

Good conversations with people with dementia: a key to improvement

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Getting Things Changed

This research analyses the detail about how interactions work, and what that means for practitioners and people with dementia.



About the research

Approximately 850,000 people in the UK live with dementia. Government policy claims that: 'we want a society where the public thinks and feels differently about dementia, where there is less fear, stigma and discrimination'. Government commitments for 2020 include a focus on greater involvement of people with dementia and their carers, in their communities and in research - so there is no time to lose.

This research was co-produced with a group of people with dementia from the 'Forget me Not' organisation. Our focus was on real-life communication when people with dementia interact with staff or volunteers. We wanted to find out what helps people with dementia to have an equal voice. Using a Conversation Analysis approach, our research team collected and analysed almost

ten hours of video-recorded interactions in group settings involving 28 people with dementia

The Forget-me-Not research group reviewed our video material, and commented on the communication they saw. They also re-imagined how they would like communication to happen, so that they can take part in conversations on a more equal basis. Based on their insights, we have made a set of videos featuring Forget-me-Not members, which we have trialled with practice organisations so they can be useful for training staff (see further information overleaf).

This research analyses the detail of how communication practices work and what that means for practitioners and people with dementia.

Policy implications

The Department of Health and Social Care

- should review the eligibility criteria for social care to include people in the early stages of dementia in personal budgets. That would enable people to have personalised forms of support in which more equal and enabling communication can take place.

Local authorities and health trusts,

- as well as non-statutory health, social care and housing providers should support the formation of local groups of people with dementia who want to have a voice in decision making about services.
- Services and practitioners need to consider further how to properly apply the second principle of the Mental Capacity Act, regarding supported decision making, which is in line with the UN Convention on the Rights of Persons with Disabilities.

Service providers and practitioners

- would benefit by adopting client-led methods of training in communication skills, using materials such as the videos produced by this project.
- Communication in dementia groups should focus on the here-and-now as well as memory talk. Practitioners need to beware that memory loss is not a feature of all forms of dementia and avoid turning a conversation into a test.
- Skills for Care and others involved in training should promote more 'equal' conversations where staff and clients can share experiences and memories.

Key findings

- None of the 28 people with dementia in this research had personalised support services. They attended settings such as activity centres, with some very skilled and effective staff.
- People with dementia managed conversations well when they met in informal settings where they were treated as equal partners. The Forget Me Not group also showed they could offer insights in research.
- Ordinary patterns of social interaction do not always work well for some individuals. Some people may need more time to get into a conversation and direct questions were frequently problematic.
- Staff members had to find activity schedules for a diverse range of people. They often ran quizzes, although the precise interactional format of the quiz had an effect on the social participation of people with dementia.
- People with dementia sometimes talked about their own past lives, but conversations could easily become like cognitive testing, driven by staff questions. Skilled staff members introduced information to prompt people at exactly the right moment in the conversation, or shared their own memories.
- Day-to-day decisions by people with dementia could be supported in a friendly, jokey way, which worked well when the interaction was led by the person with dementia.
- Managers, coordinators, staff and friends who took part in training led by people with dementia said how important it was to conduct training in mixed groups, where everyone has a voice.

Further information:

This research was part of a large grant, 'Tackling Disabling Practices: co-production and change', funded by the Economic and Social Research Council (ESRC) ES/M008339/1, led by Val Williams. For more information about the project: <http://www.bristol.ac.uk/sps/gettingthingschanged/about-the-project/>

Email: gtc-sps@bristol.ac.uk

More information about the 'Dementia Engagement and Empowerment' (DEEP) network can be found at: <http://dementiavoices.org.uk/>. The Forget Me Not group in Swindon is run by Avon and Wiltshire Care Partnership.

The Forget-me-Not training videos were produced with Moore Lavan Films, and are freely available to download by following the 'videos' link on our project website. They were produced by Moore Lavan Films.

Mental Capacity Act 2005 c9: <https://www.legislation.gov.uk>

UN Convention on the Rights of Persons with Disabilities: <https://www.un.org>

Papers published:

Webb, J., 2017 Conversation Takes Two: understanding interactions with people with dementia. *Disability & Society*, 32: 1102-1106.

Williams, V. et al., 2018 Understanding disabling barriers: a fruitful partnership between Disability Studies and Social Practices? *Disability & Society*, 33:2, 157-174, <https://doi.org/10.1080/09687599.2017.1401527>

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If someone's asked me something, and I'm telling it, I'd like to know that they are really listening. **(Forget me Not Group member)**

Personally if I saw somebody in a uniform, I'd blank them straight away...It would be a lot better if it was just 'all of us', rather than them and us **(Forget me Not Group member)**

