



Involving people with dementia as members of steering or advisory groups

Key messages

- **It is important that people with dementia can have direct influence**
- **This kind of role does not suit many people with dementia**
- **There are many adjustments that can be made to support people to be part of steering or advisory groups**

People with dementia are often invited to be a member of more formal steering/advisory groups, alongside professionals and service practitioners. This provides easy access to the views of people with dementia. Most importantly, it also means that people with dementia can have direct influence on debates and decision making.

This kind of role does not suit everybody. However many people with dementia are able to work effectively in these more formal settings, and have a lot to offer.

What adjustments can be made to support people with dementia to take an active role in steering/advisory groups?

Making these processes accessible to people with dementia can benefit everyone. First and foremost - ask the person with dementia how they can best be supported.

Here are some examples of things people have found helpful:

Before the meeting

- Send out any notes/summaries of issues to be discussed at the meeting in advance.
- Send out good instructions and maps of the meeting venue. Pictures of venues are also useful in making the destination seem more familiar. Ensure it is easy to access the building on arrival (e.g. signage). Make sure the meeting room or venue is as accessible as possible.
- Ensure there is someone available to welcome the person with dementia to the meeting. Ensure the welcome involves an orientation of the building e.g. where the toilets are located.
- Identify a consistent link person from the advisory group to be in touch beforehand (and afterwards) with the person with dementia. They should be able to respond to all practical questions relating to the meeting.
- Offer a phone (or face-to-face) pre-meeting to help people to prepare for the full meeting. Ask people how they best like to receive communications e.g. phone, email, face-to-face.
- Ensure you have communicated how expenses will be paid. If possible, sure that expenses are paid on the day or as soon as possible.
- Where possible, organise and pay for expenses in advance (e.g. booking trains or taxis). If booking ahead, either: (a) allow the person with dementia to select the transport times they prefer; or (b) make sure there is plenty of time between transport arrival times and the start of the session (and the reverse at the end of the day).

During the meeting

- Standard meeting protocol can be problematic for some people e.g. “hold that thought” or “can that go under AOB”. It can be a struggle for people to recall their point later in the meeting.
- Have an agreement that people may raise their hand when they have something to say (rather than relying on them finding a gap within discussions) or by the chair asking direct questions of them at appropriate intervals.
- Ask other participants to slow down their discussions, and to avoid using acronyms.
- Use visual materials where possible during the meeting to back up discussions (e.g. powerpoint presentations, hand-outs). Create these in a dementia friendly format.
See DEEP guide: writing dementia friendly information
<http://dementivoices.org.uk/wp-content/uploads/2013/11/DEEP-Guide-Writing-dementia-friendly-information.pdf>
- Plan breaks and refreshments into the meeting schedule at regular intervals. Identify someone who can be a support during break-times (and at the end of meetings) if needed. Some people may value quite practical support such as having hot drinks carried for them.
- Ensure the availability of a quiet space, in case people need a break from the meeting

After the meeting

- Provide minutes of the meeting quickly.
- A thank you can go a long way.
- Double check that the person enjoyed the experience and contributed how they wished to.
- If there will be more meetings, check that the person still wants to be involved.

Treat the person as an individual

- Consider with the person any individual changes that will make the experience more positive. For example: perception and spatial problems may make some people feel more comfortable sitting at the end of a table rather than in the middle.

- Ask if they would like a supporter to accompany them to the meeting.
- Check with the person that they are happy for others to know they have dementia. Sometimes, people want to stay anonymous.
- People with dementia say the bottom line is:
“Get to know me. Then you will know what I’m capable of, and the support I need.”

This guide was created by working with all the DEEP groups

DEEP guides aim to support the involvement of people with dementia. Some are aimed at DEEP groups, others at organisations wanting to work well with people with dementia. They have all been co-produced with people with dementia and will be updated regularly throughout the project. Suggestions for new guides are welcome – contact Rachael Litherland at Innovations in Dementia: email rachael@myid.org.uk or telephone 01392 420076.

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