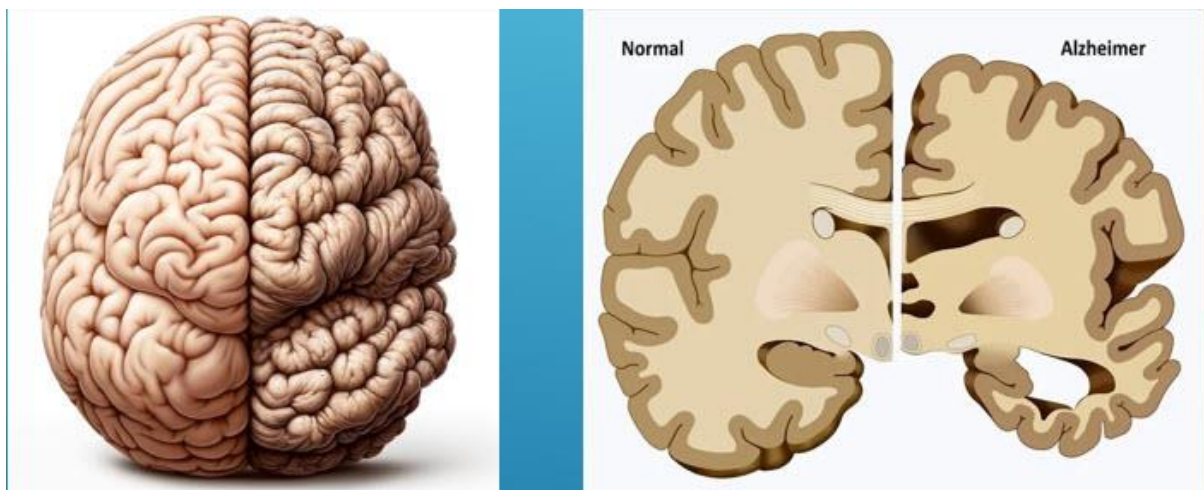


Dementia

Hi everybody, my name is Cathy Strachan and I'm going to be speaking to you today on dementia, which is part of Module 5 for your PVP program. I am a palliative care nurse, I am a qualified pastoral carer and I also have qualifications in dementia care and I worked for an aged care facility in the dementia ward for quite a few years, so I do have some experience with dementia and so I'd just like to share with you what the disease is and how we can help people that are living with this condition.

So what is dementia? It is a term for several diseases which affect your memory and your thinking and your ability to live each day and perform daily activities. The most common of these conditions is Alzheimer's, which comprises 60 to 70 percent of people that suffer with dementia.

Then you get vascular dementia, which is normally a result of some blood condition in your brain that impacts the health of the brain, like a stroke or a clot or bleeding. Then there is Lewy body dementia, which is often related to Parkinson's condition, and then there is frontotemporal dementia, which affects your personality a lot more. **So depending on where the disease impacts your brain, it is going to affect the behaviour that the person displays.**



So if you have a look at these two pictures, the first one is a picture of the **outside of the brain** and what I've chosen there is to show you a healthy side of the brain on the left and a slightly shrivelled or unhealthy one on the right, so that you can see that **it is physically the brain that is changed when you have dementia.** In the second picture, it's a slice through the brain and on the left hand side, it is the healthy side and this is a slice of an Alzheimer's brain on the right hand side, which is slightly reduced in size. **So what I'm trying to illustrate with the two pictures is that the brain itself actually changes.**

So for the person that is living with the condition - it's beyond their control. It would be like if you had a withered hand and you expected it to behave the same way and to have the same abilities that it had before it became withered. So I know that's an extreme example when I say withered, but physically what is happening in the brain is that it goes from healthy to unhealthy and shrivelled over a period of time and you progressively lose ability to think or reason or speak or hear or see or whatever part of the brain is being affected.

That will affect the behaviors that you have and the most common one that we think about and that we know about is forgetfulness or repetitive questions or getting lost.

But the thing is to remember for you as the visitor that the person cannot help it. It's not like a child. They behave like a child, but it's different from a child from the perspective of a child can learn and grow and develop and move forward. A person with dementia can't do that. They can't learn new skills because the brain itself is deteriorating.

Does that make sense? So dementia in Australia is the second leading cause of death, which shows you how many people have this condition in Australia, sorry in a year that is. The first leading cause of death is cardiovascular issues. It's the leading cause of death in women and obviously more women than men will have dementia.

Sixty to 70 percent of these people, as I've said, have Alzheimer's disease rather than vascular dementia or one of the other dementias I've mentioned. And this year, there are at least 421,000 Australians living with dementia. And as our population ages and increases, so the number of people living with dementia is going to increase and it's going to become an increasing medical problem in this country.

Some symptoms

Some of the early signs and symptoms that a patient will experience with dementia are forgetting things, especially recent events. So it will be short-term memory loss and they can remember things further back, but day-to-day stuff they tend to be a bit forgetful about. And because of that, they're going to lose and misplace things.

One of the scary things is that they get lost when they're walking or driving. Now, if they're driving and they've got a problem with dementia, your risks are great because your reaction times to things are also very much reduced. And so it can be very dangerous to have a person with dementia having a driver's license.

But if they go walking, they can't find their way home, even though they appear to be so normal on the outside. They get confused even with familiar places. So even in your home, they will go "Where's the fridge", if they're looking for something.

They may lose track of time because time is something which is difficult for them. It's a concept which is very much a front part of the brain for reasoning and cognition and decision-making. So if that area of the brain has been impacted by the disease, then losing track of time would be a big thing. They have difficulty solving problems and making decisions. Again, that's the front part of the brain. They have problems following conversations and trouble finding words.

So if the part of your brain that has been affected by the dementia is the speech area and the word and language area, then people will struggle to find a word to fit in a sentence, or they will use the wrong word, or they will go, "You know, that thing", because they can't find the appropriate word. Or sometimes, which is even more frustrating for them, is that they know what the word is, but they have difficulty in producing the speech or the ability to say the word. And this can be very frustrating for somebody if they've got the condition.

And again, that then relates to having problems following conversations and what you are saying. So although they may be able to hear you quite clearly, the processing part of their brain has been affected by the dementia. They may have difficulties performing familiar tasks, and that will get progressively worse as the disease gets worse.

So that's not normally an early onset condition. And they misjudge where things are visually, but that again would be at the back of the brain, if the visual area of the brain has been affected by

the dementia. So there's very much the signs and symptoms are dependent on where in the brain the dementia is affecting the individual.

Emotional and mood changes

But more than just their physical abilities, what are the emotional and mood and behaviour changes? And you can understand that if you are losing part of your abilities from the beginning, you don't, you realise that you can't find the word, but maybe don't understand what's going on. **And it can make you anxious, sad, angry, aggressive, because your memory is going.**

Depending on, again, where it impacts the brain, **it can affect your personality.** And some people find this really difficult to handle if they're looking after somebody. And they said they've always been the most gentle, calm, quiet, respectful man. And now suddenly he's aggressive and hitting out. And this is so unlike him. Yes, it is unlike him, because his brain has changed. Which also then causes them to have some very inappropriate behaviours.

Some people can get, as I said, aggressive and hit out at people physically or verbally. Other people can get hypersexual. Other people can get very rude and outspoken because they've lost the social filter that they've had for many years, so that they will say, I remember we had a lady in church and she used to say, "Why is she talking so loudly? Why is she holding his hand in the middle of the church service?" **It's because she's lost the filter.** She doesn't realise that we're supposed to be quiet in church while somebody's talking. **And at the beginning, when people realise that these changes are happening, they can withdraw from social activities because they are embarrassed** or they don't want to make a fool of themselves in public because they're unsure of what's happening. And a very common thing is that people become less interested in other people's emotions because, one, they may not recognise it, or two, they're having so much difficulty dealing with their own issues that they're not as outward looking or concerned about what's happening around them because they're so troubled by their own behaviours.

Frustration for carers

So all of these are very difficult things for the individual to handle when they are undergoing these changes. And also, a very important factor is that the person that has lived with them or cared for them for many, many years is seeing all this and is also learning to adjust to these changes in behaviour. And some of them can be really frustrating because you don't realise that the person is having difficulty with something.

And I'll give you an example. I took a gentleman to the toilet, said he wanted to go to the bathroom, so I took him to the bathroom and I opened the door for him, helped him to get into the bathroom and then, being courteous, gave him some privacy, closed the door and stood outside and said, "I'm here when you need me". And after about five minutes, I thought, well, surely he must have finished by now.

So I knocked on the door and I said, "Are you OK?" And I slid the door open slightly so that I could see him. And he was still standing exactly where I'd left him. And I said to him, "Have you finished?" And he said, "No, I'm looking for the toilet". He was standing right next to it but didn't recognise the toilet as the toilet and didn't know what to do. So I said to him, "You need to sit on the toilet." I thought it would be safer than having him stand. And I said, "Sit on the toilet and then you can pass urine". So he sat down on the toilet with all his clothes on and he honestly didn't understand the process. He knew he wanted to pass urine, but he didn't.

He'd forgotten that you need to pull your pants down, that you need to either stand or sit near the toilet. And so from I had thought I'll just give him some privacy out of courtesy. And this poor man didn't actually understand what was going on. **And for him, I felt grateful that he didn't understand what was going on. But at the same time, how humiliating for this poor man if he had have realised that he couldn't even do a normal, simple function anymore.** So once you understand that it's difficult for the patient and for the carers to realise what capacity they do or don't have anymore, the easier it is for you to be supportive and emotionally caring when you go and visit these people.

Self-preparation

So how do you prepare yourself? Well, obviously for me, the first thing is that you pray about it. If you're going to visit somebody like this, you're going to ask God for as much help as you can get for you to be patient and to be understanding. The more you know about the condition, the easier it is for you to be patient and understanding and supportive.

And I would really recommend that you do some reading around the behaviours and the difficulties that these people undergo, not by choice. They are not misbehaving or forgetting or doing anything deliberately.

Very difficult for carers

And then the other thing which I've already alluded to is that **we need to be very, very supportive of the carers of these people** because they are absolutely exhausted. You may go in there for half an hour or an hour, but if they are a permanent carer and they've been subjected to the same question over and over and over because the person can't remember that they've asked the question, or if they can remember they've asked the question, they will actually pre-empt it by going, 'I know I've asked this before, but I can't remember what you said', and then ask the same question again. So it's very difficult for the carer. The other thing is also very scary for the carer because if the person goes for a walk and wanders out of the yard, do they know how to come back? So it means that you've got to be on call 24-7.

It's like having a toddler around a swimming pool where if the child fell into the pool, that angst of having water and drowning with a child is very similar to the fact that you have to be on call and awake and alert 24-7 with an older person who has dementia. **So it's very, very tiring and emotionally exhausting for the carer**, and also can be quite bewildering because this person that they've known and loved has changed and is no longer the person that they know and love, but they still love them. So it's not that they don't love them anymore because somewhere inside that person is the person that they've known and loved and spent 50-60 years with, but is no longer able to behave the way that they are accustomed to.

The long goodbye

So you may have heard that dementia is considered the long goodbye because you slowly, slowly lose the person that you are accustomed to, to this disease called dementia, and you need to adjust to that, and it's not easy. **So it's a very, very slow, long, drawn-out, grieving period.** I don't know whether you've heard the saying that pneumonia is an old person's best friend, and the reason that people say that is that if a patient with dementia or any other illness gets pneumonia and passes away, the pneumonia is the cause of death, but it's also the end of the suffering of that person, that they've been living with.

Although in itself it sounds awful to say that pneumonia is your best friend, it's a way of saying that it's a kinder way of dying than having to endure the long, torturous process that is death by dementia because that is the only outcome, which is very sad.

Skills?

So what are the skills that you need to have? **Unconditional love and support**. This person is not being deliberately difficult.

You have to be patient, and I said, give them **time** to respond to a question, time to formulate a sentence, time to think of an answer if you've asked them a question, even time to walk slowly because everything starts slowing down, or eat slowly, or you cannot rush people when they have dementia and they are struggling. So you have to learn to be incredibly patient. You need to speak to them gently, with a gentle tone, and I don't mean in an infantile kind of way, I'm just talking about not impatient, not loud and aggressive, because they may very well not understand why you are being loud and aggressive.

So you might have answered the question 10 times and you are so annoyed with giving the same answer within five minutes, but **that's your frustration**. **The person can't remember that they asked it five minutes ago** and that you've said the same thing over and over, and they've got no idea why you're suddenly so angry and snappy. **So you have to control yourself a lot**.

The other thing is **don't argue and interrupt them**, because interruption will cause a break in the thought pattern of what they're saying, and that can be very difficult, because now they've got to start again, because they can't remember where they were, or now they've forgotten what the words were that they were going to say. So you need to be patient and give them time to speak when they want to, and don't argue with them, because they can't reason and understand logic the same way that they used to. And this is a very common thing.

You will find carers of dementia patients **arguing** with the person living with dementia, without realising that they are actually, you know, **it's like pushing water uphill**. You're not going to make them understand, because they can't reason the same way they used to be able to. So you keep your instructions **simple**, you keep your sentences **simple**, not like you're talking to a baby, but just give a simple instruction.

"Let's stand up and go for a walk." **Easy**. Okay, instead of saying, how about we go out into the garden? Well, going out into the garden, it sounds like a nice idea, because you understand that the garden is outside, and it means we will have to walk to get outside, but they might not put two and two together.

So you say, **"Let's stand up and go for a walk"**, and you assist them with helping to stand up, and you walk slowly with them to go outside. **Simple**. Okay, it's not complicated, but the thing is that we have to realise that we have to break it down into simpler steps for them, because **they can't process information the same way they used to**.

So **it's much easier to ask a yes and no question**. Okay. "Are you hungry?" Yes or no? Not, "Would you like something to eat?" Because that is implying that, are you hungry? "Do you feel like eating something?" So, and if you want to give them choice, say, "Would you like an apple or a banana?" And show them both, so that they can see it's simple. Or you say, "Do you want a banana?" Yes or no? Okay.

Another very easy way to spend quality time with these people is to show photographs of shared memories, and to reminisce about things that you remember together. If you do not have a shared past, you can reminisce with them about their past, not yours, because they've got no concept of what's happened in your life.

But if you say to them, where were you born? Where did you go to school? Things from the past. How did you meet your wife? You know, how many children did you have? Those sorts of things. And what you will find is that early on in the dementia, they will be able to answer those questions easier.

And as they get worse and worse, so the memories go further and further back, so that they will remember their childhood, but they may, and this is very sad and very hard for families to live with, but they may not remember that they had four children, or they may remember that they had children, but not how many, and struggle to remember their names. And [those children or the spouse find that incredibly difficult and quite hurtful](#). And that's when it gets really difficult for patients with dementia.

Respect

My biggest take-home message from all of this, apart from unconditional love and support and the patient's part, is treat them with [respect](#). [They are not children. They are not idiots.](#)

They are also struggling with what they're going through. And the medical term or the social term that we use is we don't infantilise them, so we don't treat them as if they are infants. They are not children.

[They have lived a normal life. They have loved people. They still love people, but they can't express it and show it in the same ways that they used to.](#)

And I always say to families, even if they don't remember that you visited, they will know that when you visit that they feel loved and supported, because you have no idea how much the warmth and the care and the support, if you visit a dementia person, how much they appreciate that. I remember looking after a lady in the dementia unit, and she used to call out all the time and drive everybody crazy. She was going, and it was almost like a habit that she had no control over. But if you went over her and touched her and go, "Hi, I'm here" and talk to her perfectly normal, "How are you feeling today?" And she would just respond so beautifully. And then when you said, "I need to go now", and you touch her hand, she would say, "I love you. Thank you so much".

[So the fact that you gave her five minutes of your time and gave her a little bit of love and attention, she understood that part.](#) And I feel really strongly that if we just love these people and show them the love of God, which they need just as much as we do, that that's the best that we can do. And make them feel loved and give them the warmth of your love and attention and affection, even when you don't feel like it, because they're driving you crazy.

[So it's got a lot to do with us understanding the condition and being there for them and the carer, so that we can be the hands and feet of Jesus to these people too.](#)

Cathy Strachan

Transcribed by [TurboScribe.ai](#).
