

Building Partnerships in Dementia: The Loved One, the Family Carer and the Home Carer

Bob: We've called this session "Building Partnerships in Dementia: The Family Carer, the Home Carer and the Loved One." Now, Sylvia, you are the loved one, with seven years of experience of various forms of dementia, as confirmed by quite a few brain scans. As you know, and others will soon see, this presentation has not been scripted for you. How can partnerships be built with people with dementia?

Sylvia: There needs to be love as a foundation between the care givers and the person with dementia.

Melissa: Yes, I totally agree. I suppose from my point of view, the key question is: how can home carers express that love to our clients and their families?

Bob: Perhaps a good place to start is to encourage people who are experiencing memory problems or confusion to go to their GP and ask for a diagnosis. It is reliably estimated that 42% of the people with dementia in England do not have a formal diagnosis.

Sylvia: That's awful! 42% of the people in this country who have dementia have not received a formal medical diagnosis? Therefore, they are receiving almost no care or treatment whatsoever. That is appalling!

Melissa: I remember working on a project a few years ago; and on average people were thought to have dementia for seven years before being given a formal diagnosis.

Sylvia: I did find it helpful to know that I was experiencing the early stages of dementia. I retired as a solicitor as soon as I was diagnosed with memory problems, because I didn't think it was fair to either the law firm or the clients to continue working when I was having memory problems.

Bob: Yes, you retired in July 2007, as soon as you were diagnosed with Mild Cognitive Impairment. You could have kept working for at least another year, but in your usual forthright approach to life you were decisive and decided to retire. Not everyone who receives a diagnosis of Mild Cognitive Impairment goes on to dementia, but after moving through vascular dementia, you were diagnosed with

Alzheimer's back in January 2011. I remember well when we received the results of that brain scan. In the car, as we were coming back home from the NHS memory clinic, you began to whistle the theme tune from "Bridge over the River Kwai." I thought, "Yes, that's quite appropriate. Our world has just been blown apart, but we can both still live lives of considerable purpose."

Sylvia: I couldn't whistle that tune now.

Melissa: I bet we can do it together, with some help from others. [whistle]

Sylvia: I don't always know what I can and can't do.

Bob: Yes, that's very true; and that is why we have to build partnerships in dementia so that we all learn to look after ourselves and each other to the best of our abilities. Sylvia, you are so different from that man in denial who remained in his job for two years after his diagnosis of Alzheimer's, despite the pleadings of his psychiatrist.

Sylvia: What was his job?

Bob: He was a Boeing 747 pilot! As his psychiatrist told me, "He would have been OK as long as the plane was on automatic pilot, but if any problems came up, his co-pilot better have been good!"

Melissa: Dear me, I know the implications are huge, but a diagnosis of dementia isn't something to be ashamed of. It seems to me that awareness of dementia today is where awareness of cancer was twenty years ago.

Sylvia: I quite agree.

Bob: I really liked the comment from the Chief Scientist at the Met Office, Julia Slingo, who was reflecting on the difficulty of predicting the weather. She said: "I don't think I have ever been wrong. I would say that my knowledge has been incomplete" (*The Observer, The New Review*, 31 August 2014, p. 22). The fact that the knowledge of carers and people with dementia is often incomplete seems to me a really big problem. For example, Sylvia, I sometimes don't know what events from your past are uppermost in your mind at the present moment.

Sylvia: I'm not someone who goes back into the past a lot.

Melissa: From my experience, the more we know about people the better able we are to relate to them and engage with them whether they are in the present or the past.

Bob: Sylvia, do you remember that time in the kitchen several years ago when you were standing at the sink, with your back to me; and suddenly you said in a quite clear voice, “If you have no prospects in the present or the future, you turn to the past.”

Sylvia: I don’t remember saying that, but I would agree with the sentiment.

Bob: Our helpful GP commented that lots of people who don’t have dementia also turn to the past because they believe they have no prospects in either the present or the future.

Sylvia: Oh, so what?

Bob: What do you mean, “So what?” What are you saying to us?

Sylvia: Well, it’s not that important, is it?

Melissa: I think sometimes it can be important. I’ll tell you why. When you’re trying to connect with another person; and you don’t take the trouble to find out when and where that person is, the conversation becomes quite confusing and potentially adversarial. For example, one person that we support often spends a lot of time in her mind with her kids when they were young, because that was a happy time, a safe time and a fulfilling time for her. So if we go in and say, “Your daughter has grown up and rarely comes to see you, how does that help her?”

Sylvia: Well, it doesn’t help her. It just reminds her of what she no longer has.

Melissa: Yes, so rather than saying, “Let’s talk about the time when your children were young,” we just do it.

Bob: Yes, that’s good, to just do it. I call it “relational time”—time that is linked to what relationships have been important in your past life. The author of *War Horse*, Michael Morpurgo, has written beautifully in *Christmas Stories* (pp. 105-146) about accepting the perceptions of a mother who believes that an unexpected visitor on Christmas Day is her son, Jim, killed in World War I. Once you have dementia, time is no longer linear and sequential. It’s chaotic and

dynamic, but with patterns, just not consecutive patterns. I can see that sometimes it is appropriate to stay in the past with the person with dementia, but whenever possible I try to be in the present.

Melissa: Well, that's where you are now. I wouldn't suggest that we should encourage people to go into the past, but if, for example, someone is on their own; and they are more comfortable in the past, then it's good to stay with them there as it is more likely to bring them pleasure. You are accepting them and not being intrusive.

Sylvia: I choose to stay in the present.

Melissa: Would you prefer for people to correct you, Sylvia, when you are in the past?

Sylvia: Yes, if they have a suitable knowledge of my situation.

Bob: Right, and your situation now is that I am falling in love with you.

Sylvia: What? What on earth are you on about? You fell in love with me years ago when we were both students at the London School of Economics. You were the only boyfriend I had at that point.

Bob: Yes, but even if we have been married for 52 years, now that you have Alzheimer's your personality has deepened; and we relate to each other in a different style.

Sylvia: We do?

Bob: Yes, we are each patient with each other, but we have to work hard to be patient with ourselves and with the dementia.

Melissa: Bob, I think you have hit on something really important as far as home carers are concerned. Being patient is a prerequisite to respectful support. However, all three of us need to recognize that people with dementia as well as family carers and home carers can become frustrated within themselves. How can we deal with that frustration?

Sylvia: Walk out!

Bob: Walk out, where? You never wander.

Sylvia: I never have an occasion to walk out on you.

Bob: Good!

Melissa: Do you ever get frustrated with yourself, Sylvia?

Sylvia: No, not really. I live with me.

Melissa: So in the past when you were young how did you deal with frustration?

Sylvia: Well, it would depend on who was around the house. My mother was not a very strong personality. She had been dropped as a baby; and she was not very bright. I basically stayed away from her. I didn't get into arguments with her. I would go off and peel the potatoes for lunch or supper.

Melissa: So you were really like a little carer. Did you intuitively know to take this approach?

Sylvia: Yes, my mother was a very kind person, but physically very weak and couldn't carry the shopping. I didn't have temper tantrums in front of my mum; and I wouldn't have dared in front of my dad.

Melissa: So who would you feel safe having a temper tantrum in front of?

Sylvia: My Auntie Elsie. She was a wonderful person. She was trained by the St John's Ambulance Brigade; and I knew Auntie Elsie loved me. My mother didn't really know what to do with me.

Melissa: So, Sylvia, do you think that a lot of the experience of caring is about love?

Sylvia: Yes, we each have different needs, but we can care for each other.

Bob: There's a story in Stephen Grosz's book, *The Examined Life: How We Lose and Find Ourselves* (London: Vintage, 2014), about two prisoners in adjoining cells who learn, over a very long period of time, to talk to each other by tapping on the wall. "The wall is the thing which separates them, but it is also their means of communication. They tap and they listen." Dementia is a wall of separation between you and other people, Sylvia; yet you still tap often and listen carefully to what you hear.

Sylvia: That's me! That's the way I am!

Bob: Happily for me and for you and for everyone whom our lives touch. You have taught me, Sylvia, that there is always a reason for your behaviour, just as Dr. Graham Stokes explains in *And Still the Music Plays: Stories of People with Dementia* (London: Hawker, 2010, 2nd ed.). My experience is that it is important for carers to try to work out the reasons for the behaviour of a loved one who has dementia. I do find it helpful to read about dementia in order to understand the condition better. As Dave Pulsford and Rachel Thompson explain in *Dementia: Support for Family and Friends* (London: Jessica Kingsley, 2013), a lot depends on whether someone is in an early, moderate or advanced stage of dementia.

Sylvia: What stage am I at?

Bob: Moderate, in which I as a carer am often asking: “How do I respond?” Sometimes I’m not sure what is causing your behaviour. There are at least four possibilities: first, your basic loving personality; second, some physical pain after the operation on the bone you broke a year ago in your right elbow after that fall picking blackberries; third, the Alzheimer’s disease, which is progressive and can draw you into confusion; and fourth, the experience of ageing, which is also progressive and can draw any of us into confusion and pain—as we both know well at ages 78 and 76.

Melissa: When working with seniors, one of the most important things that home carers need to appreciate is that any form or chronic condition can be exaggerated by the ageing process and so being patient and giving people time and understanding is vital. What I am looking for from staff is empathy, kindness and a willingness to be present with the client.

Bob: Let’s see what others think about how to build partnerships in dementia.