

Social Security Experience Panels: Scottish Carer's Assistance



EQUALITY, POVERTY AND SOCIAL SECURITY

Exploring this research

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Findings at a glance

- The research involved a survey with 242 Social Security Experience Panel members and follow-up interviews with 16 participants.

Scottish Carer's Assistance when it is first introduced

- Interview participants said that the information on entitlements and various sources of support needs to be streamlined across agencies, organisations and services.
- Over two thirds of survey respondents (71 per cent) agreed with setting Scottish Carer's Assistance to £0 for any week a carer earns too much money.
- Two thirds of survey respondents (66 per cent) agreed with setting Scottish Carer's Assistance to £0 if a cared for person's disability benefit is stopped or suspended.
- Over half of survey respondents (54 per cent) agreed with ending a Scottish Carer's Assistance award when it has been £0 for six months in a row.
- Most interview participants agreed with the proposal to pay Scottish Carer's Assistance to carers when the person they are caring for is receiving short-term assistance.

Extra payments for carers in Scotland

- Almost half of survey respondents (48 per cent) said Carer's Allowance Supplement should be paid at the same time with Scottish Carer's Assistance payments in the future and over a third (35 per cent) said Carer's Allowance Supplement should be paid as a lump sum.
- Three quarters of survey respondents agreed with the proposed eligibility criteria for Carer's Additional Person Payment.

Further changes to Scottish Carer's Assistance in the future

- There was a positive consensus between interview participants on the proposal to remove education restrictions to allow carers in full-time education to be eligible for Scottish Carer's Assistance.
- Just over four fifths of respondents (81 per cent) agreed with the change to allow carers to add hours spent caring for two people to reach the 35 hours per week requirement to get Scottish Carer's Assistance.
- The vast majority of survey respondents (90 per cent) agreed with the proposal to pay Scottish Carer's Assistance for 12 weeks after the death of a cared for person.
- The vast majority of respondents (91 per cent) agreed with the proposal to pay Scottish Carer's Assistance for 12 weeks when a cared for person goes into hospital or residential care.
- 90 per cent agreed with the proposal to increase the earnings limit for Scottish Carer's Assistance to a level linked to the formula of 16 hours times the hourly rate for the Real Living Wage.
- The majority of respondents (82 per cent) agreed with the idea of making payments for some weeks after a carer earns over the earnings limit.
- 89 per cent of survey respondents said that a payment for long-term carers should be considered further.

Executive summary

This report presents results from research with Social Security Experience Panel members to explore their views on proposals on how Scottish Carer's Assistance (SCA) could be different from Carer's Allowance. The research was designed to provide data for a range of proposals on: how Scottish Carer's Assistance should work when it is first introduced, extra payments for carers in Scotland, and further changes to be made to Scottish Carer's Assistance in the future.

The research took place from March to July 2022. It involved a survey completed by 242 Panel members and follow-up interviews with 16 participants¹. The sections below provide the main findings and themes which emerged from the research.

Scottish Carer's Assistance when it is first introduced

A service that works well for carers

Survey respondents were asked what support Scottish Carer's Assistance could link to that would be helpful for carers. Almost all survey respondents (93 per cent) said other Social Security benefits that carers may be entitled to and over four-fifths (85 per cent) said linking Scottish Carer's Assistance with Health and Social Care services would be helpful for carers.

Just over three quarters (76 per cent) said that it would be helpful to link Scottish Carer's Assistance with support at the end of a caring role when a cared for person has died. Similar proportions of respondents mentioned that it would be helpful to link carer centres (65 per cent), and finance/money advice services (63 per cent) to Scottish Carer's Assistance.

Survey respondents and interview participants stated it would be helpful to access support organisations, carer groups and networks. They also mentioned the importance of providing clear and detailed information taking into account accessibility and the needs of users. This information should include links to various sources of support for carers, benefit entitlements and changes to benefits. Interview participants said that the information needs to be streamlined across agencies, organisations and services.

Options when a carer is not happy with a decision: timescales for re-determinations

Most interview participants agreed with the timescales proposed for re-determinations. A few participants emphasised the need to provide clear, simple and short information about the timescales of re-determinations and appeals.

¹ The daughter of one Panel member joined the interview as she is a young carer.

A few interview participants said it would be better if Social Security Scotland provides decisions in a shorter timescale as the client may be in financial need. A small number of interview participants emphasised that carers need support for application processes and that help may not be obtained within the timescales proposed.

Changing Scottish Carer's Assistance payments to £0 instead of suspending or ending the award

Over two thirds of survey respondents (71 per cent) agreed with setting Scottish Carer's Assistance to £0 for any week a carer earns too much money. Two thirds of survey respondents (66 per cent) agreed with setting Scottish Carer's Assistance to £0 if a cared for person's disability benefit is stopped or suspended.

Several respondents and participants said these proposals would avoid carers having to go through a re-application process. Many also noted that this would make it easier to restart payments when needed.

Some respondents and participants stated that setting Scottish Carer's Assistance to £0 for any week a carer earns too much money would encourage a more flexible system and it would allow carers to take on occasional/periodical paid jobs.

Some survey respondents and interview participants mentioned that caring work, financial household expenses and/or the need of financial support do not stop when earnings fluctuate or when the disability benefit is stopped or suspended.

Some survey respondents and interview participants said that carers should be provided Scottish Carer's Assistance payments and those should not be linked to any earnings threshold limit. Some thought that it is unfair to end a payment because a carer experiences fluctuation in their earnings. A few also mentioned that the earnings threshold is very low.

Some noted that disability benefits are frequently suspended due to administrative error and in other cases they are sometimes reinstated after appeals. Others argued that the caring role does not stop when the cared for person is in hospital. Some described providing help with care in hospitals.

A small number of respondents and participants thought these proposals should include the provision of simple and clear guidance for certain scenarios.

Ending a Scottish Carer's Assistance award when it has been £0 for six months in a row

Over half of survey respondents (54 per cent) agreed with ending a Scottish Carer's Assistance award when it has been £0 for six months in a row and a fifth (20 per cent) disagreed.

Some survey respondents mentioned it is a reasonable time for a carer to sort out circumstances concerning paid employment or benefits eligibility. Some also stated that the 6-month period provides a realistic time frame to acknowledge that a change in caring circumstances is permanent. A few survey respondents noted that the proposal should allow for exceptional and personal circumstances to be taken into account in case the payments need to be reinstated.

Some survey respondents said that it is not a long enough period to cover certain situations such as longer hospital stays and lengthy appeal processes. A few also mentioned that this proposal does not consider carers who regularly earn above the earning threshold for more than six months.

Views on Short-Term Assistance

Most interview participants agreed with the proposal to pay Scottish Carer's Assistance to carers when the person they are caring for is receiving short-term assistance. They had positive views on the financial support during appeal processes. They also felt it would be reassuring for clients that they can go ahead with appeals with less financial worries.

A few interview participants argued for simplifications and clarity of the administrative processes and the rules involved in this proposal.

Extra payments for carers in Scotland

Payment of Carer's Allowance Supplement in the future

Almost half (48 per cent) said Carer's Allowance Supplement should be paid at the same time as the Scottish Carer's Assistance payments in the future and over a third (35 per cent) said Carer's Allowance Supplement should be paid as a lump sum.

Many survey respondents and interview participants commented that paying Carer's Allowance Supplement (CAS) and SCA payments at the same time would provide carers a better financial support by adding to the household budget, and it would avoid some carers missing out on payments due to the specific qualifying period/dates of the current CAS eligibility rules.

Some survey respondents and interview participants commented that paying Carer's Allowance Supplement as a lump sum would allow carers to use that money for themselves, in the form of respite, breaks or holidays. It would also allow large purchases, help for seasonal budgets like Christmas or summer holidays, and it would avoid CAS payments being used for daily living costs.

Some mentioned that both methods of payment for CAS should be available for carers so they could choose their preferred one based on their individual circumstances.

Carer's Additional Person Payment

Three quarters of survey respondents agreed with the proposed eligibility criteria for Carer's Additional Person Payment.

Many survey respondents and interview participants noted that this payment is a recognition and appreciation for carers who care for more than one person. Several mentioned that this payment takes into account the extra amount of care provided and the extra cost of caring for more than one person. A few mentioned that it was a fair payment because carers who cared for more than one person cannot take on paid employment or studying due to their caring role.

Some respondents and participants mentioned potential issues concerning the amount of hours of providing care that are required to become eligible for this new payment. The most common issues noted were: hours providing care can fluctuate between cared for people, caring is a full-time day job, consideration of travelling hours to assist cared for people, carers are unable to separate hours of care between cared for people, and the total amount of caring hours proposed is too high a threshold for eligibility.

Some survey respondents mentioned that the amount of the Carer's Additional Person Payment is too low.

A few respondents and participants highlighted caring situations in which the carer would care for two or more people, but they are still unable to qualify for Carer's Additional Person Payment. Those situations included: caring for elderly adults who are not in receipt of disability benefits, a carer who earns above the earning threshold, and a carer who receives a state pension.

The majority of interview participants agreed that Carer's Additional Person Payment should be paid at the same time as a carer's Scottish Carer's Assistance Payments. They noted that it would help with their household regular budget and monthly income. It would also simplify the process of payments.

Further changes to Scottish Carer's Assistance in the future

Remove education limits from Scottish Carer's Assistance

There was a positive consensus between interview participants on the proposal to remove education restrictions to allow carers in full-time education to be eligible for Scottish Carer's Assistance. Many noted that this proposal improves the life chances, education development and employability of young carers. A few also stated that having the option of studying full-time allows carers respite from their caring role and it also improves their mental health.

Combine hours spent caring for two people

Just over four fifths (81 per cent) of respondents agreed with the change to allow carers to add hours spent caring for two people to reach the 35 hours per week requirement to get Scottish Carer's Assistance. The majority of interview participants also agreed with this proposal.

Some survey respondents and interview participants suggested that this proposal should consider individual circumstances and flexibility as hours providing care can fluctuate and overlap between cared for people.

A few survey respondents suggested that carers who cared for more than two people should also be able to benefit from this proposal.

Some respondents mentioned the importance of providing clear eligibility information and signposting alongside the implementation of simple application processes.

Pay Scottish Carer's Assistance for 12 weeks in specific circumstances

The vast majority of survey respondents (90 per cent) agreed with the proposal to pay Scottish Carer's Assistance for 12 weeks after the death of a cared for person. The majority of interview participants also agreed with the proposal.

A few survey respondents stated the relevance of time needed to adjust for the carer when the cared for person dies. Other respondents mentioned that the carer needs time to carry out administrative tasks around the cared for person's death. Many interview participants also highlighted similar views such as the time that a carer requires to focus on practical arrangements around the death of a loved one and the time a carer needs to look at their future options.

The vast majority of respondents (91 per cent) agreed with the proposal to pay Scottish Carer's Assistance for 12 weeks when a cared for person goes into hospital or residential care. Most interview participants also agreed with this proposal.

Many survey respondents and interview participants said that caring does not stop when the cared for person goes into hospital. A few interview participants noted that the proposal to pay Scottish Carer's Assistance for 12 weeks when a cared for person goes into hospital or residential care can provide the carer with financial stability as they still have to pay household bills.

A small number of respondents suggested that Social Security Scotland should provide clear and simple information and processes to navigate the system as part of implementing these plans.

Increase the amount carers can earn and still get Scottish Carer's Assistance

90 per cent agreed with the proposal to increase the earning limit for Scottish Carer's Assistance to allow carers to work 16 hours and be paid the Real Living Wage. The majority of interview participants also agreed with this proposal.

Several survey respondents and interview participants highlighted the positive aspects of this proposal. Many mentioned that by allowing carers to increase their earnings, they will be able to participate in paid employment and improve their mental health and wellbeing by doing so.

Some survey respondents and interview participants mentioned that this proposal reduces the fear of losing the Carer's Allowance entitlement, it considers jobs with variable hours and earnings, and it helps with the rising costs of living.

Some respondents and participants provided diverse views concerning the proposed hours limit and the earnings threshold. A few mentioned that the proposal should not include a fixed number of weekly working hours. Some noted that the proposed earnings threshold is still too low.

A few survey respondents and interview participants mentioned that all carers should be paid SCA payments regardless of their personal circumstances and there should not be an earnings threshold at all.

A few survey respondents mentioned the provision of clear information and simple processes to monitor/provide proof of earnings.

Getting SCA payments for some weeks after earning over the limit

The majority of respondents (82 per cent) agreed with the idea of making payments for some weeks after a carer earns over the earnings limit. The majority of interview participants also agreed with this proposal.

Many respondents and participants noted that it allows a period of transition and financial adjustment for the carer, it considers jobs which do not pay the same amount on weekly or monthly basis, and it lets a carer take on extra paid work; including seasonal and weekend jobs.

Some respondents and interview participants mentioned that for this proposal to work well, Social Security Scotland needs to set up simple application processes. They also mentioned that information about the proposal and its rules needs to be communicated clearly.

Support for a wider group of unpaid carers: long-term carers

89 per cent of survey respondents said that a payment for long-term carers should be considered further. The majority of interview participants also welcomed this proposal.

Several respondents and participants gave views on who should be considered a long-term carer. Many stated that a long-term carer could be identified by linking it to the prognosis of the cared for person. If the cared for person has health conditions which are: unlikely to improve, progressive, chronic and/or they endure life-long debilitating diseases; their carer can be identified as a long-term carer.

Some survey respondents and interview participants said long-term carers could be identified based on a long period of time in which the carer has provided caring work. Many said a long-term carer could be identified as those who will never be able to take up paid employment or who had to give up full employment due to their intense caring work.

Several respondents and participants provided mixed views on the method of payment for long-term carers. Some suggested a lump sum (as a grant) and others suggested that the payment can be paid at the same time as SCA payments on weekly or monthly basis. A few proposed that the choice for the carer concerning the method of payment should be offered.

Further views on the Scottish Carer's Assistance proposals

General views on SCA proposals

Some survey respondents and interview participants gave positive feedback to the proposals. They mentioned that they made them feel valued, recognised and respected.

However, many survey respondents noted the experiences of carers with underlying entitlements and how unfair they felt it was that they are not eligible for the changes proposed. They said they do not have access to carer's benefits, supplements, concessions and discounts.

A few survey respondents stressed the importance of widely advertising Scottish Carer's Assistance proposals and their rules. A small number of respondents also noted that clear information and simplified processes regarding these benefit changes, their new rules and their eligibility criteria should be put in place.

Effects of SCA proposals on different groups

Many survey respondents and interview participants held negative views on how carers of state pension age would not be eligible for the changes proposed as part of the Scottish Carer's Assistance.

A few interview participants mentioned that the proposals and plans around Scottish Carer's Assistance would improve children's rights and wellbeing for young carers and also for carers who have children.

A few interview participants mentioned that carers from ethnic minorities and different religions can be impacted differently by the SCA proposals because of cultural differences, ideas about what constitutes being a carer and language barriers.

Some interview participants thought the SCA proposals would have an impact of reducing inequality. However, a few participants highlighted that the eligibility criteria are still restrictive to many carers, including those who earn above the earning threshold or work on a full-time basis.

A small number of interview participants and survey respondents stressed concerns about different circumstances which may impact on a carer's eligibility for SCA. These included disabled carers who live together and care for each other, carers who care for multiple people, and carers who also need care due to their long-term conditions or disabilities.

Impact on rural and island communities

Many interview participants noted the impact of the SCA proposals on carers who are located in rural and island communities. They mentioned the extra travel costs those carers have because the various key services they need are not near where they live.

A few interview participants noted the lack of carer's groups/networks and various services for carers and the cared for people in rural and remote areas. They also said that the caring work can be even more isolating in island communities than cities.

General views on caring work and payments for carers

Many survey respondents and interview participants perceived their caring work as replacing the caring work that public services should be carrying out. Many also stated that their unpaid caring work saves governments and public services a vast amount of money.

Many survey respondents and interview participants stressed that the current value of Carer's Allowance payments is too low and does not cover the costs of living. Many also requested to be paid minimum or real living wage that covers a basic standard of living. Some suggested they should be paid a similar value of payment to that which professional carers receive.

Background and methodology

Background

Unpaid carers provide vital support to the people they care for. The Scottish Government estimates unpaid care is currently saving Scotland £12.8 billion per year in social care costs, plus £320 million in health care costs – a total saving of £13.1 billion per year². Carer's Allowance (CA), which is paid by the Department for Work and Pensions (DWP), provides financial support to unpaid carers who meet certain criteria and provide 35 hours or more of care a week for people receiving certain disability benefits.

Carer's Allowance will be replaced with a new benefit for carers in Scotland. The current working title for this benefit Scottish Carer's Assistance (SCA) and it will be provided by Social Security Scotland (SSS). The current Carer's Allowance benefit is one of the most complex benefits of those that are being transferred from DWP to Social Security Scotland. This is because of its links with other benefits, including benefits which will still be provided by the Department for Work and Pensions.

Scottish Carer's Assistance will build on the progress already made to support carers in Scotland. The Scottish Government has already increased the value of Carer's Allowance through the Carer's Allowance Supplement and it has introduced a new benefit for carers aged 16-18, the Young Carer Grant.

The Scottish Government has been working with carers and the organisations who support them to develop proposals for this new benefit³. These proposals have also been informed by Panel members in previous [Experience Panels research](#).

The aim of this research was to understand the views of Experience Panel members on proposals and plans on how Scottish Carer's Assistance could be different from Carer's Allowance.

Methodology

The Scottish Government is becoming responsible for some of the benefits previously delivered by the Department for Work and Pensions. As part of the work to prepare for this change, the Scottish Government set up the

² [Scottish Government \(2022\) National Care Service \(Scotland\) Bill. Business and Regulatory Impact Assessment. \[Online\]](#)

³ [For more information on these proposals see: Scottish Government \(2022\) Scottish Carer's Assistance: consultation. \[Online\]](#)

Social Security Experience Panels. Panel members are people from across Scotland who have recent experience of at least one of the benefits coming to Scotland.

Over 2,400 people registered as Experience Panel members when it launched in 2017. The Scottish Government is working with Experience Panel members to design a new social security system that works for the people of Scotland, based on the principles of dignity, fairness and respect.

Panel members were invited to take part in a survey and an interview to give their views on proposals on:

- How Scottish Carer's Assistance should work when it is first introduced
- Extra payments for carers in Scotland
- Further changes to be made to Scottish Carer's Assistance in the future

Research took place in two stages between March and July 2022. The first stage involved a survey carried out between March and April and the second stage comprised of follow-up interviews which took place in June and July. Participation in research with Experience Panel members is optional.

The data have been analysed by Scottish Government researchers. It is important to note, that the results presented in this report only represent the views of Panel members who took part in the project. Assumptions cannot be drawn on the wider applicability of these findings to Panel members as a whole or for those with experience of the social security system in general.

Survey

Members of the Experience Panels who told us they had experience of Carer's Allowance, Carer's Allowance Supplement and Young Carer Grant were identified. Panel members who had told us in previous research that they were carers were also identified. Taken together, a total of 1,026 members were invited to take part in this survey. 242 panel members completed the survey, representing a response rate of 24 per cent.

Throughout the report, Panel members who completed the survey are referred to as survey respondents⁴.

Results shown in the report exclude any respondents who were either filtered out of the question or who left the response blank. Results presented in figures or tables

⁴ Survey respondents and respondents will be used interchangeably in this report.

are intended to show proportions between different answer options. The number of respondents answering a question is shown in the title of the table as (n). Quotations are taken from comments left by respondents in open-text questions. Minor edits to spelling and grammar were made as appropriate.

Who took part in the survey

Where possible, information from the survey was matched to demographic information supplied previously by panel members. Linking was not possible where there was missing or unclear information. The following demographic information is included to give context to the findings of this report. A full breakdown is provided in Annex A.

Two thirds of survey respondents (66 per cent) identified as female, woman or girl. The majority of survey respondents (86 per cent) said they were heterosexual or straight and 4 per cent said they were gay or lesbian. A small number of respondents (2 per cent) identified as transgender.

Almost a half (47 per cent) were aged 45 to 59 and almost two fifths (39 per cent) were aged 60 to 79. A small number of survey respondents (2 per cent) were from a minority ethnic group. Over three quarters (77 per cent) lived in an urban area.

Over half of respondents (55 per cent) said they had no religion or belief, almost one fifth (19 per cent) said they belonged to the Church of Scotland and over one tenth (12 per cent) said that they were Roman Catholic.

Concerning household composition, over two fifths (43 per cent) live in a household with two adults and fewer than one third (30 per cent) live in a household with only one adult. A majority (77 per cent) live in a household with no children and 15 per cent live in a household with one child.

Almost four fifths (78 per cent) said they had a disability or long-term condition. Three fifths (60 per cent) said they had another long-term health condition, over half (53 per cent) said they had chronic pain lasting at least three months and half or survey respondents said they had a physical disability.

Around three quarters (76 per cent) cared for an adult or adults with long-term physical/ mental ill-health/ a disability. Around one quarter (26 per cent) cared for a child or children with long-term physical/ mental ill-health/ a disability and over a third (34 per cent) cared for an adult or adults who needs support due to old age.

Further demographic information can be found at Annex A.

Interviews

At the end of the survey, respondents were asked if they would be interested in taking part in a follow up interview. A purposive sampling approach based on the demographic characteristics presented above was used to select a diverse group of carers to invite to the interviews. In total, 15 qualitative semi-structured interviews with 16 participants⁵ were conducted between June and July.

The interviews aimed to gather views on proposals and plans covered in the survey in more detail. Interview participants were also asked about a few themes on Scottish Carer's Assistance which were not covered in the survey.

Quotations from the interviews are used to illustrate the findings discussed in the report. Edits to improve readability were made as appropriate. Participants who took part in an interview are referred to as interview participants throughout the report⁶.

About the report

The report covers a wide range of themes that are relevant to the future development of Scottish Carer's Assistance policy. It is divided into four thematic chapters, which are in line with the themes addressed in the Scottish Carer's Assistance Consultation. These are:

1. Scottish Carer's Assistance when it is first introduced. This chapter includes their views on support that would be helpful for carers to link to SCA, timescales for re-determinations, and their views on changing SCA payments to £0 instead of suspending or ending the award. It also includes Panel members' thoughts on ending a SCA award when it has been £0 for six months in a row, and on Short-Term Assistance.
2. Extra payments for carers in Scotland. This chapter includes Panel members' views on how Carer's Allowance Supplement should be paid in the future, and their thoughts on a new payment currently called Carer's Additional Person Payment.
3. Further changes to Scottish Carer's Assistance in the future. This chapter gathers views from Panel members on removing education limits from Scottish Carer's Assistance, combining hours spent caring for two people and their feedback on paying SCA for 12 weeks in specific circumstances. It also includes members' views on increasing the amount carers can earn and still get Scottish Carer's

⁵ One interview participant was joined by her daughter who is a young carer.

⁶ Interview participants and participants will be used interchangeably in this report.

Assistance, getting SCA payments from some weeks after earning over the limit and their thoughts on a payment for long-term carers.

4. Further views on the Scottish Carer's Assistance proposals. This chapter explores the general views of panel members on the SCA proposals and their effects on different groups, and on rural and island communities. It also gathers the general views of Panel members on caring work and payments for carers.

Each chapter summarises the key themes among the responses on that topic. Because of this, there is some overlap in the findings where respondents and participants have brought up similar issues or concerns in relation to more than one question. We have not sought to remove this duplication so that the reader can select the relevant chapter for their interests without having to read the whole report in depth.

The report also includes two thematic annexes. Annex B explores the experiences of Panel members with carer benefits and Annex C looks at the experiences of members on paid employment and caring.

1. Scottish Carer's Assistance when it is first introduced

1.1. A service that works well for carers

The Scottish Government is developing a wider programme of work to support carers and those they care for. It wants to make sure that carers receiving Scottish Carer's Assistance are informed about other benefits and services.

Survey respondents were asked what support could Scottish Carer's Assistance link to that would be helpful for carers: almost all respondents (93 per cent) said other Social Security benefits that carers may be entitled to (see Table 1). Over four-fifths (85 per cent) said linking Scottish Carer's Assistance with Health and Social Care services would be helpful for carers.

Just over three quarters (76 per cent) said that it would be helpful to link Scottish Carer's Assistance with support at the end of a caring role when a cared for person has died. Similar proportions of respondents mentioned that it would be helpful for carers to link carer centres (65 per cent), and finance/money advice services (63 per cent) to Scottish Carer's Assistance.

Fewer than half of respondents said linking Scottish Carer's Assistance to employability and employment support (47 per cent), and information on education and training opportunities (44 per cent) would be helpful for carers. 12 per cent of respondents mentioned linking Scottish Carer's Assistance with "other" support would be helpful for carers.

Table 1. What support could Scottish Carer's Assistance link to that would be helpful for carers? [please tick all that apply] (n=239)

	Number of respondents	% of respondents
Other Social Security benefits that carers may be entitled to	222	93
Health and Social Care services (for the carer and cared for person)	203	85
Support at the end of a caring role when a cared for person has died (for example bereavement and other wellbeing support)	182	76
Carer centres	155	65
Finance/money advice services	151	63
Employability and employment support	112	47
Information on education and training opportunities	106	44
Other	28	12

A few survey respondents who replied to the “other” option also endorsed the options already provided in the questions such as employability support, information on training opportunities, and bereavement and wellbeing support.

Help to access support organisations

“Other” support mentioned by survey respondents were: carers groups/networks, third sector organisations advocating for specific illnesses, support for dual carers and carers who are state pension age, and provision of a hotline service to the GP for carers and the people they care for.

“Support for dual carers and old age pensioners.” (survey respondent)

“A national identity card for carers. A hotline service to the GP for carers and the people they care for.” (survey respondent)

Interview participants echoed the wide range of support noted above by survey respondents. Many of them suggested various organisations and services which Scottish Carer’s Assistance could link to. They highlighted carers centres, Citizens Advice Bureau (CAB), local groups and third sector organisations. They noted that a variety of organisations provide them with emotional, legal, advocacy and peer support; alongside with entitlement eligibility information and help with application processes such as completing forms.

“...definitely links to national and local people, organisations [...] emotional and not just legal support, but legal too! I use CAB because I am so petrified of doing it wrong and I don’t know how to do it anymore.” (interview participant)

“Any equivalent organisations, such as carer centres. Just being able to signpost people to organisations that are out there who can provide support, avenues to respite for carers and general information.” (interview participant)

A few interview participants highlighted the importance of linking support for carers locally. They also mentioned many carers needed guidance and wider help for themselves, but also for their family members who are affected by the caring environment.

“I think being in touch with the local carer’s association, I mean in [Scottish Local Authority] that’s [carer’s organisation] and also not just the carer, but for the whole family. So our daughter is classified as a young carer although we’ve been clear about her not doing any of [son’s] care, but the impact it has on her life. It would be nice to be cognisant of whole family dynamics of who is impacted by the caring role.” (interview participant)

“I think we have to appreciate that everyone will be different. There are some people who will value a presence in a local area. Whether that be a community service, GP practice, whether that be a library or something. I think there have to be actual local services available to people. [...] There gonna have to take into consideration for rural areas, not everyone lives in the heart of the city.” (interview participant)

Provision of information and signposting

A small number of survey respondents mentioned that support with clearer and detailed information as part of the caring role would be helpful to link with SCA. This information should include links to various sources of support for carers, and information on concessions for carers, eligibility entitlements and overlapping benefits.

“Any other associated information as information is difficult to find and when in crisis. It’s even more difficult to find and understand, carer services are helpful as are third sector interfaces.” (survey respondent)

A small number of interview participants mentioned that the information about signposting carer services and organisations, entitlements and their changes, and sources of support for carers should be provided using different methods which consider accessibility and the needs of users. They mentioned that the information should be simple, clear and streamlined so any person can understand it.

“This could be in the website, to have the choice too in an email, posted to you, something like that. In many accessible formats [...] Font size, braille. I guess if it’s a website the computer can read it to you, making sure the contrast is right...” (interview participant)

“I find it quite hard when you read everything can be done online, like local housing. Not everyone can afford to have broadband, not everyone can afford internet in their house, not everyone has a smart phone. So there still has to be these face to face hubs. For some people just coming out the house, they are more likely to have a conversation with someone. They are going to get more accurate information from them as well.” (interview participant)

A small number of interview participants noted the importance of having dedicated people who provide all information on entitlements, benefit changes, financial help and various forms of support. They also mentioned that the information needs to be streamlined across agencies, organisations and services which are in contact with carers.

“Have a one-stop shop for people with disability that explains everything about being a carer and knowing the terminology and how to cope and deal with it all and to get help, support. There should be no shame in receiving a benefit, it’s for helping families for those who are in need. it’s to help that family and to help that child.” (interview participant)

1.2. Options when a carer is not happy with a decision: timescales for re-determinations⁷

If carers disagree with a decision on an application for Scottish Carer’s Assistance, they can ask Social Security Scotland to look at this decision again. This is called a re-determination. The Scottish Government is proposing that carers will have 42 days to ask for a re-determination. Social Security Scotland would have 56 days to make the new decision. These times are the same as for the Scottish disability benefits. Carers may take longer than 42 days to ask for a re-determination if they have a good reason for taking longer.

The carer can then appeal if they do not agree with this new decision. An appeal is when a group of people called a Tribunal looks at all the information and makes a new decision. Carers would have 31 days from getting a re-determination decision to apply for an appeal. They will also be able to ask for an appeal after 31 days if they have a good reason for doing so. Interview participants were asked if they agreed with these timescales.

Most interview participants agreed with the timescales proposed for re-determinations. Some interview participants mentioned that the timescales seem reasonable. An interview participant stated that this is the best approach as the timescales are aligned with the timescales of the appeal processes concerning disability benefits.

“...it is best if all of the appeals processes are aligned so that you don’t need to think ‘oh, this one’s only 30 days that one’s 42 days’ so it’s better it’s aligned with the disability thing because then you know what the timelines are” (interview participant)

A few participants highlighted the need to provide clear, simple and short information about the timescales of re-determinations and appeals.

“The timescales seem acceptable and reasonable, but I think that you have to make clear on the letters sent out that if someone is appealing, that they have 40

⁷ Only interview participants were asked questions on this proposal.

days to make the appeal. Put this at the top of the letter so it is very clear to remind them of the timescales.” (interview participant)

Views on potential challenges with the timescales proposed

A couple of interview participants highlighted the lengthy time they had to wait for decisions on appeal processes. A few stated that it would be better if Social Security Scotland provides decisions in a shorter timescale as the client may be in financial need.

“I think that’s really good because I had an appeal with the Carer’s Allowance and it went on for 2 years. At the end of it they said no and there was no tribunal. For 2 years I wasn’t paid and was totally entitled to it, but they gave lots of excuses. And because there was no timescale, it just went on [...] it was so stressful”. (interview participant)

“...To make the decision, it should be shorter [...] it’s a long wait for somebody, they could be in need. The length of time should be shorter. The ‘not knowing’ is a very stressful thing.” (interview participant)

A small number of interview participants mentioned that it would be better if carers are provided more time as carers usually do not have enough time to carry out these processes due to their demanding caring role.

“Probably I agree but more time would also be helpful the reason being, as a carer, it’s going back to what I said, my needs come last, the actual caring is more important than a form. I can imagine if that was me, I got a decision I wasn’t happy with and wanted to appeal, I have other things in my life I struggle to cope with, so many things to do and not enough time, hours in the day, I would find myself putting it off and putting off until I had to do it, at the limit. Then, I would probably be sitting up in the middle of the night trying to fit it in to do. It has to be a reasonable length of time to make it happen. I think that’s the minimum you could give. (interview participant)

A small number of interview participants emphasised that carers need support for application processes and that help may not be obtained within the timescales proposed.

“I think people should also be able to get extensions on those timeframes. As we’ve just gone through a pandemic and everything was closed as I explained to you where I had to go get help from a charity, sometimes that’s not available, easily more than 30 days. So I think if someone has a reasonable excuse for something like that, they should get extensions on those timeframes as well.” (interview participant)

“I think it’s going to depend on area, where you might have, people will possibly need support in applying for [...] people are going to get this letter, it takes a few days to process, a few days getting in contact with someone then trying to arrange an appointment with someone. The 31 days is quite short, given that SSS are giving themselves 50 odd days. But I think it would depend on the area the person lives. I think that’s where we can’t just put Scotland as one place, as one size fits all. Where you might be able to see someone in Glasgow in 1 week, it may take 3 weeks in Inverness and 5 weeks in Shetland. Where a person comes down once a month or something. You have to take that into consideration.” (interview participant)

1.3. Changing Scottish Carer’s Assistance payments to £0 instead of suspending or ending the award

The Scottish Government wants to set carers’ payments of Scottish Carer’s Assistance to £0 in certain situations. Setting payments to £0 rather than ending awards in certain situations would make it easier to start payments again, without carers needing to re-apply. These situations would be:

- Any week in which a carer earns too much money to get the benefit. This will stop them from being overpaid but would not end their award.
- Any week in which a cared for person’s disability benefit is stopped or suspended. This may be if the cared for person is in hospital for longer than 4 weeks.

Survey respondents were asked if they agreed or disagreed with the reasons for setting an award of Scottish Carer’s Assistance to £0 (see Table 2).

Over two thirds (71 per cent) agreed with setting Scottish Carer’s Assistance to £0 for any week a carer earns too much money. 15 per cent disagreed and 14 per cent were not sure.

Two thirds (66 per cent) agreed with setting Scottish Carer’s Assistance to £0 if a cared for a person’s disability benefit is stopped or suspended. 23 per cent disagreed and 11 per cent were not sure.

The majority of interview participants agreed with setting Scottish Carer’s Assistance to £0 in these situations.

Table 2. Do you agree or disagree with setting Scottish Carer’s Assistance to £0:

For any week a carer earns too much money?			If a cared for a person’s disability benefit is stopped or suspended?	
	Number of respondents (n=238)	% of respondents	Number of respondents (n=239)	% of respondents
Agree	169	71	157	66
Disagree	36	15	55	23
Not sure	33	14	27	11

Survey respondents and interview participants were asked to explain why they agreed or disagreed with the options of setting Scottish Carer’s Assistance to £0. Various reasons which included complete agreement, mixed views and complete disagreement were provided.

Views in support of proposals to set £0 in certain circumstances

Several respondents and participants who said they agreed with these proposals noted that it would avoid having to go through a re-application process. Re-applying for Carer’s Allowance is perceived as time consuming and stressful, in particular because of the long waiting periods for carers to start receiving the payments.

“I agree with that definitely. The fact that you’re caring for someone. You’re struggling to cope with a change in circumstances with the person in their life that’s different, and you’re struggling to cope with that and then you have to deal with all your things changing as well it’s not ideal. Whereas putting it to zero for a week or a fortnight would mean you’re not having to start all over again, you’re just on hold, and I think that’s really helpful. These things to apply all over again would be a total nightmare for a carer, who then is probably having to readapt because maybe the person is coming out of hospital with different needs again and they’re trying to struggle with that, never mind trying to do another form. It makes total sense, common sense going in there.” (interview participant)

“The claim process is time consuming so having a zero payment period when there are mitigating circumstances therefore avoiding having to restart the whole claim sounds an excellent idea.” (survey respondent)

Many respondents and participants who agreed with setting Scottish Carer’s Assistance to £0 also noted that this would make easier to restart payments as the benefit system will show that a carer is still entitled to the benefit.

“It’s a good idea to set it to £0 because then it keeps the case live, and it’s just a case of switching it back on when the situation changes.” (interview participant)

“It’s better to have an ‘active’ benefit than restarting the whole process and the benefit can be paid quicker without hassle. Even with an account being £0.00 it may allow entry to other benefits or show an underlying entitlement to benefits. As a carer your attention is more on the person your caring for and the added stress of applying for benefit[s] is difficult to deal with and if I had to restart a process would anger me and possibly I’d not apply as it’s too much bother to go through the whole process telling the same information over and over again!!!!” (survey respondent)

Many respondents and participants also mentioned setting payments to £0 instead of ending that award would help to reduce stress levels of the carer.

“It means less stress for the carer if any temporary change happens, and I’m sure would save time and money for the social security system because of less paperwork and a smoother process in dealing with any temporary change. To make it easier to reapply just makes it less stressful, any reduction in stress levels for carers is crucial, in my experience.” (survey respondent)

“...rather than stopping someone’s benefit totally, which I’ve had in the past with another benefit is really stressful and has financial implications. Makes so much sense not giving the person the amount rather than stopping it all together. It does make sense; it would be less stressful for the carer I think.” (interview participant)

Some respondents and participants who agreed with setting Scottish Carer’s Assistance to £0 for any week a carer earns too much money noted that this proposal would encourage a more flexible system by considering fluctuating earnings.

“Many carers cut in and out of work: I’ve been doing that for 15 years - and trying to keep within the earnings threshold is a right pain when your earnings are so variable!” (survey respondent)

“It’s awful to get caught out if you’ve earned £1 over the threshold one week but in the other 4 weeks of the month you were well under! this would be a fairer system as you’d only lose the week you were over and not need to start a whole claim again!” (survey respondent)

A few survey respondents mentioned that setting Scottish Carer’s Assistance to £0 for any week a carer earns too much would allow carers to take on occasional/periodical paid jobs.

“Less stressful for carers when they know there is flexibility. Allow for seasonal work opportunities.” (survey respondent)

A few respondents provided few reasons to agree with setting an award of SCA to £0 if a cared for person’s disability benefit is stopped or suspended. They noted it is a good idea specifically when a new decision has been made to reinstate a disability benefit due to an appeal process or a sanction being lifted. The carer then would avoid the reapplication process.

“...with the current problems within the benefit system where people’s disability payments are under threat and sanctions are applied to benefits, they [carers] need to know that if their benefits are restarted; their Carer’s Allowance claim is still live and can be restarted immediately.” (survey respondent)

“If the person on disability benefit had money stopped then has it reinstated, a carer can access the benefit back within a short-time span and not have to go through a reclaim process.” (survey respondent)

Views against setting an award to £0

Some survey respondents and interview participants who disagreed or were not sure with setting an award of SCA to £0 mentioned that caring work, financial household expenses and/or the need of financial support do not stop when earnings fluctuate or when the disability benefit is stopped or suspended.

“If you are a full-time carer [and] not working elsewhere, what are you supposed to live on when the person you care for goes into hospital? Carers need to be paid their Carer’s Allowance as a retainer so that they are able to continue caring when the person they care for comes out of hospital. Carers should be paid the same amount throughout the period they are a carer regardless of whatever else they earn or whether the person they care for spends time in hospital. The commitment to caring remains the same, household expenses, etc., stay the same. Anyone providing care for 35 hours a week is doing 35 hours a week work and should be paid for it. If the person you care for is in hospital you often add care hours to your week in visiting and supporting them.” (survey respondent)

“The caring role doesn’t stop when the cared for person is in hospital. I would have to be with my son if he was in hospital so it would be worse for me and I wouldn’t be able to work so would lose my work income too. I think it’s quite an outdated thing to think that when your loved one goes to hospital they are looked after by the hospital. You keep caring but just in a different place, but still having to care in hospital. Paying for food, travel, parking and back and forward to home.” (interview participant)

Earnings Threshold

Some survey respondents and interview participants who disagreed or were not sure about setting the SCA award to £0 due to a carer earning too much, mentioned that carers should be provided with Scottish Carer's Assistance payments and those should not be linked to any earnings threshold limit.

"Carers are underpaid and over worked as it is and you want to remove just over £60 what if they are only over paid by £1? The caring and work being undertaken is still being done whether the person has a job or not." (survey respondent)

"I fail to understand how earnings should impact on receiving Carer's Allowance. Any carer who finds the energy and time to leave the house and make money to improve their life and the life of the person they care for should not be penalised for doing so." (survey respondent)

"Carers deserve to be paid a living wage. Lots of people have 2 jobs. As long as a carer is caring for the disabled person they should be able to work at the same time." (survey respondent)

Some survey respondents and interview participants thought that it was unfair to end a payment because a carer experiences fluctuation in their earnings. A few also mentioned that the earnings threshold is very low.

A few survey respondents and interview participants mentioned that some carers were losing out financially when being in employment because of the earnings limit and the resulted loss of all the Carer's Allowance payment. They provided suggestions on setting the earnings threshold of SCA payments which included a proposal to gradually reduce the carer benefit when earnings increase or the benefit is suspended. Other small number of respondents said carers frequently cannot work or do not work full-time due to their caring role.

"Carers rely on their allowance to survive; they cannot work full-time if they are responsible for caring for another. Many carers work self-employed or part-time in flexible or seasonal jobs, as these are the easiest to work when you must be 'on call' for emergencies, etc. With self-employment, wages vary from week to week, same with many seasonal jobs. If you earn 10 pounds over the limit, you lose 60 pounds for that week? Very unfair. A yearly amount would make more sense." (survey respondent)

"The amount of £128 weekly a carer is allowed to earn is ridiculous, always had been. £128+£67.60 is nowhere near a living wage rate. A full-time family carer is lifetime job, there should be different rates like DLA, high and low." (survey respondent)

"I have been caught in the "earning too much money" many times and had numerous problems with it. I am a part-time [profession]. I need to/have work. I am completely against the earnings cap as it is discriminatory against my profession. The solution to this cliff edge cut off is to base it on a maximum number of hours worked. That is fair and just and does not discriminate against what is done for a living." (survey respondent)

When the cared for person's disability payment is stopped

Some respondents who disagreed or were unsure with the proposal of setting an award of Scottish Carer's Assistance to £0 if a cared for person's disability benefit is stopped or suspended provided few reasons for their views. Some noted that disability benefits are frequently suspended due to administrative error and in other cases they are sometimes reinstated after appeals; hence they did not think that the SCA payments should be stopped. A few said that payments should not be stopped when an appeal process is still ongoing as the outcome of the benefit being reinstated is not known.

"Disability benefits are stopped in error often. If a disability claim is stopped there should be a grace period of several months to allow for appeals, etc.; as most claims are won on appeal and are returned to the disabled client." (survey respondent)

"In many cases benefits are stopped or suspended in error - this is widespread and leads to injustice, deterioration in health and collapse of support for those involved and - in many cases - suicide." (survey respondent)

"My son's disability benefit was suspended for months before an assessment and subsequent award of both rates at highest level. Carer's allowance shouldn't be suspended when DWP are unfairly denying PIP and DLA." (survey respondent)

Others argued that the caring role does not stop when the cared for person is in the hospital. A handful of respondents and participants mentioned that in some cases the financial cost of caring increases when the cared for person is in the hospital due to travelling costs and providing personal items to their cared for person such as clean washing, toiletries, snacks and entertainment. Some described providing help with care in hospitals, such as supporting mealtimes.

"When [the cared for person is] in hospital for more than 4 weeks, you will find that the carer responsibility and time do not change significantly. There are still carer responsibility involving, liaising with health care staff, giving and obtaining information, attending meetings for care packages, treatments, etc.; that involve time traveling to and from hospital with clothing to wash and return for hospitalised

patient. Often relatives are feeding their relatives in hospital due to constraints on staffing, etc. So caring responsibility does not STOP, if the person is admitted, the caring responsibility changes, but [it] is equally as demanding and time consuming.” (survey respondent)

“If the person being cared for was in hospital, the carer would still be caring; but the way in which they did it would change. They'd visit person in hospital, wash clothes and take them to hospital along with treats and drinks, speak to person on phone, etc. Visiting hospitals would also add extra costs, take time. They would also advocate on behalf of person and deal with financial changes which might affect housing benefits and council tax, electricity, etc. The carer should still be paid.” (survey respondent)

Provision of clear and simple processes

A small number of respondents and participants raised some questions concerning the administrative processes involving the proposals of setting Scottish Carer's Assistance to £0 which should include the provision of simple and clear guidance for certain scenarios.

“I can see the sense in a nil £ award, however, there is no guidance to those claimants, who's cared person passes away before the sixth month of the natural ending of any award. Basically, if the cared for person dies 6 weeks into a Carer's nil award, there is scope for an 18 week over credit of [National Insurance] NI Contributions, should the carer not/forget to inform, that their Cared for person has passed away.” (survey respondent)

“How would you know if I earned more in one week compared to another? I'm just asking the question, if you have a way of finding that out it would be good for us to know that, because carers have a lot on their plate, sorry; we've got a heck of a lot on our plate. For example, myself, I work full-time, I also was the carer for 3 different people, I was running around and I was getting like 2 or 3 hours of sleep a night because I had so much to do. So asking me to fill out a form to announce that I earnt more one week and enough the other week is an extra burden on someone who is already stressed to the highest level. So if you can make it easier for whoever is claiming it, and you saw the work we had to do in terms of filling in the form that is hugely beneficial.” (interview participant)

1.4. Ending a Scottish Carer's Assistance award when it has been £0 for six months in a row

When a Scottish Carer's Assistance award had been £0 for six months in a row, Social Security Scotland would end the award. If carers disagree with a decision to

reduce their award to £0, they would be able to ask us to look at this decision again.

Panel members were asked if they agreed or disagreed with ending a Scottish Carer's Assistance award when it has been £0 for six months in a row (see Table 3). Over half of respondents (54 per cent) agreed, a fifth (20 per cent) disagreed and over a quarter (26 per cent) were not sure.

Table 3. Do you agree or disagree with ending a Scottish Carer's Assistance award when it has been £0 for six months in a row? (n=237)

	Number of respondents	% of respondents
Agree	127	54
Disagree	48	20
Not sure	62	26

Views in support of this proposal

Many survey respondents who agreed with the proposal to end Scottish Carer's Assistance award when it has been £0 for six months in a row noted that the length of time seemed fair and proportionate. Some mentioned it is a reasonable time for a carer to sort out circumstances concerning paid employment or benefits eligibility. Some respondents also stated that the 6-month period provides a realistic time frame to acknowledge that caring circumstances are permanent.

"Seems to be a fair decision as any problems relating to payment or any issues should be cleared up in this time period." (survey respondent)

"Long enough for them to decide on whether they should make an alternative arrangement, like find work or claim another benefit." (survey respondent)

"Hopefully six months allows sufficient time to have elapsed for the carer to know what is happening long-term with the person they care for, e.g. back to caring 35 hours a week, hospitalised, deceased, etc." (survey respondent)

A few survey respondents who agreed with the proposal noted that it should allow for exceptional and personal circumstances to be taken into account in case the payments need to be reinstated. Some mentioned that the proposal should consider the right for carers to appeal and carers should also be consulted about any decisions regarding their award. A handful of participants highlighted that if a SCA award was going to be ended, it should be informed to the carer through clear communication.

“Agree as long as carers are given plenty warning, written/phone call, to ensure they can question the decision if need be.” (survey respondent)

“Always provide for exceptional circumstances where it could be re-instated with minimum paperwork if needed...” (survey respondent)

Views against this proposal

Some survey respondents who disagreed or were unsure of this proposal raised the following concerns. Some noted that it is not a long enough period to cover certain situations such as longer hospital stays and lengthy appeal processes. A few also mentioned that this proposal does not consider carers who regularly earn above the earning threshold for more than six months.

“Simply because someone earns more than £124 per week doesn’t mean to say they stop providing care, it just means the carer is now more pressed and stressed than ever before.” (survey respondent)

“PIP awards and appeals may take longer than 6 months to process. My daughter had to wait 18 months for appeal to go through.” (survey respondent)

“I’m not sure, as a carer could be providing care to someone in hospital for a long period of time and this could go over the 6-months limit, I don’t agree with the £0 award unless they no longer provide any care.” (survey respondent)

A handful of survey respondents mentioned that they disagreed with or were not sure about this proposal because ending a SCA award should be assessed on individual basis. A few noted that the carer should still be recognised as a carer (without any payment) as opposed to completely ending a Scottish Carer’s Assistance award when it has been £0 for six months. Few of these respondents stated that the award should end only when the cared for person was taken into long-term care or passed away. Some respondents suggested that instead of the 6-months proposal, which is perceived as too short; ending the award after one year seems more suitable.

“People’s individual circumstances must be taken into account and blanket decisions not applied.” (survey respondent)

“Unless the person they cared for was taken into long term care or died, there may be still a need to become a carer, there would be very little internal charges to Social Security Scotland to keep the account at £0.” (survey respondent)

“6 months is too short. 1 year would be more flexible.” (survey respondent)

1.5. Views on Short-Term Assistance⁸

Short-term assistance is a new payment in the Scottish benefits system. Social Security Scotland will give carers short-term assistance in some situations where they are asking for a decision be looked at again. This may be a decision to stop or reduce their payments. The Scottish Government also wants to pay Scottish Carer’s Assistance to carers when the person they care for is getting short-term assistance.

Most interview participants agreed with the proposal to pay Scottish Carer’s Assistance to carers when the person they are caring for is receiving short-term assistance. They had positive views on the financial support during appeal processes. They also highlighted that it reassures that clients can go ahead with appeals with less financial worries.

“I agree with the payment. This is a positive as it reduces the stress levels. People will know they still have the money coming in while the decision is under appeal. If you were to appeal and know you were going to lose money, it would be very stressful.” (interview participant)

“It goes back to that if you know if you stop everything very suddenly that can be very difficult to you, you’re trying to budget and if you’re in a state of flux for that person who’re caring for... yeah it would be good just to have that ability, just have a holding pattern until you know exactly where things are.” (interview participant)

Provision of clear and simple processes

A few participants were unsure about the administrative processes and the rules involved in this proposal. They were concerned about the complexities of processes and they argued for their simplification and clarity.

“I think it is overcomplicating the whole system, it’s getting really in-depth and complicated and it will be hard for people to understand the whole thing. It’s easier if it’s plain and simple but having said that, you need money to live, and if you’re in a crisis situation being temporarily getting paid because they’re in hospital or something; the last thing you want is the added problem of no money, you might have extra trips to hospital. Part of me is saying yes it’s useful but administratively, in complicating the entitlement to the benefit, it’s not straightforward. So I’m quite torn on that.” (interview participant)

⁸ Only interview participants were asked questions on this proposal.

2. Extra payments for carers in Scotland

2.1. Payment of Carer's Allowance Supplement in the future

Social Security Scotland already provides extra money for Scotland's carers through payments that are unique in the UK. One extra payment is Carer's Allowance Supplement (CAS) which has been paid since 2018.

Carer's Allowance Supplement is paid by Social Security Scotland to carers who are getting Carer's Allowance and living in Scotland. It gives extra support to carers by providing over £460 a year. Currently, it is paid every six months.

Social Security Scotland will continue to provide extra support through Carer's Allowance Supplement in the future when carers are getting Scottish Carer's Assistance.

It could be paid at the same time as Scottish Carer's Assistance payments every week or every 4 weeks. Or Carer's Allowance Supplement could be paid as a lump sum instead, for example, every six months.

When respondents were asked how should Carer's Allowance Supplement be paid in the future, almost half (48 per cent) said Carer's Allowance Supplement should be paid at the same time with Scottish Carer's Assistance payments, over a third (35 per cent) said Carer's Allowance Supplement should be paid as a lump sum, and almost a fifth (17 per cent) were not sure (see Table 4).

Table 4. How should Carer's Allowance Supplement be paid in future? (n=236)

	Number of respondents	% of respondents
Paid at the same time with Scottish Carer's Assistance payments	114	48
Paid as a lump sum	83	35
Not sure	39	17

Views in favour of paying CAS at the same time as SCA payments

Several survey respondents and interview participants commented on why they thought Carer's Allowance Supplement should be paid at the same time with Scottish Carer's Assistance payments.

Many survey respondents and interview participants mentioned that it would provide a better financial support by adding to the household budget for weekly or

monthly living costs. Along the same lines, many others highlighted that it would give more financial stability and budgetary control for living expenses.

“Paying it at the same time as Scottish Carer’s Assistance offers the carer better financial security and budgetary control than waiting for a fixed lump sum payment every e.g. six months.” (survey respondent)

“Personally I would prefer it to be paid the same time as the carers, not as a lump sum. Just for budgeting reasons. If you get it as a lump sum you would just spend it.” (interview participant)

Some respondents and participants mentioned that if CAS is paid at the same time as SCA, carers will be provided with better financial support in the face of their low household incomes and the wider context of sharp rising costs of living.

“I feel it’s nice to get it as a lump sum but with the sharp rising cost of living carers could really do with that money in their bank every week to help pay for living costs.” (survey respondent)

“Carers who have no other income need the money every week to cover outgoings, especially now due to cost of living crisis.” (survey respondent)

A few survey respondents and participants stated that paying CAS at the same time with SCA payments would avoid that some carers missing out on this payment due to the specific qualifying period/dates of the current CAS eligibility rules.

“Regarding the current payment schedule of six monthly payments, the problem with this is the qualifying period. If a carer provides care for fifty weeks of the year, but not for the two qualifying dates, then that carer would miss an entire year’s CA supplement payments.” (survey respondent)

“I think it should be paid with your normal payments. Some people might only claim for part of the year. The qualifying dates might mean you miss out. Having the extra money each month would allow carers to budget each month. Saving money is a luxury.” (interview participant)

A small number of survey respondents and interview participants were concerned that paying CAS as a lump sum could affect eligibility of other entitlements and cause further issues as a result of being a taxable benefit.

“If paid as a lump sum, this could affect other benefits and cause tax problems if in work.” (survey respondent)

“...if it’s taxable, people if they’re on the borderline, lump sums can quickly put them over things [...] I think it should be maybe, just run with the other one because hopefully that would be the one less likely to hurt people on the lower incomes, and they are the ones disproportionately affected by anything. Lump sums in my experience cause trouble.” (interview participant)

Views in favour of paying CAS as lump sum payments

Survey respondents commented on why they thought Carer’s Allowance Supplement should be paid as a lump sum. Some said that this method of payment would allow carers to use that money for themselves, usually in the form of respite, breaks or holidays.

“Carers don't usually work so are always on a low income. To get a lump sum payment is a big boost for them to buy something they would otherwise not be able to afford.” (survey respondent)

“It's the only time I ever have a lump sum for just me and it's a much appreciated thanks and recognition of my efforts as a carer. I want to keep being paid this way in a lump sum as I find it easier to access some respite or buy something just for me, if it's paid weekly in small amounts it'll be gobbled up paying bills and every day expenses.” (survey respondent)

Some survey respondents and interview participants noted that lump sum payments would also allow large purchases and large household bills which they would not be able to afford with their regular budget. A few mentioned that the lump sums would help for seasonal budgets like Christmas or summer holidays.

“The lump sum twice a year comes in very handy for larger necessary household bills and purchases.” (survey respondent)

“I think the Carer’s Allowance Supplements' are a massive help and when paid in a lump sum, can really help towards paying a bill, and for Christmas, etc. which is always a stressful time financially. It has saved me from debt at Christmas and helped pay electricity bills. It keeps my bank account in the black!” (survey respondent)

A few respondents stated that by paying CAS in lump sums as opposed to regular payments with SCA it would avoid the CAS payments to be used for ongoing and daily living costs.

“The two lump sum payments are more likely to mean the carer themselves uses it, rather than it being swallowed up by the rise of living costs.” (survey respondent)

“Paid twice a year is a bonus amount of money and can offer opportunity to do more with that amount other than every 4 weeks when it’s just easier to assimilate into daily living. The lump sum method feels like a bonus and allows you use it on things out with your normal budgetary concerns. If it was regular, then it would be swallowed up through regular everyday living expenses.” (survey respondent)

Both options should be available for carers

Some survey respondents and interview participants who were not sure about the best method of payment for Carer’s Allowance supplement in the future mentioned that both options should be available for carers so they could choose their preferred method of payment based on their individual circumstances.

“This depends very much on the personal circumstances of the applicant. It would be good if carers had the choice.” (survey respondent)

“I believe the recipients should be able to choose the method of payment which best meets their individual circumstances e.g. weekly, monthly 6 monthly or annual lump sum.” (survey respondent)

2.2. Carer’s Additional Person Payment

The Scottish Government is planning to make a new payment (called ‘Carer’s Additional Person Payment’ for now) to give extra support to carers who are caring for more than one person.

To be able to get the Carer’s Additional Person Payment (CAPP), carers:

- must be getting Scottish Carer’s Assistance.
- must be caring for at least two people who are getting a disability benefit.
- will need to give 35 or more hours of care a week for the person they are getting Scottish Carer’s Assistance for. Carers should be providing at least 20 hours of care a week for each additional person.

It is not planned to limit how many additional people a carer could get this payment for.

Respondents were asked if they agreed or disagreed with the proposed eligibility criteria for Carer’s Additional Person Payment (see Table 5). 75 per cent of respondents agreed with the proposed eligibility criteria, 10 per cent disagreed and 15 per cent were not sure.

Table 5. Do you agree or disagree with the proposed eligibility criteria for Carer’s Additional Person Payment? (n=237)

	Number of respondents	% of respondents
Agree	177	75
Disagree	24	10
Not sure	36	15

Support for the proposals

Many survey respondents and interview participants who agreed with the proposed eligibility criteria noted that this payment is a recognition and appreciation for carers who care for more than one person. Several mentioned that this payment takes into account the extra amount of care provided and the extra cost of caring for more than one person.

“It’s difficult enough caring for one person, but when that increases to caring for multiple people; more financial assistance should be provided and all available help should be given!” (survey respondent)

“People who are caring for more than one person have extra expenses incurred as a result and additional payment would help with this.” (survey respondent)

Many supported this proposal based on their previous and current experiences of caring for more than one person and on how demanding their caring role was/is.

“I completely agree with this. I care for 4 disabled children, the only time I have respite is when they are at school and this is when I work 20 hours a week during term time. I am exhausted, yet I receive 1 Carer’s Allowance, the same as someone else who looks after 1 person for a minimum of 35 hours per week. It is grossly unfair and puts me at huge disadvantage as I can’t earn any more either if I want to keep my Carer’s Allowance. I’m actually having to pay any wage increase I get in to my pension just so I can carry on receiving Carer’s Allowance.” (survey respondent)

A few respondents and participants who agreed with the proposed eligibility criteria for Carer’s Additional Payment mentioned that it was a fair payment because carers who cared for more than one person cannot take on paid employment or study due to their caring role.

“I had direct experience of caring for two family members, different households and locations at the same time. I had to give up my career and income, use personal

savings, take cash from pension pot to make this possible. I had no income other than one Carer's allowance." (survey respondent)

"I agree because I myself care for 2 children with disabilities and one adult child with disabilities. It is hard going. It's exhausting. It means I cannot ever work because it is 24/7 and I don't ever get a break so that extra money would help massively basically because I know I will never even be able to get a wee part-time job. My 3 children's disabilities are lifelong therefore my caring role is lifelong and constant." (survey respondent)

Questions and concerns about the proposals: hours spent caring

Questions and concerns about different aspects of the Carer's Additional Person Payment proposal were raised by some survey respondents and interview participants.

A few respondents questioned the amount of caring hours to be eligible. They also had questions about what can constitute the caring hours, for instance if travelling to the cared for person's household can be considered in the calculation of caring hours.

"I care for two sons with [name of disability], one with more serious learning support needs, both have different needs and levels of needs. It's a struggle financially and certainly impacts on my own mental and physical wellbeing. I am not so sure about the minimum 20 hours of additional support/care given to qualify for the additional payment, 55 hours of care is massive, it's exhausting no matter how many hours spent, and no doubt 55 hours is the least amount of time spent caring for two people, but I think it could be reduced to a normal working week maximum of 48 hours in total. In terms of hourly rate, and saving the state a lot of money by caring for people at home, the DWP's Carer's Allowance is an insult as it stands now. Scotland can do a lot better for those caring for people who would otherwise need a huge amount of support from care services, to manage on a day to day basis and stay safe, etc." (survey respondent)

"Agree, but the number of additional hours should be looked at. Even if someone is looking after another person for less than 20 hours a week, it's not only the additional hours of physical care that affects mental health and physical wellbeing. It's the additional stress and worry about that person, it's the additional form filling and phone calls required to ensure they are also getting the support they're entitled to as well as the initial person I'm caring for." (survey respondent)

Some respondents and participants mentioned potential issues concerning the amount of hours providing care to become eligible to this new payment. The most common issues noted were: hours providing care can fluctuate between cared for people, caring is a full-time day job, consideration of travelling hours to assist cared

for people, carers are unable to separate hours of care between cared for people, and the total amount of caring hours proposed is too high a threshold for eligibility.

“Leniency should be shown to the carer, an example would be, where the carer cooks the same meal for two cared for people, each meal and its preparation, should be considered individually in the assessment of care hours and not amalgamated as if two meals were one meal. Each cared for person may have entirely differing facilitation needs in order to consume said meal.” (survey respondent)

“One person may not have to do 35 hours care for 1 person. But you may be doing 25 hours a week for each of the three. In which case you would be doing 75 hours a week but you would fall through the gap because you weren’t providing at least 20 hours for a subsequent one and at least 35 for another one. I think it should be based on total hours that you are caring. And if you are caring for more than 35 hours a week and you are caring for different, slightly different if they are all in your home for example. But if like me, I had to travel between three different properties, one of which was like 30 miles from my home and two were 4 miles from my home. That travel time as well should be considered caring time, because the only reason I was travelling was to provide care to the person I was going to care for. So caring, it should be based on the total hours, not just the amount of hours you spend for one person. Can you imagine if you’ve got like, I’ve got 3 siblings, I would have to do 35 with [name], 20 hours with [name] and 20 for [name] which would equate to 75 hours per week.” (interview participant)

Questions and concerns about the proposals: limiting caring hours

A few survey respondents and interview participants mentioned that carers should have a limit to how many people they cared for because the excessive amount of caring working hours.

“Shouldn't be more than two people as two is more than enough to deal with.” (survey respondent)

“...I think realistically can someone be a carer for more than 2 people a week? It's 55 hours a week? That's a lot, a lot as well as having your own life and things like that.” (interview participant)

A small number of participants and respondents were concerned about the potential for a rise in fraudulent claims and abuse of the system as a result of the proposal. Specifically, their concerns related to the proposal to not put a limit on how many cared for people an applicant can receive this payment for.

“I agree with them completely, but I think you would need to put some kind of limit on it or it could be up for total abuse.” (interview participant)

“I would agree with the rules, but you had said you don’t intend to limit the number of people could care for – I think this could be slightly open to abuse, as you need some sort of proof that the money is going to the right people. Someone could say that they are caring for two or three other people, but need some proof.” (interview participant)

Questions and concerns about the proposals: the payment amount

Some survey respondents highlighted that the amount of the Carer’s Additional Person payment is too low.

“Agree with the eligibility, but certainly not the payment. If I care for my mother I get £3515.20 and only £520 per year for my dad, it should be the same for both.” (survey respondent)

“I agree with the eligibility, disagree with the amount. The needs of a second person should not be second place to a first person. Equality in need, equality in payment. £520 is far too low for second person.” (survey respondent)

A small number of respondents and participants mentioned that asking carers to work that amount of hours to receive £10 as a CAPP weekly payment goes against the health and wellbeing of the carer and it does not provide a minimum wage.

“I have a problem with the law there. Because what they’re doing now is they’re saying someone has to work 55 hours a week and I think employer’s legislation wouldn’t allow that. So that’s not gonna work. If they gave me a form saying that, I would immediately go to court. You’re saying that I would have to work 55 hours a week to get a payment. That goes against legislation [...] As soon as I saw that, I would immediate go to lawyers or go to MSPs if I saw that on the Scottish Government. Essentially demanding carers work 55 hours a week for 70p an hour; that’s human slavery.” (interview participant)

“It’s just a kick in the teeth, that’s like 10 quid a week... sorry let’s just elaborate on this. £520 per year is £10 per week, and you’ve got to be doing at least 20 hours for that person. So £10 per week, divided by 20 hours, that’s 50p an hour, and if you’re doing more than 20 hours, that’s really; this is what I’m trying to say, carers get treated like rubbish. We’re expected to work for like £8 less than the minimum wage per hour. And we need to feed and clothe ourselves. We also need to have transport to be able to get to the people we care for, and we can’t do that on Carer’s Allowance. I honestly don’t know how anybody anywhere can survive on that, unless they have someone in the background supporting them. But for a single

person like myself with no other family. That's why I'm forced to work and be a full-time carer because it is just not enough." (interview participant)

Questions and concerns about the proposals: eligibility criteria

A few respondents and participants highlighted caring situations in which the carer would care for two or more people, but they still not be able to qualify for Carer's Additional Person Payment. Those situations included: caring for elderly adults who are not in receipt of disability benefits, a carer who earns above the earning threshold, and a carer who receives a state pension.

"I care for my husband who has a disability and PIP. I also care for my mother [87 years] who does not have PIP." (survey respondent)

"I am caring for more than 35 hours each week, but I get ZERO benefits, I have to work full-time, I am stressed and have stress-induced memory loss, depression, anxiety, autism and other mental health issues and I have 1 arm and limited mobility. I do the best I can to help these people, but my Dad maybe only needs 3-6 hours a week, my "brother" only about 2-3 hours each week and my sister several hours a day, and a friend a couple of hours each week. So based on that I would not qualify for carers benefit at all, but I am doing the job that this bloody government and local government is failing to do - care for these people. I did not choose to be born, I have had to be a carer since 1985, and it has caused me to have several nervous breakdowns, and has exacerbated my own disabilities." (survey respondent)

Some survey respondents suggested that the eligibility criteria should be widened to give this benefit entitlement to: all carers, elderly carers or carers who cared for a person who is not entitled to disability benefits.

"We save you hundreds of thousands of pounds annually we deserve every penny that we get for what we do. Why not make it simple and pay every carer a decent amount of Carer's Allowance regardless of how many people they care for not the less than £10 per day we currently receive!!!!" (survey respondent)

"Carers deserve to be paid more regardless how many people they care for. It's a full-time job, the deserve a full-time wage." (survey respondent)

"I currently care for 4 people as an unpaid carer. It's so hard. So should be recognised. That said, I currently feel like a second class unpaid carer as I don't get Carer's Allowance so don't get any additional bonuses like others. Left out on a limb just over the cut off and no one cared whilst others doing less caring get all benefits and bonuses - So Unfair!!" (survey respondent)

Carer's Additional Person Payment would not be paid to people who get another overlapping benefit. This includes people who get a State Pension. The Scottish Government will only pay Carer's Additional Person Payment to carers who get Scottish Carer's Assistance. This is because carers getting Scottish Carer's Assistance are likely to be on lower incomes. The Scottish Government wants to target the new payment at carers on the lowest incomes.

Interview participants were asked if they agree or disagree with the idea to target Carer's Additional Person Payment at carers who are getting payments of Scottish Carer's Assistance⁹. There were mixed views on this across the interviews. Some participants noted that the payment should be targeted to carers on low incomes whereas others disagreed because the proposal would rule out carers who get underlying entitlements, but are also in need.

"Agree with the idea to target this payment. As they're already in receipt of one part of the payment, so if I go back a bit, people who are caring for additional children or adults, they're already in the system. What I think I was alluding to is that checks are in place for new applicants, to make sure that they are claiming the money properly and not abusing it." (interview participant)

"We only want to target people most in need. Pensioners working 70,80-hours a week, some weeks; they're in need as well. The reason they're on pension credit is because they're in need. I understand carers should be get the payment regardless because of the contribution of being a carer." (interview participant)

"I disagree because it would rule me out [...] Back to the two-tier system. You're doing all this caring but you can't be recognised as a dual-carer because you have underlying benefits. It seems grossly unfair and makes me feel like a second-class carer." (interview participant)

Timing of CAPP payments

Interview participants were asked if they agreed or disagreed that Carer's Additional Person Payment should be paid at the same time as a carer's Scottish Carer's Assistance Payments¹⁰. The majority of interview participants welcomed this idea. They noted that it would help with their household regular budget and monthly income. It would also simplify the process of payments. One interview participant said that the carer should have the choice of when it should be paid.

"Yeah. I think you need to try and keep stuff together as much as possible. Some are paid weekly, some fortnightly, some four weekly. The more you simplify it; the better for budgeting. The impact of it being together will enable carers to budget

⁹ This question was only asked to interview participants.

¹⁰ This question was only asked to interview participants.

properly and do stuff with it rather than getting small amounts.” (interview participant)

“It should be every 4 weeks or whenever someone chooses to have it.” (interview participant)

3. Further changes to Scottish Carer's Assistance in the future

3.1. Remove education limits from Scottish Carer's Assistance¹¹

At the moment, carers in education for 21 hours or more a week cannot get Carer's Allowance. This may stop carers from accessing further and higher education courses on a full-time basis. Changing the rules could allow more carers to study. It would mean those wishing to go to university could continue to get Scottish Carer's Assistance so they would have more financial stability.

Interview participants were asked their views on the proposal to remove education restrictions to allow carers in full-time education to be eligible for Scottish Carer's Assistance. There was a positive consensus about this plan. Many highlighted that this proposal improves the life chances, education development and employability of young carers.

"These young people need a chance. Imagine coming out at 18 and your whole future is caring for your loved ones [...] If something happens and the cared for person dies then they have no further education. Young carers need to be employable." (interview participant)

"If we stop them from having Carer's Allowance, it will really penalise them and stop them going to college to set themselves up for the future. So you're penalising them once by giving them low pay, then you're penalising them again by making them postpone their education until their caring role ceases. So you're actually helping them to deliver the care, and actually feel better about themselves because they are actually doing something for themselves. [...] And having young people feel that they can be doing something positive for their future will enable them to be better carers as well, so I think that it's important." (interview participant)

A few also stated that having the possibility to study full-time allows carers respite from their caring role and it also improves their mental health.

"One of my friends is also a young carer and he was really stressed out at home, and wasn't studying as much as he wanted to, but he also just wanted any reason to get out of the house." (interview participant)

"You could get a different focus from your caring to your studies, I think that would be good for mental health as well." (interview participant)

¹¹ Only interview participants were asked questions on this proposal.

A few interview participants mentioned their own experiences or their relative's ones of not being able to study full-time because of the Carer's Allowance eligibility restriction. As a result, they fully welcomed this proposal.

"I think that's a fantastic idea because personally speaking when my husband was caring for me, he had just been made redundant, he wanted to go to college and study something full-time at college but, he looked into it and he was told that he couldn't receive Carer's Allowance because he wanted to go to college. And I never really understood that. And at the time, we both thought that was really unfair. Because why should someone be penalised if they want to go to college or university for their own benefit or it may be out of that caring role and they want to broaden their prospects. For it to be changed now it's very good, I think a lot of carers who are pleased about it. Because I think there are a lot of carers who would like to study, so I think that's very good." (interview participant)

3.2. Combine hours spent caring for two people

Currently, Carer's Allowance is only paid where 35 hours or more of care is provided each week for one person. This means if someone is caring 35 hours a week across two or more people, they will not get Carer's Allowance. The Scottish Government wants to allow carers to add up hours spent caring for two people to reach the 35 hours per week caring requirement.

Survey respondents were asked if they agreed or disagreed with the change to allow carers to add hours spent caring for two people. 81 per cent of respondents agreed, while 6 per cent disagreed. 13 per cent of respondents were not sure (see Table 6). The majority of interview participants also agreed with this proposal.

Table 6. Do you agree or disagree with the change to allow carers to add together hours spent caring for two people? (n=241)

	Number of respondents	% of respondents
Agree	195	81
Disagree	14	6
Not sure	32	13

Some survey respondents noted that this proposal recognises and supports the extra work of carers who care for more than one person. Within this context, a few also noted how demanding the caring role is and how much pressure carers experience. A small number of respondents also mentioned how the caring role can be a full-time daily activity and cannot easily be broken down to a set number of hours.

“This is a great step forward to recognise a carers accumulation of hours to two or more people...” (survey respondent)

“...caring for 2 people will be immensely difficult and so you need to assume that the majority of carers are doing 35 hours or more of care for their loved ones as they will be rushed off their feet and hardly have time for themselves.” (survey respondent)

“Looking after someone can be 24/7 so the figure of 35 hours underestimates caring. [I] find it difficult to see how caring for someone is less than 35 hours; never mind divided between 2 people, unless it is in the same family home; taking into consideration day care and often night care.” (survey respondent)

Survey respondents were asked their thoughts on what would need to be considered for this proposal to work well. Many provided their views on eligibility criteria regarding hours, caring tasks and location of the carer and cared for people.

Caring hours and caring tasks

Some survey respondents gave suggestions on how the hours can be added and recorded as evidence of eligibility based on tasks or timetables which identify caring work, as well as how to communicate to carers what caring tasks could be included to make up the required hours. There were a few comments about specific caring tasks that should be recognised, including travel time, administrative and advocacy work around caring, leisure caring activities with the cared for person, etc.

“A simple timesheet of caring hours to evidence the total number of hours spent. With guidance on what is considered care, as it's not just the physical intimate care, it's getting the groceries every week, it's phoning doctors and specialists about appointments, and rescheduling. It's all the paperwork that needs to be completed. It's the planning and thought that goes in to taking them out for the day. I suspect every unpaid carer in the country spends well over the 35 hours in their caring role, whether it's 1 person, 2 or more they are caring for.” (survey respondent)

“Travel time i.e. my brother stays in Edinburgh, I'm in Glasgow so this travel should come into my "care hours".” (survey respondent)

“A work sheet articulating all tasks carried out e.g. shopping, prescriptions, hospital appointments, drugs given to clients.” (survey respondent)

A few survey respondents suggested that this proposal should consider individual circumstances and flexibility as hours providing care can fluctuate and overlap between cared for people. Some interview participants echoed similar ideas: they highlighted that frequently carers cannot divide the caring hours consistently and the hours of caring fluctuate depending on the needs of the cared for person on a

weekly basis. A few interview participants also highlighted that individual caring circumstances should be considered for the proposal to work well.

“It needs to be flexible as each person's needs may differ day to day.” (survey respondent)

“I don't think you can actually divide it up, like you're only getting 10 hours care, and you're getting the next 10. Generally, you're caring all day. So I wouldn't be splitting my time up between the 2 caring roles [...] I don't think anyone in the caring role would say you're only getting 5 hours to one person, and you're getting 10 hours of my caring time. I hope that carers are sympathetic in their caring roles; it would just roll into one.” (interview participant)

“I had to distribute my hours depending on the needs of the 3 of them [cared for people], and the quality that some of them got was abysmal, but it was based on my time and priority, you know. So just because a caree dies, it doesn't mean that a carer is going to be doing less hours, they may just redistribute their hours to the other two or however many they are caring for.” (interview participant)

Eligibility criteria

A few survey respondents suggested that carers who cared for more than two people should also be able to benefit from this proposal. A handful of respondents raised questions on the locations of the cared for people and how that would impact eligibility.

“The change could be set to apply for carers looking after two or more people for 35 hours per week, rather than simply two, at least initially.” (survey respondent)

“Caring is hard and if caring for 2 or 3 people adds up to the 35+ hours then the allowance should be paid as the carer is still providing 35+ hours care regardless.” (survey respondent)

“Presume this question applies to caring for two different people in different locations? Many carers live in with people they are caring for; how would it work then if household has two more people requiring assistance?” (survey respondent)

Provision of clear information and simple processes

Some respondents mentioned the importance of providing clear eligibility information and signposting alongside the implementation of simple application processes. A small number of respondents referred to the evidence required such as proof that the cared for person is in receipt of qualifying benefits.

“The application process needs to be straight forward; the evidence provided to claim the benefit needs to be reasonably easy for the carer to provide (e.g. one piece of evidence per person being cared for, i.e. letter from GP or copy of the carer for person’s disability benefit award letter); those dealing with the application need to be aware of the stresses and strains associated with being a carer and ensure their interactions with the claimant are kind and easy to understand and follow.” (survey respondent)

“Clear and concise eligibility rules and an uncomplicated application process, plus shorter timescales for decisions to be made.” (survey respondent)

A few mentioned that the proposal needs careful thought so it is not open to abuse and fraud. A small number of interview participants also repeated similar views concerning suggestions of proof of evidence and fears that the proposal can be open to abuse.

“Need to consider how this could be easily abused.” (survey respondent)

“I do agree, but there has to be the limits again because I think that’s again open to abuse, because how many people do you then start linking and so on [...] it needs to be linked to the people concerned because a lot of people can say I care for this person [...] the more is open up, the more is subject to abuse because three or four people can say they care for the person [...] you would need to somehow link to the cared for person's benefits to say there is only one person caring here.” (interview participant)

3.3. Pay Scottish Carer’s Assistance for 12 weeks in specific circumstances

After the death of a cared for person

The Scottish Government is proposing to keep paying Scottish Carer’s Assistance for 12 weeks after a cared for person has died. Currently, when a cared for person dies, Carer’s Allowance payments stop after 8 weeks.

When respondents were asked if they agreed or disagreed with the proposal to pay Scottish Carer’s Assistance for 12 weeks after the death of a cared for person, 90 per cent of respondents agreed, 6 per cent disagreed and 4 per cent were not sure (see Table 7). The majority of interview participants also agreed with the proposal.

Table 7. Do you agree or disagree with the proposal to pay Scottish Carer’s Assistance for 12 weeks (rather than 8 weeks) after the death of a cared for person? (n=241)

	Number of respondents	% of respondents
Agree	217	90
Disagree	14	6
Not sure	10	4

A few survey respondents stated the relevance of time needed to adjust for the carer when the cared for person dies. Other respondents mentioned that the carer needs time to carry out administrative tasks around the cared for person's death. A handful of respondents also mentioned this time provides the carer time to decide and look for options available for their future which included look for paid employment.

"The death of someone you have cared for has a massive impact on the carer. You not only lose a loved one but you lose your purpose in life and I personally struggled very badly." (survey respondent)

"I do agree that extending the time when a cared for person dies is a positive. Carers will have lots of paperwork to complete, and having one less thing to worry about can only be a good thing. It also gives them time to decide if they could perhaps go back to paid employment." (survey respondent)

"That probably the carer has given up work to care for their loved one and it may take them up to 12 weeks or more to get the carer back to employment or to where their life was before they started caring. Also, it will be a difficult time for them emotionally and they need to readjust to life without caring for that person and a bit of help financially will be a lifeline to some people." (survey respondent)

Many interview participants also highlighted similar views such as the time that a carer required to focus on practical arrangements around the death of a loved one and the time a carer needs to look at their future options. A few interview participants also stressed the grieving time of the carer and how the SCA payments could support the carer who usually has the financial responsibilities around the death of the cared for person.

"It would give you more time to grieve really, because the caring role, just say the person was deceased, it would take a long time to adjust to the person not being there, that was 24/7 care, then suddenly, you would be lost, lost situation". (interview participant)

"That's quite okay because the first week or two you have to sort the funeral and then you've got to sort out the house if they lived independently, and you know, the form filling and to let everyone know and can take a lot of effort when you don't

know what you're doing. 12 weeks is generous, 8 weeks is fine, I didn't even know you got that. But the carers should have more support too. Their whole life has to change. They will have to transfer onto an unemployment benefit while they're looking for work, or new job..." (interview participant)

Hospital stays and residential care

The Scottish Government wants to keep paying Scottish Carer's Assistance for 12 weeks when a cared for adult goes into hospital or residential care. Currently, Carer's Allowance payments stop after 4 weeks when a cared for person goes into hospital.

Respondents were asked if they agreed or disagreed with the proposal to pay Scottish Carer's Assistance for 12 weeks when a cared for person goes into hospital or residential care (see Table 8). 91 per cent of respondents agreed, while 5 per cent disagreed. 4 per cent of respondent were not sure. Most interview participants also agreed with this proposal.

Table 8. Do you agree or disagree with the proposal to pay Scottish Carer's Assistance for 12 weeks when a cared for person goes into hospital or residential care? (n=241)

	Number of respondents	% of respondents
Agree	219	91
Disagree	12	5
Not sure	10	4

Survey respondents and interview participants were asked what it needs to be considered for these proposals to work well.

Many survey respondents highlighted that caring does not stop when the cared for person goes to the hospital. Various caring tasks were mentioned as part of the cared for person being in hospital or residential care: travelling to visit, provision of personal supplies, laundry, managing the household and finances of the cared for person, provision of home meals in the hospital, etc. A few mentioned that in these circumstances financial costs increase. Similar views were highlighted by some interview participants.

"Carers duties do not cease when the cared for adult goes into hospital or residential care - they still normally require support help and assistance which may be more difficult and expensive to provide if the carer has to travel further at greater expense." (survey respondent)

“When the cared for person goes into hospital or care, it could be due to multiple reasons and may be a temporary measure to extend care package, etc. The carer’s role and time does not necessarily alter, time traveling to and from, taking soiled clothing to launder, sorting paperwork, bills, attending meetings to discuss care requirement package for discharge etc., etc., feeding the cared for person due to staffing issues, providing emotional support, etc., all factor into the carer’s time spent caring.” (survey respondent)

“I have to stay with my husband when he is in hospital as the nurses cannot help him without hurting him as he needs a lot of assistance in a specific way, caring for him in hospital for me is more difficult than at home.” (survey respondent)

A few interview participants noted that the proposal to pay Scottish Carer’s Assistance for 12 weeks when a cared for person goes into hospital or residential care can provide carer with financial stability as they still have to pay household bills. A couple of interview participants noted that the permanency of a cared for person into hospital can be unpredictable whereas residential care seems a more permanent situation.

“CA is not a lot of money, but if you’re relying on it for rent or to pay bills; these don’t go away because the cared for person is in hospital.” (interview participant)

“It’s very unlikely that you can walk into a job in four weeks. Or even apply for different benefits in that time. It might be a number of weeks for a new decision and people need money coming in.” (interview participant)

“...hospital might not be a permanent thing; you don’t know how that’s going. (The cared-for person) may improve and get much better or they probably need more care. But to get into a residential accommodation like a care home or some kind of care environment seems more permanent.” (interview participant)

Support at the end of a caring role

Some survey respondents and interview participants also mentioned that the carer requires support when their caring role ends. As they were aware it is a time to adjust and search for their available options for the future; a few carers suggested emotional, employability support and financial advice could be offered during this critical time.

“Unpaid carers have sometimes delivered care to the disabled loved one or relative for many years and if the cared for person dies or goes into residential care it is very difficult for the carer to get employment. This is a good idea but it should go hand-in-hand with employment support, training and possibly even counselling

because the carer can feel very isolated when the cared for person is no longer there.” (survey respondent)

“Good communication with carer to support this period with compassion and transition such as other services, bereavement support, hospital liaison, new circumstances.” (survey respondent)

“I just think there should be sign-posting to help people maximise their income in other ways. How is that done, not just leaving somebody and saying, ‘that’s it goodbye,’ it’s having the support in place to help people work out what their options are.” (interview participant)

Questions and concerns about the proposals

Some survey respondents had suggestions and queries regarding the implementation of these proposals. They particularly focussed on how the carer will have to inform changing of circumstances of the cared for person. This included comments about having fluent and clear communication between Social Security Scotland and the carer. A small number of respondents suggested that Social Security should provide clear and simple information and processes to navigate the system as part of implementing these plans. A few wondered about the funding of the proposals and if these plans will negatively affect other entitlements.

“Put in place an easy and simple method to navigate to tell Social Security Scotland of a change in the carer’s circumstances and also have a straight forward process for repayment of any assistance paid beyond the 12-week period [with reasonable, achievable and person-centred amount to be repaid each week/month] bearing in mind that the carer may be distressed at the loss of the person they cared for, and/or be unsure how long a cared for person may be in hospital at least at the outset.” (survey respondent)

“It needs to be seamless. Carers are under a great deal of stress and it massively increases when someone goes into hospital etc. So you need to make them informing you of this as simple as possible. And it needs to not negatively affect other benefits.” (survey respondent)

Many survey respondents and interview participants welcomed these plans and the increase of 12 weeks to pay Scottish Carer’s Assistance when a cared for person goes into hospital, residential care or died. However, a few suggested either more weeks or fewer weeks of SCA payments or stop the payment if there are no more caring responsibilities.

“If someone is in hospital, I don’t think they should be entitled to Scottish Carer’s Assistance as they will be receiving the care in hospital, nor do I think payment

should be made to the carer for 12 weeks if the cared for person passes away.”
(survey respondent)

“The carer would need time to adjust to their new role and circumstances. If a cared for person goes into hospital, SCA should be paid until the person is discharged surely, if they are going to be returning to live with their carer. Re: residential care, usually longer term so 12 weeks seems fair, perhaps a bit longer; 16 weeks so that the carer can adjust and find paid work. They might have been caring for many years and need time to come to terms with the change in their caring role. When a person goes into residential care, the carer will still have to make sure they are safe and well cared for, and access any advocacy, etc. required. Residential care for the cared for person, would not mean an absolute end to the caring role of the carer.”
(survey respondent)

3.4. Increase the amount carers can earn and still get Scottish Carer’s Assistance

Carers are not currently able to get Carer’s Allowance if they have earnings from employment or self-employment of more than £132 per week, after tax and some deductions for things like pension contributions and childcare. This is the amount for this year and may change in future. This is because the benefit is designed to provide support to people who are less able to work because of their caring role. If carers earn £1 over this amount, they lose all of their Carer’s Allowance award.

The Scottish Government wants to increase the amount carers can earn and still get Scottish Carer’s Assistance. The Scottish Government has suggested that the earnings threshold could be increased to a level based on a formula of 16 times the hourly rate of the Real Living Wage. This would mean carers could earn £158 a week and still get Scottish Carer’s Assistance.

Respondents were asked if they agreed or disagreed with a change to increase the earning limit for Scottish Carer’s Assistance to a level based on 16 times the hourly rate of the Real Living Wage. 90 per cent agreed with this proposal, 3 per cent disagreed and 7 per cent did not know (see Table 9). The majority of interview participants also agreed with this proposal.

Table 9. Do you agree or disagree with the change to increase the earnings limit for Scottish Carer’s Assistance? This would allow carers to work 16 hours a week and be paid the Real Living Wage. (n=240)

	Number of respondents	% of respondents
Agree	215	90
Disagree	<10	3

Improving quality of life

Several survey respondents and interview participants highlighted the positive aspects of this proposal. Many mentioned that by allowing carers to increase their earnings, they will be able to participate in paid employment and improve their mental health and wellbeing by doing so. They mentioned having a job allows carers to experience a normal and balanced life.

“Carers need a change of scene from the stressful work caring for a disabled person, allowing this will be a sort of respite from their caring hours.” (survey respondent)

“Carers’ mental health could be improved by working and reduces fear of losing C.A. entitlement”. (survey respondent)

“...that also helps the carer to have some normality in their life away from their caring role.” (interview participant)

A few survey respondents highlighted that the proposal takes into account most part-time jobs which usually are composed of 16 working hours. A small number of respondents noted that it would also allow carers to engage with paid employment and use their skills in the labour market.

“I always found the earning limits could be increased to allow a person to work 16-20 hours so earnings set a £158 seems a good figure to allow carers to combine working and caring is a better balanced life for them and also keeps their skills and work a focus in life.” (survey respondent)

“I think this is more reasonable than the current rules. Carers should be encouraged to earn more given the skills and experience they have.” (survey respondent)

Financial stability

Some survey respondents and interview participants mentioned that this proposal reduces the fear of losing the Carer’s Allowance entitlement, it considers jobs with variable hours and earnings, and it helps with the rising costs of living.

“This would be good because many people juggling work and caring duties are in jobs which have variable hours and opportunities for earning.” (survey respondent)

“Surely we want to encourage people to work and you can only get very few semi decent jobs to help. I’ve had people say ‘oh I can’t work because it affects this benefit ‘and it’s seen as a downfall, but we should be trying to do things that encourage a good standard of living and any increase to allow people to have some breathing space would be positive. [...] A lot of the carers can’t physically leave or do work due to the nature of their care and they need a different level of support. But someone who wants to work and can work and will work should be encouraged to work to raise their family’s standard of living and the benefit system should encourage this.” (interview participant)

“This year I had to drop hours because of the increase in wages which then makes my benefits stop. It’s really important to tag it onto the living wage so that when that goes up the earnings limit goes up.” (interview participant)

Some respondents provided diverse views concerning the proposed earnings threshold¹². A particular concern was whether the proposal would offer flexibility for people who work variable hours or shift patterns, or whose income may fluctuate slightly above the threshold.

“This simply moves the threshold for cut-off, with no flexibility. If a carer is able to take on a part-time role for 20 hrs/wk., can they not simply lose 4 hours’ worth of Carer’s Allowance, rather than all of it?” (survey respondent)

A small number of survey respondents mentioned that this earning threshold proposal does not consider jobs which earnings are beyond the real living wage. A handful of respondents felt that the earnings threshold tied carers to low paid jobs.

“Whilst this is an improvement, I still think it discriminates against professions. Therefore, it should not be based on earnings. It should be based on the amount of hours we care for.” (survey respondent)

“I think it is still not high enough. You are restricting unpaid carers to only being able to do low paid minimum wage jobs no matter what their skills are. No matter their income, they are still unpaid carers.” (survey respondent)

Suggestions

Some survey respondents and interview participants highlighted that the proposed earnings threshold is still too low. A small number of respondents and participants

¹² A few participants misunderstood the proposals relating to the earnings threshold to involve a cap on weekly hours worked. This proposal is not intended to do that. However, a few mentioned that the proposal should not include a fixed number of weekly working hours because that change would adversely affect carers who have their weekly working hours changing frequently.

suggested an earning threshold based on monthly payments as opposed to weekly ones. It is worth noting that this is something that is technically feasible within the current proposals, though it requires going through additional processes.

“The cost of living is so expensive, living on £132 pound a week. And if you earn more, you are not eligible [to SCA]. I think it is far too low, but it has to be reviewed quite frequently. The way things are going, what a pint of milk costs and a litre of fuel for the car.” (interview participant)

“The other thing I’d like to say is that it should be an average of earnings instead of each week and tapering instead of losing all the benefit. It should be averaged out over ‘x’ number of months because you can earn differently some weeks.” (interview participant)

A few respondents and participants suggested the ‘earnings taper’ as an option, that is that the Scottish Carer’s Assistance payment would continue when a carer earns more than the limit; but these payments would be reduced as the earnings increased.

“I think the CA amount should gradually reduce, rather than the current totally unfair system where earning £1 over reduces the CA to nil.” (survey respondent)

“A taper should be applied instead of a cut-off point, as with Universal Credit. I get Carer’s Allowance and currently work as an event steward for [name of company]. I apply for shifts, but don’t always get them. Shifts can be scheduled as anything from 4 to 17 hours at a time. The hours paid and rate of pay can change. I’ve found it very stressful whenever my earnings are close to the threshold, knowing that I could lose not only my CA, but sometimes also 6 months of the additional payment. This can happen if my shift is extended because my relief doesn’t turn up or an event overruns. Or where the rate paid for a particular shift is higher than our usual rate since the rate of pay is seldom included in the information provided about the shift. [...] In most months, I could earn over the threshold but don’t want to be worse off by earning less than the CA I’d lose. I’d be happy coming out with the same amount, even if for every £1 earned I lost £1 in benefit. To be totally fair the taper would allow for deductions and expenses.” (survey respondent)

A few survey respondents and interview participants felt that all carers should be paid SCA payments regardless of their personal circumstances and there should not be an earnings threshold at all.

“I think people who are doing the caring role should be paid the same as a person who is doing it for a professional reason. Regardless of how many they care for, regardless of how long, and regardless of whether they’ve got another job.” (interview participant)

“I don’t think there should be an earnings limit. If people can care and get themselves out the door to work, then there shouldn’t be a limit on what they’re allowed to earn, but it’s a step in the right direction.” (interview participant)

Self-employment

A small number of respondents highlighted the issues of people who are self-employed and as result their earnings are very variable. They suggested an earnings threshold based on yearly earnings.

“I think there should be an annual amount rather than weekly. Many people who are self-employed may earn more one week, but much less over the next few weeks.” (survey respondent)

“You should also consider freelancers’ earnings on an annualised basis. Some people, such as artists or writers can spend several years working but not earning then getting a large payment in a short space of time, which would distort perceptions if viewed on its own.” (survey respondent)

Provision of clear information and simple processes

A few survey respondents mentioned the provision of clear information and simple processes to monitor/provide proof of earnings and weekly working hours. A very small number of respondents stated that carers who work and care should also be provided tailored support. A handful of respondents indicated that their caring role is full-time and they could not take up paid employment.

“Carers need a written summary of the rules when they start to receive Carer’s Allowance and what to do if they change. This should be brief, without jargon. They could maybe get a carers package when they start to care for someone with this, timesheets, support numbers and cheap or free things for them to enable them to continue to care without burn out. E.g. access to counselling, holistic therapies, driving lessons, short breaks, etc.” (survey respondent)

“For carers who can work this is a good idea, but for the majority of carers their caring role is a full-time job and this will not affect them.” (survey respondent)

Overlapping benefits

Questions were raised by a small number of respondents concerning carers who are not eligible due to experiencing overlapping benefits, carers who are state pension age and carers who earn above the earning threshold.

“I personally would still not qualify. But I am struggling financially as a part-time [profession/job]. Current cost of living needs to be considered along with those cared for needing a special diet. I currently supplement my son’s benefits so that he eats according to his intolerances and to address his type 2 diabetes on top of his several disabilities.” (survey respondent)

“All unpaid carers should get benefit not just [the] lowest paid ones. At 17 years of age [there is] no incentive to better myself when unpaid caring as I would lose my Young Carer Grant. I never get top-ups like older people.” (survey respondent)

3.5. Getting SCA payments for some weeks after earning over the limit

The Scottish Government also wants to bring in rules that would mean carers keep getting payments for some weeks after they earn over the limit.

The majority of respondents (82 per cent) agreed with the idea of making payments for some weeks after a carer earns over the earnings limit (see Table 10). 6 per cent of respondents disagreed and 11 per cent were not sure. The majority of interview participants also agreed with this proposal.

Table 10. Do you agree or disagree with the idea of making payments for some weeks after a carer earns over the earnings limit? (n=239)

	Number of respondents	% of respondents*
Agree	197	82
Disagree	15	6
Not sure	27	11

* Figures may not add to 100% due to rounding

Many respondents and participants welcomed this proposal. They highlighted that it allows a period of transition and financial adjustment for the carer, it considers jobs which do not pay the same amount on weekly or monthly basis, and it lets a carer take on extra paid work; including seasonal and weekend jobs.

“I think to keep payments as a stop gap to help carers transition to work is an excellent idea. If a person moved from having to rely on carer’s payments, into work, they would need time to adjust and cope financially. The DWP system actively discourages and more or less bars carers from moving into work if they so wish, and self-employment for example is just simply off the table.” (survey respondent)

“Hundred percent that needs to be done. As I said, during COVID people were expected to work more hours by their employer and it was having a big impact on their benefits a month or two down the line.” (interview participant)

A small number of survey respondents mentioned that making payments for some weeks after a carer earns over the earnings limit would avoid carers being penalised when they earn above the earning threshold inadvertently.

“Not sure how easy it is to manage, but I do think it is something that needs to be facilitated as sometimes you go over the amount unintentionally and are therefore penalised for it.” (survey respondent)

“It would stop them worrying if they [carers] have over stepped their working hours”. (survey respondent)

A few respondents said that the proposal of making SCA payments for some weeks after a carer earns over the limit help carers who are in zero hour contracts jobs, which are mainly characterised by wage and hour fluctuations.

“Zero hour contracts can benefit the owners of the means of production, perhaps less so for the workers. This alone means that guaranteed wages are not assured, so a period of adjustment from at least one money source may actually help a person more than you will ever know. 4 weeks of hardly any hours the previous month, then 2 hours over the next month possibly means no reserves in the bank/purse; but a penalty for caring seems very harsh.” (survey respondent)

“That some people's wages fluctuate, especially those on zero hours who can't plan ahead how many hours they will work in a week and so this arrangement will help them a lot.” (survey respondent)

“So many jobs have variable hours that it makes sense to continue payments based on average earnings. Many carers have different hours during term-time too.” (survey respondent)

Extending timeframes for earnings limit

A few respondents and interview participants suggested that a yearly earnings threshold would be a better approach for the earnings proposals, in particular for those carers who are self-employed or are involved in seasonal jobs. An interview participant mentioned that with a yearly earnings threshold, the overpayment issue would be avoided for carers who are self-employed.

“My husband is self-employed technically, if he were the carer that can be a problem because he doesn't know at the time what his earnings are going to be, he doesn't know until all it is put full at the end of the financial year where it can be a while after the end of the tax year [...] whether if in the case they [self-employed carers] can do it retrospectively at the end of the year somehow, they would avoid the overpayment. I could see that all be a problem, but how does it work because you don't know your income at the time, you are saying my income is less than that, but you don't know because it is all done in a yearly basis” (interview participant)

“A yearly earnings amount would be more sensible for those who work seasonal jobs or self-employed whose earnings change from week to week. My husband works self-employed as a gardener; he works close to home so he is available if i need him. In summer there is enough work for him to work three days a week if my health permits, in winter it drops to one day a week. With your system, he would lose the allowance if he managed to work the third day at any point in summer, despite earning way under the limit in winter! The allowance amount would be constantly changing; and over the year we would lose a lot of money despite him earning under the required amount over the 12 months.” (survey respondent)

A handful of respondents suggested earning thresholds on a monthly or quarterly basis. A small number of respondents mentioned that this proposal needs to have some flexibility inbuilt which considers the individual circumstances of the carer.

“Holiday pay, working overtime can change a person's monthly income, this has to be taken into consideration. And people who are paid monthly can increase that month and take them over the threshold, this should also be recognised and not penalised.” (survey respondent)

“It needs to be flexible as there will be times when things are stable and the carer will know how many hours they can work, while other times the health of the cared for person could change meaning some weeks the carer would work less.” (survey respondent)

A few survey respondents suggested the earning taper option would be a better approach than the weekly earning threshold. As with previous questions, a handful of respondents mentioned that there should not be an earning threshold and instead Scottish Carer's Allowance payment should be paid to all carers.

“But I think it sound fairer that there could be reduced payments for the weeks they earn more, and not for the others. Life has to be flexible. No one should be punished because they are a carer, it's tough enough.” (survey respondent)

“Tapering rather than flat axing is the best way.” (survey respondent)

“I think all carers, regardless of their earnings, should qualify for financial support. As I said before, if we all stopped doing what we do the Government would be facing an absolute disaster.” (survey respondent)

Concerns about the proposal

A few respondents and interview participants had some views on aspects related to the proposal of making payments for some weeks after a carer earns over the earnings limit. These included their thoughts on overpayment issues and on setting up the number of weeks of making SCA payments after a carer earns over the limit.

“I agree but don't believe this overpayment should be deducted after all they still provide the 35 hours of care and the overpayment maybe for reasons out with their control, unearned income such as bonus's or holiday pay.” (survey respondent)

“We need to be mindful of any build-up of arrears or timescales to allow a pay back, as carers would probably find paying back any over payment very difficult.” (survey respondent)

“Put a time limit on how many weeks that they can be over the earnings limit, e.g. 5 times in 1 year.” (survey respondent)

Provision of clear information and simple processes

Some respondents and interview participants mentioned that for this proposal to work well, Social Security Scotland needs to set up simple application processes for the client to report change of circumstances and the provision of evidence concerning earnings. They also mentioned that information about the proposal and its rules needs to be communicated clearly.

“Some way to get carers to accurately and promptly report changes. This would need to be brief, easily understood and accessible.” (survey respondent)

“It needs to be made very simple as this could easily become overwhelming and confusing, like trying to understand tax credits. (survey respondent)”

“I think they need to do something. My earnings were flexible and it was constantly stop start. If there was a system that was easy enough for everyone to understand. People give up claiming as its more hassle than its worth. The system is too complicated; it needs to be simpler. People don't understand that you can make deductions too. It's too complicated which stops people applying. Clearer guidance is needed.” (interview participant)

3.6. Support for a wider group of unpaid carers: long-term carers

The Scottish Government is aware that many carers have been caring for a long time. As a result, it wants to consider a new payment for long-term carers who are more likely to be on lower incomes.

Respondents were asked if they thought that a payment for long-term carers should be considered further (see Table 11). 89 per cent said yes, 3 per cent said no and 9 per cent were not sure. The majority of interview participants also thought a payment for long-term carers should be considered further.

Table 11. Do you think that a payment for long-term carers should be considered further? (n=241)

	Number of respondents	% of respondents*
Yes	214	89
No	<10	3
Not sure	21	9

* Figures may not add to 100% due to rounding

Views on who a “long-term carer” is

Survey respondents and interview participants were asked their views on this payment and who should be entitled to it. Several mentioned who should be considered a long-term carer. Many stated that a long-term carer could be identified by linking it to the prognosis of the cared for person. If the cared for person has health conditions which are: unlikely to improve, progressive, chronic and/or they endure life-long debilitating diseases; their carer can be identified as a long-term carer.

“It should be for people who care for individuals on long term DLA/PIP. Neither my son or my parent are going to 'get better' from their disability, they have lifelong disabilities, and will need lifelong care.” (survey respondent)

“For certain conditions that are not going to improve. To say somebody did have a, can you still get a PIP lifetime award? If they had a PIP lifetime award it's not going to change [...] amputations things like that, blindness, you should be getting a long-term award that isn't going to impact other benefits, that's not going to change.” (interview participant)

“I imagine most people giving long term care are caring for someone with a terminal or life limiting illness or lifelong severe disability where independent living is not possible. These carers should have a higher rate of Carer’s Allowance as our savings quickly become depleted.” (survey respondent)

Some survey respondents and interview participants said long-term carers could be identified based on a long period of time in which the carer has provided caring work. They mentioned their particular experiences of caring for several years. A few stated a set amount of time such as three years, five years and ten years.

“Long-term carers would benefit from some financial assistance/payments for respite breaks and replacement care where appropriate. My own health started to have a serious impact after five years intense caring so maybe prior to 3 years would be a good benchmark as I'd have really benefited from some help and respite around that time frame.” (survey respondent)

“I think long-term caring should be described as caring for someone for over five years.” (survey respondent)

“It’s hard to put a figure on it, but we have been doing caring role now for, how much extra on top, say 10-12 years, hospital appointments, handling, equipment, trying, meetings [...] so many meetings, from education to health to social work, so many forms. My son’s condition is a progressive one so his care needs are not going to get lighter as he gets older.” (interview participant)

Many respondents and participants said a long-term carer could be identified as those who will never be able to take up paid employment or who had to give up full employment due to their intense caring work.

“I’ll probably never work to my capacity again, so my pension is down the toilet, god knows what I’ll do what I’m older as I’ve not earned anywhere near my full pension and never will. I know social workers, teachers, bank managers, all sorts who’ve all had kids with additional needs who have just had to walk away [from their jobs]. Their earnings potential is then stuffed.” (interview participant)

“We are full time-carers. Our son has a 2:1 care ratio and requires to be looked after by 2 carers 24/7 for the rest of his life due to the complexity of both his physical and mental disabilities not to mention his complex health needs. We cannot work even if we wanted to and we had to give up full-time jobs to support our son. Caring for our son IS our job and this has to be recognised. Maybe about different caring situations?” (survey respondent)

“I have been caring for my son for almost 30 years now and have missed out on career, development, colleagues, occupational pension.” (survey respondent)

A small number of survey respondents and interview participants mentioned the longer they are carers, the less employable are in the labour market. Lack of savings due to not having a paid job was also highlighted by a handful of respondents and participants.

“I’m in my 13th year being a carer. Before I gave up my job to look after my Dad, I had savings, I had an ISA, I had a credit card with a good limit. Two years in to being a carer, savings and ISA were gone. Credit card limit is under £500.” (survey respondent)

“I think the longer a carer is out of the working market, the less employable the person becomes. the longer they’re employed as a carer, the less employable they become to the working market.” (interview participant)

“Long-term caring has a huge impact on earning potential, living arrangements and giving up many of the essentials of a basic life. There is a world of difference between adjusting to live on £69 a week for a relatively short period of time and having to do it more or less permanently.” (survey respondent)

Eligibility criteria for a future long-term carers payment and impact on overlapping benefits

Some survey respondents and interview participants gave further thoughts on the eligibility criteria. Many supported the proposal that the payment should target those carers who are on the lowest incomes, which would be achieved by paying it to those in receipt of Scottish Carer’s Assistance.

Some felt that the payment should not be targeted at those on lower incomes highlighting that elderly carers should receive this payment and/or all carers who have been caring for long-time regardless of their household income.

“It should be paid to all long- term carers, not just low income. Long-term carers are more likely to be elderly and on pensions that are low income. Start with people who lose their Carer’s Allowance when they reach pension age and the people who lost their allowance in the last 10/15 years. Should be easy enough DWP must have details. It should be at least the same amount as the rest of the carers.” (survey respondent)

“All unpaid long-term carers regardless of income. Treat everyone equally not some as second class unpaid carers who do not matter to ANYONE!! Yes, that’s how it feels to ME!!” (survey respondent)

“I think carers should be paid until the person they are caring for has passed on or gone into a care home and unlikely to get back home. This payment should also be made to those of us carers who have cared for many, many years and have had carers benefit cut off due to receiving pension which we actually worked and paid for. When the Scottish Parliament takes these over in full this would be their opportunity to put this ancient rule to bed and to make their own rules to pay all carers if they qualify a sum of money regardless of age or having a pension.” (survey respondent)

A handful of survey respondents and interview participants suggested that the long-term carer payment should be a unique payment which will depend on certain eligibility criteria.

“Not sure, but it should be for people with low incomes.” (survey respondent)

“Simply separate it from the rest of the carers payments. ‘Cos I think this one would be quite unique. I don’t think everybody would qualify for it so I think it needs to be set apart from the rest of the payments.” (interview participant)

Value and method of payments

A concern raised by many respondents was that long-term carers are often living on low-incomes for a long period of time. It was highlighted that this can negatively impact not only their immediate quality of life, but also long-term prospects in terms of pension contributions and savings. Some respondents and participants felt that future proposals to introduce additional payments for long term carers could try to address some of these issues. Suggestions included pension contributions, discount schemes or help towards respite care.

“My daughter has a lifelong genetic condition and will need care all her life. I worry about what the future means for her, particularly as we struggle to save money since my wage is practically non-existent (approx. £25/week at present due to childcare restrictions) for her future care. I am unable to pay into a pension as well so am worried about my own future once I reach that age. Perhaps pension contributions could be included somehow in this payment.” (survey respondent)

“The payment could be financial but also in the form of free bus/train travel, driving lessons, support sessions, counselling, therapies. Maybe the enhanced rate could be for carers who either have cared for someone for more than a couple of years but also the nature of caring, the intensity of the role should be looked at and the enhanced rate awarded.” (survey respondent)

As in previous sections of the research, some survey respondents also argued for carer payments to be higher than is proposed. Some suggested they should be equivalent to an hourly living wage or similar to the wage of a professional care worker. A handful of respondents mentioned that the payment should be frequently reviewed in line with increases to the cost of living.

These suggestions unfortunately go beyond the scope of the current proposals for the new Scottish Carer's Assistance. Scottish Government is currently conducting research to inform plans to introduce a new Minimum Income Guarantee, and the views of carers will be part of this work.

Several respondents and participants provided mixed views on the method of payment for long-term carers. Some suggested a lump sum (as a grant) and others suggested that the payment should be paid at the same time as SCA payments on a weekly or monthly basis. A few proposed that the choice for the carer concerning the method of payment should be offered.

"Let the carer choose a regular, increased, payment, or a lump sum once a year, e.g. before Christmas." (survey respondent)

"It could be similar to the supplement payments used now. Either twice a year or once a year as a bonus." (survey respondent)

"Should take the form of a weekly or monthly stipend." (survey respondent)

Evidencing your caring role

A small number of respondents raised questions or concerns about how carers would evidence that they were a long-term carer in order to receive the additional payment. A few others mentioned distinctions between caring in terms of the intensity of the care work or individual circumstances of the carer.

"It should be based on an individual's need. Some people may need support while others don't." (survey respondent)

"Assessed every 3 years. A journal of such could be implemented to prove long-term care has been carried out." (survey respondent)

Under the proposal, there will be no need for long-term carers to provide any additional evidence of their caring role. This would be assessed based on their long-term receipt of Scottish Carer's Assistance.

4. Further views on the Scottish Carer's Assistance proposals

4.1. General views on SCA proposals

Some survey respondents and interview participants gave positive feedback to the proposals. They mentioned that they made them feel valued, recognised and respected. Some mentioned that the SCA proposals were an improvement in comparison to what the DWP provides to carers. A few highlighted the negative interactions they had experienced with DWP.

“Thank you for listening and considering much better ideas than the DWP. Carers are treated abysmally by the DWP and deliberately kept in poverty. I'm so glad you're not going down this route.” (survey respondent)

“I can't wait for it to be all handled by SSS, and not be with DWP anymore. You always get the feeling DWP thinks you are a criminal first, and you have to prove to them you are not. Social security Scotland always treat you as a human being, and a valid one at that. Thank you.” (survey respondent)

“I feel extremely grateful that the Scottish Government is taking over this benefit, and that they are considering all these changes, most of which will make a big difference. If the carers earned more for their efforts, could earn more on top and not lose their benefits as soon as they go over their amount for a week; it would be a much better system. Thank you for overhauling it!” (survey respondent)

However, many survey respondents noted the experiences of carers with underlying entitlements and how unfair they felt it was that they are not eligible for the changes proposed. They highlighted they do not have access to carers benefits, supplements, concessions and discounts.

“Nothing will change as to treat carers fairly will cost too much so we have to just get on with it and struggle. Carers with underlying entitlements get screwed over by the [Carer's Allowance] Supplement as it would have been too much work and would have require the DWP to work with you so we get nothing, not even the COVID top-ups. We can't get any discount cards like carers working for local councils or care homes.” (survey respondent)

“Please make it fair to ALL unpaid carers, carers doing a vital role for people who need cared for. DO NOT introduce discrimination and unfair and unequal system. That's SO wrong in this day and age.” (survey respondent)

“It’s highly unfair that those who have underlying claims for carers, totally miss out on supplements etc., talk about 3rd class carers!” (survey respondent)

A few survey respondents stressed the importance of widely advertising Scottish Carer’s Assistance proposals and their rules. They mentioned many carers do not take up some benefits because they are not aware of them or their eligibility.

“Let people know it is available. Carers often miss out as they are not aware there is a benefit. I missed out for a long time, until advised by council’s welfare reform team.” (survey respondent)

“It must be more widely advertised and simpler to understand if you qualify. Many don’t go near a carers centre because it is mostly for older people.” (survey respondent)

A small number of respondents suggested that the process to notify a carer’s change of circumstances and change of carers benefits should be simplified. They also noted that clear information and simplified processes regarding these benefit changes, their new rules and their eligibility criteria should be put in place.

“Just a plea to make the transition as seamless and admin free as possible. So many carers have had a tough couple of years and are already inundated with paperwork, appointments and reviews for the person they care for.” (survey respondent)

“Please make sure as much as possible that changes in circumstances where a person will continue to be entitled to claim (but perhaps caring for a different person) won’t lead to other benefits being ended in the meantime. Currently, this can mean being moved off legacy benefits onto new benefits which might make you worse off or leave you with a big gap and no money.” (survey respondent)

4.2. Effects of SCA proposals on different groups

Older carers

Many survey respondents and interview participants held negative views on how carers of state pension age would not be eligible for the changes proposed as part of the Scottish Carer’s Assistance. Some older carers were also critical of not currently receiving Carer’s Allowance.

“I’m over 70 and retired. My caring role is 24 hours per day, 7 days per week and 52 weeks per year. The proposed new allowance will not assist me in any way. As a full-time carer, I believe I am being ignored by a system that seems to have

been formed and perpetuated by an erroneous view that a state pension is a benefit paid for the same reason as Carer's Allowance." (survey respondent)

"I'll be a pensioner by the time my son is classed as an adult, that means in effect I'm not eligible because I'm of pension age, that's not fair. It seems quite discriminatory and unfair, targeted against in effect, 'we don't want carers over pension age', you're suitable up to that age, but now you're not." (interview participant)

"As a pensioner, worker and carer I think we need to address the elephant in the room: many of us feel that this age discrimination is the worst aspect of carers support, and it is potentially illegal." (survey respondent)

A few survey respondents mentioned feeling undervalued and left behind by the proposed changes. They thought it was not appropriate to lose eligibility after certain age if the caring role was still performed. A handful of respondents highlighted that the caring work gets even harder when becoming an older carer.

"Ageing carers who reach state pension age and Carer's Allowance is stopped and are still caring is totally unjustifiable and immoral in all ways. We are still caring and it is harder. Being undervalued is an understatement." (survey respondent)

"There are days I have been broken. I have driven off and cried in a lay-by to just be away from demands and needs. I have wept and not slept well for a week because it all gets too much but at the end of the day, as a critical carer, I get on with it or he dies but I get no allowance as I have a pension, the same pension my neighbours have; but are not caring for anyone. The pension which is not a full pension because I had to give up work early and no one told me about Carer's Allowance. As we get older and more infirm, it is harder to care." (survey respondent)

"I don't feel the changes suggested go far enough to support hard working carers, there is no mention of carers who reach retirement age and care for their loved ones often at breaking point due to their own poor health and age, they feel abandoned by the system that refuses to acknowledge them and support them in their caring roles, this was more evident when the Carer's Supplement was introduced. It seems fruitless to overhaul a benefit only to replace it with almost the same, the changes being considered do not go far enough to keep carers out of poverty and hardship, giving them the energy and strength to do their roles which they have selflessly taken on board." (survey respondent)

A small number of interview participants highlighted the age difference of carers and the impact on the methods of communication used for application processes

and information of carer benefits. They mentioned the limited use of online sources and services by older carers.

“Older people’s access to applications is also limited. Their use of online services is limited [...] younger generations can access stuff online but the older generation are less likely.” (interview participant)

Children and young people

A few interview participants mentioned that the proposals and plans around Scottish Carer’s Assistance will improve children’s rights and wellbeing for young carers and also for carers who have children. They mentioned that young carers also need further wellbeing support.

“I think young carers need a lot more help from the mental health side.” (interview participant)

“I have worked with young carers in the islands. They are providing care and should be able to be children. Providing extra help can let them get a break.” (interview participant)

Carers from ethnic minority or religious groups

A few interview participants mentioned that carers from ethnic minorities and different religions can be impacted differently by the SCA proposals because of cultural differences, ideas about what constitutes being a carer and language barriers. They also mentioned that these communities may not contact social security services unless they are in very challenging financial difficulties. An interview participant suggested providing information about the SCA proposals in multiple languages to reach different communities.

“Ethnic minority communities don’t identify with a lot of things or they don’t understand. If English is not your first language, then it’s really difficult for applications, etc. They will stay away from the system if they can keep themselves afloat.” (interview participant)

“Certain ethnic groups or religions will rarely come forward to claim benefits because it’s in their culture [not to]. I did some work with Indian communities and found it’s in their culture to want to support each other and they are very closed, therefore they won’t apply for benefits or they won’t approach agencies.” (interview participant)

Household or family make-up

An interview participant noted the different circumstances of carers who are single and do not have a support network to help them with their caring role.

“I think you should look at the circumstances of the carer. I am single. I have no support from anybody else. I am the sole support for the people I cared for. Therefore, the burden on me, mentally, physically and financially in making sure my carees were looked after properly, was astronomical. Whereas if somebody is married and they are caring for someone in their own home that is so much easier! Because they have got someone else going out and earning money and they can have that luxury of being the carer and getting loads of extra money for caring for someone. And so I think you need to look at if someone is a single person, not married and is providing that level of care, they need to have greater consideration than someone who is married, and has a partner, and has that level of financial support...” (interview participant)

Income level

Some interview participants thought the SCA proposals have an impact of reducing inequality by giving extra financial payments through extending Carer’s Allowance eligibility and also by allowing carers to study full-time if they want to do so. However, a few participants highlighted that the eligibility criteria are still restrictive to many carers, including those who earn above the earning threshold or work on a full-time basis.

“It would reduce it slightly. But there are still people who will be penalised because they will have to work and they have to earn a certain amount to pay their own living expense and they will still be penalised and expected to drive themselves into the ground because they don’t get any support and I do think that the fairer way would be to pay everybody, regardless of how many hours per week, because they are caring. And give them a living wage for that caring time. But obviously that would bankrupt the government completely because they’ve been getting away with treating us like rubbish for the last 40 years; but in an ideal world we should be compensated, however long we spend caring, and we should be compensated at a reasonable wage.” (interview participant)

“I think what happens with Carer’s Allowance, it just makes massive divisions between different types of carers. If we changed the eligibility, it would help.” (interview participant)

Disabled carers

A small number of interview participants and survey respondents stressed concerns about different circumstances which may impact on a carer’s eligibility for SCA. These included disabled carers who live together and care for each other, carers

who care for multiple people, and carers who also need care due to their long-term conditions or disabilities.

“I’m one of the ones that falls into the gaps, because often the main carer is needing care themselves. And if you have good networks things go well, but things can fall through. Our social security system needs to go further. But right now none of us are entitled to claim anything apart from Young Carers [...] The system actually does not help. It doesn’t work for us [...] it’s actually all relevant, because I’m a disabled person who is caring, but if I get a carer, more gets taken off me. And the kids are having to do things that they shouldn’t have to be doing at 16 and 17...” (interview participant)

“...a disability limits what I can do, but I would be concerned that if I was getting SCA, DWP would think that I then don’t deserve my other benefit ‘if she’s well enough to do that caring then’. The DWP can be arsy about it. [Social Security Scotland and SCA should] not assume that just because you can care for somebody you don’t need to be cared for yourself [...] we should have a universal income. It would improve life expectancy and wellbeing. I mention it every time I can. (interview participant)

“I am penalised as is my partner for our ill health pension and our Employment and Support [Allowance] payment, so we get nothing for caring for each other which is saving a care package payment for each of us and special housing, it is all wrong.” (Survey respondent)

4.3. Impact on rural and island communities

Many interview participants highlighted the impact of the SCA proposals on carers who are located in rural and island communities. They mentioned the extra travel costs those carers have because the various key services they need are not near where they live.

“I mean, it’s difficult to quantify it at the moment. Definitely regionally, especially in remote and rural areas. Extra costs going to the nearest hospital [...] Additional cost, transport costs. Still got areas in island communities where you can’t get online to apply, elderly people may not have smart phones.” (interview participant)

“I think the rural living community stuff can be impacted for cost and stuff because I can’t tell you how much we have spent on petrol taking my son to hospital. We have done 2 trips to [city], 2 trips to [city] [...] If we were living in the middle of Edinburgh 5 minutes from [Hospital], having all the great support you know that would be a different cost case. We do 70-80 miles round trip for hospital, we had to buy a wheelchair adapted vehicle, we had to buy it ourselves, we got the motability bit, but yeah it’s so specific to everybody’s situation.” (interview participant)

A small number of interview participants noted the lack of means of transport, including infrequent buses, in rural and remote areas. They mentioned how, in some cases, they need to plan their trip to nearby cities to have access to services in advance. They also mentioned the longer time they spent to get into those services compared to carers who live in cities or near them.

“My mum has offered to take me to many clubs, but I’m like ‘yeh, you might be tired’, but then it’s annoying getting the bus and it costs money [...] especially when you have to plan everything; maybe weeks upon weeks in advance, like if we want to get to [city], we would have to plan the week before, and days before about how we get there and back.” (interview participant)

A few interview participants highlighted the lack of carers groups/networks and various services for carers and the cared for people in rural and remote areas. They also said that the caring work can be even more isolating in island communities than cities.

“The services that people use in more rural areas. In my local authority we don’t have access to special schools. This is where you find out a lot of information, but we don’t have access to that.” (interview participant)

A small number of interview participants suggested giving an added payment to carers who live in rural and remote locations as a result of the financial impact of not living near basic and key services.

“But one thing that I think every Government, and I think whether it’s the Scottish Government or the English Government have failed on, is people in rural areas. Because caring for someone in rural areas costs a heck of a lot more than caring for someone in a town. I think for people in rural and remote locations should get an additional supplement because of the cost of travelling everywhere to do their caring.” (interview participant)

“I think maybe in an island community; employment isn’t so great. If you are working in tourism or retail, or farming, crafting, whatever. To help people out there should be some kind of payment. I imagine if you are a carer on an island community it would be very isolating. Caring is isolating anyway, wherever you are. But maybe more so if you are on an island because you have a reduction in support. To have some kind of financial award would be kinda helpful I think.” (interview participant)

4.4. General views on caring work and payments for carers

Common themes concerning caring work and payments for carers were emphasised across the SCA proposals by several survey respondents and interview participants.

Many survey respondents and interview participants perceived their caring work as replacing the caring work that public services should be carrying out. As a result, they stressed the importance of recognising and valuing their work as unpaid carers. A few respondents and participants felt their caring role is still undervalued.

“...that’s what’s important. It’s people being recognised that unpaid carers are valuable. It saves billions of pounds a year. We can’t get care staff, we need to rely on unpaid carers. [...] I do think if people are doing that then where there are not statutory services people do need to be getting that recognition and the support they need [...] And I don’t think there is enough recognition for unpaid carers.”
(interview participant)

“I think that the carer role is a vital one to society. Many people do it through a sense of family obligation. Regardless, this results in a cost saving to the government and the taxpayers. The Social Care system would simply collapse if it weren't for carers. I think the Scottish Government approach is more humane and fair in comparison to UK Governments to date, but I'd ask that you consider the cost/saving balance and set Carer's Assistance at a realistic level and be as generous as budgets will allow.” (survey respondent)

Along the same lines, many respondents and participants stated that their unpaid caring work saves governments and public services a vast amount of money. A few provided details of how much money they had calculated the public purse was saving as a result of them providing care to their loved ones.

“Personally, I think you should pay carers whether they work or not, as caring is a vital job. The only reason I am having to be a carer is because the local authority does not have the resources to provide the care. I need care myself, but I am way down the list and I am suffering physically and mentally. If the councils had the resources then I would not be a carer, and I would become a caree. The councils would then have to pay a ‘professional’ carer. Non-professional carers often do far more than a professional carer, and really they should be paid for all the time they are doing this role as it is still a job, however many hours it takes.” (survey respondent)

“I’ve sat down and worked out if the government paid minimum wage for someone to look after my son at £10.90 an hour, for 24-hour care. They wouldn’t pay someone £10.90 as they’d need a band 5 staff nurse for health and safety reasons. That’s £261.60 for 24 hours and 7 days a week is £1831.20 a week. Multiply this by

52, that's £95,220.40 bare minimum cost if I were to say that I couldn't do this anymore. Then, he would need residential facility, you'd need NI and pension contributions, then holiday pay and cover. If they paid me £30,000 I'd be quiet and wouldn't ask for holiday pay! And you'd need occupational therapists, specialist feeding staff, incontinence staff, all that additional stuff. This is what it would cost for 1 year to look after my son, and his needs aren't massively complex." (interview participant)

Many survey respondents and interview participants stressed that the current value of Carer's Allowance payments is too low and does not cover the costs of living.

"Carers are paid a ridiculously low amount of money for the role that they perform. Carers do not even receive £10 per day in benefits, I would love to see those in government try to live on less than £10 per day. We save the government hundreds of thousands of pounds annually on care costs and yet we are the lowest paid of all the state benefits. Why? The work that we do on a daily basis is one of the most stressful and all-consuming jobs that it is possible to have with most of us not having the choice to do anything else [...] even if you doubled Carer's Allowance which you won't the amount would still not reflect what we have to do for the frugal amount that carers receive! Hang your heads in shame!" (survey respondent)

"There would be no need for this award if the CA was paid at a reasonable amount, a cost of living amount. Carers give up employment to care and lose a vast amount of their income, for example if I earn £600 per week and have to give up this job to care for my loved one, I can get £67.60 per week topped up with UC to the value of £324.84 per month and a carer premium of £163.73 per month, baring in mind the CA is then deducted so my new monthly income will be £488.57 a big drop from from £2400 i was once earning. From this miserly sum I would have to pay housing costs, energy costs, food and clothing. This is why Carers suffer poor health, anxiety and deprivation, forced into a damaging lifestyle." (survey respondent)

Many survey respondents and interview participants requested to be paid minimum or real living wage that covers a basic standard of living. Some suggested they should be paid a similar payment to that of professional carers.

"Carers get the rough end of the stick all the time and let down continually [...] it doesn't even equate to the minimum wage, so they should, still get compensation even if there is assistance going through to the caree [...] I personally think carers should be paid for how long they work, so even if they're caring for 10 hours a week, you should get minimum wage for that. Because if someone was paid to do it, then they would get paid minimum wage so what do we get left out?" (interview participant)

“Make it realistic and fair. Pay carers for the hours they care for by way of a living hourly wage. Carer’s Allowance payment must not be discriminatory and based on capped earnings, but base it how many hours the cared for individual is receiving.” (survey respondent)

“...somewhere along the line you also need to make it a wage, because you can’t say if you’re not working, you’re caring, so you’re expected to live off less. I worry for people who have less and less time to even live. A lot of families suffer. People expect too much from us.” (interview participant)

What's next?

The Scottish Government will continue to work with stakeholders and the Experience Panels in the design and development of Scotland's social security system.

The findings in this report and the response to the public consultation on Scottish Carer's Assistance will be used by teams working on designing and implementing the new Scottish Carer's Assistance benefit and the Carer's Additional Person Payment.

The Scottish Government will publish a response to the consultation and further information on plans for Scottish Carer's Assistance later this year. They plan to begin to roll out Scottish Carer's Assistance by the end of 2023, with full national introduction by spring 2024.

Wider work is also ongoing in the Scottish Government to consider the potential for a Minimum Income Guarantee in Scotland. This work includes carer representatives so that the perspectives of unpaid carers is considered. The findings of this report will also be shared with the team working on this policy area.

Annex A: About Survey Respondents

Where possible, information from the survey was matched to demographic information supplied previously by Experience Panel members. The following demographic tables are included to give context to the findings presented in this report.

Table 12: Gender of survey respondents (n= 203)

	Number of respondents	% of respondents*
Female/woman/girl	134	66
Male/man/boy	66	33
Non-binary	<10	1
Other response	<10	1

* Figures may not add to 100% due to rounding

Table 13: Age of survey respondents (n=202)

	Number of respondents	% of respondents*
25-44	28	14
45-59	95	47
60-79	78	39
Prefer not to say	<10	1

* Figures may not add to 100% due to rounding

Table 14: Ethnicity of survey respondents (n=181)

	Number of respondents	% of respondents
White	176	97
Ethnic minority	<10	2
Prefer not to say	<10	1

Table 15: Disability or long-term health condition (n=203)

	Number of respondents	% of respondents
A disability or long term health condition	159	78
Another long-term condition	122	60
Chronic pain lasting at least three months	108	53
A physical disability	102	50
Mental health condition	69	34
Deafness or severe hearing impairment	19	10
A learning disability	14	7
Blindness or severe vision impairment	<10	4

Table 16: Which of the following do you give regular help or support to? Please tick all that apply (n=203)

	Number of respondents	% of respondents
An adult or adults with long-term physical/ mental ill-health/ a disability	154	76
A child or children with long-term physical/ mental ill-health/ a disability	53	26
An adult or adults who needs support due to old age	69	34

Table 17: Location of respondents (n=205)

	Number of respondents	% of respondents
Urban	157	77
Rural	48	23

Table 18: Religion or belief of respondents (n=182)

	Number of respondents	% of respondents
None	100	55
Church of Scotland	34	19
Roman Catholic	21	12
Other Christian	13	7
Other faith or belief	<10	4
Prefer not to say	<10	3

Table 19: Sexual orientation (n=181)

	Number of respondents	% of respondents*
Heterosexual/straight	155	86
Prefer not to say	12	7
Gay/lesbian	<10	4
Bisexual	<10	2
In another way	<10	1
Pansexual	<10	1
Other response	<10	1

* Figures may not add to 100% due to rounding

Table 20: Gender Identity (n=177)

	Number of respondents	% of respondents*
Identify as cis-gendered (not transgender)	169	96
Prefer not to say	<10	3
Identify as transgender	<10	2

* Figures may not add to 100% due to rounding

Table 21: Household composition I: Including yourself, how many adults (aged 16 or over) are living in your household? (n=200)

	Number of respondents	% of respondents*
Two adults	86	43
One adult	59	30
Three adults	37	19
Four adults	15	8
Five adults	<10	2

* Figures may not add to 100% due to rounding

Table 22: Household composition II: Including yourself, how many children (aged under 16) are living in your household? (n=196)

	Number of respondents	% of respondents
None	151	77
One child	30	15
Two children	<10	4
Three children	<10	2
More than five children	<10	1
Four children	<10	1

Annex B: Experiences of Carer Benefits

Which benefits respondents had received

The selected Panel members were asked if they have ever received any of the carer benefits shown in Table 23. A total of 241 respondents answered this question. More than three in five respondents (62 per cent) reported receiving Carer's Allowance and over a third (36 per cent) mentioned receiving Carer's Allowance Supplement. 10 per cent said they received the Carer's Premium of other benefit, and a third reported not receiving any of the benefits.

Table 23. Have you ever received any of the following benefits? [please tick all that apply] (n=241)

	Number of respondents	% of respondents
Carer's Allowance	150	62
Carer's Allowance Supplement	86	36
Carer's Premium of other benefit (Income Support, Employment Support Allowance, etc.)	24	10
Carer's Element (or Carer's Amount) of Universal Credit	10	4
Carer's Premium (or Carer's Addition) of Pension Credit	<10	2
Young Carer Grant	<10	1
None of the above	80	33

Why had respondents not received a carer benefit

Respondents who said that they received none of the above benefits were asked to explain why they have not received them (see Table 24). The three most common reasons they noted were: they receive State Pension or other overlapping benefit (28 per cent), they earn above the earning limit (25 per cent), and the lack of information or understanding about carer benefits and eligibility (23 per cent). 22 per cent stated "other" reasons why they have not received any carer benefits.

Table 24. Could you explain why you have not received any carer benefits? [please tick all that apply] (n=79)

	Number of respondents	% of respondents
Receive State Pension or other overlapping benefit	22	28
Earning above the earnings limit	20	25
Lack of information or understanding about carer benefits and eligibility	18	23
Caring for a person who is not eligible for disability benefits	<10	11
Not caring enough hours to be eligible for carer benefits	<10	11
Being in full time education	<10	1
Other	17	22

The “other” reasons for not for having received carer benefits which were noted by survey respondents and interview participants included variations on the options already provided in the survey question. In particular, experiences with overlapping benefits and having an income above the earnings limit. This included those who were above the earnings threshold due to receiving state pension. However, it is worth noting that concerns around overlapping entitlements also included those taking the decision not to apply for carer benefits to avoid negatively affecting the benefits that the cared for person receives.

“I’m kind of, stuck there, because the Child Tax Credits are more valuable. It’s definitely better to be on child tax credits [...] You’re doing all this caring, but you can’t be recognised as a dual-carer because you have underlying benefits. It seems grossly unfair and makes me feel like a second-class carer.” (interview participant)

“Other” reasons for not receiving carer benefits mentioned by respondents and participants were: only one carer receives Carer’s Allowance even though there are two adults providing care in one household, the cared for person is going through a disability benefit appeal process, and the carer does not want to interact with DWP.

“My wife and I care for our adult daughter. My wife received Carer’s Allowance when eligible. Now, we are both pensioners, we receive no Allowance and are ineligible.” (survey respondent)

“ I remember phoning [to DWP] to enquire about it [CA’s award] once and I remember being told if you are lying this could affect your relative’s other benefits. What personal actually says this? You become quite, you have to prioritise what is important. You’ll always get by, we fortunately did. I know people who can’t afford

to get by without having CA applications. But the stress it puts people under to wait for a decision..." (interview participant)

A small number of participants highlighted they did not have information about benefit entitlements and eligibility criteria for carers until they looked for help due to being in financial difficulties.

"For Carer's Allowance I have applied for yeah. I applied very late, basically when I had no money left, I didn't know there was such a thing as Carer's Allowance [...] It's only when I couldn't pay my mortgage; that's when I went for help basically." (interview participant)

A few interview participants highlighted their previous negative experiences of benefit application processes. They described negative experiences when communicating with DWP staff. They also described the application forms as complex and said that they needed support to complete them correctly as otherwise they would have had their application rejected.

"We got told [by advisors from support organisation] under no circumstances to fill out the form without their advice to apply for the benefit. And we got told that if we didn't get the form right or we didn't do things properly then we wouldn't get the benefit for it. When there's somebody telling you are having intense scrutiny and saying if you don't get things right then you can't get anything. there's no turning back, it's quite overwhelming. I just hope that it doesn't feel as though I will be getting tripped up at every hurdle to apply for a benefit when this shouldn't be how benefits are applied for." (interview participant)

Annex C: Experiences of paid employment and caring

Survey respondents and interview participants were asked about their experiences and views on paid employment to help the Scottish Government to consider how to support carers who wish to work or stay in work outside their caring role.

Respondents were asked if they are currently in paid employment. Almost three quarters (74 per cent) said no. 22 per cent said yes they were employees and 4 per cent said yes, they were self-employed. 1 per cent prefer not to say (see Table 25).

Table 25. Are you currently in paid employment? (n=242)

	Number of respondents	% of respondents*
/No	178	74
Yes, employee	52	22
Yes, s.elf-employed	<10	4
Prefer not to say	<10	1

* Figures may not add to 100% due to rounding

From those respondents who answered yes to be currently in paid employment, over half (53 per cent) said they work on a part-time basis and over a quarter (26 per cent) said they work full-time. 20 per cent said their work hours vary on weekly basis and 2 per cent said they prefer not to say (see Table 26).

Table 26. What type of employment are you currently in? (n=61)

	Number of respondents	% of respondents*
Part-time (34 hours or less)	32	53
Full-time (35 hours or more)	16	26
Hours vary on weekly basis	12	20
Prefer not to say	<10	2

* Figures may not add to 100% due to rounding

Benefits of carers having employment

Respondents and participants who were in paid employment were asked what were the benefits of having a paid job and being a carer.

Several survey respondents said having a paid job helps their mental health and their wellbeing, and it also enhances their lifestyle and self-esteem. Additionally, they mentioned that it reduces isolation and loneliness, allowing them to socialise and have other activities outside their caring role.

“I love my job. I only recently started paid employment after caring at home full-time for 12 years. Having a job allows me to do something I enjoy, meet people, have a social life. Feel like me again. It helps my mental health.” (survey respondent)

“Being able to use my qualifications and skills to help others, feel useful, earn a small wage to contribute to the family, have some pride in myself, have different things to talk about, be a role model to my kids, great mental health benefits. Not having to pay for childcare as my work is flexible, still being able to fulfil my role as a parent and carer for my child. It's a good balance being able to do both, something I've not been in a position to do for 9 years, until fairly recently.” (survey respondent)

“Dignity, self-respect. A life outside of caring is better for mental health. Build ability to have a life after caring stops.” (survey respondent)

Some survey respondents and interview participants emphasised that the benefits of having a paid job is to have financial security for their household income.

“It tops up your income. I am a [profession]. I can only work one day as I am almost at my income limit. I can earn that in one day when it takes 35 hours of caring to earn a similar amount in a week. It's really a no brainer as it gives a little extra income for treats, etc.” (survey respondent)

“I have to have a paid job because I can't survive purely on benefits. I was unemployed for 8 years and my mental health was really poor. I was just the boys' mum. Having colleagues and relationships with other adults is important [...] I found myself getting really demotivated when I wasn't working.” (interview participant)

“Carer's Allowance and disability benefits are a fixed amount; and not a very big amount in today's financial climate. Working part-time helps a little with extra money, and also helps with self-esteem and mental health in general.” (Survey respondent)

Challenges for carers who are in employment

Survey respondents and interview participants who were in paid employment were also asked what were the challenges of having a paid job and being a carer. Many noted that it was very challenging to juggle both activities. They stated that being

able to get flexible jobs with cooperative and understanding employers which consider the cared for person's needs was very difficult. In particular, because of the changing nature of the caring needs for the cared for person and also due to several hospital appointments. A few mentioned that sometimes those changing caring needs and emergencies can happen at very short notice.

"It can be challenging to meet the demands of caring for someone with working, e.g. not all employers offer flexible hours, carer's leave or have insight into the challenges of caring for a person and their often changing care needs. It can also be a challenge to secure paid employment that fits around a care role at all."
(survey respondent)

"Finding work flexible enough to be available for the person you care for when needed; ensuring the person you care for is ok while you are at work. Hardest part is on 'good days' when you could work an extra day for some much needed extra earnings being unable to do so as it would lose you your Carer's Allowance and make working that day pointless, this makes you feel like a failure as a provider and is extremely frustrating."
(survey respondent)

"Probably trying to fit appointments in around my work life. Going to meetings, going to care reviews [...] That's the biggest challenges, trying to juggle everything. And make sure you still doing your job to the standard your employer expects you to, but also you are also doing the best you can. 'Cos there's nothing worse than feeling guilt, that you have prioritised a paid job over a family member. But I think it's very difficult."
(interview participant)

Some survey respondents and interview participants mentioned further challenges such as the lack of work/life balance. They highlighted suffering from exhaustion, stress and tiredness. They were always lacking time, including time for their personal activities. A few mentioned that this situation could lead them to have poor health.

"Financial, time, balancing work with caring, fitting one in with the other. And a personal toll on the carer's health and finances."
(survey respondent)

"It is unbelievably stressful. I'm constantly having to change work arrangements for care issues and I never have enough hours to do everything. I never get any time for myself between work and caring."
(survey respondent)

"Sheer exhaustion, taking time off for appointments, managing to focus on work when your loved-one is unwell, knowing every second you spend away from them is a waste of time you could have with them, guilt, stress, anxiety and depression. This list is not exhaustive."
(survey respondent)

A handful of survey respondents mentioned the following as challenges of having a paid job and being a carer: financial insecurity, a limited career progression and the issue that self-employed carers have with yearly earnings.

“Career progression is limited, often stay on minimum/living wage, unable to get a mortgage or have any financial security in the longer term.” (survey respondent)

“Trying to juggle all my responsibilities and trying to deal with each crisis as it arises always putting my own needs and health to the back of the queue. Also self-employed don't know profit/loss until end of tax year so can't claim as don't know weekly income during the year as its yearly to claim then it's too late!!” (survey respondent)

Views of those not in employment

Survey respondents who mentioned they were not currently in paid employment were asked if they would like to participate in paid employment if they could work outside their caring role (see Table 27). Half of respondents said yes, a third said no and a just over a sixth (17 per cent) preferred not to say if they would like to participate in paid employment.

Table 27. If you could work outside your caring role, would you like to participate in paid employment? (n=175)

	Number of respondents	% of respondents
Yes	88	50
No	58	33
Prefer not to say	29	17

Some survey respondents mentioned that if they could, they would like to participate in paid employment because it would improve their mental health, wellbeing, self-esteem and it would reduce their feelings of isolation.

“Being a carer is an isolating life, with a low income and often time limited. Opportunities for work allow for breadth in a carer's life, time outside their caring environment and the social aspect this provides. It also allows the carer to keep a continuous work history which will be necessary to compete with others in the job market should their caring duties end or change.” (Survey respondent)

“Working would mean I would have less than my benefits, so financially worse off is not an option even though the personal benefits are huge, less isolation, more self-esteem, a bit of respite and mental health benefits.” (Survey respondent)

Several survey respondents and interview participants mentioned that their caring responsibilities do not allow them to have any time or energy to carry out other work beyond caring. They highlighted their work is 24/7 due to the nature of the health conditions of the cared for person. A few also noted their own health conditions, disabilities or their caring situation for multiple people as challenges to take on paid employment.

“I have to care 24/7 for two disabled children. There are no hours left to do a job outside the home.” (survey respondent)

“As I have a disability myself as well as caring for my child with additional support needs I have no energy to be able to work.” (survey respondent)

“I have always been a worker since the age of 15. I enjoyed the feeling of working and giving to society. As things have worked out though it is impossible for me to work. My caring role to my disabled children takes precedence and has also gone towards some of my own mobility issues. As much as the will is there and I'd love to work again, even if I had time from my caring role I'm not as able to be a reliable employee as I once was.” (survey respondent)

A few survey respondents and interview participants mentioned that it was difficult to find paid employment flexible enough that can go in hand with their caring role. A small number of respondents and participants highlighted that carers need support to balance employment and caring responsibilities.

“It's often the time off work you need for sudden illness or because the child has been sent home from school [for who knows how long], the medical appointments, etc., etc. It's not just about getting a job; it's about being able to keep the job.” (survey respondent)

“I worked for my local authority until caring responsibilities made it untenable. If carers can continue to work and care, there should be additional supports in place to allow them to do so. It's very stressful doing both long-term and can impact on the carer's own health so addition support (time out to care, hospital appointments, respite, counselling etc.) are key to allow this to happen.” (survey respondent)

“The challenges are endless. I had a job recently and it was a 2.5 day a week job, I had hoped to work the hours in the mornings, but they wanted me to go in for 2 full days and a half day, on the half day they wanted me to have an unpaid lunch hour, meaning I was in for most of the day as they wanted me to stay until late into the afternoon. Every minute of the hours I was in office, I was missing out on time where I could be making [cared for person's] food, so my mental wellbeing was suffering the whole time. There's also hospital appointments which come out of

nowhere, I sometimes get 3 or 4 letters a day about hospital appointments. Whichever person you care for, there's always additional difficult and unexpected situations which arise. It's really difficult, as the caring is manageable and predictable, but it's the unpredictable stuff that you can't manage or build in. He's a tough little boy, but it's just constant. I really want to work, especially because it's so difficult to survive on benefits." (interview participant)

A small numbers of survey respondents noted the possibility of becoming self-employed, but they were concerned about the potential issues that can arise about earning thresholds. A few also mentioned that taking on paid employment would not provide them with more financial security.

"Because of where I live [very rural], I am limited as to what I can apply for anyway because of transport - I don't drive, but equally there have been jobs advertised that I know would take me over the threshold for losing CA, when also factoring in UC and bus fares. I end up significantly worse off, all for £1 or £2. There's no incentive there." (survey respondent)

"I occasional have been offered the chance to do short-term contracts for a day here and there, but as it would take me over the limit for earnings I have declined as the loss of the allowance would end up with me being worse off." (survey respondent)

Many respondents emphasised that they cannot engage in paid employment because they are retired, disabled or have long-term conditions.

"I cannot work now as I have some physical disabilities." (survey respondent)

"Approaching my 65th birthday hence not looking for employment! Looking forward to my state pension next year, but I will lose my Carer's Allowance, yet I will continue to be a carer which is a conundrum."(survey respondent)

"I'm disabled and a carer for my disabled husband and 3 daughters still at home. 1 of which is disabled and another has extra needs, as they do care for me and until recently we all including my disabled brother in-law, all cared for my late father in-law. Sometimes, it's those of us who are struggling hardest with our own health that are left to pick up the pieces at the cost of our own health. I don't know what the answer is, but hopefully if it can be made easier and more affordable for people who may like to help more, especially those who otherwise now say they can't because of work." (survey respondent)

Annex D: List of abbreviations

List of Commonly used abbreviations in this report

CA: Carer's Allowance

CAS: Carer's Allowance Supplement

CAPP: Carer's Additional Person Payment

CB: Child Benefit

CTC: Child Tax Credit

ESA: Employment and Support Allowance

DLA: Disability Living Allowance

DWP: Department for Work and Pensions

HB: Housing Benefit

JCP: Job Centre Plus

JSA: Job Seekers Allowance

NI: National Insurance

PC: Pension Credit

PIP: Personal Independence Payment

SCA: Scottish Carer's Assistance

SSS: Social Security Scotland

UC: Universal Credit

How to access background or source data

The data collected for this social research publication:

- Are available in more detail through Scottish Neighbourhood Statistics
- May be made available on request, subject to consideration of legal and ethical factors. Please contact socialsecurityexperience@gov.scot for further information.
- Cannot be made available by Scottish Government for further analysis as Scottish Government is not the data controller.



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This document is also available from our website at www.gov.scot.
ISBN: 978-1-80525-062-3

The Scottish Government
St Andrew's House
Edinburgh
EH1 3DG

Produced for
the Scottish Government
by APS Group Scotland
PPDAS1173382 (11/22)
Published by
the Scottish Government,
November 2022



Social Research series
ISSN 2045-6964
ISBN 978-1-80525-062-3

Web Publication
www.gov.scot/socialresearch

PPDAS1173382 (11/22)