

Communication training: creating videos together

A study of everyday interactions between people with dementia and their supporters gave valuable insights into the principles of good communication.

Joseph Webb and colleagues report on their findings

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Good communication not only helps us to understand, be understood and get things done in everyday life; interactions have the power to shape how we see ourselves and how we are seen by others. People with dementia may require support from conversation partners who can help them maintain their identity through these interactions.

Bearing this in mind, we should communicate with people with dementia in ways that are most appropriate to them. Research in this area is often done “on” people with dementia rather than “with” them, even though they are one side of the conversations being studied. Conversation is a shared activity and people with dementia have real world experience that can illuminate how interactions with staff members or conversation partners can be facilitated or impeded.

It is for this reason that three members of the Forget Me Not group in Swindon, a service run by the Avon and Wiltshire Health Trust for people with early onset dementia, are launching a new set of training videos about communication, based on research done in collaboration with the University of Bristol. We will outline the “Getting Good Support” research project, in which co-authors Sandie, Harry and Roy acted as co-researchers, supporting the study of everyday interactions between people living with dementia and their conversation partners.

As researchers from the University of Bristol, the other co-authors Val and Joseph set out in 2015 to consult the Forget Me Not group, as part of a large research programme about disabling practices called “Getting Things Changed”. We were interested in the detail of the interactions which go on between people with dementia and those they meet in their daily lives. Using the method of “Conversation Analysis” (Sidnell & Stivers 2014) allowed us to shift the focus away from the supposed deficits of people with dementia, recognising that conversation (and its successful enactment) always involves at least two people (Webb 2017).

Collecting the data

Our research data was largely collected in dementia activity groups, memory cafes and other settings where people with dementia meet each other and engage in activities. It consisted of

videos of activities and conversations which were happening in real life. In all, we collected almost 10 hours of video data, which included 28 participants, supplemented by some 14 interviews.

One of the things we noticed was that people in dementia groups engaged in a lot of quiz-type games. We started to feel this was rather odd, as finding answers to quiz questions could be difficult and did not always work for everyone in the group. However, when we asked Roy, Sandie and Harry they defended the idea of quizzes, Harry in particular saying that he really enjoyed going to pub quizzes. Our discussion in that session included some insights from other group members about the kind of quizzes that could really work. Sandie said:

You see I think quizzes are all very well, but if you sat round a table and had half a dozen people, we could first of all introduce ourselves and the interests in our lives... and then go on to a quiz. Because you know what sort of quiz would be so interesting for each person.

We started to get excited about the possibilities of really doing analysis together, building on the insights which group members were sharing.

Research findings

Findings from this research are practical and have direct relevance for all of us who communicate regularly with people with dementia. They are much more than “tips for talk”, as interaction unfolds in real time, where one thing that is said always relates directly to what has gone before. One of the concerns of supporters in dementia groups is to elicit or facilitate talk about memories and to encourage people with dementia to recall fondly remembered things. Forget Me Not members support the view that this type of talk is extremely important, as Roy said:

Knowing about someone’s past tells you about who they are, gives you an insight into their life. It’s a way of getting into them. You are a product of your past. Your experiences have shaped who you are now.

But eliciting this type of talk can be an extremely sensitive thing to do. In our data, there were



Getting Things Changed

The Getting Things Changed research logo

several occasions on which questions were put to people with dementia which were unsuccessful in their outcome. We found that conversations could easily become like tests, with specific questioning techniques being used that resulted in people with dementia focusing on their cognitive problems (Webb 2017). The following conversation took place during a reminiscence session:

Laura: *I wanted you to tell me a bit about what you used to do for your job. Can you remember (slight pause) when you were employed what your job was?*

Jim: *(chuckling) Work.*

One of the problems here is that the supporter Laura is asking a question which is re-framed several times. "I wanted you to tell me a bit..." is quite an indirect, open-ended offer. However, it is immediately followed by foregrounding the possibility that Jim might not remember, and he comes out with a face-saving answer, which is taken as a joke by Laura and indeed by himself. We found that direct questions (eg "What was your wife's name?") were often unsuccessful, and that interactions became very tricky when the supporter in fact already knew the answer (Williams *et al* 2018). When the person with dementia finally responded, the supporter might then say "That's right", instead of showing surprise or interest as they would if they were being given some news.

All this became interesting to the Forget Me Not members, and Harry himself suggested that direct questions were often problematic. He particularly referred to questions which were too specific, or which caused a sense of panic when people failed to remember. Instead, he and Sandie acted out a way of talking about the past which relied on:

- indirect prompts from one's own experience
- open recall of previous conversations, to share what they already knew about each other
- peer-peer talk, rather than the power differential inevitable in staff-client talk.



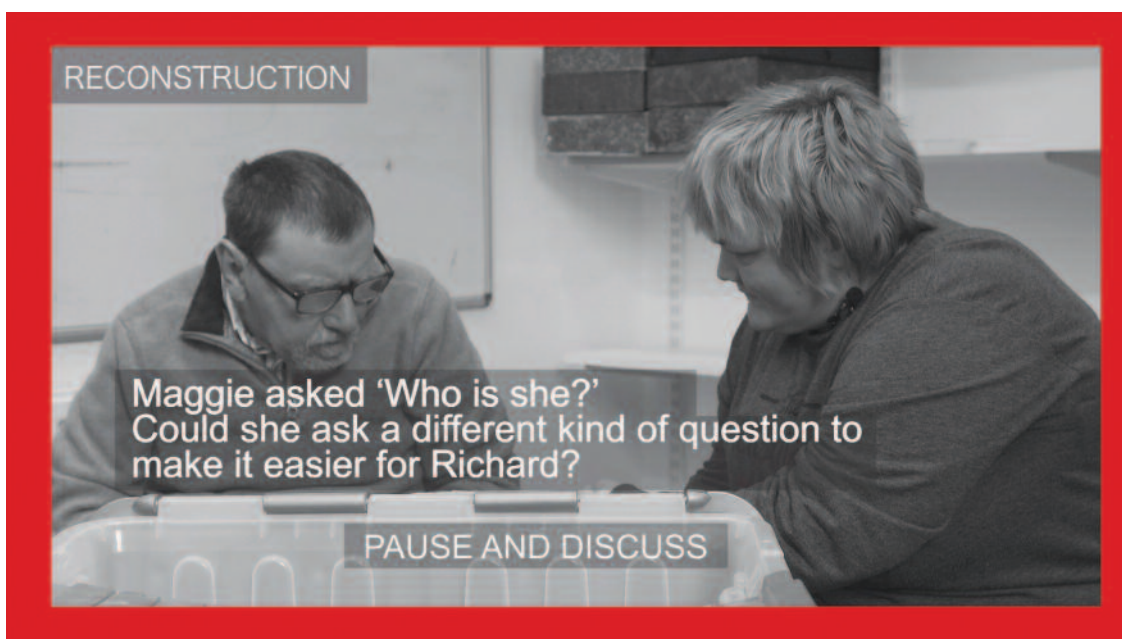
Above: Roy James (left) and Harry Davis from the Forget Me Not group with supporter Isis Thomas

These things are not easy to do, and we all fall into traps when trying to start this kind of conversation. So in our first training video we and amateur actors along with the Forget Me Not members re-created some scenes based on our data. The Forget Me Nots gave these bits of advice, which are from a collective conversation:

Your memories can trigger off memories from other people. The unsuccessful way is going in strong, instead of making people feel comfortable, and be relaxed. I usually start it by sharing my own experiences ("I remember doing that, do you?"). It's also good when things prompt you, like a piece of music playing in the background.

Doing a quiz

In every group setting we visited for data collection, we saw quizzes being put on for people living with dementia. However, not all quizzes are constructed in the same way, and we were keen to see how a quiz could go wrong as well as how a quiz could create opportunities for fun and achievement. ➤



Left: A still from one of the dementia training videos

Roy James from the Forget Me Not group with Isis Thomas, a supporter



► For instance, if the quiz-master asks a question which is too complex or which requires an answer that fits two categories, then this can result in problems. Here is an example from our data:

Staff member: Tom, can you think of a food beginning with R?

Sal: *Radish*

Tom: *Potatoes [two second gap]*

Staff member: *Not quite, have another go.*

This was part of a team quiz, but individuals were given turns to have a question directed specifically at them, which meant that only their response counted. As everyone in the group was listening to each question, it was hard to enforce the rule that only one person should answer. Correct answers shouted out during pauses were awkward and, in this case, the question master ignored them.

In consequence, it was all too easy to fall into a type of classroom scenario, where “pupils” were expected to keep quiet. Of course, in a dementia group all this was done with a real sense of fun, but they were also alive to the challenges. When Forget Me Not members reconstructed this type of quiz, they were affected by seeing how one member could be put on the spot and feel embarrassed about not knowing an answer, and how powerful the role of question master could be. As Harry said:

Quizzes should be fun and not regimental. It is supposed to be fun and not taken seriously. It is important to not put people on the spot. If you give the wrong answer, does it matter?! It is supposed to be a light hearted event. It is not so important to get the right answer, but to have a good time.

Instead, Forget Me Not members created quizzes that were less threatening. They put on a peer-led quiz, where someone with dementia took the role of quiz-master, and they did quizzes in which there were no “correct” answers. In other quiz scenarios, they accepted and chatted about answers that were

incorrect on the basis that recognition should be given to answers that were simply interesting. And they used stimuli such as music from the 1960s to create a quiz-type activity which became an enjoyable sharing of past memories.

Dementia training videos

Here we have shared just some of the examples of what we have discovered through recording everyday interactions and working with the Forget-Me-Nots. In our videos, we have reconstructed real interactions in which the members are actors, creating opportunities for viewers to think about new ways of interacting and perhaps to try them out in practice.

Each video raises questions and pauses to allow for discussion. They are not intended to show correct and incorrect ways of communicating, because everyone is different, but they do stimulate reflection on how to overcome those awkward moments that we saw regularly come up and how they could have been avoided or overcome.

We finish with the words of Roy, Harry and Sandie, who would like to see this research make a difference to the lives of all people living with dementia:

- *We've seen the kinds of things that happen on these videos. These aren't stories. These are facts of life for us (Sandie).*
- *There is room for us to learn from each other, and try to do things differently, to make life easier for each other (Harry).*
- *We hope these videos will travel like wildfire. They are useful for everybody to see (Sandie).*
- *From the doctors to the patients... We've got to get it across to them that people have to listen to us. We are the experts (Roy).*

Our training videos are due to be launched in May and will be free of charge:
www.bristol.ac.uk/sps/gettingthingschanged/about-the-project/dementiatalk ■

References

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