called for the removal of the full-time study restriction for many years, and this was reflected in our 2021 Scottish Parliament election manifesto *A Manifesto for Unpaid Carers and Young Carers*<sup>3</sup>. The current rule limits unpaid carers' ability to live their own life alongside caring and is a barrier for them progressing their own education or future employment aspirations:

- *"Carers are from different age brackets. Whether you are a young carer still in full time education or a person needing to upgrade their employment chances, it is imperative that taking on full time education should not be a barrier to financial support. It is not a question of either/or. The carer needs to safeguard their future too."* (Unpaid carer)

Research highlights<sup>4</sup> that young adult carers are four times more likely to drop out of college and university than their peers who are not unpaid carers. Unpaid carers have told us that removing the full-time study restriction for accessing Scottish Carer's Assistance could help many student carers maintain and be successful in their education, as financial difficulties are listed often as one of the primary reasons why student carers drop out of further and higher education:

- *"A lot of students are worse off and often do not study or drop out due to finances. Not being able to work as caring role is too intense as well as studying."* (Unpaid carer)

Carers Trust Scotland research<sup>5</sup> found that 75% of student carers find finances and budgeting a challenge. Unlike many other students, unpaid carers are often unable to supplement income with paid employment due to their caring responsibilities:

- *"I currently care for 2 disabled family members for around 60 hours a week and study full time. However, I am not entitled to Carer's Allowance due to this despite the fact that most of my learning is completed at home and I fit it in around my caring responsibilities. I only attend campus twice a week; 2 hours one day and 4 hours the next therefore I don't understand why students aren't eligible to claim Carer's Allowance, especially when the only*

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<sup>3</sup> National Carer Organisations (2021) A Manifesto for Unpaid Carers and Young Carers:

<https://carers.org/downloads/scotland-pdfs/nco-carers-manifesto-for-scottish-parliament-election-2021.pdf>

<sup>4</sup> Sempik, J and Becker, S, (2014): Young Adult Carers at College and University: <https://carers.org/downloads/resources-pdfs/young-adult-carers-at-college-and-university.pdf>

<sup>5</sup> Carers Trust Scotland (2020): The Student Carer Experience in Scotland: <https://carers.org/downloads/scotland-pdfs/the-student-carer-experience-in-scotland.pdf>

*income I receive is my student loan and a bursary. It makes caring for these family members more difficult and it's stressful trying to juggle the financial responsibilities.” (Student carer)*

In preparation for this response, the National Carer Organisations undertook social media polling, 99% of the 203 respondents supported that *“All carers regardless of how many hours they study, should be eligible for Scottish Carer’s Assistance.”* The National Carers Organisation also undertook a survey over April 2022 to help inform our response. 89% of 179 respondents agreed with the proposal to remove the full-time study rule:

- *“I’m a full time university student and I feel discriminated against because I want to get an education and still have to care for my parents.” (Student carer)*

Finally, the National Carer Organisations would like to highlight that caring whilst studying restricts the income of student carers. They are often not able to combine studying with part-time working like their non-carer peers, making access to Scottish Carer’s Assistance even more important.

**Question 28: Do you agree or disagree with the proposed future change to allow carers to add together hours spent caring for two people to reach the 35 hour caring requirement?**  
Agree.

**Question 29: Please write the reason why you agree or disagree with the proposed future change to allow carers to add together hours spent caring for two people to reach the 35 hour caring requirement, or any other information you want to share on this question.**

Agree: The National Carer Organisations agree with the proposal to allow unpaid carers to add together hours spent caring for two people to reach the required 35 hour caring requirement:

- *“I care for both mother in law and husband although combined hours for me would be well over 35 hours.” (Unpaid carer)*

We believe this change should be introduced as soon as is practical. However, we believe this should not be restricted to two people and should be extended to all people being cared for, similar to Young Carer Grant. Although the majority of unpaid carers may be caring for one or two people, there will be some that do provide unpaid care for more than two people and these unpaid carers should not be disadvantaged. The wellbeing and financial impact of caring for multiple people can mean that these unpaid carers are most in need of support:

- *“This is a practical solution. If somebody is looking after more than one person, the chances are that different care needs are involved. The amount of time and energy increases especially if employment and caring for a family are added into the equation. In these circumstances, the carer is doing the job of ten and needs financial acknowledgement of this to make their lives more meaningful.” (Unpaid carer)*
- *“I do agree...Care is one of the key areas of women’s inequality in Scotland, with women representing the majority of service users, the vast majority of the social care workforce, and the majority of unpaid carers. Care continues to be undervalued and underpaid, precisely because of its long association with ‘women’s work’ and outdated gender norms.” (Unpaid carer)*

- *“Caring for more than one person should be equally recognised - 2 elderly parents in different houses may both need daily visits of 2-3 hours, with neither needing more than 35 hours of care a week, but the total amount of time spent providing care can easily be over that.”* (Unpaid carer)

From our social media polling, 97% of 113 respondents agreed that *“Carers who provide less than 35 hours of care to one person, should be allowed to add hours together if they are caring for two people.”* From our survey, 89% of 179 participants agreed that unpaid carers should be able to add hours of care provided together to be eligible for Scottish Carer’s Assistance.

**Question 30: Do you agree or disagree with the proposed future change to continue to pay Scottish Carer’s Assistance for 12 weeks (rather than 8 weeks) after the death of a cared for person?**

Agree.

**Question 31: Please write the reason why you agree or disagree with the proposed future change to continue to pay Scottish Carer’s Assistance for 12 weeks (rather than 8 weeks) after the death of a cared for person, or any other information you want to share on this question.**

Agree: The National Carer Organisations support the proposal to extend and continue to pay Scottish Carer’s Assistance for twelve weeks after the death of a cared for person. This is an improvement to current Carer’s Allowance practice where payments end eight weeks after the death of a cared for person. We believe this change should be introduced for the launch of Scottish Carer’s Assistance:

- *“My mother died on Tuesday, and I have been a full time 24 hours a day 7 days a week for the past three years. The small amount I got put petrol in my car and just that made a difference so to not get it is going to be hard. I think it should continue 12 weeks to give some help to the carer.”* (Unpaid carer)

However, in *A Manifesto for Unpaid Carers and Young Carers* we have advocated that Scottish Carer’s Assistance should continue to be paid to at least six months after the death of a cared for person. The death of a cared for person is an extremely difficult time for an unpaid carer. The person’s life will have changed significantly, and they require time to grieve and adjust. It is vital that unpaid carers can rely on financial stability of Scottish Carer’s Assistance during this time. It will likely be that wider household income will be impacted by the death of a cared for person also, which may cause further financial worries:

- *“Because Carer’s Allowance doesn’t let many carers work or study while being a carer, they are often stuck in a poverty trap where they have very limited ability to earn. Then when the cared for person dies, goes into a home, etc - the carer may well be unemployable. The household income will have disappeared and there are also all the emotional consequences to consider! In many cases it’s very likely there has been a huge emotional impact from the bereavement of the stress of change of circumstances.”* (Unpaid carer)

- *“There is a huge emotional and psychological and professional tole to caring. And a recently bereaved carer needs time to grieve and deal with paperwork. Time to connect their thoughts and plan next life steps. Time to retrain and look for work. All of this takes so much time and who looks after them!?”* (Unpaid carer)

From our social media polling 100% of 160 respondents agreed that Scottish Carer’s Assistance should be paid for a minimum of 12 weeks after the death of a cared for person. 66% agreed that *“Scottish Carer’s Assistance should be paid for 12 weeks after the cared for person has died.”* However, 34% believe that *“Scottish Carer’s Assistance should be paid for longer than 12 weeks after the cared for person has died”*:

- *“I feel it should continue for a minimum of 12 months. People can’t just be expected to snap their fingers and make adjustments after the person they care for, devote their lives to, passes away.”* (Unpaid carer)

From our survey, 92% of 164 participants agreed with the proposal to increase the time period that an unpaid carer will receive Scottish Carer’s Assistance from eight to twelve weeks after the death of a cared for person.

**Question 32: Do you agree or disagree with the proposed future change to continue to pay Scottish Carer’s Assistance for 12 weeks when a cared for person goes into hospital or residential care?**

Agree.

**Question 33: Please write the reason why you agree or disagree with the proposed future change to continue to pay Scottish Carer’s Assistance for 12 weeks when a cared for person goes into hospital or residential care, or any other information you want to share on this question.**

Agree: The National Carer Organisations support this proposal and believe it should be introduced as soon as is practical. It is a very difficult time for unpaid carers when a cared for person goes into hospital or residential care. The current Carer’s Allowance arrangement where payments cease after four weeks when a cared for person goes into hospital is unfair and doesn’t recognise the stress caused for many unpaid carers that experience this.

In addition, to meet the needs of the person they care for, many carers often continue to provide care while the person they care for is in hospital. This includes, for example, personal care, emotional support for a person with dementia or a learning disability, help with eating and taking in sufficient fluids. Some individuals may have significant and complex needs necessitating their carer to stay with them throughout their hospital stay. Carers can also be faced with high transport costs to visit hospital and in some cases overnight accommodation is required, such as carers visiting from rural or island communities.

- *“The caring doesn’t stop, all that is added is constant travelling, which costs money, and generally having to buy different things to take to the patient. A hospital stay isn’t as free as you think.”* (Unpaid carer)

Extending the time period to twelve weeks provides more time for unpaid carers to evaluate whether their cared for person will be required to stay in hospital longer term or if a more permanent move to residential care is necessary. This will give unpaid carers more time to plan and make more informed decisions about their own lives:

- *“Whilst caring for my adult son with autism, we received 50% discount on our council tax, had use of his mobility car, and he paid us "rent" from his benefits. When he moved into accommodation, not only did I lose Carer's Allowance, our council tax doubled, we lost his "rent", and we had to find money to buy a car.” (Unpaid carer)*

180 people responded to our social media poll and 70% agreed that *“If the cared for person goes into hospital, Carer's Assistance Payments should still continue for the duration that they are in hospital or residential care, as the carer is still providing care during that period”*. We agree with those polled and encourage Scottish Government to consider continuing payments for the duration that a cared for person is in hospital or residential care:

- *“It should be paid for as long as the person remains in hospital and not a finite period.” (Unpaid carer)*
- *“I agree it takes both of us to care for my son when he is in hospital as he has autism. Especially if we are in a 4 bed ward. Not too bad if we have a room but that doesn't happen very often at all. Actually more care is needed in hospital from parents for their child than if they are at home. Therefore the payments should continue.” (Unpaid parent carer)*
- *“Any psychotic illness would unlikely be fully treated in 4 weeks, the huge burden of worrying about bills not getting paid whilst trying to support the cared for person during their most difficult periods could easily put the carer past breaking point.” (Unpaid carer)*

The response from our survey found that 93% of 179 participants agreed with the proposal to extend the period of payments when a cared for person goes into hospital or residential care from four to twelve weeks:

- *“It is hard enough worrying about loved ones who need hospitalisation or care home admission without having to stop/start the carers allowance. Care never stops - even when a loved one is absent from their domestic environment. The twelve week extension seems more practicable and realistic.” (Unpaid carer)*

**Question 34: Do you agree or disagree with the proposed future change to increase the earnings limit for Scottish Carer's Assistance?**

Agree.

**Question 35: Please write the reason why you agree or disagree with the proposed future change to increase the earnings limit for Scottish Carer's Assistance, or any other information you want to share on this question.**

Agree: The National Carer Organisations welcome this proposal, which we called for in our *A Manifesto for Unpaid Carers and Young Carers*. Increasing the earnings limit for Scottish Carer's



Assistance means more working carers will be eligible for support, will feel more valued and it provides more financial stability.

99% of 225 people polled on social media agreed that the earnings threshold should be increased. However, 70% think that the earnings limits should be higher than 16 hours at the real living wage:

- *“The earnings should definitely be more than 16 hours, I work in a school, with school hours that suits because my son at school, but I still care for him full time out with school hours!” (Unpaid carer)*
- *“My son has full care needs 24/7. My husband works full time and I work school hours so we have never claimed carers allowance. The care hours we care for my son are the same as parents who do not work school hours- but we have never been helped with carers allowance. We do over the amount of care hours to many other people even with working, as my son needs care throughout the night too. No wages should be taken into account - it should be the hours cared for.” (Unpaid carer)*
- *“100% agree that no wages should be taken into account. I’ve had to reduce my working hours to 2 days to care for my daughter plus I run my own business to try and bring in extra cash in a way that is flexible and can work around her. I think it’s appalling that I can’t claim carers allowance when I’m trying my best to stay in work despite many, many practical challenges.” (Unpaid carer)*
- *“Carers allowance should be available to all carers, regardless of income or working hours. Full time carers can’t work many hours anyway and so they will never earn a huge amount. For most of us, we do it partly as a break from our caring role, which is essential for our mental health and wellbeing therefore saves the NHS money! The only criteria for carers allowance should be that you are a full time carer.” (Unpaid carer)*

From our survey 95% of 180 respondents supported the proposal to increase the earnings threshold to 16 hours at the Real Living Wage:

- *“Any increase is welcome, but every effort should be made to allow carers to work without detriment to their benefits.” (Unpaid carer)*

**Question 36: Do you agree or disagree that the earnings threshold should be set at a level which would allow carers to work 16 hours a week alongside their caring role?**

Agree.

**Question 37: Please write the reason why you agree or disagree that the earnings threshold should be set at a level which would allow carers to work 16 hours a week alongside their caring role, or any other information you want to share on this question.**

Agree: The National Carer Organisations support the proposed increase to the earnings threshold, which we called for also in our *A Manifesto for Unpaid Carers and Young Carers*. We believe this should be introduced as soon as practical.

However, the earnings 'cliff edge' does need to be addressed, this may impact those working carers most that have fluctuating incomes. Working carers may be working 16 hours per week but are paid above the Real Living Wage rate and may not realise how this will impact their entitlement to Scottish Carer's Assistance. Clear and concise information is required so unpaid carers can make informed decisions regarding working hours:

- *"When accepting the role, carers have had to weigh their obligation against the fiscal boundaries. Having to work out the arithmetic of the earnings threshold in relation to the allowance is an extra burden."* (Unpaid carer)

Please also see our response to question 35.

**Question 38: Do you agree or disagree with the proposal to look at a 'run on' after a carer earns over the earnings limit in future?**

Agree.

**Question 39: Please write the reason why you agree or disagree with the proposal to look at a 'run on' after a carer earns over the earnings limit in future, or any other information you want to share on this question.**

Agree: The National Carer Organisations support the proposal to introduce a 'run on' after a working carer earns over the earnings limits and we believe this is the best option proposed for addressing the earnings 'cliff edge'. We support for the 'run on' to be introduced as soon as is practical to do so.

We believe that the 'run-on' approach is the best outcome for working carers with fluctuating and less predictable incomes. 78% of 179 people that we surveyed agreed with the proposal to look at a 'run on' after a working carer earns over the earnings limit.

However, we would encourage for earnings to be considered over a longer period. For example, over a four-week period would be more realistic to provide an accurate picture of average earnings rather than weekly earnings. There are also considerations required for those who are self-employed and may have unpredictable earnings:

- *"I think consideration also needs to be given to the self employed who often can get different amounts each month and so an average must be taken across the year rather than the week."* (Unpaid carer)

## **Section 4: Other proposals for further investigation**

### **Introduce a new payment for long term carers**

**Question 40: Do you agree or disagree that a payment for long term carers should be considered further?**

Agree but disagree that such a "recognition payment" should be limited to long term carers.

**Question 41: Please write the reason why you agree or disagree that a payment for long term carers should be considered further, or any other information you want to share on this question.**

Whilst we agree that this should be considered, we disagree that it should be limited only to long term carers. The majority of carers we surveyed and polled agreed that there should be a payment available to all carers with an underlying entitlement, including those who have reached State Pension age.

- *“In 1.5 years I will still be caring for my son but will lose carers allowance as I will have my old age pension. I won't get pension credit as I have savings. What about older carers?”*

**Question 42: If a payment for long term carers was considered, what should the payment look like and who should it be for?**

The payment should seek to recognise all carers with an underlying entitlement, particularly those who are no longer entitled to Scottish Carer's Assistance/Carer's Allowance when they reach State Pension Age.

**Question 43: Please give us any other views you want to share about the proposals for future changes to Scottish Carer's Assistance.**

In broad terms, carers and the national carer organisations are supportive of the proposals within the consultation. Scottish Carer's Assistance will represent a step change in improvement of benefits for carers which we have sought for many years – indeed decades. However, more action is needed to truly show the value of caring to our society.

Carers face more challenges now than ever with the toll of the pandemic and rising cost of living impacting on all aspects of their lives. Whilst we recognise that the Minimum Income Guarantee may offer a long term strategy to prevent carers falling into poverty – simply because they care – this is a piece of work unlikely to lead to quick changes and it is too early to say what it could deliver under current devolved powers.

The Scottish Government should look for every opportunity within the social security system to reduce carer poverty. There is a need for an action focused, funded Carer Poverty Action Plan with clear measurable actions. This includes ensuring that the new Scottish Carer's Assistance and the Carer's Additional Person Payment are set at a level that reduces poverty – recognising both the value of caring and the impact of caring on an individual's income and economic and social opportunities. The Scottish Government should also take the opportunity to legislate to include Scottish Carer's Assistance as a qualifying benefit for free dental and optical care, help with travel to hospital, access to leisure, help with housing costs and free travel.

**Question 45: Please set out any information you wish to share on the impact of Scottish Carer's Assistance on Island communities.**

As part of our engagement activities in relation to this consultation we held a meeting with carers support workers from rural and island communities. They emphasised the particular challenges faced by carers from these communities which should be noted, with steps taken to mitigate them where possible. These additional challenges include:

- Communications can be more challenging, both online and in person. While there are some benefits arising from advances in digital communication over the last few years, there is a high level of digital exclusion in rural and island communities, particularly amongst older people. In addition, broadband is not reliable in some areas. There are also challenges with more direct communication, such as face-to-face due to the lower population density and

distance from population centres, making it much harder for people to meet in person and to access information and support to make a claim

- Caring roles are often more intensive in rural and island communities as there is less social care provision available to enable carers to have a break from caring. In addition, due to an ageing population many carers are older. They are therefore faced with a double-whammy of requiring more support, but being unable to access it and not qualifying for financial support through Carers Allowance
- There are additional costs associated with rurality, including increased costs for fuel, food and transport. Therefore carers from rural and island communities are economically disadvantaged compared to those in more urban areas and many of the proposals set out by the government will have a lesser impact. For example, the cost of accessing employment is higher, so the increased earnings limit will not compensate for the rising cost of living. In addition the additional £10 for caring for more than one person, would be unlikely to even cover the costs of fuel needed to travel to the cared-for person, where they do not live in the same household

The group felt that given these challenges that a rural supplement should be considered to help to address the additional costs of fuel, food and transport.

### **Contacts**

For further information on this response, please do not hesitate to contact one of the following from the national carer organisations.

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