

## **About Dementia 12 May 2022**

### **Background and Participants**

Three attendees were employees of About Dementia, a project run by Age Scotland. Four attendees were/had been carers for people with dementia. Attendees came from across Scotland including Clackmannanshire, Aberdeen, Dundee, Edinburgh, Glasgow and the Western Isles.

Within the staff, one had worked at the Scottish Parliament previously, and another had engaged through work at Age Scotland, but not as an individual.

Within the attendees, two had not been involved with the Scottish Parliament before.

Of the two attendees who had been involved with the Scottish Parliament, one of them had attended Coalition of Carers Scotland meetings, to which the Scottish Parliament had sent representatives. The second had been a campaigner/activist for people with dementia, now rights of carers, and had engaged with MSPs/ministers in this capacity.

### **Discussion**

#### **What stops people from engaging?**

- A feeling like the Parliament would not be interested in what they have to say. For example, as a result of not having sufficient “clout” or “education” to be taken seriously, or due to the perceived formality of the way in which the Scottish Parliament works. This was also reflected in people stating that they felt more powerful/heard when working collectively. However, this came with the caveat that in doing so there is often pressure to “toe the party line”, leaving their own specific personal viewpoints out of the discussion.
- A lack of trust in governmental organisations, or authorities. “Trust takes time to build”, and it was felt by some in the meeting that in the past their voices have fallen on deaf ears. They stated that this was very “disheartening”, and as a result lessens the energy they have to get involved in the future.
- This lack of trust is also reflected in the perception that things take a very long time to resolve when issues arise, which can be demotivating. It was understood that this is part of the process, but it still causes people to not want to participate when they feel that there will be no point to it in the long run.
- Uncertainty around what the “correct” route to take would be when an issue arises, or where to begin. There are a lot of bodies that are perceived as having overlapping responsibilities. For example, some would go to the

council, others to their MSP/MP, and others to more specific bodies, such as auditors. Often people felt that the Parliament wasn't their first port of call.

## **What could we change to make people more likely to engage in future?**

- Easier to access results. This includes more visibility, as well as more accessible language and format when reports and feedback are written.
- The feeling that in a stakeholder meeting, everyone attends on equal footing. One attendee stated that the goal in meetings should be “no hierarchy, only people”. The formality of committee meetings can put people off, and some people get nervous talking to people in positions of power. In-person meetings, informality, and the feeling that people can speak directly and honestly helps to break down that barrier.
- The idea of a “link worker for participation” was raised. This would be one person who could be a port of call for getting involved with the Scottish Parliament. They could highlight opportunities for people to get involved and make it more accessible.
- Host Open days where people can come visit and hear about how they can get involved in the work of Parliament.
- Travel and respite support should be considered for those with disabilities such as dementia and their caregivers to make it easier for people to participate in engagement events.