



Involving people with dementia at conferences and events

Key messages

- People with dementia are often invited to take part in conferences and events. These opportunities provide positive ways for people to raise awareness about dementia.
- Good pre-event information and an identified supporter can help people with dementia feel more confident.
- Make sure you have a clear plan in place for how you are going to support the person with dementia.

Why involve people with dementia

Increasingly, people with dementia are being invited to take part in dementia conferences and events, small and large, local and national. Organisers of these conferences usually want to include presentations from people with dementia and their carers. This is a great way of raising awareness – helping people working in dementia services understand what it is like to live with dementia.

How can people be involved?

Traditionally, contributing to an event involves presentations or delivering workshops.

Main presentation

Some people with dementia are happy to give a presentation on the main stage at an event. This usually involves speaking to the entire audience, which can be a lot of people! Group presentations involving several people, some with dementia, may be less daunting. Main presentations can be anything from 10 minutes to one hour.

Workshops

A workshop usually takes place in a smaller room and involves fewer people. There is usually a short presentation followed by a discussion with the audience. It can feel more informal than giving a presentation on a main stage. A workshop usually lasts about 45 minutes to one hour.

There are other ways that people with dementia can contribute, which might be less stressful.

Interviews on stage

This can be a good way of supporting people with dementia to give a presentation and can work well on the main stage. Someone takes on the role of interviewer and asks the person with dementia a series of questions, which can feel more natural than planning and presenting a longer talk. The interviewer keeps the person with dementia on track and asks questions that help the audience understand their perspective.

Being part of the audience

One of the main ways people with dementia can contribute to an event is by being part of the audience. Making sure that people with dementia are invited to dementia conferences and events is very important – they, and their carers, bring a different perspective to discussions about dementia policies and services. It can be very enlightening for those who work in dementia services to talk to the people who are using those services. The best discussions are often those over a cup of coffee during the breaks!

It is important that people with dementia enjoy the experience of being at an event. There are some simple things you can do to make the venue more dementia-friendly (see *Choosing a dementia-friendly meeting space*).

When planning for numbers attending the meeting, remember that people with dementia will often need support to attend – from a family member, friend or support worker. Consider offering free places.

Film

Some people would rather not speak formally at a conference or event, but they would still like the audience to understand what it is like to live with dementia. A short film can be a good way of making sure the views of people with dementia are included.

For a guide on how to make a film with people with dementia, visit www.innovationsindementia.org.uk/films/ and click on 'Telling our stories'.

Inviting people with dementia to take part

You will want your event to be a good experience for people with dementia. This might be very new to them – they may feel nervous or unconfident about giving a presentation. Being able to reassure them by being supportive from the beginning is essential.

Be clear what you want from people with dementia

Do you want people to give a formal presentation? Can you be flexible about their approach? How much time is available? Can you offer them a time slot that suits them?

Do you want the person to focus on anything in particular in their presentation? Some people may feel confident about telling their individual story. However, if you want the person to talk about their experience of receiving a dementia service, you may need to provide prompt questions to help them prepare.

Ensure there is enough planning time before the event

People with dementia usually like plenty of time to prepare their presentation. However, the pressure of organising an event sometimes means that they are asked very late in the day to be involved. People who are experienced at public speaking may be fine with this, but it can feel very stressful. Time pressures may also mean you can't give as much support as you might like to the person with dementia.

Make sure there is support for the person to attend

Attending a meeting can be daunting, especially the first time. Remember that a person with dementia might need assistance with travel or reminders to attend, as well as planning what they want to say. They may be able to identify someone who can help with this and may want this supporter to come with them to the event. Being clear about the support that is needed and where it will come from can help the day run smoothly.

Inviting people early on in your planning process reduces stress for everyone.

Identify a named person from your organisation to be a point of contact

It is helpful for the person with dementia to liaise with the same person in the run-up to the event. Ideally, that person will also be available on the day.

Keep in touch

As the event approaches, keep in touch with the person with dementia.

- Are they feeling ok; do they have any worries?
- Have they prepared their presentation?

- What equipment do they need?
- Do they know what will happen on the day?
- How are they travelling to the venue – do you need to book transport for them?
- Who will meet them when they arrive at the venue?
- Do they plan to stay for the whole event?

Have a contingency plan

As with all presenters, it is possible that the person with dementia may not be available on the day. They may be ill or just not feel up to it. You still need to ensure that the views of people with dementia are reflected in your programme?

You may know other people with dementia who could step in at short notice. Or perhaps the person has prepared a presentation that someone else could present on his or her behalf. You may be able to show a film made by people with dementia instead. Try to think of a way that the perspective of people with dementia can still be included.

After the event

Your named person should be available to support the person with dementia during and after the event.

In the couple of days following the event, contact the person to thank them again for their contribution. Share feedback with them about the audience response to their presentation. While you are presenting, it can be hard to judge reaction. People should feel valued for the contribution they have made to the success of your event.

Ensure that any expenses are paid quickly. If you are giving thanks and other acknowledgements and payments to speakers at the conference, it is important to give the same courtesy to people with dementia.

**This guide was created
with the help of the DEEP
reference group**

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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