

Methods and approaches for enhancing communication with people with moderate-to-severe dementia that can facilitate their inclusion in research and service evaluation: findings from the IDEAL programme

How can we include people with severe dementia in research?

Understanding the thoughts and opinions of people with severe dementia is important. If researchers and care providers know how a person is feeling or what help that person needs, they can use this information to design and develop the best methods of care. As dementia progresses people find it harder to express what they feel or need. Therefore, researchers need to know how to communicate effectively with people who have severe dementia.

We wanted to know what methods researchers can use to find out what people with severe dementia think. To do this we:

- Asked 17 people who are experts in dementia research and communication what are the best methods
- Looked for similarities and differences in these experts' opinions
- Identified themes that summarise how researchers can best communicate with people with severe dementia
- Talked to care home staff and family members to see whether they agreed with the themes we found

Important aspects of good communication identified by our experts are:

- Thinking creatively
- Being friendly and approachable
- Getting to know the person before starting a research interview
- Keeping the person with dementia at the centre of the conversation
- Making sure discussions are two-way

Even so, conversation is not always easy. Our experts described some methods that can help. Using personalized pictures, photographs or objects that reflect personal preferences and are matched to the person's ability, can support a good conversation. There are various resources available to help with this.

Researchers should know the available methods and be able to choose the method that works best for each person with severe dementia. This will enable researchers to obtain the thoughts and opinions of people with severe



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dementia and reflect these in their findings. This in turn can help ensure that needs are met.

This is a summary of a [research article](#) which appeared in the **Dementia** journal in February 2022.