

General principles when involving people with dementia

- > **Pay a lot of attention to the practicalities.** For example, transport (booking taxis, etc); choosing the venue; time of day; refreshments; support; reminders, etc. This can be expensive and requires time and patience.
- > **Use a range of methods to help people with dementia to understand the issue or the engagement activity.** This might include visual prompts to reinforce the discussion (for example discussing menus in a dining room or kitchen), using photos and pictures, using flip charts and posters to record ideas, summarising discussions at regular intervals so that people can reconnect to the ideas.
- > **Check and double-check people's viewpoints.** It may be that your own expectations or feelings colour what you think you are hearing people say or communicate.
- > **Think about the words you use** to talk about dementia (see DEEP guidance notes).
- > **Allow sufficient time** for any specific involvement activity. Give people the space to communicate their ideas and ensure people who need support to contribute receive the support they need.
- > **Be aware that involvement can be challenging** - it may raise emotions, cause people to be cross or anxious or invite people to think about tricky issues. This doesn't mean you should avoid these tricky issues, but pre-empt as much as possible the issues that may arise and ensure you have thought through how you might respond.
- > **Make any involvement experience as accessible as possible** - but without being patronising! Ensure any written materials are accessible, that straightforward language is used without any acronyms and that events and meetings are structured well - with restricted agendas and good approaches for a range of people with dementia to participate fully.
- > **Involving people with dementia can feel challenging.** It needs time, creativity, flexibility, strong listening skills and, often, a real drive to keep it a priority within stretched organisational settings. Create your own support by linking with organisations who are working to support people with dementia to be more involved.
- > **Make it enjoyable** - friendly supporters, good food, frequent comfort breaks, time to socialise, nice venue, laughter.
- > **Be prepared to provide information** (perhaps on an individual basis at the end). People often turn up because they need to find something out.
- > **If you are also planning to involve family carers, ensure that the voices of people with dementia can be heard separately.** Sometimes it can help to split people into different groups (with support) to have discussions and then bring people back together to share these discussions.
- > **Remember to keep people informed about what happened because of their involvement.** What changed? What were you not able to change and why?
- > **Ensure people with dementia are *consenting* to be involved and engaged.** Involvement isn't something that should be *done* to people. Follow an appropriate consent procedure that is accessible for people with dementia.