

For Broadcast: 18th September 2022

Richard: Hi, I'm Richard Fox from Messages of Hope. And I'm here with Jo Chamberlain and with Dr. Chris Materne, who has done her PhD in memory rehabilitation for people with dementia. Welcome Chris to Messages of Hope.

Jo: Chris. I'm curious to know, how dementia impacts families.

Chris: Looking back at my father-in-law. He had dementia, but we joke that about 20 years ago, he was down at the beach and he rang us up and said, my car's been stolen. Can you come and get me? So we did go and get him. But it turns out he'd forgotten where he'd parked the car. My husband had gone down and I said, look, just check, but it's not on the Esplanade somewhere. And it was, and so I took him back and goes, no, no, it's definitely in a different place, but all the keys are exactly where I had left them. And it looks like there's petrol gone. And we are like, mm, probably not. So 20 years ago there something happened. But at that time we didn't know.

When I was working at Flinder's university, I was involved with the Australian longitudinal study of aging. And we did some research that showed that people thought their memory was better than it was. If we asked people how good they thought their memory was, they went, yeah, that's pretty good. And then we did an objective memory test and it as good or it was not so good or it wasn't very good at all. And people weren't very good at thinking how well they had done on this test. But also family members weren't good at working out how good someone's memory was. So we worked out and thought that perhaps there was something in people's environments that was helping support their memory function.

Take my father in-law For example, out of his normal environment, put him down at the beach and he got disorientated and he didn't know where the car was. So those environmental supports can really help memory function. But if you disturb them, often that's when you can see that things are not going right. What happened much later on with my father-in-law when his wife went to hospital, became much more apparent that they weren't coping. She wasn't doing so well in the hospital environment and he wasn't managing so well at home and they were supporting each other in the context, but take someone out of the equation and all of a sudden the memory problems became much more obvious to everyone. So someone who's been fairly quiet might become more aggressive or more uninhibited. Someone who's been fairly outgoing could become quieter and more withdrawn. So that behaviour change is often a trigger for families. Things like, changes in how well people can solve problems. So navigating, to a different route. If they're driving somewhere, they can become lost and confused. Or they can't work out what to do. How to do the banking at home and can end up in all sorts of financial trouble, because they haven't paid bills or have spent more money than they should have. Which might be linked to a couple of other things as well. So some of those changes are really profound and can be really challenging.

Richard: A good friend of mine, both her parents have now been diagnosed with dementia and just seeing the grief that's on her that she's lost her mum and dad. So what has helped families?

Chris: For some people getting a diagnosis of something is really important. Often what that does is, enable people to get help and support from places like dementia Australia,

which a fabulous place to get support for people living with dementia for their families, or if you're a friend who knows someone with dementia, because often there are around. That can be really challenging as well. And then educating yourself as a person with dementia and also as a family caregiver about what's around and what to do and what can help. All of those things can be really helpful and give some sense of agency back to the people who are living with dementia, but also their family as well and to then help make decisions. Perhaps earlier have conversations that you might not have had until much later, if you didn't know what was going on. Those things can be really helpful.

Richard: What did you use in your research then that helped you with your father-in-law or your father-in-law's family help cope with him?

Chris: Yeah. So whilst we talk about people having memory problems in dementia, they can learn things and they can learn to use new tools and tricks. So be careful about what you want them to learn, and how you can create some support in those areas. When my father-in-law had a car accident and ended up in a rehabilitation hospital. And we got some supports in place to support him before he left the hospital. Cuz we were to see if he could go home. So getting some meals delivered so that he would eat because it was pretty obvious too at that point then that he hadn't been eating by looking at the fridge. He'd just forget to eat. So someone delivering a meal at lunchtime triggered to eat that meal and he would eat it. So going right back those basics of life just take for granted at times Yeah. Making sure that he had a one of the red cross support things so that if he fell, he could push it. That wasn't a great success because he put it in his coat pocket, hang his coat up and then lost the thing that he had to press. So that was interesting. We had to go and check every day to make sure it was on him. And it wasn't long before he then went into residential care because he wanted to be with his wife who was then in residential care as well. So they were for a time able to live together in the same nursing home. And that was great.

Jo: Seeing somebody go through dementia, that they're actually still good things that can come out of the time with that person. Is there a way of introducing some level of hope in their interactions?

Chris: If every day is a new day, there are always opportunities to create positive experiences for people with dementia and the people around them and for the family, that can be really beneficial. Even if the person with dementia doesn't remember it, but the family can remember that positive experience that they had taking grandma or grandpa or mum or dad down to the beach and eating chips with them. If mum or dad doesn't remember it, that doesn't matter. But they had a meaningful engagement with their family at the time and created a happy experience for the whole family. And maybe taking mum or dad or grandma or grandpa out of the nursing home to be with extended family is a way that can get the younger children, if they're around grandchildren, involved who might feel really uncomfortable in being in a nursing home environment, for example, and may resist wanting to go, but having them somewhere familiar, that's not threatening and that the person with dementia can just watch kids playing on a beach. It doesn't matter that they don't know that they're their grandchildren. They might remember the positive experience and how they've people will remember how they felt, how it made them feel.

There's a lot of research coming out now around the value of music therapy. So if they have a positive association with church and church music that might really help and going back to music that was around when they were a young person is proving to be really helpful. If I'm in a nursing home and not engaging, you put a seventies disco music on and that might have a really profound effect for me. Yeah. But at church music and hymns, and those songs that people grew up with can be really helpful. Even singing Jesus loves me

that they might have sung to their grandchildren. There's a really important message in there that they might not remember the song, but they might remember that Jesus loves them. And somewhere down that connects with part of their soul that we can't see or understand. Reading the same Bible versus that they might really enjoy or psalm you know, Psalm 23 is a really popular Psalm just reading that to someone. The really simple things can be really profound being with God can be really profound.

Jo: And it's interesting, you mentioned about Jesus loves me because I know somebody who had dementia and when that song came on, her eyes lit up and I, wondered whether it was about them remembering something or whether it was actually a faith filled experience for them. It was actually a connection with God. And so it's beautiful to see somebody who is nonresponsive, responding that way to that particular song.

Chris: So knowing that God holds us all and that God still loves all of us. God loves the person with dementia. God loves me as a family caregiver loves my children who can see their grandparent changing in ways they might not understand or struggle with that can really help.

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