Helping people with dementia to feel safe

From years spent exploring and observing the points of view and experiences of people diagnosed with dementia, **Steven R Sabat** demonstrates that there are ways to facilitate communication and social interaction even when the person has great difficulty finding the words he or she wants to use

The title of this article implies at least two things: that people with dementia often do not feel safe in social situations and that they need the help of others to do so. Why would this be the case and what kind of actions on the part of others might be helpful?

When I engaged people diagnosed with dementia as my teachers and earned their trust by spending extended periods of time with them (up to two years, once a week), I came to understand that they often find social situations to be anxiety-provoking for a number of reasons. First, there is the person's psychological reaction to their losses due to brain damage. Reactions such as frustration, sadness and anger can result when the losses a person experiences affect abilities that they valued dearly during decades of adult life. Those feelings are compounded when, in their eyes at least, such losses have a negative effect on their ability to engage with others in social situations. As well, there is the need that most people feel, regardless of medical status, to present themselves in the most positive way socially by not displaying faults or dysfunctions to others. We all wish to 'save face' whenever necessary and many people with dementia even in the moderate to severe stages are no different.

Dr M, for example, was a retired professor when I met her. Her entire adult life was marked by her love of language and her ability to use it gracefully and wittily so as to engage her students compellingly as a teacher, as well as engaging other adults in enlivening ways in informal conversation. She experienced memory problems and was diagnosed with probable Alzheimer's disease (AD) years before I met her. One of the losses she experienced due to AD was her ability to recall and pronounce correctly the words she wanted to use. By her own admission, words had been akin to a musical instrument for her and now she could not 'play her music', as it were, and speak with élan and in the erudite manner she knew before AD. As a result, she was very reluctant to speak and was, for the most part, silent at her support group meetings because she did not want to embarrass herself by struggling in front of others to find the words she wished to use. That is, she did not feel safe to be herself in those situations.

For people living with dementia to enjoy social relationships with others they need reassurance, understanding, and the feeling that they are safe to be themselves with others. This photo was taken during the 'Opening Minds Through Art' (OMA) program, founded by Dr Elizabeth Lokon at the Scripps Gerontology Centre, Miami University in Ohio, US. Details: www.scrippsoma.org. Photo courtesy Steven Sabat

At the same time, she sorely missed having enlivening social relationships with people, a fact that emerged when we were discussing her experience of having gone to a speech therapist who gave her standard language assessment tests. In order for this fact of her experience to emerge in conversation with me, however, Dr M had to feel safe in the first place. She had to trust that I would be patient with her and support her in whatever ways I could so that she could express herself without fear of embarrassment.

The Intentional Stance

We can do a number of things to help people living with dementia to feel safe. We can do something called 'taking the Intentional Stance' (Dennett 1990) toward the person living with dementia. This means that we assume that the person is trying to communicate something even if we don't understand it at first, even if what the person is saying sounds incoherent initially. From this point of view, each utterance is assumed to be an attempt to communicate.

In the following conversational extract, not only did I take the Intentional Stance, but I also used what linguists call 'Indirect

Repair': checking with the speaker to determine if the listener understands correctly what the speaker is trying to say.

For example, when I was not sure that I understood what Dr M was saying, I did not assume that she was 'confused'. Rather, I assumed that she knew what she wanted to say and I assumed further that *I* was the one who was confused! In this situation, I *listened actively* to what she was saying, took responsibility for not understanding her clearly, and so said things like, "I'm not sure that I understand what you're saying… Let's see if I do… You're saying that…", and then I said what I thought she was trying to say, thereby giving her the opportunity to answer yes or no, or to add something else.

By listening actively this way, I was conveying to Dr M that (a) I was paying close attention to her and not dismissing her as being confused, (b) I was very interested in what she was saying and trying to say, (c) I was invested in working *with her* in the process of understanding her thoughts, (d) that I viewed our conversation as something important and (e) that *by working together*, we would communicate meaningfully. In this way, she could feel safe because I was not judging her for her foibles, but moving past them and attending closely to her as a person worthy of my attention and time.

In the following conversational extract about Dr M's reaction to having seen a speech therapist, the numbers in brackets indicate the use of Indirect Repair (Sabat 1991 p291).

Dr M: *I had three days, no, times, and on the third day I told her [the speech therapist] that I would have to give up the program. It was, and she wanted very much to know why, and I said uh, that uh, 'I have too many things on my head and they aren't, don't fit together' or something like that. At any rate, that's not something that's helping me uh, if, and then she – before we're going away, you will tell me what you feel about this.* (Shows me the results of the tests.)

SRS (Steven R Sabat): Well, I'm familiar with some of the tests that they gave you.

Dr M: *And uh, this was at the time, it was about three weeks ago and um, I was doing other things and it didn't, it didn't give me a feeling that there's something that I should have another thing.*

SRS: It didn't give you the feeling that going back and doing some kind of speech therapy would be helpful to you? (1)

Dr M: *No, I didn't think about that and uh, I, it wasn't, it wasn't important and I, you know, at this time too, I found that I really don't like to be uh, talking about what, what's my trouble. It's gotten, I know what my trouble is. And I think that what I would like it uh, only if there's something that is, uh, a time, a uh, a time and with a person who there is a real* (gestures with hands, holding them vertically in front of her, parallel to one another about 12cm apart and moving the right hand toward the left hand and then the left hand toward the right hand back and forth repeatedly).

SRS: Back and forth – a relationship? (2)

Dr M: *Um hum. You know you could go out, out of this area, and you could get so many people who would want to, to for one reason or another, to do uh, something uh, with me, and I don't want that. I don't want my life to be uh, not uh, I don't want to be part of what does this person can do, what that person do.*

SRS: Let me back up for a second because I think I'm missing your point. You don't want your life to be…? (3)

Dr M: *Going always to see people to see what's wrong with me.*

SRS: Ah!

Dr M: *And how to, and how and how it could sometimes uh, what can we do about it? But otherwise, I've, I've, I've had it.*

SRS: Ya... let me see if I understand. At least one of the things that you're saying is that it's, it's not something you, you don't want to put yourself in situations where you're constantly being shown what you can't do? (4)

Dr M: *That's one. That a real thing.*

So feeling safe means, at least in part, being in a social situation in which one is not being shown or reminded often about what one cannot do and then judged accordingly. This is entirely reasonable for anyone, whether or not the person is diagnosed with dementia. In this sense, Dr M was reacting as would any person deemed healthy. Who among those deemed healthy wants 'desperately' to be in an embarrassing situation that shines light on his or her foibles and to experience embarrassing situations most of the time?

In her support group Dr M was often 'put on the spot' by the group leader who would call on her to say something ("And what do you think about this, Dr M?"). In conversation with me, however, she was willing to talk because I worked hard to help her to feel safe in a number of ways, as demonstrated in the preceding paragraphs, including (1) not putting her on the spot, as it were, (2) actively listening to her, (3) using Indirect Repair in working with her so that I could come to an understanding of what she wanted to convey, and (4) allowing for long pauses in the conversation when she was attempting to recall the words she wanted to use. This last point is very important because, oftentimes, people are uncomfortable with long periods of silence in a conversation and feel that they have to "fill the unforgiving minute", as Kipling would say, with chatter.

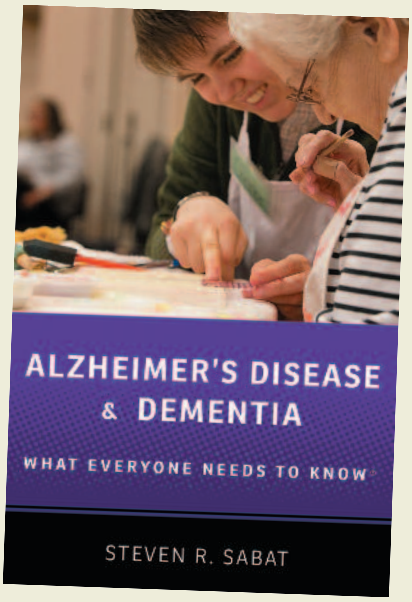
A non-anxious presence

Allowing the person with dementia to have the time to think about what they want to say is tremendously important because that person really does need the time to think and truly does not need to be burdened by the need to respond quickly.

So another way to help the person with dementia to feel safe is to be relaxed about long pauses in conversation and to bring a *non-anxious presence* to the conversation. This is especially important because most people, including those diagnosed with dementia, can sense whether or not those around them are relaxed or on edge. Anxiety can be 'contagious' and when a person with dementia feels anxiety in

What everyone needs to know

Alzheimer's disease and dementia: what everyone needs to know, by Steven R Sabat, was published by Oxford University Press in February 2018. It explores key topics related to Alzheimer's disease and dementia; identifies strengths of people with dementia in the areas of thinking, emotion, memory, selfhood, creativity, spirituality and social cognition/awareness; helps caregivers identify how these strengths manifest; and how people with dementia experience their diagnosis, sense of self and social world – in their own words. Details: https://bit.ly/2u50s69



others, this, in turn, can have a tremendously negative effect on that person's ability to recall the words they want to use to communicate their thoughts. So maintaining a non-anxious presence can be extremely helpful to those diagnosed so that they remain calm and feel the safety that that brings and thereby communicate clearly with the help of interested and facilitative partners.

In addition, I made it clear to Dr M several times that she could still communicate even without the use of words, as in years past. The famous mime, Marcel Marceau entertained people the world over and communicated a great deal without uttering even a single word and I brought that to her attention a number of times. Indeed, in the previous conversational extract, Dr M used a gesture with her hands to communicate the idea of the mutuality of a social relationship. She did likewise on a number of other occasions and so I called that to her attention by saying that she actually did communicate what she wanted to convey with gestures and I said, "You made your point." She replied immediately with a brilliant insight saying, "I made your point" and then, a few moments later, she said with great exuberance, feeling utterly free, "Who needs words!". Here, she felt safe enough to express herself in whatever ways worked to achieve clear communication.

Giving undivided attention

Active listening can take forms other than that exemplified in the preceding conversational extract. When we are truly interested in what another person is saying to us, we give that person our *undivided attention* and when we do not quite understand their point we say as much, thereby taking the responsibility for not understanding clearly. There is a difference between saying, "You're not being clear" and "I am sorry, but I don't think I am understanding what you're trying to tell me". Or, for instance, if the person is talking about a painful situation we might commiserate and say something like, "That really must have been difficult for you, especially after having gone through that other difficulty so recently". In other words, we do not utter, "Uh-huh" in that flat-toned, vacant way that is spoken usually at the wrong time because we are not paying careful attention to what our partner in conversation is saying, but doing something else instead, like thinking about what we need to do later in the day or looking at our computer screen and reading something.

Listening actively to the person with dementia is truly nothing less than showing that person the common courtesy that says, "I am with you completely in this conversation and I will do all I can to work with you and thereby try to understand what you want to say to me".

Reassurance, understanding, safety

In summary, people diagnosed with dementia often experience great sadness, frustration, and embarrassment in connection with the losses they experience in various abilities due to brain damage. These altogether appropriate reactions can have negative effects on their ability to enjoy social interactions with others and they often withdraw from a variety of social situations as a result. Therefore, in order for people living with dementia to enjoy social relationships with others, they need reassurance, understanding, and the feeling that they are safe to be themselves with others. That feeling of safety can be enhanced by how others act toward and with the person diagnosed, as I have discussed in this article.

A diagnosis of dementia does not strip a person of their humanity or their ability to enjoy and benefit from social interactions with others, especially if that person has a history of enjoying such interactions. The degree to which a person diagnosed can feel safe among other people is, in the end, dependent on the humanity and understanding of healthy others and their willingness to extend their minds and hearts in the process. People in general and people living with dementia in particular deserve nothing less. ■

References

Dennett DC (1990) An instrumentalist theory. In: Lycan WG (Ed) *Mind and cognition.* Oxford: Blackwell.

Sabat SR (1991) Facilitating conversation via Indirect Repair: a case study of Alzheimer's disease. *Georgetown Journal of Languages and Linguistics* 2 284-296.

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Supporting spouses of residents with dementia

Placing a partner with dementia into residential care has been described by spouses as being amongst the most difficult and stressful times of their lives. A research project led by Deborah Brooks from the Dementia Centre for Research Collaboration (DCRC) at Queensland University of Technology (QUT) is seeking to improve support to partners of people with dementia who have moved into residential care.

The Dementia Australia/DCRC Consumer Priority PhD research project aims to test the effectiveness of a multi-component psychosocial intervention designed to improve the psychological and emotional health of spouses and partners of people with dementia following placement into permanent residential care.

Ms Brooks is now seeking residential aged care facilities in Queensland and NSW to take part in the research. Care home personnel will be asked to complete a short seven-item survey about their facility and help with recruitment by passing on a letter, information sheet and consent form to English-speaking spouses of residents with dementia who have moved into the care home in the past 12 months.

Spouses of residents who agree to participate will be randomly allocated to either an intervention group (telephone support program) or a control group (printed information) depending on the residential care facility where their relative lives. If you are interested in helping with this research, contact: Deborah.brooks@qut.edu.au

Study to measure physiological responses to art

University of Canberra researcher Nathan D'Cunha is currently working with the National Gallery of Australia's long-running Art and Dementia program to assess the physiological and quality of life impact it has on its participants.

The research will use questionnaires (aimed at family carers) and saliva samples (from participants) over a six-week period to investigate the benefits of participation in the program, which began in July.

The saliva samples will be tested for the stress hormone cortisol, as well as various markers of inflammation in the body. The questionnaires will explore quality of life and any changes in relation to responsive behaviours and nutritional status.

While the benefits of such interventions have been probed before, Mr D'Cunha said that, "To our knowledge, this is the first study of its kind to look at the physiological effects of an art gallery intervention for people with dementia."

Mr D'Cunha is a recipient of a Dementia Australia PhD scholarship.