

Let's Talk Dementia:

Supporting communication in research partnerships involving people with dementia

Guidance for researchers

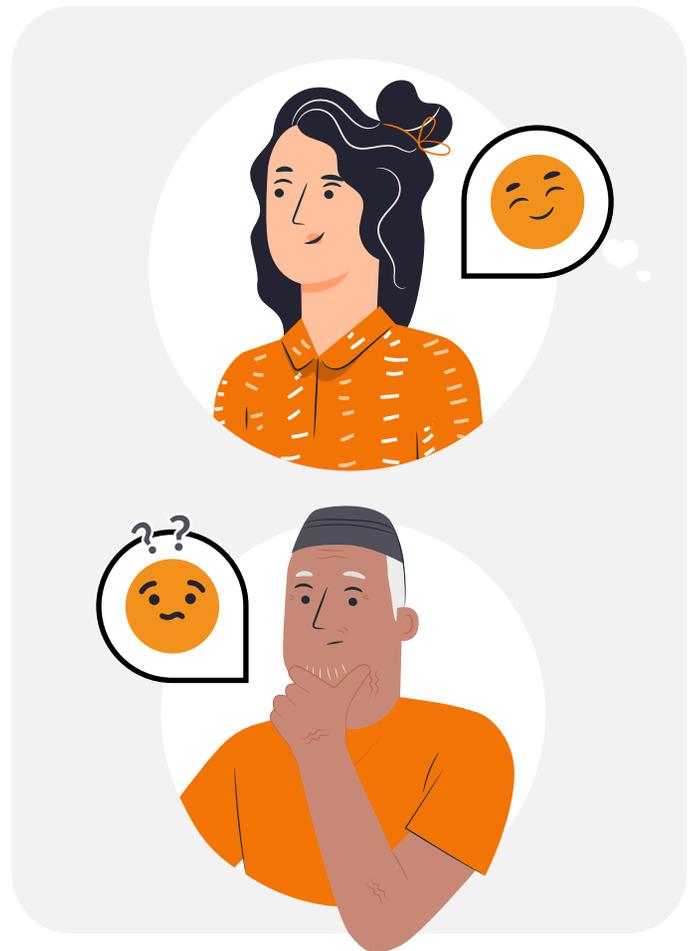
We are a group of people with dementia, their supporters, and researchers. We have created this guidance on how to communicate in a way that is accessible to people with dementia, as partners in research. By partners we mean people with dementia acting as advisors or collaborators rather than participants in research. We have also created a video of top tips for communication which can be found here [\[insert link\]](#).



Introduction

Good communication is essential for meaningful involvement of people with dementia in research partnerships. Dementia covers a broad range of cognitive, physical, and sensory challenges, so it is important not to make assumptions. Each person will have different communication needs and experiences. The main thing is to be flexible and find out what works for each individual at an early stage. Adapt to the group you have, considering that the group is made of individuals, rather than one size fits all.

Be aware that people with dementia may have feelings of anxiety or embarrassment, which need to be overcome. This can be due to a variety of reasons including wariness of talking to strangers, worries about being judged, and feeling intimidated by researchers. Focus on building trusting relationships rather than the importance of the research.



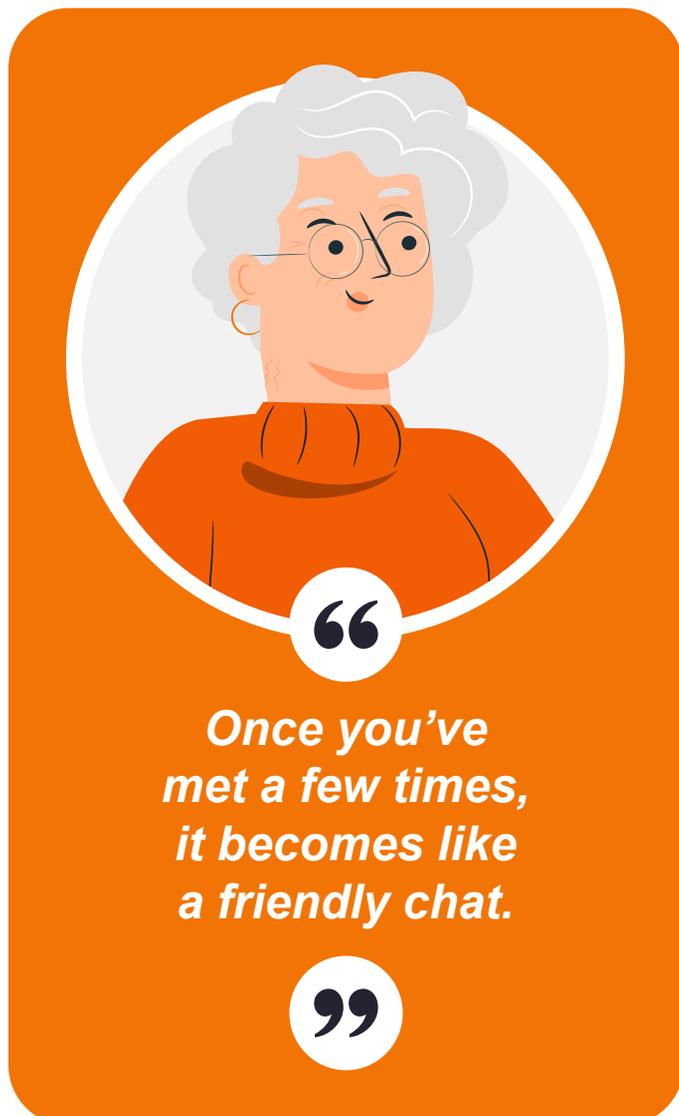
Learn about different types of dementia and how they may affect communication differently, but do not assume that all people with a certain type will experience the same difficulties.

Explore resources that can support your practice, e.g., 'What works when working together: A practical guide for involving people with different neurodegenerative conditions in policy research.'

This guide is split into four parts:

1. **Planning carefully for the involvement activity** (page 3)
2. **Communication tips for first group meetings** (page 5)
3. **General communication tips for all meetings** (page 5)
4. **Communication tips for the end of meetings** (page 7)

Each section offers practical communication advice to support meaningful involvement of people with dementia as partners in research.



1. Planning carefully for the involvement activity

Meet people individually before meeting as a group

An initial one-to-one meeting can be a chance for you to demonstrate that academics can be empathetic and approachable.

Find out about their backgrounds and communication needs – what will help them to contribute? Notice how they communicate in your one-to-one meeting. This can give you an idea of how they might interact within a group meeting.

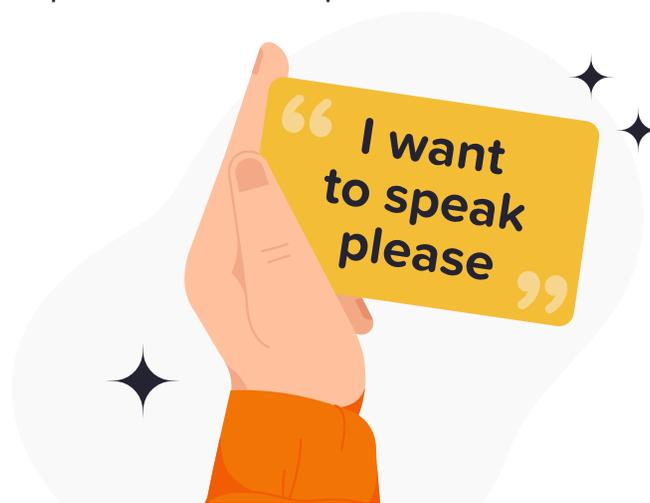
Give them options for involvement, e.g., group/individual meetings, in person/online. Some people may only want to contribute via email, as they benefit from having time and space to construct their thoughts.

Ask about:

- Spoken language(s) and the need for an interpreter.
- Preferences for communicating outside of meetings – e.g., email, text, phone.
- Preferences for communicating in meetings – e.g., how do they like to indicate they want to speak in meetings? Are 'I want to speak' cards helpful or are other ways better? How does the person want the researcher to support them to have their say?
- Are they able to use the chat function in online meetings or is it too much of a distraction? Consider switching off this function.
- What helps when communication is difficult – for instance, if someone tends to go off-topic or struggles to find the right words, what can you do that is helpful for them? Some people may get stuck mid-sentence and forget what they were going to say or have difficulty constructing the rest of the sentence. Ask them what is helpful to say or do, e.g., if it is clear they have more to say, they might want you to just wait and not jump in. Some people might like a prompt such as repeating the

first bit of the sentence: *'You were saying you think it's important to...'*

- Visual and hearing difficulties – what does the person need to be able to fully engage? How is it best to make information accessible? Some people require written information to be in a specific font, size, spacing, and colour.
- Previous experience of involvement in research or meetings in general – what helped them to engage and what did not?
- Their thoughts on contributors keeping their videos off in online meetings. Although there may be good reasons, it can make it difficult for people with dementia to process information when faces cannot be seen. It can also make individuals want to shut down and not speak.
- Preferences for terminology, e.g., many people do not like the word 'carer' and prefer 'supporter,' 'loved one' or 'companion.' In this document we use the word 'supporter' to reflect a wide range of potential relationships.



Ahead of a first group meeting

- If possible, plan for at least one group meeting to be in person. It might be that people prefer the first meeting to be online, as they find that less intimidating. It may be that not everyone will be able to attend a meeting in person, e.g., due to distance or disability. Facilitating hybrid meetings in an inclusive manner can be challenging, so if the group is keen to pursue them, it will be essential to approach them with thorough planning and consideration.

- Consider the benefits and disadvantages for communication of holding meetings online or in person. Online meetings are a cost-effective way of bringing people together who live distantly and cannot travel, but some people may be overly distracted by things going on in their own environment. Where people have perceptual difficulties or hallucinations, online meetings can be especially challenging. Advantages of in-person meetings include building relationships and being able to observe and respond to nonverbal behaviours. For example, fidgeting or foot tapping may be signs of stress or boredom.
- Carefully plan the timing and duration of meetings to fit the needs and preferences of your group. Meetings that last only 45 minutes rarely lead to meaningful involvement, so move away from an efficiency mindset towards flexibility. Longer meetings with regular breaks are often needed. Feeling rushed can inhibit people from contributing. Attending early or late in the day can also be problematic for many people with dementia, who may need plenty of time to get ready in the morning and may become more fatigued in the afternoon.

- Keep the number of people in meetings as small as possible, whilst still allowing for ideas to be bounced around. Around four to six is a suitable number for everyone to have a chance to speak. If a larger number of participants is required, consider breaking into smaller groups. 'Breakout rooms' can be used in online meetings.
- Consider having a co-chair. This could be someone with dementia from the group. They can help keep an eye on people to see if someone wants to speak in the meetings. The co-chair can keep a list of those who wish to speak and acknowledge to each speaker that their request to speak has been seen. The co-chair can also be sent resources before the meeting to give an opinion on their accessibility.
- There is a significant difference between living with the diagnosis yourself and being the supporter of that person. If your project involves both people with dementia and supporters, aim for these groups to attend separate meetings where possible. Discussing issues all together can make people with dementia and supporters feel less able to speak their mind. With good intentions, supporters might speak for people with dementia. It might also be harder to control the pace of talk. If you do combine these groups, make sure you have good reasons to do so. For example, supporters can help with translation, preparing ideas in advance of a meeting or repeating points for those with hearing difficulties. You can agree with the group that people with dementia will speak first when they wish to contribute.



- Create a concise, clear agenda. Send it in advance of the meeting so people can start thinking about the issues that will be discussed. Keep agenda items to a minimum. People need time to process new ideas and think about their responses. For in person meetings, include an image of the entrance to the building and clear guidance on directions. Arranging to meet people at a main entrance or other key location can also help reduce anxiety. Some people might be extremely nervous about introducing themselves in a meeting, so include guidance for introductions on the agenda, e.g., *'Everyone will briefly introduce themselves: who you are, where you live and why you are interested in the research topic.'*

2. Communication tips for first group meetings

Introductions

- Devote the first meeting to getting to know each other and finding out about the project, with no specific research tasks. This takes pressure off and helps to build relationships.
- Researchers should introduce themselves first, to remind everyone who they are. Do not assume people have remembered. People can get very nervous waiting for their turn to speak, so it is important to keep introductions short.
- You might become aware that some people know each other and already feel part of a group. Make sure to support and include those who do not.

Co-develop a mutual working agreement for the meetings

This might include:

- Sharing how people wish to communicate.
- Agreeing that individuals will not talk for too long. Facilitators need to be prepared to cut people off politely, e.g., *'Bill, I'm just going to cut in here. Thanks for those points. I just need to move things on so that everyone has a chance to talk.'*
- If it is a mixed group of people with dementia and supporters, agreeing to prioritise the contributions of people with dementia. People often need to speak before they lose a train of thought.
- Agreeing on the importance of silence – i.e., giving people time to process what they have heard and construct a response.

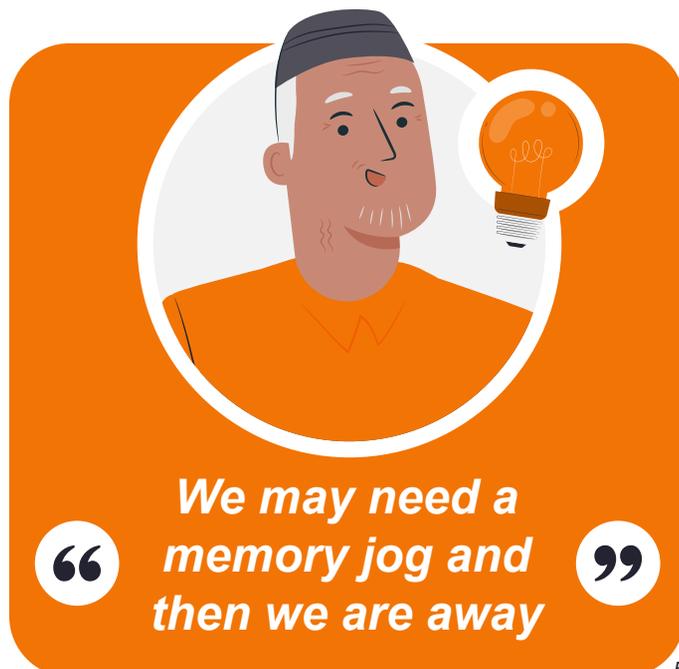
3. General communication tips for all meetings

Personal preference is key, so be guided by your group in terms of which strategies are most helpful for them.

- Be aware of fluctuations people can experience – check if they are having a good/difficult day for communication. Regularly check how everyone is doing, and whether a break is required.
- Teams should catch up and share news, so include a few minutes at beginning and/or ends of meetings for this purpose. Offering refreshments during in-person meetings creates a relaxed atmosphere that encourages informal conversation and connection.
- Consider using icebreakers suggested by the group, e.g., everyone talks about their favourite food. Icebreaker topics should be common to all and should not highlight inequalities in experience. Alternatively, if people do not like icebreakers you could spark conversation around a shared interest. Artefacts could also be used to get

conversation going, e.g., bring an object to the meeting and have a 'show and tell' activity. This can help people become confident talking - then it is easier to move the conversation onto the research. Always ensure the group is comfortable with these activities to avoid adding stress.

- Always remind people of what the project is at the start of meetings. Do not assume people have remembered.



- Slow the pace. Being excited about your project might make you speak too fast. People with dementia often need extra time to process information, so slow the pace, but not too much. Overly slowing the pace or exaggerating your tone of voice can come across as demeaning.

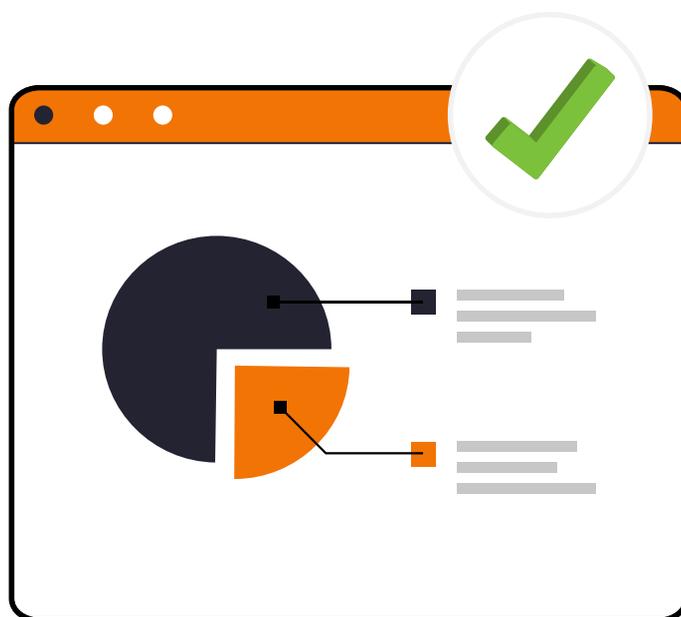


- Some people need to build up the confidence to talk. Notice when people haven't said anything for a while and create opportunities for involvement without putting them under pressure, e.g., You could say '*Does anyone else want to say anything who hasn't shared their thoughts yet?*' or do a 'round robin', ensuring each person has an equal opportunity to speak.
- **Visual resources:** Support people's understanding and expression, by using multiple communication modes: verbal, written, drawing, gesture, use of images and objects.
 - Use of visual resources keeps people focused on the purpose of the meeting/the discussion, e.g., agendas can include images to illustrate activities.
 - You could take photos at each meeting and share these on the minutes, with reminders of group members' names, if everyone agrees.
 - Use name tags for in person meetings. Offer to help with displaying names in online meetings.

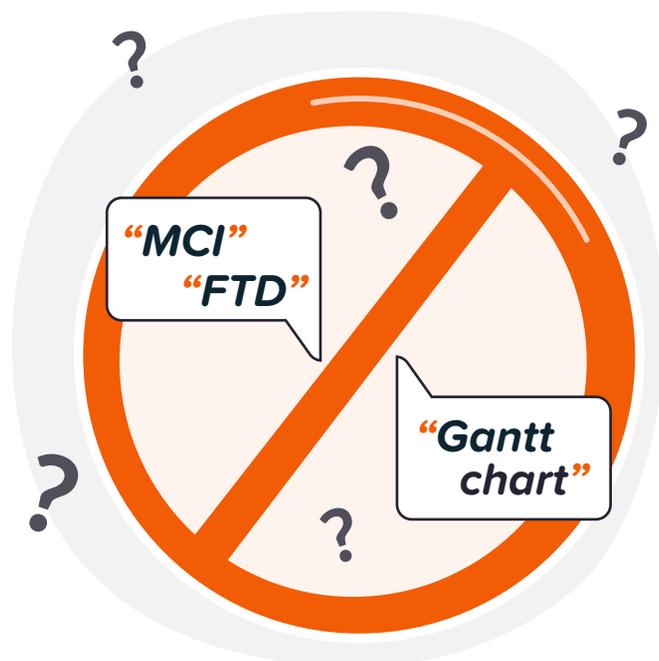
- Illustrations or animations can also be helpful for people with limited English or lower reading ages.
- It can be useful for some people to include creative activities like drawing or photography as part of the involvement. This can take the pressure off speaking.

- **Use of presentation slides and written resources:**

- Keep presentations short and simple. A photograph, illustration, or simple graphic can be clearer than a lot of words. Avoid speaking a lot when showing slides and let people read at their own pace.
- Avoid technology like Mentimeter, Padlet, and Miro boards in presentations. Things appearing and disappearing can confuse people, so keep presentations simple.
- If showing video clips or sharing podcasts, consider using the speed controls.
- Follow guidance on accessible writing such as using bold or highlighting for key phrases so those stand out. See: [Innovations in dementia: Accessible writing guide](#).
- Consider [colour contrasts](#).



- **Online meetings:**
 - It is important for people with dementia to see people's faces, so keep screen sharing to a minimum and avoid turning cameras off.
 - Keep backgrounds simple, stationary and quiet to support concentration, e.g., blur your background in online meetings.
 - Some people find scrolling very distracting or hard to cope with visually, e.g., researchers scrolling down the page sharing a screen and talking. Moving things about and writing on the screen can also be highly distracting and hard to follow.
- Do not use acronyms and technical words. This is especially important for people with dementia, who can fixate on trying to work out what things mean and therefore miss much of the ongoing conversation.
- Build confidence by using opportunities to feedback positively to people about their contributions, e.g., *'That was a great point'*, *'What a helpful insight'*, *'Thanks for all your important contributions.'*
- Some people, e.g., those with Primary Progressive Aphasia, are supported by lip-reading, so make sure people are not obscuring their mouths with their hands.
- People can become distracted by too much gesturing. However, also be aware that some people with dementia use gestures to convey ideas and help themselves to find the right words. Specific gestures used by researchers can also help people with dementia to understand key messages e.g., pointing or miming, for example miming 'writing' to support understanding of 'write down your ideas'. Like with pace and tone, be careful not to overdo gestures. They should feel natural, not exaggerated or childlike.



4. Communication tips for the end of meetings

- Always do an individual person-by-person 'round robin' at the end to pick up any final comments.
- Even with plenty of preparation and time, people may still find it hard to formulate their ideas in the meeting. Offer the choice to email you with thoughts that occur to them after the meeting.
- Take time at the end to summarise the contributions of everyone and go over next steps.
- If someone has been particularly quiet during the meeting, check in with them afterwards to see if they are okay. There may be something you could do differently to better support their communication.
- Gather regular feedback from the contributors on how you have communicated and allowed them to communicate. Give them the space to say if there have been issues with communication and use this for continued learning. Offer a choice of how to give this feedback. Often people with dementia prefer to feedback verbally during the last part of the meeting rather than in writing. Some might choose to email you later. Offer the choice to email or phone you with thoughts that occur to them.

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