Methods and approaches to facilitate inclusion of the views, perspectives, and preferences of people with moderate-to-severe dementia in research: a narrative systematic review

How can we include people with advanced dementia in research conversations?

Dementia research needs to involve people who live with the condition. It is important to ask people their views. We wanted to find the best ways to get the views of people with more severe dementia.

We looked at past research to see what other people had done. We did not find one specific tool to recommend. We did find some examples of useful methods.

Using pictures and images is a useful way to find out people’s views. Having a practice conversation first can help identify what works well. Group activities are useful for asking a lot of people their opinion at the same time.

We found five suggestions for improving conversations:

1. Focus the conversation on the person with dementia.
2. Identify a suitable time and place for the conversation, free of distractions.
3. Have somebody else around to help the person with dementia.
4. Have a clear list of topics to cover.
5. Ensure that researchers have the right skills and understand what is being expressed, even if the person with dementia does not speak very much.

These methods and ideas can help researchers understand the views of people with more severe dementia. This could help research be more inclusive and improve future work.

This is a summary of a research article which was published in the International Journal of Older People Nursing in December 2023.