

Social Security Experience Panels: Help us design carer benefits

Background

The Scottish Government is becoming responsible for some of the benefits currently delivered by the Department for Work and Pensions (DWP). As part of work to prepare for this change, the Scottish Government set up the Social Security Experience Panels.

**Department
for Work and
Pensions**



**Scottish
Government**



Over 2,400 people registered as panel members when Experience Panels launched in 2017. They all have recent experience of the benefits that are coming to Scotland.

The Scottish Government is working with Experience Panel members to create Scotland's new social security system.



**2,400+
Experience Panel
members**

About the research

This report gives the findings of research on the design of carer benefits in Scotland.

The research looked at the introduction of a new payment for carers of more than one disabled child. It also looked at people's experiences of Carer's Allowance.



696

Invites



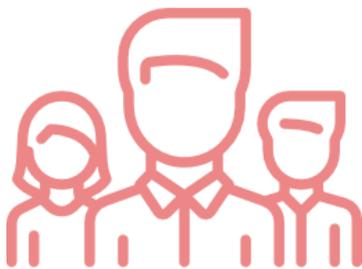
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Survey responses

The research took place in



2019



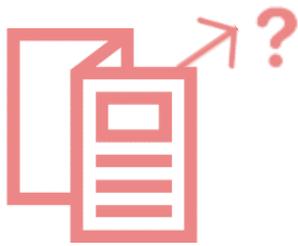
11 per cent

Of respondents answered questions about a new benefit for people caring for more than one disabled child.

Respondents who have experience of caring for more than one disabled child were asked:



How they would want to apply for a new benefit for people caring for more than one disabled child.



What the benefit should be called.

All respondents were asked about:



Their experience as a carer



Experience and views of applying for Carer's Allowance

About the survey respondents

Respondents were aged between

16 – 79

years old



31%

Man or boy



68%

Woman or girl



73%

lived in an urban location



27%

lived in an rural location



Respondents took part from

28

local authority areas

Most survey respondents had a disability or long term health condition (67 per cent), including:



chronic pain



severe hearing
impairments



severe visual
impairments



other kinds of long
term health
condition

Most (86 per cent) of survey respondents were:



a carer due
to **old age**,



a carer to a
child, or



a carer to an
adult.

Almost all (96 per cent) had experience of Carer's Allowance

Designing the new benefit

Social Security Scotland is planning to start a new benefit for carers of more than one disabled child.

Finding out about the benefit



Respondents were asked **where they would want to see information** about this payment.



The most popular option was to **send information about the benefit as a leaflet** with Carer's Allowance Supplement letters.



Many said they would want a **letter to be sent with an application form**.



Many said they would want information through a carers' organisation.



Around half said they would want to see **information on social media**.



Some said they would want to see information in **community hubs**.

How people want to apply



Around two thirds said online



Around a fifth said using a paper form

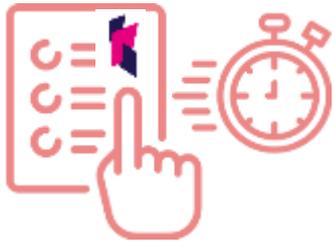


A few said by phone



A few said face to face with someone helping me

What the form should be like



The form should be short and simple



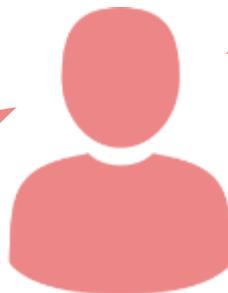
The wording of the form should be easy to understand



There should be a choice of how to apply

Word the questions so people understand what they're being asked so they can fill out without worry or pressure

I think you should be able to apply online, via normal mail, and over the phone

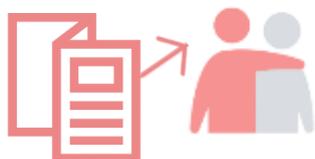


I care 24/7 for my children with disabilities so I don't have much time for long, complicated forms

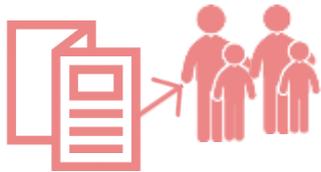
Naming the new benefit



Respondents were asked for suggestions for the **name of the new benefit**.



Most responses felt the new benefit name should include the word "**carer**".



Many suggested a name that also included a reference to **children or families**.

Confirming you care for more than one disabled child

Carers may need to **confirm** each year that they are still caring for more than one disabled child.

Half of the respondents said they would want to confirm this **by email**.



Just over a third said they would want to confirm this **by letter**.



Only a few people said they would want to confirm this by text, by phone, or in another way.

Entitlement to the benefit

Many respondents felt that this benefit should **not just be for those caring for children**.



People said it should be available to parents whose children require **care at any age**, including if their children are now adults.



Some people said more support should be available if you have **more than 2 disabled children**.

Just because they become 18 doesn't mean they automatically stop needing care.

There should be an additional payment for each additional child.

I think it should go beyond 18. My eldest son will be 18 next year and I will still have the exact same caring responsibilities as now.



It needs to recognise that there are families where there are more than two disabled children in the family.



Some also said that it was **difficult to access** Disability Living Allowance and Carer's Allowance. They felt this should not be a criteria for the new benefit.



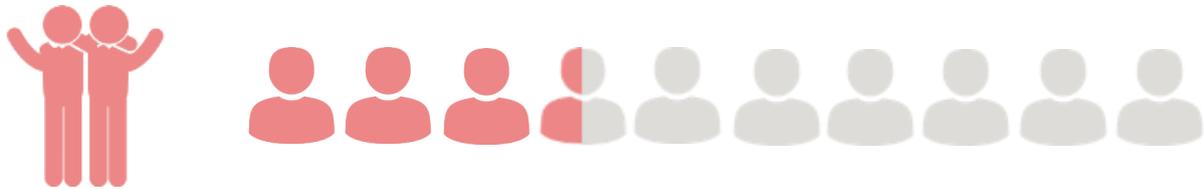
They said the benefit should be **available to all carers of disabled children**.

Experiences of applying for Carer's Allowance

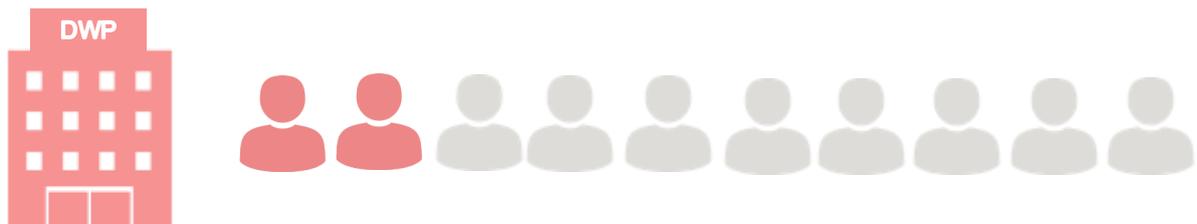
How people found out about Carer's Allowance

Respondents found out about Carer's Allowance a number of ways.

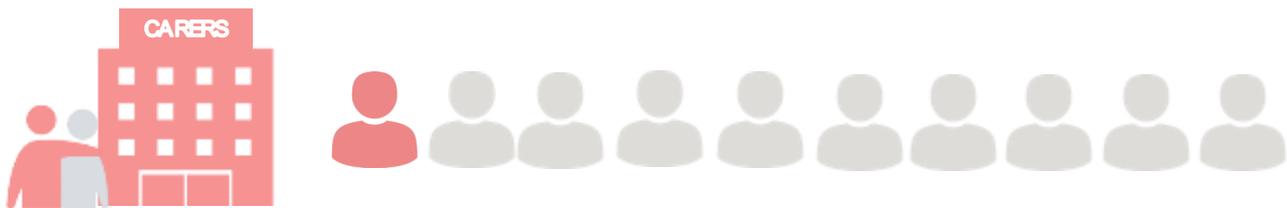
A third (34 per cent) found out through **family or friends**



One in five (20 per cent) found out through **DWP**



One in ten (11 per cent) found out through their **Local Carers' Centre**



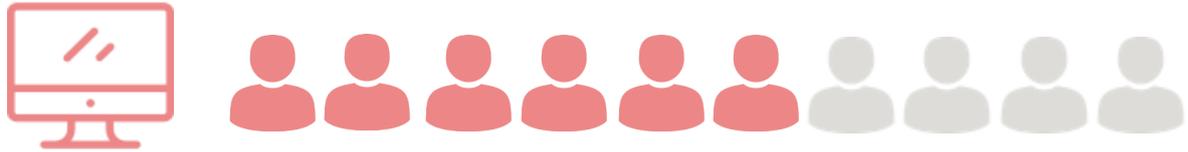
A small number of people (6 per cent) said they found out through **social media**.



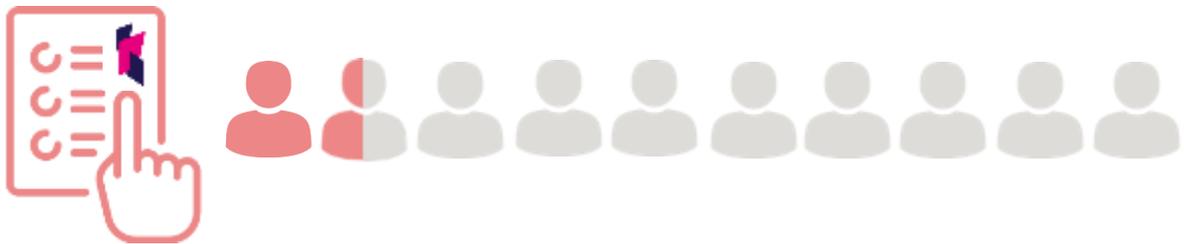
Around a third said they found out **another way**. This included a third sector organisation, local support groups or Citizens Advice. Some had found out through their work or by looking online.

How respondents would apply for Carer's Allowance if they were applying again

More than 3 in 5 (62 per cent) would apply **online**



16 per cent would apply using a **paper form**



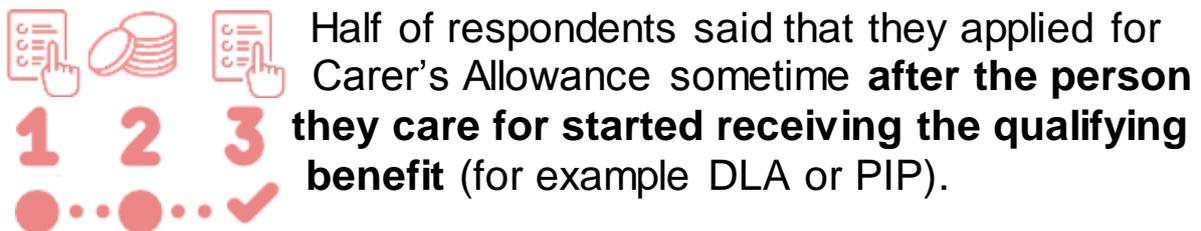
14 per cent would apply through **a support organisation**



7 per cent would apply **face to face**



When people applied for Carer's Allowance





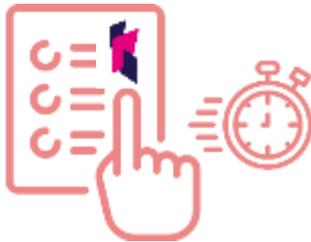
A third of respondents said that it was when the person they care for started receiving the qualifying benefit.



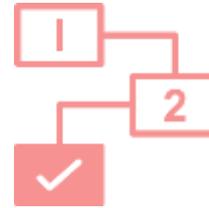
One in ten said it was at the same time as the person they care for was applying for the qualifying benefit.

What worked well about the Carer's Allowance application process

Respondents were asked what worked well about the application process for Carer's Allowance.



Quick application process



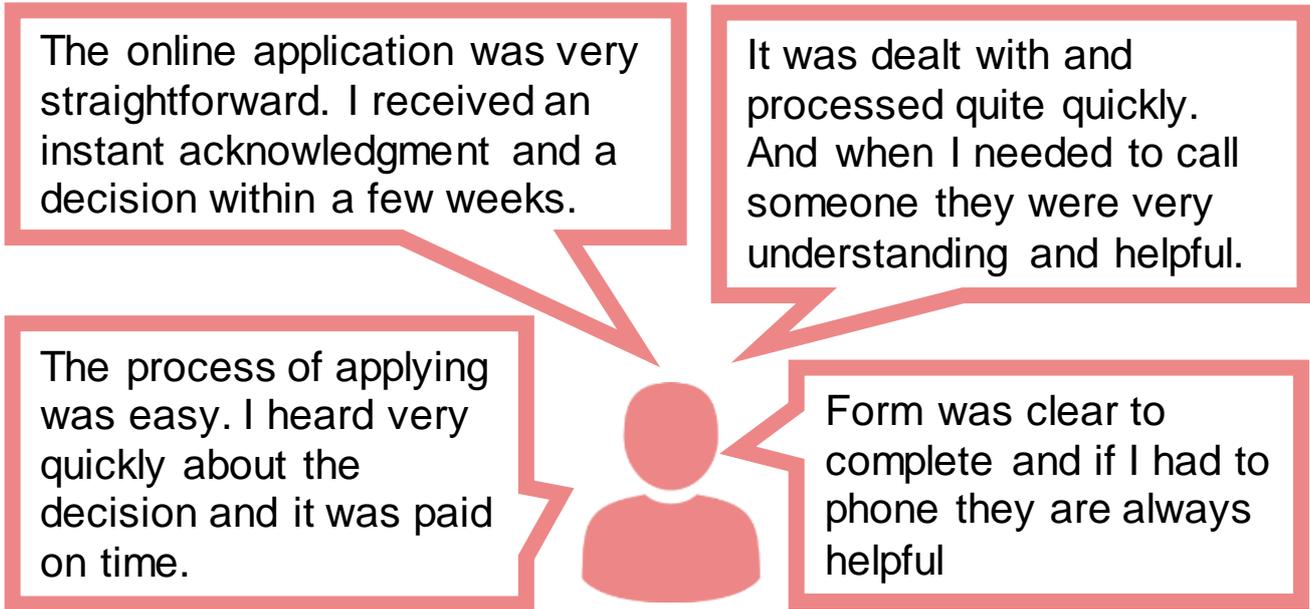
Straightforward application process



Helpful staff



Online application process



What did not work well about the Carer's Allowance application process

Respondents were asked what did not work well about the application process for Carer's Allowance.



Unclear pre-application information



Repetition of questions in application form

Maybe state what alternate benefits preclude you from receiving Carer's Allowance

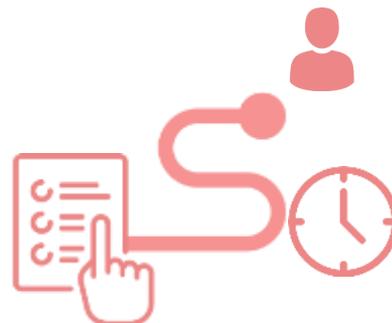
You are asked repeatedly what sort of care you provide. It gets overwhelming for most people.

Losing some of other benefits once accepted for Carer's Allowance

Just so many questions going over the same things.



Reliance on qualifying benefits



Waiting period for payments

I did have to wait until DLA came through and it would have helped to have it before. My son's diagnosis took a long time and in that time I had to sign on and look for jobs when it would have been incredibly difficult for me to hold down any employment... this caused me stress and financial hardship.

Waiting 11 weeks before I got a decision. 11 weeks of no income whatsoever.





Accessibility of information about Carer's Allowance and application process



Errors in the application process

Don't assume everyone can or wants to do things online, there should always be an option to do.

There is quite a lot of bureaucracy, pedantry, and stupid mistakes made by the CA unit such as making incorrect calculations relating to dates.

Maybe having someone on a helpline or being able to apply over the phone would maybe help too as paperwork doesn't work for everyone.



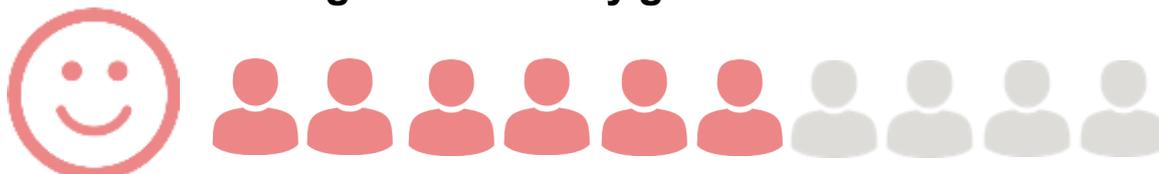
The organisation claimed they lost the paperwork. I had to call daily for updates. The application repeated the same questions over and over and were difficult to answer.

Experience of receiving Carer's Allowance

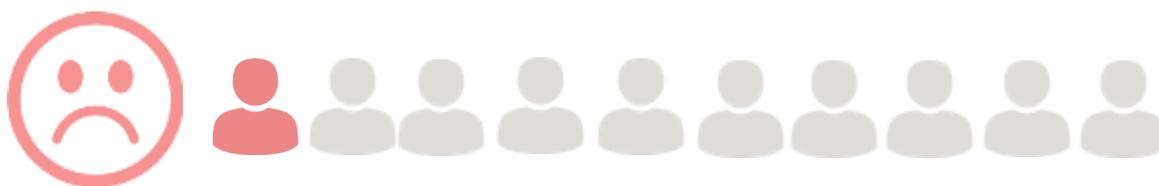
Respondents told us about their overall experience of receiving Carer's Allowance.

Overall experience

6 in 10 respondents said their overall experience of Carer's Allowance was “good” or “very good”.



1 in 10 respondents said their overall experience of Carer's Allowance was “bad” or “very bad”.



Respondents highlighted a number of areas where they felt Carer's Allowance could be improved.

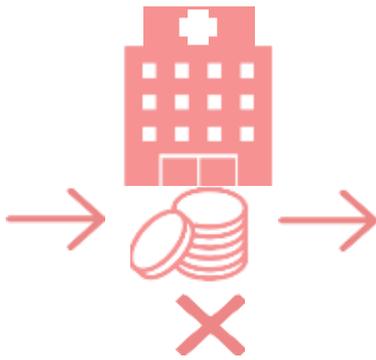
Payment amount



Many respondents said that the **amount given for Carer's Allowance is too low.**



Some highlighted that carers often **work many more hours** than required for Carer's Allowance. Some feel they are always on call.



If the person that is cared for is in hospital, this can lead to a **gap in payments** that are difficult to manage.

My biggest problem with it is that it just doesn't provide much to live on, even with my mum's disability benefits taken into account. We've had to borrow a lot of money from friends and family recently – not for luxuries, but to make sure we can top up the gas or get food enough to last us until we get money in.

When my son is in hospital for more than 4 weeks I lose carers and am made to sign on and look for work, it's a difficult enough time without going through this.

It's an allowance in name only. We're on duty 24/7, not 9 till 5.



Working or studying while caring



Many respondents said that the eligibility criteria for Carer's Allowance are **unfair if they work part time**.



Respondents said that Carer's Allowance should not be affected by the **number of hours they work** or **how much they earn**.



Respondents said it was **confusing to calculate** how whether their work will stop their payments.



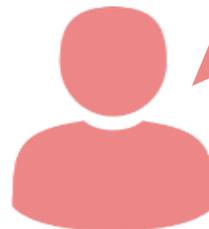
Some pointed out that a carer may be the **only person in the household able to work** and have to support the whole household with their income.



Respondents felt it was **unfair that people cannot receive Carer's Allowance while studying**.

Many carers have no choice but to work as they are supporting more than themselves – either another disabled adult or a disabled child. Their caring responsibilities do not stop because they are working a few extra hours every week. It unfairly penalises people on low incomes.

I am going to university next year. I will be at university only a few days a week although because of this I will lose my Carer's Allowance. My caring duties don't stop. I think it's unfair that I can no longer receive the extra help and support.



Carer's Allowance beyond pension age



PENSION

A few respondents said that **Carer's Allowance should not stop at pension age**. They said that the caring responsibilities go on.



Respondents said they had to **rely on their own pension** to look after the person they care for.

Often carers don't know Carer's Allowance stops with payment of state pension even though caring role continues. It is confusing and feels as if you are being undermined.

Impacts on other benefits



Similarly to comments made about the application process, some respondents said that it was **hard to understand the impact that Carer's Allowance can have on the other benefits you're eligible for.**



Likewise, they also said it was **unfair** that if you receive Carer's Allowance that **other payments can be reduced.**

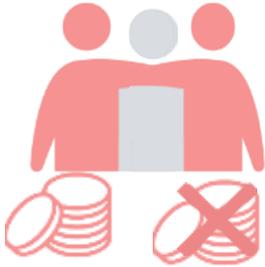
I was shocked when my income support was reduced £ for £ i.e. cancelling out Carer's Allowance. That seems quite wrong, given the amount of energy and time spent caring.

Eligibility Criteria

Some respondents commented that the eligibility criteria related to the number of hours of caring are too restrictive. For example:



If a person **cares for more than one person** they wouldn't be eligible if their caring hours for each person individually were lower than 30 hours.



If two **people share a caring role**, they cannot combine the hours they care for or both apply for Carer's Allowance, even if both care for more than 30 hours per week.

What about two carers who share a caring role and both care for 24 hours each – or a single carer caring for two disabled people e.g. parents, neither of whom quite meets the higher dependence threshold?

What's Next?



We will use these findings to inform the design of the new support for people caring for more than one disabled child.



It will also be used for the development of the Scottish replacement for Carer's Allowance.



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