



Annex A: Qualitative Research for the Evaluation of Carer's Allowance Supplement



EQUALITY AND WELFARE

Contents

Chapter 1: Introduction	2
Chapter 2: Methodology	3
Chapter 3: Awareness of Carer’s Allowance Supplement among carers	7
Chapter 4: Impact of Carer’s Allowance Supplement on carers’ finances	9
Chapter 5: Impact of Carer’s Allowance Supplement on quality of life	19
Chapter 6: Impact of Carer’s Allowance Supplement on feeling recognised and valued by society	27
Chapter 7: Conclusions and implications for policy	31
Annex A: Topic guide	34
Annex B: Pen portraits	40

1. Introduction

Background to the research

The Scottish Government has an overall aim of supporting carers to protect their health and wellbeing, so they can continue to care if they so wish, and have a life alongside caring.¹ Social Security delivers one aspect of this overall government approach to supporting carers, including through the provision of Carer's Allowance Supplement (CAS). CAS was introduced by the Scottish Government in 2018. It is an additional payment, paid twice annually, to all those in Scotland receiving Carer's Allowance and has two main policy objectives:

1. To improve outcomes for carers by providing some additional financial support. Specifically, to positively impact on:
 - Carers' financial wellbeing
 - Carers' quality of life (mental health and wellbeing, physical health, and sense of control and empowerment).
2. To recognise the contribution that carers make to society.

Carers in Scotland who receive Carer's Allowance do not need to apply for CAS – if they are in receipt of Carer's Allowance on the qualifying dates, they will receive the Supplement automatically. To be entitled to Carer's Allowance, carers must meet certain conditions. For example, they must be over 16 years old, not be in full-time education, not earn more than £128 per week after tax, and provide at least 35 hours of unpaid care per week to someone in receipt of certain disability benefits.

Ipsos MORI was commissioned by the Scottish Government to carry out qualitative research with carers exploring any impact CAS may have had on their lives. The findings from the qualitative research in this report will sit alongside other sources of data to inform the Scottish Government's full evaluation of CAS and feed in to the Scottish replacement for Carer's Allowance.

Structure of this report

The next chapter describes the research methods. Chapter 3 looks at carers' awareness of CAS and its purpose. Chapter 4 discusses the way carers used the payment and the impact on their financial wellbeing. Chapter 5 explores the wider impact of CAS on carers' quality of life and Chapter 6 looks at whether CAS has made carers feel recognised for their role. The conclusions and implications for policy are discussed in Chapter 7.

The topic guide used for the interviews is shown at Annex A and four short pen portraits, illustrating the different experiences of CAS recipients, are provided in Annex B.

¹ Scottish Government (2019) <https://www.gov.scot/publications/support-carers-policy-position-paper/>

2. Methodology

Aims of this qualitative research

This qualitative research is one strand of a wider programme of evaluative research to assess the impact of CAS. It had five main objectives:

1. To provide information on the extent to which carers were aware of CAS and its purpose (see Chapter 3)
2. To provide information on the ways, and extent to which, CAS impacts on carers' financial wellbeing (see Chapter 4)
3. To provide information on the ways, and extent to which, CAS impacts on carers' quality of life including mental health and wellbeing, physical health, and sense of control and empowerment (see Chapter 5)
4. To provide information on the ways, and the extent to which, CAS impacts on carers' feelings of recognition (see Chapter 6)
5. To identify any implications for policy development (see Chapter 7).

What was involved?

In-depth qualitative interviews, lasting around 45 minutes to 1 hour, were conducted with 41 carers. This methodology was felt to be the most suitable approach for three main reasons:

- It is the most appropriate method for exploring sensitive topics, maximising participants' sense of privacy, and the opportunity for rapport-building between the researcher and the participant
- It enabled us to include carers from across Scotland, including very remote areas
- It allowed us to accommodate the round-the-clock responsibilities of some carers.

Fieldwork took place in March and April 2020.

All interviews were conducted by telephone. While the majority of interviews were originally planned to be conducted by telephone, 12 interviews originally planned to be conducted face-to-face were moved to telephone due to the COVID-19 outbreak. To utilise the savings made on researcher travel, an additional five interviews were conducted.

Interviews were conducted by researchers from Ipsos MORI Scotland (the authors of this report), using a flexible topic guide to ensure key issues were covered with each participant. The topic guide is attached at Annex A.

The discussions were audio-recorded with participants' permission and detailed notes were made after each interview, summarising views on key topics. The data collected was systematically reviewed to identify the full range of views expressed.

All carers received £30 as a 'thank you' for their time. They were offered a choice of a BACS transfer or an e-voucher which could be spent online.

Despite the fact that fieldwork took place at the time of the COVID-19 outbreak, and 23 of the 41 interviews took place during the resultant lockdown in Scotland, this did not appear to affect the data collected. Carers remained comfortable participating and we were able to conduct focused and in-depth discussions of their experiences of the Supplement in these circumstances. Indeed, its universal relevance helped researchers to build rapport with participants. Further, interviews were purposely focused on perceptions of experiences of previous payments, which were last received in 2019, rather than on participants' current circumstances.

Who we spoke to

All participants were carers who had received CAS within the last year.

Our approach to recruitment involved two strands:

1. From respondents to the 2018 Scottish Household Survey who agreed to be contacted for further research (34 carers were recruited this way)
2. Through gatekeeper organisations, including the Minority Ethnic Carers of People Project (MECOPP) and Lanarkshire Carers' Centre (7 carers were recruited through these two organisations). This approach helped to ensure that we were able to represent carers of different ethnicities.

Table 1.1 Profile of participating carers

Gender	Female	32
	Male	9
Age	18-34	4
	35-54	21
	55+	16
Person caring for	Child under 18	10
	Adult son or daughter	12
	Partner	13
	Parent	1
	Sibling	1

	Friend	1
	More than one person	3
Disability or serious long-term health condition	Yes	12
	No	29
Geographical area	Urban ²	33
	Rural	8
	The sample included participants from 20 of the 32 local authority areas in Scotland	
Ethnicity	White Scottish/British	37
	White Polish	1
	Asian Indian	1
	Asian Pakistani	1
	Asian Other	1
Total in each category		41

Scope and limitations

Qualitative samples are designed to ensure that a range of different views and experiences are captured. It is not appropriate to draw conclusions from qualitative data about the prevalence of particular views or experiences. As such, quantifying language, such as 'all', 'most' or 'a few' is avoided as far as possible when discussing qualitative findings in this report. Relatedly, while we aimed to ensure some representation across different groups (e.g. by disability and by ethnic group) we are not suggesting it is appropriate to identify patterns or trends in the experiences of these groups.

Furthermore, it must be acknowledged that, while the research seeks to assess the impact of CAS, we are reporting carers' perceptions of the impacts rather than definitive impacts. When dealing with perceived impacts there is inevitably room for error. There is a risk that impacts may be over or under-stated or misattributed, given the difficulty of individuals accurately identifying and isolating the impact of a specific intervention from all other contextual factors that might influence their behaviour or experience.

² Based on the Scottish Government's 2-fold urban/rural classification ('urban' being settlements with 3,000 or more people and 'rural' being areas with fewer than 3,000 people).
<https://www2.gov.scot/Topics/Statistics/About/Methodology/UrbanRuralClassification>

We were only able to interview two participants who had started receiving Carer's Allowance after CAS was introduced (April 2018) and so had always received both payments. The findings are therefore based very largely on carers who had experienced the introduction of CAS and who could compare the situation before and after. If CAS was to continue longer-term in a similar form, the impact on those becoming carers in the future might be different (for example, they may not see CAS as a bonus in the same way, and they may not see it as an acknowledgement of their role by the Scottish Government). Similarly, even among carers who received Carer's Allowance before the introduction of CAS, these aspects of its impact may lessen over time as they become more accustomed to receiving it.

3 Awareness of Carer's Allowance Supplement among carers

Key finding

Levels of awareness about CAS were high – carers generally knew when it had last arrived, how much it was, and were able to at least speculate at the reasons it was introduced by the Scottish Government with some accuracy.

Awareness of Carer's Allowance Supplement and its purpose

Awareness of the existence of CAS was very high. Generally, carers were very aware of having received the payment, knew roughly when they had last received it, and had a very good idea of the amount.

Carers had typically first heard about the Supplement by letter. Much less commonly, others had heard by word-of-mouth or on the news. When they first learned about the Supplement, carers were pleased, surprised and grateful, and started thinking about how they could spend it.

Some carers did not remember receiving a letter and said the money had just arrived in their account without warning. Participants' experience of this varied – for some it had been a pleasant surprise, while for others it had caused some initial stress because they were worried a mistake had been made. However, in those latter cases, participants had fairly quickly been able to establish – through looking on the internet or asking professionals – that the payment was intended for them and at that point they were very pleased.

With exceptions, participants knew that CAS was paid by the Scottish Government.

Knowledge about what made them eligible for CAS varied, with carers falling into three groups: one group knew that you had to be receiving Carer's Allowance to get CAS, another thought you just had to be a carer, and the third group was unable to give any information about eligibility for CAS.

Overall, levels of awareness about the purpose of CAS were mixed. Carers were generally able to name at least one objective of the policy, but participants sometimes had to make a guess and tended to be a little unsure. Reasons given by carers included:

- That the Scottish Government recognised that Carer's Allowance alone is not enough money and brought in the Supplement to help carers pay for the things they need

- That the Scottish Government recognised how much more expensive it would be if care was no longer provided by unpaid carers, and instead was provided by paid carers carrying out home visits or caring in residential care homes. The Scottish Government therefore wanted to thank carers and incentivise (both current and potential) carers to keep care in the home
- More generally, that the Scottish Government wanted to show their appreciation and recognition of carers
- That the Scottish Government wanted to top up Carer's Allowance to make it the same amount as Jobseeker's Allowance, so they brought in CAS to bridge the gap – carers who identified themselves as politically engaged were in some cases able to give this level of specificity.

4. Impact of Carer's Allowance Supplement on carers' finances

Key findings

Typically, carers liked the current payment schedule (two lump sums per year) as it meant they could spend on bigger things and felt they had more to show for it.

Carers used payments in various ways, including spending on Christmas, on general household needs, on home improvements, or on trips and other treats. There was no clear pattern in terms of participants' financial position and how they chose to use the payment.

Carers who were struggling the most financially felt the biggest impact – whether they had spent it on treats or trips away, which they would not have otherwise been able to have, or whether they had spent it on essential household expenses, which they would otherwise have struggled to pay for. Carers who were financially comfortable but had spent it on treats also felt a benefit, as they were unlikely to have had those enjoyable experiences without the payment. The least impact was felt by carers who had spent it on general household needs but who already had enough money to pay for these things.

While carers were grateful for the payment and could identify positive impacts, they tended to say that the payment had not helped their day-to-day finances – they felt they only benefitted during the months that CAS arrived. This was the case regardless of their financial circumstances.

This chapter seeks to shed light on the following research objective:

To provide information on the impact of receiving CAS on the perceived financial wellbeing of carers, exploring:

- the ways, and extent to which, it has impacted on household budgets
- the ways, and extent to which, it has impacted on the financial implications of caring.

Carers' finances

The carers we interviewed for this project fell broadly into three groups in relation to their finances.

One group was really struggling to meet their daily living costs. They had no savings (or extremely limited savings), and often had debt which caused them stress. They had to borrow from family or lenders from time to time, and some months had to go to foodbanks. They frequently worried about finding the money to pay for their day-to-day needs, like food, heating the house, or taxis to hospital appointments.

This situation was most common when no-one in the household worked: for example, among single parent families (including those looking after adult children) or those who had given up work to look after their partner.

"We're really struggling every month. Of course finances worry me, the situation worries me, I'm really stressed – physically and mentally."

Female, 35-54, Caring for partner

The second group did not necessarily have high incomes, but they did not have to worry about paying for daily essentials. They did not have to consider turning to lenders during financially stressful months or using a foodbank. However, there was still some level of pressure about money. They did have to think carefully before buying, or paying for, more expensive things such as a trip away, or housing improvements.

"Last year I decided I'd give driving lessons a go – [my daughter] has a lot of hospital appointments and so do I, and just for the freedom factor as well it seemed sensible to try and drive. So, it's kind of things like that – big things that would benefit us where I'm like 'Right. Can I afford this? Can I do this?' It's more that. But there's always food in the cupboard, [...] in regard to food, heating, electric, essentials... they're always, always covered."

Female, 35-54, Caring for child under 18

The third group expressed little to no worry about money issues. This was for a range of reasons. Some people had a partner who was in well-paid work, which allowed them to live comfortably even if they felt that their own income (from Carer's Allowance, CAS and sometimes other benefits) was inadequate to meet daily living costs. Others had already retired when they became a carer. They had anticipated and planned for their current financial situation and, although their income was not high, they often owned their home outright and had minimal outgoings. Other participants had received a cash injection at some point in the past (such as money gained in a divorce, or a life insurance payment), which meant they did not have to worry about money.

"I am very fortunate that my husband has a decent wage, not hundreds, but circumstances mean that we don't have a big outlay ourselves, we are mortgage-free through another circumstance, so my husband's wage kind of keeps us."

Female, 35-54, Caring for adult daughter

The impact of caring on finances

Carers consistently reported that becoming a carer had had a major, negative effect on their household finances. It was more exceptional for carers to say that becoming a carer had made no financial impact (or even had a positive impact).

The main way that caring had affected finances was that participants were unable to work due to their caring responsibilities. Participants had often been working full-time before they became a carer, and one carer had been forced to shut down a business as it became unfeasible to manage her company alongside her caring responsibilities.

Where carers, generally mothers, were looking after their children who were disabled or had additional needs, they had typically been unable to return to work when they otherwise might have done (for example, when their children reached nursery or school age).

Participants stressed that being unable to work also had significant impacts on their wellbeing and sense of identity, as will be discussed in the next chapter. For some participants, this had affected them more than any financial repercussions. Those who had gone back to work after taking a break to care had done so not for financial reasons but mental health ones.

Participants reported issues relating to the conditionality of Carer's Allowance – specifically, the fact that they were not permitted to earn very much (and therefore not able to work many hours) before they became ineligible for it. This meant that some carers who wanted to work – who would have benefitted mentally from having a job and who could have combined part-time work with their care responsibilities – were unable to do so. By going back to work, they would quickly lose Carer's Allowance, but still not be working enough hours to support their household.

“I wish they could do more so that people could go back, because I would love to go back to work, even part-time, I would love to go back to something, because I feel like there is not a lot for the carers and sitting in the house 24/7, I'm only 55 and I feel like that's the end of my life really.”

Female, 55+, Caring for partner

Another related impact felt by some carers was that their educational aspirations, and possible related long-term earning potential, had been interrupted by the demands of caring. One participant had been pursuing a PhD and had hoped to find a career in the same field, but when his caring responsibilities became too much, he had to withdraw. Another carer stated that she would have liked to go to college to gain the skills and qualifications to start working in the childcare sector. However, although she had been considering this for some time, she now felt that she had no energy for it due to the volume of care work required within her own household. As well as the immediate consequences of this educational disruption,

carers' longer-term earning potential and ability to pursue their ideal career were also affected.

A third impact of caring on finances related to the extra costs carers experienced as result of their caring responsibilities. For example, one participant who cared for a friend who lived several miles away reported difficulty paying for petrol to get there, petrol for drives/outings with her friend and for the additional costs associated with an outing (such as coffees or ice-creams). Carers also mentioned taxis to hospital appointments. In one case, a participant's husband had been taken by ambulance to hospital in the evening, and when he was kept in overnight, she did not have £20 to pay for a taxi home – so she had to walk two hours in the middle of the night to get back. In these cases, being a carer had resulted in direct costs which participants struggled to meet.

Views on how Carer's Allowance Supplement is paid

CAS is paid every six months in lump sum payments – the December 2019 payment (the most recent one at the time of fieldwork) was £226.20. The dominant perspective among carers was that this twice-yearly payment schedule was better than any alternatives. Carers gave the following reasons for this preference:

- Lump sum payments allowed them to spend on bigger expenses – either bigger treats (such as a trip away) or more expensive necessities (such as larger, quarterly bills). Carers who were struggling financially found it difficult to find a large sum of money, as they had limited savings or disposable income. It was therefore perceived as very helpful that the Supplement came in a lump sum, and carers felt that they subsequently had more to show for it.
- They felt that they would not notice the money to the same extent if it was split up and paid with their regular Carer's Allowance money throughout the year as it would be spent on day-to-day household needs and they would not benefit from it in the way described above. They thought it would also get mixed up with other sources of income (wages, partner's wages, other benefits etc.) and not spent on something specific.
- The lump sum gave carers something to look forward to – they could plan how to spend it and anticipate its arrival.

A more exceptional view was held by those carers who would have preferred to receive the payment split up and paid with Carer's Allowance. The carers who held this opinion tended to have spent the payment on on-going household expenses rather than bigger items, treats or activities. They felt that more regular payments would make it easier for them manage their daily needs and pay for regular expenses. One carer mentioned that she had worked for a long time before becoming a full-time carer, and had always organised her money monthly as that was how she was paid.

A third group of carers had no preference for how the payment was scheduled.

How carers used Carer's Allowance Supplement

Carers were grateful for the Supplement and had used the money in a range of ways. At the time of fieldwork, the most recent payment of CAS would have been paid during winter 2019. Carers were asked how they had spent this last payment. They reported spending on Christmas, spending on general household needs and bills, spending on home improvements or spending on a trip away or other 'treats'. Participants did not report saving the payment.

As the Scottish Government intended, carers did not seem to think the payment should be spent in any particular way – they felt it was their decision.

There was no clear pattern between those in different financial groups (described at the beginning of this chapter) and the way they spent the money – some of those who were struggling the most financially spent it on treats, some of those who were most financially comfortable spent it on bills, and vice versa.

Spending on Christmas

One group had spent their supplement on Christmas expenses. Participants commented that December is a long and often expensive month and the payment helped them cope with the costs of the festive season. For example, one participant had spent their supplement on presents for grandparents, and on Christmas dinner. Another had spent the payment on VIP concert tickets to a band her daughter (the person she cared for) loved. A third had spent the payment on toys for her children, including a tablet and a Lego set. One participant had given a large portion of the Supplement directly to her son in his Christmas card, for him to spend however he liked.

Financially, this group would generally have been able to pay for some type of celebration even without the Supplement. However, they would have had less money to spend on food or presents, and Christmas might have been more financially stressful.

"I wouldn't have been able to do as much [without CAS], like I wouldn't have bought the extra things I wanted to buy [my son] – he would have just gone without it. In terms of the dinner, I would have still bought something, but it would either be the same thing or similar but not so much of it, or maybe from a different shop – because everything has different prices. So, it definitely helped."

Female, 18-34, Caring for child under 18

Others indicated that, without the payment, they would not have been able to spend on Christmas in the way they would like, or be able to pay for what they saw as a 'normal' Christmas.

"We spent it on Christmas presents for the grandkids because we were panicking, we didn't have enough to get them anything. The kids were saying 'don't worry about it, they won't know'. But we

would know. But then when that came in [...] we were able to go and get them a wee thing which made a difference to us. I know it sounds silly, but just even to get them a wee thing from us made a difference.”

Female, 55+, Caring for partner

Spending on general household expenses

Another group had spent the most recent payment on general bills and household expenses. In some cases it had been absorbed into their normal budget, and in other cases, carers remembered spending it on particular bills or expenses.

For example, some carers in this group had spent the payment on groceries. One carer said that she had spent most of the payment on a big supermarket shop to fill up the freezer and left the rest of the money in her bank account to help when the next set of direct debits were due in January. Another carer was especially glad to have the Supplement to help with their food expenses – which were particularly high both because they lived very rurally and because they had to buy gluten-free items.

Other carers in this group used the payment on bills. Some carers worried about the cold season and how they would afford to keep their home warm enough. One carer who had spent the payment in this way was particularly worried about paying for heating, because the person they cared for was on dialysis and needed to be kept warm for medical reasons. Their family could only afford to keep one room as consistently warm as he required, which meant that he was generally confined to this one room, and the rest of the house was not as well-heated. Receiving the Supplement in winter was therefore particularly appreciated as it alleviated some of this worry.

“Grateful for having it [the Supplement], because at that point of time we don't really know what the winter is going to bring to us or what the weather is going to be like. [...] Mainly heating, yes, it's our main thing [worry].”

Female, 35-54, Caring for adult sons

In some cases, carers would have struggled to pay for these essentials without the payment, or would have had to go into debt or go to a food bank. It is important to note, however, that not everyone who said the money had been absorbed into their normal budget would otherwise have worried about paying for necessities. In some cases, the money just went into their bank account and was spent, along with the rest of their money, on the things they needed or wanted – it was not the case that they would have had difficulties paying for these things without the Supplement.

Spending on trips away, treats, or other enjoyable activities

A third group spent the money on trips away, treats or other enjoyable activities. These were generally things that they would not have been able to do without the Supplement.

For example, one carer had spent the payment on a few nights away in Edinburgh for her and her family. They visited the Christmas markets, which her daughter enjoyed, and were able to have a genuine break from the stresses of normal life. Without the payment, they might still have been able to go, but would have had a shorter stay or would not have been able to bring her daughter's grandmother along – which would have meant less of a break for the carer and her husband.

“Well, we probably wouldn't have been able to go, or we might have gone but we might just have gone for the day or one night and maybe just gone on our own, but because we had enough to pay for two rooms for two nights, we did that. [...] Well, it just meant we could have a longer lie one morning, or my mother-in-law could take our daughter down for breakfast and then we can come down and catch up with her. Or we might have had time for a coffee or for me to pop into a couple of shops while [my mother-in-law] looked after her.”

Female, 35-54, Caring for daughter

A different carer had spent some of the money on going to the hairdressers which was something she very rarely did (partly because of the need to find someone to look after her husband while she was out). However, her husband had suggested she did that with the Supplement, saying “you go and treat yourself”, and she had arranged for her sister to look after the family while she was out. Another carer had used part of it to take her son and grandson to an autism-friendly cinema showing.

In another case, a carer had spent the money on her child's trip to play wheelchair curling. They stayed in a hotel, and the CAS payment meant that they were able to make it into a family holiday and join in with the social aspects of the trip (such as meals out).

Spending on home improvements

The last group of carers spent the money on home improvements. One carer had spent the money on carpeting for their new home – they had just moved out of a homelessness unit and were happy to be able to spend on their new accommodation. Another carer had used the payment (along with some other money) to redecorate parts of their house – this gave the home an upgrade they had been struggling to find the money for and he said it gave them ‘a real boost’ as a family.

How previous payments were spent and plans for future payments

When asked how they had spent previous payments, participants tended to report that they had spent it in the same way as the most recent one. This seemed to depend on carers' perception of what they felt the Supplement should be used for. For example, if they had decided that the payment was for treating the person they cared for, they would spend it that way every time, or if they saw it as something to help them pay the bills they would spend it that way every time. To be clear, carers did not think that the government had given any instructions on how it should be used, they felt it was their decision.

“No, everything that we get like that when it comes goes to my daughter, we spend it on her, the stuff that she needs. I don't spend it on myself even though it's my Carer's Allowance, if you know what I mean. [...] No, I see it as more for her.”

Female, 35-54, Caring for child under 18

Another carer mentioned that she could easily have spent a previous payment on credit card bills which needed paying. Instead, she had put the money in an envelope and used it on activities and enjoyable things, because she felt that the government had introduced the payment to be a bit of money that carers did not have to worry about – she perceived CAS as a payment separate to her other income, intended to give carers “a breath of fresh air”.

Carers were also asked about how they planned to spend the next payment. Generally, they either planned to spend it in the same way they had spent previous payments, or they had not yet made any plans. Some spent the payment according to the time of year it arrived and had mentally set aside the summer payment for things like school uniform, holidays, or their TV license (in the same way that they had mentally set aside the winter payment for things like Christmas and heating bills).

For the carers who were interviewed after the COVID-19 lockdown began³, their answers about how they would spend the next payment were influenced by that situation. For example, one carer usually used her payment on enjoyable activities, like taking her son out for a meal. She assumed this would no longer be possible due to the lockdown, so instead she planned to let him buy things online. Others were more uncertain about how to spend the payment because of heightened financial insecurity due to the crisis – their decision about how to spend the summer 2020 payment would depend on the extent to which the COVID-19 crisis affected their household income⁴.

The impact of Carer's Allowance Supplement on finances

CAS impacted different groups of carers in different ways.

Overall, the payment seemed to mean the most, and made the biggest difference, to those who were struggling the most financially. For those in this group who had used it on bills and general expenses, they were able to identify clear impacts, and in some cases the payment had stopped participants from having to go to a foodbank or get into debt.

“Well, I would have been at foodbanks, either that or I wouldn't have paid a bill in December and left it 'til January then I would have struggled a bit in January, because it would have been double bills in

³ 23 of the 41 participants were interviewed after the 24 March 2020 when the Government advice across the UK was to stay at home and only leave for certain specified reasons

⁴ All the interviews took place before the announcement of the Scottish Government's proposal for an additional COVID-19 supplement for carers.

January then coming out, so I would have been at foodbanks either December or January.”

Female, 55+, Caring for partner

For others who were struggling financially, the payment allowed them to spend on less ‘essential’, more enjoyable things that would have been financially impossible without the Supplement. This group found it very difficult to find larger sums of money – they had little income, and their income covered their outgoings just barely, if at all. They therefore felt unable to save and would have found it very difficult to find £226 at one time without borrowing money. The payment therefore allowed them to spend on more expensive, but often much-needed, enjoyable experiences like trips away. They reported feeling relief at being able to take a break from the stresses of their normal life and going away as a family helped bring them together.

In summary, whether they spent the payment on necessities like food, or on treats like a weekend away, the carers in this group benefitted from the payment the most and felt the biggest impact as a result of the payment.

Those who were not struggling financially to any great degree also felt the benefit of the payment when they had spent it on a trip or other enjoyable activities. They might not have been particularly worried about money, but they still felt it made a difference and were grateful for its impact because they had deliberately set it aside to spend on their family’s enjoyment.

Where CAS seemed to have the least financial impact was when it was absorbed into the general budget of households who generally had enough money anyway. In these cases, carers were grateful to have the payment but were unable to name any real financial impacts. When asked what they would have done without the payment, they reported that they would have had no problem still paying for the things they needed and wanted.

Participants of every income group appreciated the payment as “a wee boost” and for some carers the Supplement had made a real difference to their lives – it had allowed them to spend on things that were important to them that they otherwise would not have been able to afford. However, even among those struggling financially, carers had not typically noticed a more general, day-to-day difference in their finances as a result of the Supplement. Carers gave various reasons for this, including:

- They were only aware of benefitting from CAS in the two months a year that it arrives – they did not feel that it changed their financial situation the rest of the year
- They used the payment on a treat, so it did not affect their day-to-day budgeting for more usual expenses
- Although they appreciated the payment, they had noticed other costs going up (such as living expenses and council tax) so there was a feeling that they were still “chasing their tail” financially

- They do not worry about money anyway, so it had not had an impact on their perceptions of household budgets.

When participants were asked whether they rely upon CAS, responses were mixed. Among carers who said they did not rely on it, one reason was that they viewed the payment as a bonus rather than relying it as part of their normal income. Specific references were made to welfare cuts, with some carers feeling that CAS was a bonus that could be stopped at any time.

“It just gets swallowed up, so [my household] doesn’t rely on it, because it’s quite new and I’m sure the government could quite easily just take it away as soon as they give you it. I don’t know how long, if they’re talking about indefinitely for this, I really don’t know, but definitely you can’t rely on it, no.”

Female, 35-54, Caring for child under 18

On the other hand, there were those who did report relying on CAS. These tended to be among the carers who were struggling the most financially. They described the payment as a “Godsend” and a “lifesaver” which went a little way to alleviating their near-constant money worries.

5. Impact of Carer's Allowance Supplement on quality of life

Key findings

In general, the carers that we interviewed reported that their mental health was poor or variable, and had been negatively impacted by their caring responsibilities. Issues commonly raised included the physical and emotional toil of round-the-clock care; anxieties about the health and wellbeing of the person they care for; worries about finances; isolation; and not being able to undertake paid work.

Typically, CAS had helped improve their mental health and wellbeing a little: it had a positive impact on relieving money worries around the months carers received the payment, and had given them “a wee lift”.

More exceptionally, its impact on mental health and wellbeing had been transformative. This was in cases where it had enabled carers in great financial difficulty to pay off debts or where it had been used towards a trip away when carers felt they were close to breaking point.

There were mixed views on the impact of CAS on carers' sense of control and empowerment. It had made the biggest difference to those who were struggling the most financially by helping them to feel more on top of their finances and more prepared for upcoming expenses. Others thought it had made little difference overall.

CAS had generally not had a big impact on carers' physical health. However, there were a few examples of it being used to support physical health including buying healthier food, affording more heating in winter, facilitating exercise hobbies, or enabling the purchase of back and knee support items.

This chapter explores the impact of CAS on carers' quality of life, looking specifically at any impact on mental health and wellbeing; feelings of control and empowerment; and physical health.

Carers' mental health and wellbeing

Typically, when asked about their mental health and wellbeing, carers reported that they tried to stay positive, but that they experienced variable or poor mental health. It was common for carers to remark that life was “difficult at times” or that they had been “up and down” or had “good days and bad days”. However, there was also evidence of factors which had help maintain or improve wellbeing among some carers.

Some carers, in addition, had experienced anxiety and depression to varying levels of severity. Among this group, there were carers who said that they had “reached breaking point” in the past, had “cracked”, had suicidal thoughts, or had been

through “dark times”. Generally, these carers reported that the worst period had been when the person they were caring for received their diagnosis or the point where their condition had worsened significantly.

There were four main ways in which caring was reported to negatively affect carers’ mental health and wellbeing: the round-the-clock demands and anxiety about their loved one’s condition; the social isolation; worries about finances; and having to give up work. This reflects wider research on the experience of intensive unpaid caring. Each of these is discussed in more detail below followed by an outline of the factors contributing to good mental health and wellbeing among some carers.

The round-the-clock demands and anxieties of caring

Firstly, caring responsibilities had contributed directly to heightened anxiety and stress. Carers consistently made reference to the mental stress associated with needing to frequently attend to, or be constantly available for, the person for whom they were caring. There were also the underlying fears about their loved one’s condition deteriorating. This often led to carers feeling constantly anxious which could impact negatively on carers’ sleep.

“You’re constantly on alert, can never get to relax mentally.”

Female, 35-54, Caring for adult daughter

Carers were typically unable to obtain any respite care (whether formal or informal) but also unable to find any momentary respite in the form of short breaks during the day or even throughout the week. For the most part, carers had not found the time or care cover to attend carers’ group meetings. One carer contrasted this aspect of caring with working as a teacher, reflecting that, while the school staff room had made the challenges of teaching manageable by providing “breathing space”, and opportunities to “diffuse” by talking through experiences with colleagues, she really suffered from the lack of such a space available to her as a carer.

Isolation and lack of social interaction

A second way in which caring responsibilities affected mental health was through limiting social interactions. Those caring full-time reported feeling isolated due to few or no opportunities to socialise, with some losing friends as a result of having to care round-the-clock and not being able to leave home. Some carers commented that they had not been out for an evening in years. This sense of isolation tended to be heightened among single mothers caring for children (who specifically missed adult company), and in cases where the person for whom they were caring had a disability or condition which limited the quality of their social interaction (e.g. dementia).

Among those who lived with others besides the person for whom they were caring, there were those who felt quality time with their partner and/or family had been limited as a result of caring.

Worries about finances

Thirdly there were worries about finances. As discussed in Chapter 3, there were three groups of carers: one group was really struggling to meet their basic needs and frequently worried about money; a second group did not have to worry about paying for daily essentials but still felt some level of pressure about money; and a third expressed little to no worry about money issues. For more details on this, including the impact of caring on finances, please see Chapter 3.

Having to give up work

Some carers reported that caring had impacted on their employment and career. This not only impacted on finances and feelings of social isolation (referenced above), but on their sense of identity.

There were carers who had been forced give up their jobs as a result of caring which had an immediate impact on their sense of identity. They expressed a sense of loss of a prior, more independent, way of life.

For others, being out of work for an extended period had caused concerns about future employment prospects and the potential to pursue their desired career path. In some cases, this was because becoming a carer had interrupted their education while others had wished to pursue vocational courses while they were caring, but not had the time or energy to do so. These carers felt that their inability to pursue a career of their choice had compromised their identity, autonomy and sense of purpose.

Factors contributing to good mental health and wellbeing

There were carers who said they maintained good mental health. There were those who felt that caring had no negative impact because they felt being able to spend their time with their loved one, for whom they cared, was the most important factor for their wellbeing.

Others indicated that they had been able to prevent or offset any the negative impacts of caring on their mental health through taking measures to promote their wellbeing. These included working, pursuing hobbies, exercising and attending support groups.

A more exceptional perspective was that caring had an overall positive effect on mental health and wellbeing. These carers felt supported by family and friends and had made valuable connections with other carers. One described how caring had changed her outlook, making her more open-minded and accepting, and less judgmental of others.

“Not negative, positive – I’ve made friends for life in other carers. It opens your eyes and makes you non-judgmental.”

Female, 18-34, Caring for children under 18

Impact of Carer's Allowance Supplement on mental health and wellbeing

The dominant view among carers was that CAS had helped improve their mental wellbeing a little. Carers repeatedly described feeling “excited” in anticipation of receiving it, and “happy” and “relieved” when they received it.

“It’s nice to think there’s something coming to be excited about.”

Female, 35-54, Caring for adult daughter

“Ok – I can breathe!”

(Another) Female, 35-54, Caring for adult daughter

Carers consistently reported that CAS had given them “a wee lift” in the context of their round-the-clock responsibilities, or commented that it had taken a little of the “weight off the shoulders” by slightly reducing stress about money. Among those struggling more financially, CAS reduced their worries about money for a few weeks, and in some cases their uncertainty about being able to pay off bills. For those who were just “getting by” – able to afford essentials but little else – CAS was a welcome “bonus”, enabling them to have some disposable income to spend on themselves and other family members.

A main perceived limitation to CAS’s impact on carers’ financial worries was the time-frame over which it had an impact. Carers tended to report that it generally only made a difference in the few weeks after they received it.

For those who did not have to use CAS on day-to-day expenses, it helped to promote carers’ wellbeing in other ways. A common way that carers in this position had used it was on holidays, short breaks away or days out, which they felt were very beneficial, and offered “a breather” from their isolation and round-the-clock demands of their day-to-day responsibilities. In addition to enjoying the breaks at the time, carers found value in being able to look forward to them in the preceding weeks and months, and creating happy family memories to look back on. Other carers got a “boost” from being able to celebrate family birthdays with a meal out – which was particularly cherished in the context of the limited range of special occasions they were able to enjoy.

While the dominant view was that CAS had helped improve their mental health and wellbeing a little – rather than a great deal – for others it had a transformative impact. There were two main circumstances in which it made such a difference.

The first was in the context of great financial difficulty, where CAS had been used to pay off debts. For these carers, CAS had provided a huge sense of relief and lifted a great burden.

“[Being able to clear debts] was amazing – they had felt never-ending before.”

Female, 55+, Caring for adult son

A second circumstance in which CAS had been transformative was among carers for whom it enabled a trip away at a critical moment, when they felt they were really suffering with their mental health.

“Without money to go on trip I might have had a breakdown – I was on the mental edge.”

Female, 35-54, Caring for a child under 18

In exceptional cases, carers felt CAS had not helped their mental health or wellbeing at all. This was generally for one of two reasons.

For some carers who were struggling financially, CAS was felt to be too little money to ease their financial worries. They remarked that even with CAS, money remained a constant concern and that it was therefore not able to change their situation.

“I still have to worry about money every week, so [it makes] no difference.”

Female, 35-54, Caring for a child under 18

For other carers, any relief of financial worries was overwhelmed by other issues which they felt money could not address. These included feeling socially isolated, feeling that they lacked support, and feeling fearful about the health of the person for whom they care. Among those for whom these were the main contributing factors to poor mental health, CAS was unable to provide a sense of emotional relief.

Carers' sense of control and empowerment

Carers generally expressed a sense that their caring responsibilities had impacted negatively on their feelings of control and empowerment. There were a range of ways in which it had this effect: through contributing to worries about money and finances; through making it more difficult to plan for the future or to plan social activities; and by limiting where they could go or what they could do on a day-to-day basis.

Impact on control and empowerment

There were mixed experiences in terms of the impact of CAS on carers' sense of control and empowerment. Carers' experiences in this regard tended to align with the extent to which CAS had reduced financial worries.

For those who were struggling the most financially, it had helped them to feel more in control by enabling them to stay “in the black”, reducing the likelihood or frequency that their essential outgoings would exceed their income.

“Seeing my debt come down was brilliant and knowing there were only a couple of months to go [before the next payment].”

Female, 55+, Caring for adult son

For other carers, who were not necessarily in debt, but nonetheless had some financial worries, CAS improved their sense of control and empowerment by enabling them to plan their future spending rather than living reactively.

“Instead of worrying about paying things last minute, I think ‘that’s in place’, and I can plan.”

Female, 18-34, Caring for child under 18

“It allows you to plan to use it in a beneficial way.”

Female, 35-54, Caring for adult son

For carers who were able to put the money towards holidays and birthday celebrations, they described how planning these special occasions gave them a sense of empowerment. It helped them focus on the nice things they could still do with their family, rather than on the ways in which their caring responsibilities restricted them.

“Being able to plan birthday meals helps [me feel in control] – gives me something to look forward to.”

Female, 35-54, Caring for partner

For others, CAS had not really enhanced their sense of control or empowerment, or its impact in this respect was limited to the few weeks immediately after they received it. There were two perspectives on this.

The main perspective among this group was that the amount of money they received was not enough to make a significant difference to their sense of financial security and money remained a worry. It was felt that the money was not enough for large expenses and was more of an “extra” or top-up to their main income.

“It’s only twice a year, it’s only a small amount. It’s a nice cushion but it’s not life-changing money. It did help but just as an extra. It’s not £100 per month – that would be life changing money.”

Female, 35-54, Caring for child under 18

“It’s not enough to affect that [sense of control and empowerment].”

Male, 55+, Caring for partner and children under 18

Others emphasised the short-term nature of the effect, saying that while it helped

them at the time they received it, its impact on their life was limited to just a few weeks.

“In June yes [increases sense of control and empowerment], and at Christmas, but not the rest of the year.”

Female, 55+, Caring for partner

A more exceptional perspective was that, while CAS helped carers to feel more in control of their finances, this faded into insignificance in comparison with the overwhelming lack of control they continued to feel in other areas of their life – such as where they could go, and what they could do, on a day-to-day basis, and the health of the person they cared for.

Carers' physical health

There was a wide spectrum in terms of the physical health of the carers interviewed, ranging from those generally in very good or pretty good health, to those with long-term health conditions which were manageable and did not have too much impact on them day-to-day, to those who were more seriously affected by long-term conditions.

However, carers across all three of these groups felt their physical health had been affected by caring. A variety of different impacts were mentioned.

The chronic stress experienced by many carers was discussed in the section above on mental health and wellbeing. It is worth noting here that stress, of course, also affects physical health with proven links to many conditions.

In some cases, either the caring responsibilities themselves, or the anxieties associated, had led to severe sleep deprivation which is also linked to many physical health conditions. Other carers emphasised the exhaustion, the “draining” nature of caring, and the rare opportunity for respite.

The physical demands of caring were also mentioned. Most commonly these included soreness and muscle pain/strain resulting from lifting or providing physical support.

“[I have] sore shoulders from lifting my daughter, stiff, a bit arthritic.”

Female, 35-54, Caring for child under 18

“I get tired and sore [using the hoist]”.

(Another) Female, 35-54, Caring for child under 18

Finally, in some cases, caring had affected carers' physical health by acting as a barrier to regular exercise.

In a few exceptional cases, carers reported that caring had not affected their physical health. These carers tended to emphasise that the effects of caring were solely mental and emotional – which they differentiated from their physical health.

Impact of Carer's Allowance Supplement on physical health

Regardless of their physical health, carers generally felt CAS had no real impact on it. Among carers who had conditions for which they were receiving treatment, CAS had no impact on those. Meanwhile, although it had helped relieve financial worries a little and allowed some carers to take short breaks, overall it had not had a significant impact for those with chronic exhaustion or stress.

However, there were a few exceptions where carers felt CAS had positively impacted their physical health. Most commonly, this was where CAS helped them to afford healthier food, such as fresh fruit and vegetables, that they might not otherwise have been able to afford.

In other cases, CAS had been used to pay for more adequate heating in winter, which these carers said they would otherwise have gone without.

Among those that were generally more physically fit and active, CAS had sometimes helped support their exercise hobbies and examples included participating in a boxing competition and affording a consultation with a coach on weight-lifting technique.

In another case, CAS had been used to directly aid a physical difficulty where a carer had been able to use CAS towards back and knee support items which they would not have been able to afford without it.

6. Impact of Carer's Allowance Supplement on feeling recognised and valued by society

Key findings

Overwhelmingly, the feeling among carers was that the general public have very little awareness of the work they do.

CAS was not perceived to have raised awareness or the profile of carers among the general public and had not, therefore, made them feel more recognised or valued by society in general.

However, the introduction of CAS had made carers feel a little more recognised and valued by the Scottish Government: it showed the government had thought about them; felt like an acknowledgement and a 'thank you'; and showed their work had value.

This chapter explores the extent to which carers currently feel valued and recognised for their role by different elements of society, and the impact that CAS has had on this.

Awareness of the role of carers

Overwhelmingly, the feeling among carers was that the general public have very little awareness of the work they do and therefore the role is not valued by wider society. Carers thought the public were:

- not aware of the societal contribution they make and how much money they save the public purse
- not aware of how much work is involved and how relentless it can often feel
- not aware of the stress and emotional toil that is often involved.

"I have had people saying to me, oh, it must be great you are able to sit at home and watch TV all day and do nothing – I have had actually people saying that. You're like, you have no idea what we do, and the pressure always to make sure that my husband is okay".

Female, 55+, Caring for partner

Participants highlighted a number of misconceptions of the role that they felt were common. Examples included the view that a carer was "just being a parent" when caring for their severely disabled child, that caring for a friend was "just chatting and going for coffee" and a confusion between paid and unpaid carers. Others, who were caring for people with mental health issues, suggested that those conditions were often "invisible" – which meant that the carer's role was invisible too.

Carers felt that most people just lacked awareness and had never thought about the issue. However, a minority of people were perceived to have negative or even hostile views: carers were being “lazy” or “sponging” off the state. One carer reported that he had been “vilified” locally and told to “get a job”.

This lack of awareness was attributed to the fact that most caring work is unseen, “behind closed doors” and not talked about enough. But, more fundamentally, carers felt that it was impossible to understand what was involved unless you were in that situation yourself – and even their close family and friends did not fully appreciate it. Several participants acknowledged that they did not realise themselves what it meant to be a carer until they were in that position.

“I don't bang on to my friends or most of them what we have to do, you know, things for [daughter] with her personal care and one thing and another, it's not something I throw in their face, I just say I've got extra things to do and they just generally kind of leave it. They don't ask and I don't really say. [...] So, I think in a lot of ways people they do underestimate what people have to do. I think they just see me pushing a kid in a wheelchair and they just think, oh, you have to have a ramp or whatever, and there is just so much more, you know, in the background, that I just don't think that a lot of people either understand or they don't want to understand, they don't care, they just go, well it's not me that's having to do it and that's it. So, I think in a lot of ways, no, people don't understand, no”.

Female, 35-54, Caring for child under 18

“I've got brothers and sisters that haven't a Scooby what I do”.

Female, 35-54, Caring for adult daughter

Suggestions for raising awareness included: carers talking more about the role – one participant suggested that they should ‘open up about it’ as people have done more recently with mental health issues; increased representation on television and in the media; and education. There was a view that slightly more attention has been paid to carers recently and that social media has played a part in that. There was also a feeling that the COVID-19 lockdown may help increase understanding a little by giving people a ‘taste’ of what some aspects of full-time caring can be like.

Although carers did not feel recognised by wider society, they did tend to feel that their role was recognised – to some extent at least – by their family and friends, and by professionals who were more closely involved and saw some of what they did first-hand. Examples mentioned included doctors, other health professionals, teachers, social workers and carers groups. However, others reported negative experiences with agencies – such as battles with their local authority over respite bills or what equipment was essential, or having to repeatedly provide proof about the illness of the person they cared for. In those circumstances, they did not feel valued or recognised.

Our questions focused on perceptions of being valued and recognised by wider society but some participants did talk spontaneously about being valued and appreciated by the person they cared for.

The impact of CAS on societal awareness

The consensus among participants was that CAS had not raised awareness or the profile of carers among the general public and had not made them feel more recognised or valued by society in general.

“I don't think anybody else knows about it. Carers highlight it and go, oh, that was good, but I don't think anybody else, I don't even think they know it exists”.

Male, 55+, Caring for adult son

However, there was a less common view that it may have raised the profile of carers a little – mainly through news stories at the time it was introduced.

Recognition by government

The dominant view was that government did not generally recognise the role of carers. Evidence of this cited by carers included:

- The low level of Carer's Allowance (currently a maximum of £67.25 per week⁵). Some compared this with the significantly higher costs of professional carers visiting the home or residential care and one participant equated it to an hourly rate of 39p⁶ (based on 24/7 care)
- A view that the government “only provide money” and not other help (e.g. practical assistance or respite care)
- A view that the government “don't listen” to carers

“They just don't care, as I say, they give you your money and that's it, you just do your job. As long as they're not having to pay for somebody to go and do that, they're happy”.

Female, 35-54, Caring for child under 18

Where participants made distinctions between the UK Government and the Scottish Government, they tended to feel that the Scottish Government recognised carers more – and this was largely due to the provision of CAS.

⁵ As at May 2020

⁶ Her calculation was based on the CA rate of £66.15 per week which applied when she was interviewed in March 2020.

“Certainly not the UK government, I've got to say the fact that the Scottish Government has come up with that, then they must obviously be recognising people who are caring and that's a good thing”.

Male, 55+, Caring for adult son

Others, however, felt unrecognised by both the UK and Scottish Governments.

CAS has therefore gone some way to making carers feel more recognised and valued by the Scottish Government. They thought the introduction of CAS:

- showed the government had thought about them
- felt like an acknowledgement and a ‘thank you’
- showed their work had value and was a recognition that the level of Carer’s Allowance was low.

“I feel more recognised – not by the people of Scotland but by the Scottish Government”.

Female, 35-54, Caring for friend

“[It feels] as if someone out there knows what you're doing”.

Female, 55+, Caring for adult daughter

This was true even amongst those who did not think CAS had made much difference to them personally (in terms of financial impact, or impact on their quality of life).

However, it was generally judged to have had ‘a little’ impact, rather than a big impact, on feelings of recognition and value – and, more exceptionally, there was a view that it had made no difference.

“It's nice to get a small bonus and that, but I don't really know if £500 or £450 a year actually makes you feel any more valued, I would have said not, probably no”.

Female, 35-54, Caring for child under 18

7. Conclusions and implications for policy

Has Carer's Allowance Supplement improved outcomes for carers?

The research provides evidence on the extent to which CAS has had a positive impact on carers' financial wellbeing, quality of life and feelings of recognition.

Financial wellbeing

Carers who were struggling the most financially felt the biggest impact – whether they had spent it on treats or trips away, which they would not have otherwise been able to have, or whether they had spent it on essential household expenses, which they would otherwise have struggled to pay for. Carers who were financially comfortable but had spent it on treats also felt a benefit, as they were unlikely to have had those enjoyable experiences (trips, outings etc.) without the payment. The least impact was felt by carers who had spent it on general household needs but who already had enough money to pay for these things.

Overall, while carers were grateful for the payment and could identify impacts, they tended to say that the payment had not helped their day-to-day finances – they felt they only benefitted during the months that CAS arrived.

Quality of life

Typically, CAS had helped improve carers' mental health and wellbeing a little: it had a positive impact on relieving money worries around the months carers received the payment, and had given them "a wee lift".

More exceptionally, its impact on mental health and wellbeing had been transformative. This was in cases where it had enabled carers in great financial difficulty to pay off debts or where it had been used towards a trip away when carers felt they were close to breaking point.

CAS had generally not had an impact on carers' physical health. However, there were a few examples of it being used to support physical health including buying healthier food, affording more heating in winter, facilitating exercise hobbies, or enabling the purchase of back and knee support items.

There were mixed views on the impact of CAS on carers' sense of control and empowerment. It had made the biggest difference to those struggling most financially by helping them to feel more on top of their finances and prepared for upcoming expenses. Others thought it had made little difference overall.

Feelings of recognition

CAS was not perceived to have raised awareness or the profile of carers among the general public and had not, therefore, made them feel more recognised or valued by society in general.

However, the introduction of CAS had made carers feel a little more recognised and valued by the Scottish Government: it showed the government had thought about

them; felt like an acknowledgement and a ‘thank you’; and showed their work had value.

The overall impact of the Carer’s Allowance Supplement

The experiences of CAS recipients demonstrate that the Supplement has gone some way to meeting its overall aims: to improve outcomes for carers by providing extra financial support and to provide greater recognition of the essential societal contribution that carers make.

The extent of its impact on carers lives has, overall, been relatively modest. The impact that around £450 per annum could reasonably be expected to make, however, should be borne in mind when considering this finding – as should the fact that Social Security is just one aspect of the Government’s overall approach to supporting carers. It is also worth bearing in mind that, while caring can be a rewarding and positive experience, it can also be extremely challenging. Even small improvements to carers’ quality of life and their sense of being valued and recognised do matter. It was very clear from the research that carers appreciated the payments and thought they should continue. And, although it was a more exceptional experience, the transformative impact that CAS has had for certain carers should not be overlooked.

Implications for policy

While CAS has gone a little way to helping improve carers’ quality of life, the findings indicate that more significant improvements would require significantly higher levels of financial support. They also highlight the fact that some of the desired long-term outcomes require different, or at least additional, actions rather than just financial support.

1. Improvements in quality of life and reducing the negative impacts of caring also require increased access to respite care – to give those carers feeling the mental and physical stresses of providing round-the-clock care more frequent and regular breaks and some opportunity to pursue other activities.
2. Providing carers with advice and support on reducing the sense of isolation would also help in this regard. (Taking advantage, perhaps, of some of the initiatives and technological solutions that have been developed across the wider community during the COVID-19 crises).
3. Increasing recognition of the role of carers among the general public will also require a different approach. Suggestions from participants included carers talking more about the role – one said that they should ‘open up about it’ as people have done more recently with mental health issues – and increased representation on television and in the media.

Beyond the overall level of financial support, the findings point to a further two issues which should be considered in the development of the Scottish replacement for Carer’s Allowance.

1. CAS was introduced as a temporary measure and its payment in two lump sums was a relatively simple and pragmatic way of delivering the payments. However, it was clear that carers liked receiving the payment in two lump sums and there was a strong preference for this over including it with the weekly Carer's Allowance payment. They felt it allowed them to spend on bigger expenses – either bigger treats (such as a trip away) or more expensive necessities (such as larger quarterly bills) and they felt they subsequently had more to show for it. They also saw it as something to look forward to. However, there were carers (among those who spent the payments on general, on-going expenses) who would have preferred more regular payments which would help them budget throughout the year. Ideally then, the new system would include an element of individual choice about the structure of payments.
2. The findings suggest that there are issues relating to the conditionality of the current Carer's Allowance benefit. It effectively inhibits more than a small amount of part-time work which would be very beneficial for the wellbeing of some carers who would be able to undertake it. In particular, they felt it would provide a sense of identity outwith the caring role and help reduce their sense of isolation.

Annex A - Topic guide

INTRODUCTION (5 minutes)

- Introduce self and Ipsos MORI
- Introduce the research: The Scottish Government wants to hear about the experiences of people who receive Carer's Allowance Supplement. It has commissioned us (Ipsos MORI) to carry out research to help assess its impact on carers. This interview will allow us to hear in a bit more depth about your experience and your thoughts on the Supplement. The anonymised findings will be published as part of an evaluation of CAS that will inform the development of Carers Assistance in Scotland.
- Explain that the interview will last about 1 hour. Remind them that they will get £30 as a 'thank you'.
- Provide reassurances of anonymity and confidentiality. Explain that no identifying information about individuals will be passed on to anyone outwith the Ipsos MORI research team, so it will not be possible for the Scottish Government or anyone else to identify individuals in any reports that Ipsos MORI produce.
- Remind participant that they don't have to answer any questions they don't want to answer, and that they are welcome to stop the interview at any time.
- Request permission to record interview. Explain that this is for transcription and analysis purposes and that recordings will not be shared outside the research team at Ipsos MORI.

PARTICIPANT'S BACKGROUND (7 minutes)

Firstly, it would be great if we could get some background on your life as a carer.

- Could you tell me a bit about your caring responsibilities?

PROBES:

- Who do you care for?
- How much time do you spend caring in a normal week?
- How long have you been a carer?
 - How did you become a carer?

- What's a typical day like for you?
-
- Could you tell me a bit about any other responsibilities you may have in your life?

PROMPTS:

- Other caring responsibilities including childcare
 - Studying
 - Working
- How long have you been receiving Carer's Allowance? [IF NECESSARY: not the Supplement- the main Carer's Allowance]

AWARENESS OF CAS (5 minutes)

I'd now like to ask some questions about Carer's Allowance Supplement.

- What, if anything, do you know about Carer's Allowance Supplement?

PROBES

- Why do you think Carer's Allowance Supplement was introduced?
 - What is the purpose of Carer's Allowance Supplement?
 - Do you know what makes a person eligible for CAS?
 - How much money is the payment?
 - How is it paid?
 - Do you know where the money comes from/who pays for it?
- Can you tell me about how you first became aware of CAS?

PROBES:

- When did you first hear about it?
 - How did you hear about it?
- What did you think about it when you first heard about it?

- We're going to go into more detail about this later, but would you say that CAS has had any impact on your life as a carer?

FINANCES (20 minutes)

I'd now like to move on to ask some questions about your finances and any financial impact of CAS. To be clear, there are no right or wrong answers, and all your responses will be kept anonymous. Just let me know if there is a question you would rather not answer.

So, I'd like to start with some general questions about money if that's ok.

- Does your overall income cover your outgoings?
- Does money ever worry you?
- Taking everything together, which of these phrases best describes how you and your household are managing financially these days? [PHRASES WILL BE ON A SHOWCARD]
 1. Manage very well
 2. Manage quite well
 3. Get by alright
 4. Don't manage very well
 5. Have some financial difficulties
 6. Are in deep financial trouble
- Research has shown that carers often experience financial difficulties because of their caring responsibilities. Has becoming a carer had any financial impact on you?
PROMPTS: loss of work, additional costs, changes to benefits

Now I'd like to ask more specifically about Carer's Allowance Supplement in relation to your finances.

- Do you remember when you last received Carer's Allowance Supplement? How much money was the payment?
- IF RECEIVING CA BEFORE CAS WAS BROUGHT IN: Have you noticed a difference in your financial situation since you started receiving Carer's Allowance Supplement?
PROMPTS:

- Level of worry about money
- Ability to pay bills/meet household expenses, ability to pay off debts
- Ability to spend on nice things/activities

So, just to reassure you, Carer's Allowance Supplement is not intended to be spent in any specific way, and it's completely up to you how you choose to spend it. So, the last payment of Carer's Allowance Supplement would have been in December...

- Can you remember if you spent it and, if so, what you spent that payment on?

PROMPTS:

- Day-to-day expenses e.g. groceries, bills, household essentials
- Family activities
- Clothing
- Christmas
- Did it just get absorbed into your budget and you didn't spend it on anything in particular?
- Have you saved it?

- IF THEY GIVE AN ANSWER TO THE PREVIOUS QUESTION:

- So, you spent the payment on [x]. What would you have done about [x] if you hadn't received Carer's Allowance Supplement?
 - PROMPTS: gone without it? spent other money on it? gone without something else to pay for it?
- And what difference did [x] make to you?
- Did you plan in advance how you were going to spend the payment?

- How did you feel when you received the last payment?
 - PROMPT: Happy? Relieved? Nothing in particular?

- Would you say that you rely on Carer's Allowance Supplement at all?

- IF HAS RECEIVED MORE THAN ONE PAYMENT OF CAS:

- Do you remember what you spent any previous CAS payments on?

- CAS payments are every six months, so the next payment should be in Summer. Do you have any idea how you might be likely to use it?

- Carer's Allowance Supplement is paid in two lump sums each year. What do you think about it being paid this way?
PROBE: Would you prefer that it was split up by week and paid with your Carer's Allowance money? Or in one lump sum each year?

HEALTH AND WELLBEING (10 minutes)

The next questions are about your health and wellbeing, and any impact that CAS might have had in that area.

- Firstly, how would you say your physical health is these days?
- And how would you say your mental health and general wellbeing is these days?
PROMPT: Feelings of happiness, calm, control over own life etc.
- Research from carers organisations has shown that many carers experience poor health and isolation. Would you say that being a carer has impacted on your health or general wellbeing in any way?
- Do you receive any help or support as a carer?

Thinking now more specifically about Carer's Allowance Supplement...

- Would you say that CAS has had any impact on your physical health?
 - PROMPTS: being able to look after your own health better (e.g. travel fare to doctor), being able to buy healthier food or be more active?
- Would you say that CAS has had any impact on your mental health and general wellbeing?
 - PROMPTS: reduced worries about money, being able to do things couldn't previously afford, increased self-confidence, reduced isolation
- Has CAS made you feel any more in control of things?

FEELINGS OF RECOGNITION (8 minutes)

I'd like to move on and talk about something else now.

- Would you say that you feel that people are generally aware of the work that carers do and the societal contribution they make?
 - IF NOT: What do you think could help change that?
- Would you say that you feel recognised as a carer? By that I mean recognised by society.
 - IF THEY FEEL RECOGNISED: What/who is it that makes you feel recognised?
 - The government? People you care for? The people in your life? Wider society?
 - IF THEY DON'T FEEL RECOGNISED: What do you think would make you feel recognised?

Thinking now about Carer's Allowance Supplement in particular...

- Do you feel that Carer's Allowance Supplement has raised the profile of carers in Scotland at all?
- Do you feel that Carer's Allowance Supplement has made any difference to how valued or recognised you feel as a carer?

WRAP UP (5 minutes)

We're nearing the end of our interview, I just have a few final questions to wrap up.

- If you were to try and sum up the impact of Carer's Allowance Supplement on your life, what would you say?
- Is there anything you would like to feed back to the Scottish Government about your experience of Carer's Allowance Supplement?

THANK AND CLOSE

Annex B - Pen portraits

The following pen portraits of four carers are designed to provide a richer picture of some carers lives and their experiences of CAS. They have been selected to show a range of different impacts and should not be seen as representative. Names and some personal details have been amended to ensure anonymity.

Louise's experience of CAS

Louise is 35 and lives in the Borders with her husband and four children. She cares full-time for her husband. She often has to attend to him during the night and then has to get up at 6am to get the children ready for school. She takes her husband to frequent medical appointments during the day, does housework and then looks after the children when they get home from school. **"It's hard and exhausting"**. Her mother lives nearby and has Chronic Obstructive Pulmonary Disease (COPD) but Louise is not able to help her as much as she would like to. She has not been able to go to the local Carer's Group because she would need someone to look after the children.

She frequently feels stressed and anxious about her husband's worsening health. However, she said she rarely worries about money. Although their income dropped dramatically when her husband had to give up work and she gave up work to care for him, she says she is very **"frugal"** and they therefore **"get by alright"**.

Louise spent the June 2019 CAS payment on a new washing machine. If she hadn't received the payment, she said she would probably have just got the old washing machine repaired – even though she knew repairing it would be more expensive in the long run than replacing it.

She spend the December 2019 payment on Christmas presents for the children and on getting her hair done. She was very rarely able to get her hair done but her husband had suggested she did that, saying "you go and treat yourself." Without the payment, she would still have bought the same Christmas presents but would have been a little more worried about money that month. She wouldn't have gone to the hairdressers.

The impact of CAS on Louise's financial wellbeing and quality of life seemed fairly limited and short-lived (in part because she tends not to worry too much about money), but it did make her feel more valued by the government:

"[CAS] helped a bit, yeah...not that it makes things easier, but nice for them to appreciate... just seems like a little 'thank you' compared to the weekly payment. [...] They've recognised what we're doing and that's the biggest thing."

There was something about the surprise and unexpectedness of CAS, and the fact that carers don't have to apply for it, that meant she appreciated it more than Carer's Allowance.

John's experience of CAS

John is 64 and lives on Harris with his wife and three youngest children, 17, 15 and 12. He cares full-time for both his wife who has multiple health conditions and his 17 year old daughter, who is physically disabled. As well as looking after his wife and daughter, he also supports his eldest daughter, 21, who lives separately but has ASD. He has been receiving Carer's Allowance for 17 years.

“CAS has been a blessing – a real lifesaver in darker moments [when suffering from depression]...It's made a real difference when changing over to Universal Credit.”

John was unable to complete his MSc in Computer Science because of his caring responsibilities, which caused him worry about his future career prospects. He has also suffered from severe depression in recent years.

He has found the CAS a huge help – it has made a transformational difference to his life. It has enabled him to afford fresh food including fruit and vegetables, despite the high prices of these in his local shops. This means he can cook with fresh ingredients for his family and does not have to travel for three hours by bus to use a food bank.

“It has really made a difference and provided an element of [financial] security.”

CAS has also helped towards preserving both his physical and mental wellbeing as it helped him afford a running technique consultation with a coach – a hobby which provides valuable respite and he finds crucial to his mental health.

John finds the twice-year payments work particularly well for him, as they enable CAS to be used towards bigger household bills.

“Having a lump sum that you notice is really good. Especially if you have a bill come in and are desperate.”

He feels that carers are not widely recognised by society. In the past his neighbours have told him to **“get a job”**.

However, he thinks carers are more recognised by authorities generally and that CAS has made him feel more recognised by the Scottish Government.

Jane's experience of CAS

Jane is 51 years old and lives in Stirling. She cares for her teenage son, Sean, who is disabled and uses a wheelchair. Sean needs lots of support, and Jane cares for Sean whenever he is not in school. Jane and her husband both work, but they still worry about money. Becoming a carer affected Jane's finances significantly – she had been working full-time before her son was born, and she says that becoming a carer has meant dropping to less than half her old salary, while her expenses are slightly higher than before. Jane's caring responsibilities have also affected her health, as using a hoist to lift her son up makes her back hurt.

She was glad that CAS was introduced, but although she said her family lived **“hand to mouth”**, she felt that the Supplement had only a very small impact – the debt they had was still there, and the Supplement hadn't changed their ongoing money difficulties. She couldn't remember how exactly they had spent it- she guessed that it probably went towards credit card bills or household supplies. She thought maybe it had allowed them to bulk buy higher quality personal care products for her son, but she wasn't sure. She said that she almost forgets that the Supplement is coming because it's so infrequent and she doesn't feel confident it'll continue indefinitely.

“If you do break it down, you know, £10 a week really probably is what it equates to, it's neither here nor there, it's really not.”

She doesn't feel that the work of carers is widely recognised – she thinks that people just see their child in a wheelchair and don't realise the amount of work and personal care that is required behind the scenes. She also noted that **some people mistakenly think “the government just throws money at you”** if you are a carer. She stressed the amount of work she does as a carer, as well as the amount of money carers save the government by providing unpaid care. She felt the Supplement was a **“nice wee bonus”** but compared to the work they do and the hours they put in, it did not come close to fair compensation. She had calculated that Carer's Allowance worked out to nowhere near minimum wage and said the low earnings limit (to still qualify for Carer's Allowance) caused extra difficulty. She sometimes felt forgotten, and if CAS had any impact at all on her life as a carer it was a very small one, and purely financial.

“...it's nice to get a small bonus but I don't really know if £500 or £450 a year actually makes you feel any more valued, I would have said not, probably no.”

Cheryl's experience of CAS

Cheryl is 49 and lives in Dundee with her adult daughter and her daughter's children (aged 13 and 4). She cares full-time for her daughter who has severe mental health problems. She has been on Carer's Allowance for around 5 years. As well as looking after her daughter, including sorting out her medications and looking after her finances, she helps a great deal with the grandchildren. She also has elderly parents nearby and helps them when she can.

"The way my life has been for the last few years has just been hell, just hectic, you're just running about like a headless chicken. It's just constant, just constant stress, let's put it that way, just constantly. You don't get a day off or anything, it's just absolute non-stop."

Cheryl used to work full-time as receptionist but had to give up work when her daughter's mental health problems worsened. She has found the loss of a full-time wage very difficult. She says she worries constantly about money and feels **"either just above water or just under water."** She has built up some debts from spending a bit more than she could afford when she was working. She sometimes has to get loan from her brother.

She described CAS as a **"massive relief."** She has spent all the payments on household bills, food and on bringing down her debt a little. When asked what she would have done without the payments, she said would have had to delay paying some of her bills and repay less of her debt.

The payment has had notable impact on her finances and mental wellbeing but it seemed that the impact was largely in the two months that it was paid: **"You feel more positive and upbeat that month – just a relief."** She would prefer the payments were spread out rather than paid in two lump sums because this would enable her to budget better. **"I could work it out better if I got it every week."**

Cheryl does not think the general public understand what carers do and CAS has made no difference to this. But she does think that the Government are **"starting to realise what it's like and what people are going through so they are stepping up and really helping - I'm so grateful they are thinking about us."**

Summing up the impact of CAS, Cheryl said **"It's been a great help – one less thing [to worry about] in the chaos we're all in. Money's not everything, but if you're struggling every week it's a great, great help."**



© Crown copyright 2020

You may re-use this information (excluding logos and images) free of charge in any format or medium, under the terms of the Open Government Licence. To view this licence, visit <http://www.nationalarchives.gov.uk/doc/open-government-licence/> or e-mail: psi@nationalarchives.gsi.gov.uk. Where we have identified any third party copyright information you will need to obtain permission from the copyright holders concerned.

The views expressed in this report are those of the researcher and do not necessarily represent those of the Scottish Government or Scottish Ministers.

This document is also available from our website at www.gov.scot.
ISBN: 978-1-80004-262-9

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

Produced for
the Scottish Government
by APS Group Scotland
PPDAS783588 (12/20)
Published by
the Scottish Government,
December 2020



Social Research series
ISSN 2045-6964
ISBN 978-1-80004-262-9

Web Publication
www.gov.scot/socialresearch

PPDAS783588 (12/20)