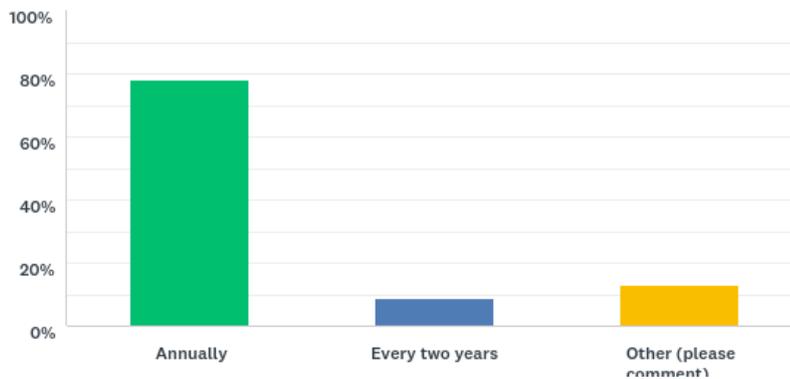


## Shaping the Future of the Carers Parliament

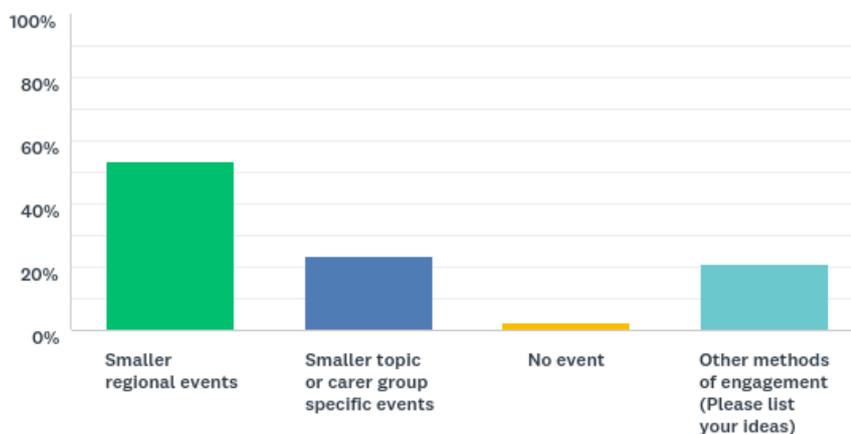
At the recent Carers Parliament and via an online survey, carers were asked for their views on the future and shape of the Carers Parliament. A total of 46 people responded and this is a summary of their responses.

Thinking about the future of the Carers Parliament, how often do you think it should be held?



The majority of respondents (78%) said that they think the Carers Parliament should be held annually.

If the Carers Parliament was to be held every two years, what should happen in the intervening year? (Please select your one preferred option)



**If the Carers Parliament was to be held every two years, the majority (53%) of respondents said that in the intervening year, smaller regional events should be held.**

Of the nine respondents who said other methods of engagement in the intervening year the following suggestions were made:

- Online forum
- A mixture of the top two suggestions e.g. feedback sought from carers of specific groups e.g. regional meetings of those who care for the elderly, children adults, and/or specific disabilities such as Autism, Mental Health Issues, Cancer, Multiple Sclerosis, etc. as these are the experts on their particular disability.
- Review of previous commitments and implementation
- Smaller topic events. But also committee work which carries forward the agenda set by Carers Parliament
- But must have high level political involvement.
- Online video and webchat opportunity to review progress from the previous event and allow carers to contribute and provide feedback
- Opportunity at a local level which involves councils so they can act on feedback and be held accountable
- Engagement with local carers organisations who may offer consultancy events with carers to air issues collectively and ensure carers know their rights.
- I do not believe in regional events because I think the decision-makers are at a higher level. Why would I want to engage regionally when I could address the decision maker?

How do you think we can make sure that the Carers Parliament has the biggest impact for carers attending on the day?

There were a range of responses to this question:

- **Greater publicity**, relevant attendees
- Making sure the **[local] forum has discussed before attending** the parliament meeting.
- Have **specific theme relating** to current Government policy at the time. Ensure attendance of MSPs and Minister(s). Hold it in Scottish Parliament.
- Whilst interesting to hear from ministers/politicians/organisers about latest developments, it's just as (more?) important that they hear from us - **important for carers to feel they have had the chance to speak** and to know how that information will be taken forward/used.
- **Report back on outcomes** from their views in previous years. Be honest and transparent. Don't allow too much negativity.
- Make a difference!!! **Action speaks volumes**
- **Venue with good public transport links** from all over Scotland. The **cared for person to attend** also (perhaps in an adjacent hall with people watching out for them.)
- Just to make the **information as clear as possible for people to discuss** what it is they need and what can be delivered. Bringing people together so that they don't feel isolated, and **giving carers information** to take away with them.

- Send the papers out with **pre-prepared questions**, but also include gaps or opportunities for people to raise their concerns or issues that matter to them, in fact, it might be an idea to have regional gatherings 8 to 12 weeks before the Carers Parliament to discuss the issues they wish to be raised.
- By ensuring they have **care for the people they care for**
- **Less political**. Change the name, it is not a parliament.
- **Ensure that everyone who wants to contribute can do so**. There may be a need to consider how the agenda can accommodate this
- **Take it around the country** as carers can't always spend time travelling and being too far away from home.
- **Involvement of carers in planning**. Issuing pre-event surveys. Ensuring that there is a rolling programme so that the same topics are not repeated every year without progress being made. Generate position statements.
- **Personal letters to people who have attended** in the past, Facebook and Twitter ads, notifying local Carers groups
- Make sure they're being **listened to and the correct people** (as in people that will take action) **attend**.
- **Themes and topics for all** e.g. by condition of cared for and by interest of carer
- The issue is not you - it's the **lack of action and buy in politically**. Until politicians truly get (and care) that families are breaking, these events will have limited impact.
- Organisers need to have **knowledge of the main issues that are affecting carers** in their specific region
- **Accommodate carers in bringing cared for person**. Provide facilities and support for cared for person on the date and even overnight accommodation the night before and transport. **Ability for carers to skype in** or dial in remotely to listen to the proceeding and also having a webchat forum where carers can remotely provide their input and feedback during the event
- **Do it over two days** it was too rushed
- Think it would be better **if the MSPs were there for the duration** to participate in the discussions instead of disappearing.
- Possibly a **slightly later start** as some people can't travel the day before and have to leave to get there quite early. As an example I had to leave at 6am to ensure I arrived in time for the registration and start
- **Carers speaking at the event**
- By having a **carer on stage** giving speeches too - a chosen person who is representative of all
- Make sure that what we say is heard and **ACTED UPON**.
- Perhaps focusing on **less topics and concentrating on a few core subjects which have come up over the course of previous Parliaments**. i.e., I heard a lot of talk at this meeting about the local authorities lack of action in certain situations. If the recurring themes were to be extracted and concentrated on for future discussions that could address some of the real issues being continually discussed.
- Perhaps have those booked to attend **submit their questions in advance of the day**. The idea to stick to 3 minutes each didn't really work, plus many speakers weren't actually asking a question. They were just venting.
- Ensure that the **relevant government ministers are involved** and that there **is feedback on any progress** of the debated & raised problems that carers are experiencing.
- **Ensuring that both MSP's and government officers are in attendance and that they provide feedback in writing to the questions raised**.
- Current format very good but perhaps also **opportunity for regional discussions would be good**.
- **Feedback and updates as to issues raised** at previous parliaments and what impact we have had to affect change

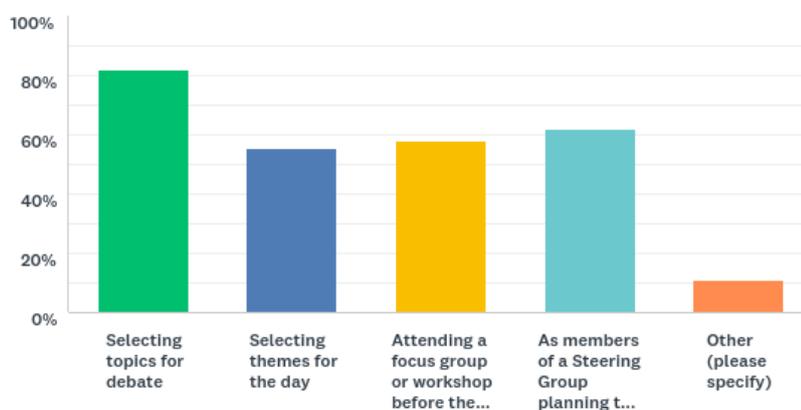
## How do you think we can ensure that the Carers Parliament has the biggest impact for carers who cannot attend?

There were a range of responses to this question:

- Making sure they can be involved in **consultation before the event**
- Use **Facebook to give feedback** on parliament meeting.
- Plenty of opportunity to give **feedback using online and non-online ways**. Also **involve carers centres and carers support groups** to gather feedback
- **Live stream** available with promotion and easy access to link in at a later date leaving those not in attendance feeling actively involved in the session
- **Web link on day for interaction**. Chance to feed in views ahead of event. Prompt reporting after event. Find out why they can't attend and try to address.
- You may already do this: using technology such as **webcams** so events can be followed from home, plenty of opportunities via online/social media/email for carers to input to debate/discussion.
- Share **bite size information documents**
- **Good feedback**
- That they are sent **minutes/notes** and **kept up to date with future events and developments**.
- Possibly **filmed live** to enable carers to see what's being discussed?
- **Post or email questions**
- Hold **regional meetings to suggest topics/raise concerns** or **to feed back** what was discussed at the Carers Parliament.
- By ensuring they can either join in by **Skype or emailing** all the items discussed
- **Opportunities to be consulted beforehand and informed afterwards**. **Stream it live online** with contributions from carers
- **Broadcast live** on social media
- Provision of **Skype** opportunity etc.
- Email carers with **pre-event surveys to select and prioritise topics**. Ask them to **elect regional representatives** either for the Steering Committee or for the Parliament, as happens in the Scottish and Youth Parliaments. **Requiring delegates to make themselves aware of local issues** and to promote those views at the event.
- Maybe **contact local Carers centres and ask them to pass on the information** that was discussed on the day.
- Reach out and do a **survey like this to help them voice their opinion**.
- **Live stream**
- **Reach everyone on mailing list before the event** to ascertain their views and **contact afterwards** to update with content and summary of discussions
- **Reports including any votes, video clips, live web streaming**
- **Stream online**. Have someone live tweeting?
- Very difficult to reach everyone, but **sharing information with carer specific groups** and organisations from that area
- Allow carers who can't attend to **see a video of the conference** or just the debate and let them provide their own feedback and questions
- **Gather information from carers so views and feedback is not from minority** make events bigger and invite more carers not professional bodies
- **Podcasts** shared via email and social media, with interactive activities for people to join in from home

- **Engaging with carers organisations** and they can share information both ways. Asking carers what they want to campaign about and feeding back what's working or not.
- **Stream it on youtube**
- I think if a **condensed report on the proceedings** could be drafted and emailed to known carers it would help keep them informed
- **Video link**
- **Sending questionnaires to them prior to event**
- **We all have 'hubs' in our local area so perhaps printed information could be provided for those who attend to distribute.** Perhaps local Carers Centres can be brought into the discussion. I myself have used my local centre many times over the years and found them extremely useful.
- Offer **live streaming** so those unable to travel can still take part?
- **Make the proceedings available on-line or in hard copy**, for those not on-line, with ability to respond or comment.
- **Ask for questions to be submitted beforehand.** These questions can then be put forward at the Parliament.
- **Sharing information** on the event by email/online/accessible documents.
- **Have smaller events, where your reps are able to show a video on what was discussed** and get feedback
- **Smaller more local events**

What is the best way for carers to be involved in the planning and delivery of the event?

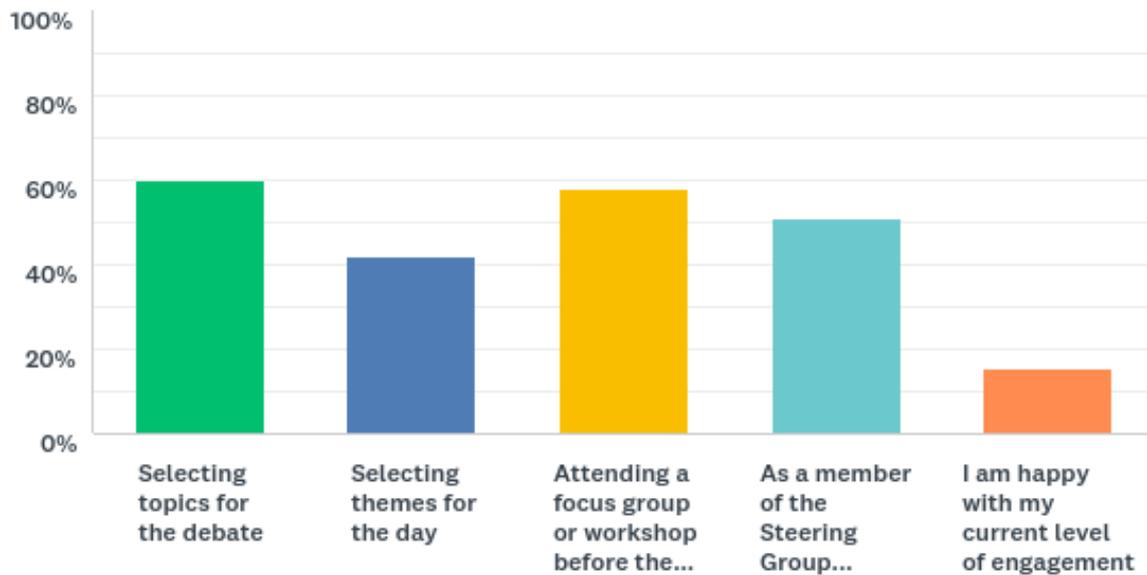


The largest proportion of responses (82%) were to be involved in selecting topics for the debate with the other three options, selecting themes (56%), attending a focus group or workshop beforehand (58%) and as members of a steering group (62%) all receiving support.

“Other” responses included:

- We choose what's discussed with no input or refusal from politicians
- Have online forum to gather views and to share best practices etc.
- Hold regional meetings to suggest topics/raise concerns

## Which of these options would you be likely to get involved in?



## Carers were also provided with a space for additional suggestions or ideas they have for future Carers Parliaments

- Local authorities MUST be involved in helping get as much information and engagement from carers as possible. It is part of the Act, but meaningful participation with the public is still something they are not good at.
- Need to be clear what Carers Parliament is about, i.e., not about telling personal stories, but thinking of how we can influence/lobby for change. Celebrate where things have worked to share best practice. Get local authority buy in as well as Government, money is allocated to LA so it's easy for Government to opt out of blame as they have done their bit, it's local authorities who need to answer and COSLA.
- I couldn't make the last Carers' Parliament so this may have already changed, but it would be great to have a carers' meeting point so that individual carers, who may not know anyone else there, have a place they can head to when they arrive to meet and connect with other carers.
- I know we need to hear Carers stories but keep it minimal and focus on positive ones.
- I personally disheartened by the lack of action and results for carers, all we hear is how much they save the government, there has been no increase or changes to the support offered. Either make a positive difference or stop giving false hope and wasting everyone's time... MAKE A DIFFERENCE
- Though this maybe takes place annually, to make sure that people have information and a platform to share their views as much as possible, caring can be very isolating, so knowing where to find groups, etc. is crucial.
- [The inclusion of] the Adults with Incapacity Act. It effectively gags caters who may have spent most of their lives caring very well for said adult.
- Ensure that carers are made aware of the existence of and scope of the Carers Parliament by increased press participation
- It must be an opportunity to hold politicians to account and not merely be a platform for them
- Move it out of Edinburgh

- [Including] refreshing and adapting The Charter of Rights for People with Dementia and their Carers to apply to all groups. Getting such a Charter enacted as law. Getting "Equal Partners in Care" incorporated into the Charter. Getting the expertise of carers to be recognised in law.
- I really enjoyed the last Carers Parliament and would happily attend another
- I am not sure if I feel posing questions for a set time, one after the other from delegates, is the best way to find solutions to the many difficulties carers are facing at the moment. As it is a completely open floor, the questions/personal stories that were raised varied greatly and many did not have an adequate or suitable response. Prior to the day, could themes be chosen and questions sent in on those themes/topics for part of the session, giving time for these to be responded to, then open the floor to any other question? This year, I have to say, I found very disheartening and worrying, we are not finding solutions.
- Accountability for councils as they implement the policy and legislation or they are supposed to. Why is everything a fight? Why is everyone not made aware of rights? Make it like question time and have councils there too Why is a needs assessment a postcode lottery?
- Q&A panel with questions which would be submitted beforehand allowing the best person to be there on the day to answer the issues arising.
- I would like more focus to be spent on working-age carers and those who do not get means-tested benefits but are able to do some small amount of part time employment.
- I think there should be a greater focus on how much carers save the state. There should also be a greater emphasis on how caring can impact on life long after the caring ceases
- In order to maximise the day, have a working lunch break. i.e. afternoon groups could start earlier.