

Getting Good Support

Newsletter - Joe Webb and Val Williams

Over the last two years, our research about communication has been very active, and will be finished in May 2018.

It is timely therefore to say a big THANK YOU to everyone who took part in the research, and to summarise for you the findings from the project. Our aim was to find out more about how support workers, practitioners or volunteers and friends talk with people with dementia, and what works best so that both people can have a good conversation.



We made videos of people talking together. Sometimes they were on their own, and other times they were in groups like memory cafes or day centres.



Working with the Forget-me-Not group

We wanted to make sure that people with dementia had a voice in our project. The Forget-me-Not group in Swindon offered to help, and three of them formed a research group, Roy James, Sandie Read and Harry Davis. They gave us good advice about their own experiences since diagnosis. They also watched some of the videos we had made, and discussed them with us. Based on their ideas, they are making training materials which we hope will be useful for other dementia groups.



“ I don't know where it came from, for all this panic to set in, and I think that because I've got dementia, all of a sudden I feel I don't have rights. And people who are caring for me, have taken all those rights away from me, and they're doing it for me, and I don't have a say in it. But we've learnt that we have to fight for our rights. ”



What did we find out?

Talking about the past

People in 'memory' groups naturally talked about memories quite a lot. This came up during activities, but sometimes people also had one-one conversations about someone's past life.

Direct questions, such as 'Do you remember?' were often hard for people with dementia, because they panicked. We also found that it was hard when there were several questions together. People rightly wondered what they were expected to say next.

Another thing we all do very easily is to ask questions to which we already know the answer. The trouble is that it can sound like a test, and that seemed odd when the question related to the life of the person with dementia.

As the Forget-me-Not group said, a lot of this is about listening. They also felt that friends could talk together in ways that staff could not. Often they already knew something about the person's life, so they could simply remind them. Their general rule was 'Don't ask questions'.

In our training materials, the Forget-me-Not group have thought of different ways of opening up talk about the past. They show how:

- People need time to think and respond.
- You can use pictures or music to bring back the past, and that leads to people's stories about their own lives.
- When someone talks about their life, you may have heard the story before. But it is always new and interesting, and the conversation partner can show their interest by relating it to their own life. That is more like a natural conversation.

“ And a friend will listen, and often a friend knows what they're going through... And also, when they're talking, you make the right noises and that, so that they know that you're actually listening. If you're sat there keeping quiet about it while they're talking, they'll be thinking 'Are they listening?' ”

Quizzes and group activities

In the groups we went to, there were many different people with dementia, all of whom had different needs and personalities. The people running these groups were really skilled in working out different games and group activities, so that people could join in if they wanted.

We saw lots of quizzes!



In some quizzes, people had to take turns, and so a person with dementia might be asked a question which they could not answer. That could cause problems.

In other quizzes, people with dementia got shut out of the conversation, because their carers took over. And it often felt as though the staff were the ones in control, rather than the clients.

But... Quizzes can be fun, and they are popular. So we looked at these with the Forget-me-Not group too.

In our training materials, the Forget-me-Not group show how quizzes could work differently. For instance,

- You can ask questions which do not have one right answer.
- People can get points for saying something interesting, rather than saying something that is 'correct'
- People with dementia can run their own quiz, so that it is not so much a 'them and us' quiz.
- People can laugh and have fun.

Making things more informal



In groups like the Forget-me-Not centre, the furniture and surroundings are just like someone's own home. Unfortunately, many groups are held in large halls, with tables arranged in the centre of the space, and difficult acoustics. But activities could work better when:

- There were ordinary, interesting soft furnishings – like cushions or comfortable chairs.
- Furniture was arranged in small groups.
- Screens were used to divide up the space.



Our recommendations

- More people with dementia should get personal budgets, so that they can have one-one support and better personalised care. That would help better communication to happen.
- There should be more groups like the Forget-me-Not centre, where people with dementia can make their own decisions.
- Staff or supporters can help people to make decisions, by supporting them and talking about their choices.
- People with dementia can help to lead training for staff and supporters. The training videos we have made will help them.
- Talking about the past should not become like a test, but it should be fun. It's also important to talk about the here-and-now. People with dementia are leading interesting lives and have plenty to say.
- Skills for Care and others involved in training should promote more 'equal' conversations where staff and clients can share experiences and memories.

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.

www.bristol.ac.uk/sps/gettingthingschanged

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Thank you to everyone who helped us with the research, especially Roy James, Harry Davis, Sandie Read from the Forget-me-Not group