

Carers Parliament 2024 Report



Introduction

The 2024 Carers Parliament took place on 27th November at the COSLA Conference Centre in Edinburgh. At the event, unpaid carers from across the country sought to address their concerns and questions on caring directly with national and local Government representatives.

The event was organised by Carers Scotland on behalf of the Scottish Government and chaired by Professor Ian Welsh, OBE, former Chief Executive of the Health and Social Care Alliance Scotland. The day was funded by the Scottish Government with some additional sponsorship provided by Mobilise to support the catering.

The Carers Parliament 2024 was a hybrid event, with 72 attending in person on the day while 43 more were able to join online, ask questions and participate in the discussion via a video link.

The agenda for the day can be found in the appendix.



Morning Programme

Professor Welsh introduced the day, setting the scene for discussions and debate. He then introduced Maree Todd MSP, Minister for Social Care, Mental Wellbeing and Sport, and Councillor Paul Kelly, COSLA Spokesperson for Health and Social Care to open a debate on *“The future of social care and the National Care Service”*.

Ms Todd outlined her admiration for the work done by carers as she said:

“I truly appreciate your bravery, boldness and passion in sharing your personal experiences and stories. I know that this isn’t always easy to do. It is however vital that we hear from carers and understand the challenges that you are facing.”

Cllr Kelly then detailed his support for carers as he said:

“COSLA works in partnership with the National Carer Organisations, local partners and unpaid carers to ensure the voices of carers and local system leaders are reflected throughout our work.”

“Local government is strongly committed to improving support for unpaid carers, aligned to their individual needs.”

Contributions were then invited from both the room and online and several key issues were raised. Below is not a verbatim copy of the contributions made by unpaid carers but instead provides a summary of the issues.

A prevalent thread throughout the debate was health. Many carers who spoke highlighted the fact that caring was having a negative impact on both their physical and mental health.

Carers asked questions about Carer Support Payment, particularly about how much carers receive. Additionally, the issue of Carer Support Payment not being paid, or paid at a reduced rate, once carers start to get their State Pensions was raised, with one carer directly asking the Minister what the Scottish Government will do to address this.

Multiple issues around services for carers were detailed, including the problem of cuts to services. A particular issue was the lack of suitable replacement care places when the carer is taking a break, and the impact this can have on their mental health.

“If I want a Saturday or Sunday out to just to go for a walk with friends, quite often the care service are understaffed at the weekend and I can't get that support, so I can't get the day out. I've not had a night away for probably two years.”

There was also a sense of frustration around the lack of progress which has been made, particularly around establishing the National Care Service.

“The Government knows what needs to be done. We need to stop having these meetings and stop talking about things and just have some action.”

“I appreciate you want to put something in that works perfectly on day one, but realistically, with the way things are going, that is not going to happen. So, we just need to work out what we can implement quickly and easily to start helping to resolve the problems.”

“Local authorities pay lip service to co-production. We are fed up telling our story. Now we need change. We need action.”



Reflecting at the end of the debate both Maree Todd MSP and Councillor Paul Kelly thanked carers for their contributions and responded to points raised.

Ms Todd said: *“Your words highlight your commitment and dedication to getting the best possible services and support for your loved ones, and they hold us to account to ensure that we are doing everything possible to make sure this*

happens.

“You have my absolute commitment that I will work tirelessly alongside the people who really matter - the people of Scotland, all of you here today - to deliver the improvements that we all want and need to see through social care reform to bring about fundamental and sustainable change. It's been an absolute privilege to be here today.”

In conclusion, Cllr Kelly said: *“The need for greater support mechanisms for carers came through strongly in the debate, in particular around a right to breaks, which has been promised by the end of this parliamentary term. A right to breaks without any further delays and backed by sustainable funding is what carers deserve. COSLA is absolutely committed to advocating for this at every opportunity.”*

Afternoon Session



The afternoon session of the Carers Parliament was opened with a short introduction from the chair followed by a presentation given by the Youth Engagement Officer from Carers Trust Scotland, Sally Hendry, who shared short films created by young carer media ambassadors as part of the 2024 Scottish Young Carers Festival. Links to the videos can be found in the appendix.

These films were designed by the young carers to explore key themes: The first film offered a behind-the-scenes look at the making of the films, featuring media ambassadors discussing the benefits of participating in the media ambassador programme, which is funded by the Scottish Government. The second film, entitled “Echoes of Caring”, highlighted the mixed emotions young carers experience when

away from the person they care for. It explored both the welcome relief of taking a break but also the stresses of being apart, and the struggle young carers can have with “switching off”. The final film urged decision-makers to better understand the challenges faced by young carers and to take steps to better support them.

Shirley-Anne Somerville MSP, Cabinet Secretary for Social Justice, provided a video address reflecting on the work to improve carer benefits in Scotland, since Scottish Ministers took responsibility in 2018, and thanking carers and support organisations for the key role they have played in developing and delivering these improvements. Ms Somerville also provided an update on the further important improvements that will be made once all carers in Scotland have had their awards transferred safely and securely to Carer Support Payment.

This was followed by officials from the Social Security Policy Division within the Scottish Government, who answered questions on social security and the new Carer Support Payment, which is in the process of replacing Carer's Allowance in Scotland, as well as on the plans for future improvements. There were positive comments from unpaid carers around the case transfer process, which most experienced as smooth. They also highlighted that the extension to full time students under Carer Support Payment and that the proposed improvements were positive.

Attendees then split into discussion groups, which focused on benefits and financial security for unpaid carers. There was a wide ranging conversation on what works well in the current system as well as areas for further improvement. The following provides a summary of these discussions and highlights key areas of concern.

Views on Carer Benefits

- Carer benefits are far too low. Especially in recognition of how many carers reduce their working hours or give up employment entirely.
- Some carers stated that dealing with Social Security Scotland is much simpler than the Department of Work and Pensions – it feels more personable, e.g. they had a disabled person working with another disabled person.
- Older carers stop receiving Carer Support Payment or get a reduced payment when they start to receive their State Pension, this is due to the over lapping benefit rules but is leading to financial and emotional distress for some carers.
- There was a strong consensus that unpaid carers, especially women, face systemic discrimination and a lack of recognition.

Experience of Accessing Benefits

- Some felt that there is a lack of straightforward, accessible information and advice services.
- Child disability payment has now been transferred to Social Security Scotland and that's been so much easier.
- Social Security Scotland do things much quicker than Department of Work and Pensions.
- Some viewed the system as difficult, discouraging carers from claiming entitlements as carers and for those they care for.
- There were mixed views expressed on moving to digital with some welcoming it as easier and quicker but also an acknowledgement that there is room for improvement and it was important to ensure there was no digital exclusion and different communication needs being fully met.
- It is often unclear which benefits carers are entitled to, so they have to go looking for this information.
- Services are complicated to access and there is cost associated with so many elements - e.g. Power of Attorney, will writing, legal assistance, etc. It was suggested that legal aid should be available for carers.

Paid Work While Caring

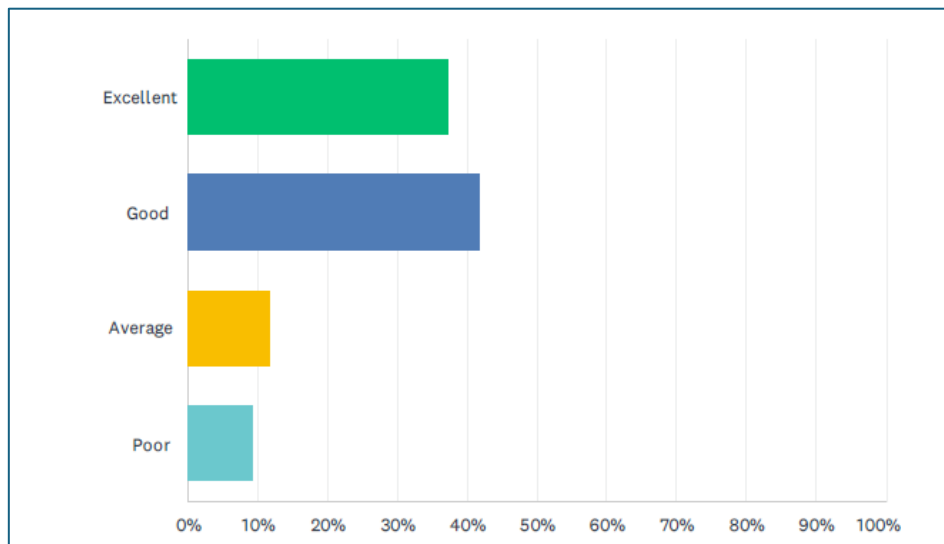
- The earnings threshold should be higher – unpaid carers should be able to work part-time for more hours or in a higher paid role.
- Some carers expressed their opinion that extra costs in benefits would be cancelled out by the income tax working carers would pay.
- Although some carers are able to receive Carers Support Payment alongside paid employment, others felt unable to take up paid work, instead being limited to volunteering, so their Carer Support Payment was not affected.
- The social security and tax systems are currently hindering carers who want to work.
- There needs to be better communication with people if they go over the Carer Support Payment threshold, rather than benefits immediately being taken away.



Evaluation

Following the event, Carers Scotland contacted all those who attended for feedback. We received 46 responses to the evaluation, meaning the survey was completed by 37.4% of attendees. Most of the respondents (73%) were carers, with the remainder being speakers, facilitators or exhibitors.

Delegates were asked to rate the overall experience of this year's Carers Parliament. The majority (73%) of respondents answered positively, rating the Carers Parliament as either good or excellent.



“I thought that there was particularly good organisation in terms of involving the online participants in debates and discussions. There were a few technical glitches but on the whole technology worked well.”

“For my first event it was good to join online hope we can do this again at future events.”

“The conference was very informative”

“Thanks for another informative and well organised event.”

Carers were also asked to rate each of the elements of the Carers Parliament.

Debate: the future of social care	71% rated good or excellent
Young carers: presentation and film	81% rated good or excellent
Video address from Cabinet Secretary on Social Justice	55% rated good or excellent
Q&A on Carer Support Payment/priority improvements	69% rated good or excellent
Table discussions on financial support	53% rated good or excellent
Exhibition and engagement zone	32% rated good or excellent

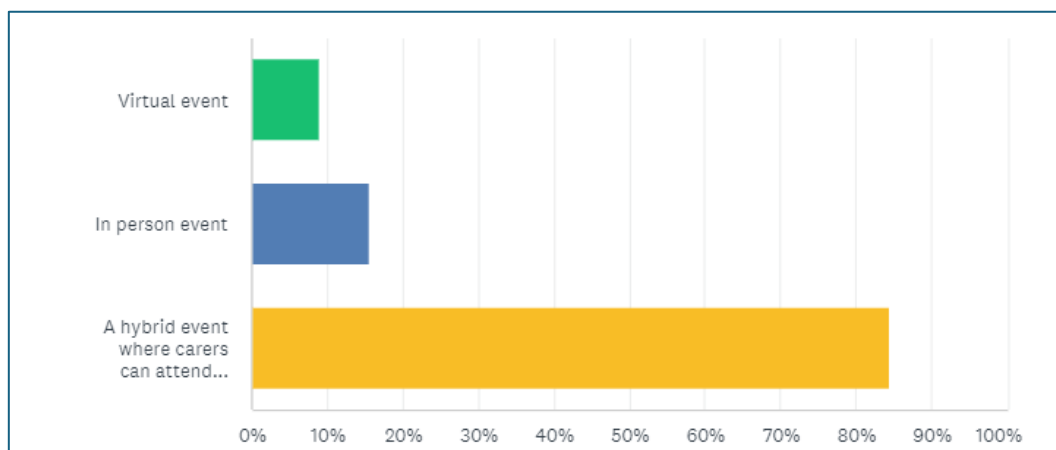
Carers were asked what they would like to see in the future at the Carers Parliament.

“One session dedicated to mental health and caring roles”

“More marketplace with info stalls with an emphasis on caring and carers.”

“Accountability from decision makers - You Said, We Did”

Lastly, carers were asked what form they would like future events to take, they replied overwhelmingly in favour of continuing hybrid events.



Profile of carers attending the Carers Parliament

Most of the respondents identified as female (83%) and 17% male, with most being in the 50-59 age range.

68% of carers who responded to the questionnaire had a disability or longer-term condition.

A significant number (82%) of the respondents identified as heterosexual with 2% identifying as gay. The remaining 16% preferred not to state their sexuality.

The majority of those responding specified that they were of white ethnicity (96%) with these respondents primarily coming from a white Scottish (80%) background. The remaining respondents (4%) were from an African, African Scottish, African British background.

We asked the delegates a range of questions about their caring role, including the number of people they care for, the disability or illness of the person they care for.

How many people do you provide care for?

ANSWER CHOICES	RESPONSES	
▼ 1	64.29%	27
▼ 2	26.19%	11
▼ 3	4.76%	2
▼ 4	2.38%	1
▼ 5 or more	2.38%	1

Who do you care for?

ANSWER CHOICES	RESPONSES	
▼ Husband/wife/partner	19.05%	8
▼ Child under 18	9.52%	4
▼ Child over 18	30.95%	13
▼ Sibling under 18	0.00%	0
▼ Sibling over 18	9.52%	4
▼ Parent or parent-in-law	21.43%	9
▼ Grandparent	0.00%	0
▼ Another relative	2.38%	1
▼ Friend or neighbour	7.14%	3

How long have you provided care?

ANSWER CHOICES	RESPONSES
Less than 1 year	2.44% 1
1-2 years	7.32% 3
5-9 years	14.63% 6
10-14 years	14.63% 6
15-19 years	21.95% 9
20+ years	39.02% 16

Please tell us why the person you help needs care

ANSWER CHOICES	RESPONSES
Physical disability	5.13% 2
Learning disability	30.77% 12
Mental illness	12.82% 5
Drug or alcohol dependency	2.56% 1
Frail because of old age	12.82% 5
Dementia	7.69% 3
Long term condition or illness	28.21% 11



W - <https://www.carersuk.org/scotland/>

E - info@carerscotland.org

Appendix 1: Agenda for the day

9:45am	Arrival and registration
10:30am	Welcome and introduction Professor Ian Welsh OBE
10:40am	Introductory remarks to debate: The future of social care and the National Care Service Maree Todd MSP, Minister for Social Care, Mental Wellbeing and Sport and Councillor Paul Kelly, COSLA Spokesperson for Health and Social
10:50am	Debate points from in person and online audience (3 minutes each)
11:50am	Response to debate from Minister and COSLA Spokesperson and next steps from Chair
12:00pm	Young Carers Film Sally Hendry, Carers Trust Scotland
12:20pm	Next steps Professor Ian Welsh OBE
12.30pm	Lunch
1.30pm	Video address Shirley-Anne Somerville MSP, Cabinet Secretary for Social Justice
1.40pm	Q & A on Carers Support Payment and Priority Improvements Kate Thomson-McDermott, Head of Carer Benefits and Case Transfer Policy Unit, Social Security Policy Division, Scottish Government
1.50pm	Discussion tables
2.50pm	Feedback from tables
3.05pm	Final comments by chair and close Professor Ian Welsh OBE
3:20pm	Informal networking, exhibition and engagement zone, tea/coffee
4:15pm	Event close

Appendix 2: Young Carer Film Links

Echoes of Care - <https://www.youtube.com/watch?v=vmhoXaRe6jo>

This Could Be You - <https://www.youtube.com/watch?v=i4qwSsjjJFw>

Making of Film - <https://www.youtube.com/watch?v=T6oFugxEpoo>