

For Broadcast: 26<sup>th</sup> September 2021

## Living with Dementia

### Interview

**Gaye:** *“We can make life better for people with dementia and a diagnosis of dementia does not mean the end.”*

**Celia:** This is Messages of Hope and I'm Celia Fielke. More and more people are being diagnosed with Dementia, including early onset Dementia for people even in their 30's. There are positive signs for better ways to deal with the disease medically but they are still just a hope for the future. What about now? How do you face Dementia with hope, when a cure may not be ready in time for you or your loved ones? Today I'm talking with Gaye who is an aged care manager with over 20 years experience. She has some surprising insights to debug some of the misconceptions about Dementia and can offer hope and encouragement despite the negative aspects of the disease.

**Celia:** Gaye, what attracted you to aged care and in particular Dementia?

**Gaye:** I recognized fairly early on in my career in aged care that people with Dementia were getting a raw deal. They were far more intelligent and interactive than what people gave them credit for. And it's just remained a real passion to see that we can make life better for people with Dementia and a diagnosis of Dementia does not mean the end. It's an illness like every other illness and there's a journey to be had.

**Celia:** I hear a lot of people talk about dementia in terms of just memory loss? Is that accurate?

**Gaye:** It's far more than just memory loss. It can change mood, it can change emotion, it changes perception. It all comes down to what part of the brain is being affected, right down to millimeters of the part of the brain that's being affected and that's why no two Dementias are ever the same.

**Celia:** Are there other misconceptions about Dementia?

**Gaye:** Probably one of the biggest ones is that people assume that people with Dementia can't think for themselves. It's not true, people with Dementia certainly have areas of the brain that are being affected by the Dementia and they can't function in a way that we normally would. But other areas of their brain are working perfectly well. We assume that a person with Dementia can't make decisions about their lives. Well, sure they may have a problem with say finances because that's often one of the early areas that people struggle with but yet they're perfectly

capable of deciding where they want to live, what they want to do, whether they want to wear certain clothing. Those day to day decisions that affect your life and your well being. People often take those decisions away from those people that have Dementia without realizing that they're taking away a lot of their self-worth with it, by not allowing people to decide their own outcomes.

**Celia:** So when people take those choices and decisions away – out of love and care for their family member – how does that affect the person with Dementia?

**Gaye:** It's very dis-empowering and people become very depressed and hopeless and helpless. We all need to have some control over what our lives are doing and people with Dementia are no different. We need to respect their choices and decisions.

**Celia:** What if the family is worried about them making poor decisions?

**Gaye:** If they're not making one that is perhaps as sound as what it should be, then there are ways of discussing it with people, providing them with alternatives that are simple and that they can get their head around. Sometimes you've just got to spend a little bit more time, you know. That's probably the most significant thing for someone who has dementia. They struggle with getting information delivered too quickly, so you need to slow it down in a manner that makes it easy for them to take it in.

**Celia:** Dementia makes it difficult for people to find the right words and keep their thoughts together. It's easy to get muddled and confused. So how do family members deal with it when their loved ones can't find the right words anymore?

**Gaye:** Language is one of the areas that often is affected for people with Dementia. They struggle to find the right word and that's really frustrating because they know they're struggling to find the right word very often too. And so, they often communicate more on an emotional level and using non-verbals. My advice for loved ones would be to keep communicating through your feelings and emotions and through touch. Gentle touch on the shoulder, gentle touch on the hand communicates a lot of feeling quite often. A lot of people need that reassurance to know that they're being reached.

**Celia:** I've heard that some people with Dementia can be quite aggressive and maybe don't want to be touched – what's going on there?

**Gaye:** Often aggression comes about through frustration and very often that's what's behind the person with Dementia. It could be their communication skills, it could be because someone's being mean to them, who knows? But their frustration builds and builds and unless you can find an outlet for frustration, it can overflow into aggression. For someone who's aggressive like that, the first thing is to recognize personal space. Letting people be heard, giving them an opportunity to voice their concerns or the issue they want to discuss. Giving them enough time to get it out. Creating an environment where people are comfortable to have fun, to be silly. All those things can help to reduce the level of frustration that people are feeling. Of course, that's not for everybody, for some people unfortunately the area of the brain

that's damaged is causing that aggression in the first place. But even in those people, if you can reduce frustration, you're at least not adding to it. We can't take away the brain damage unfortunately, we don't have that capacity yet, but we can reduce the factors around it that are compounding the issues being faced by the person with Dementia.

**Celia:** The changes Dementia brings to a person are obviously going to change the relationship you have with them – what are the unique challenges for adult children with parents with Dementia?

**Gaye:** You often hear about the child becomes the parent and you're forced to take on decision-making that you never actually envisaged that you would. You may also be forced to take on personal cares for your parent that you never envisaged that you would do, you would never have imagined having to assist a parent to go to the toilet or to have a shower. A lot of family members really struggle with that because that's not the right relationship. So they actually compensate by taking on the parental role but that doesn't work so well either if you're taking away choices. Trying to remember that person is still your mum or dad underneath and it's interesting the little glimpses that you still get of what was there before if you look for them. You can often build a whole new relationship around that person too. Yes, they're not the parent that they were before, but there's still value, there's value in every relationship.

**Celia:** People dealing with Dementia often talk about the long goodbye, particularly if they're a spouse. Can you explain what the long goodbye means?

**Gaye:** As the disease takes over, they're constantly saying goodbye to some part of their loved one that they valued before. So, it is a long goodbye and it is very, very difficult. Really the only way to deal with those is to try and keep that communication and to try and keep the honesty happening within relationships. So, one of my catch cries is don't lie, don't lie to people with dementia. When someone says to you, "You know, I want to go home," or, "When am I going home?" It's easy to say "At 5:00" because you hope that by 5:00 they won't remember! It's not the way to do it because that's undermining relationship and building strong relationships is so important. They need to know they can trust in what you're going to say to them, even if sometimes they don't like the answer.

**Celia:** But how do you handle it when they don't like the answer?

**Gaye:** If I have a resident here who has Dementia who asks me a question and I don't know the answer, I'll say "I don't know." It's okay to not know. If they ask me a question about a loved one who's passed on, for example, "Is my wife coming today?" Instead of saying yes or no, I will usually bring up a conversation about the wife. "How many years were you married for? What colour of hair did she have? What did she like to do?" Very often in the process of the conversation, the resident himself will say to me, "Oh, she passed away in 1998." So, I'll have a resident who'll come and say to me "I want to go home." And I'll say, "Yes, I know you want to go home, that's fine to want to go home but at the moment, you need to stay here." Now, they might get cranky at me because I said that, but they know that it's the truth and they'll come back the next time and ask me again. And I've had residents say to

me, "I've asked you because I know you'll tell me." So, don't lie to your loved one with Dementia, tell them the truth. Certainly you haven't got to be brutally honest, you haven't got to throw it in people's face, but you do need to have that honesty and that authentic relationship there.

**Celia:** One of the hardest times for people visiting their loved ones is having to leave them and say goodbye. Do you have any advice for those who really struggle with that moment?

**Gaye:** It is hard. The more you visit, the more used to it you'll get and I don't believe in not visiting. I think people with Dementia really need to know that their loved ones are there and are still connected and are still interested. Yes, saying goodbye is hard. With farewells keep it short and sweet. "It's time to go now mum, I'll see you on Wednesday at 3:00." And go and trust that wherever your mother is that the people there will then support her to get over it. Chances are she'll actually get over it quicker than what the relative who's just left her will. The relative is just left to dwell on the fact that mum was upset, mum's gone off and had a cup of tea and is quite happy again. So short and sweet but honest.

**Celia:** Gaye, what inspires you to keep making a difference in this area of care?

**Gaye:** What keeps inspiring me is seeing the results of giving back autonomy to people who have had it taken away, who have now regained quality of life. Seeing residents laughing, happy, having fun, having happy hour down in the room, seeing that they are able to still do so much. Seeing people who are really involved and connected and staying connected right to the end. Staying mobile because we're putting in things like false preventions and we try and use strategies around keeping them going. We use a lot of physio to keep people's muscles strong so they can keep walking, so they can keep doing things for themselves. That gives people a really high quality of life, to be able to keep doing things for yourself. And you know, yes, quality of life might not be what we would expect or what they would have expected to have, but quality of life is still present. And it's really nice when the residents themselves are really comfortable in their own skin. That's what keeps me coming back.

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