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Dementia

a real life challenge

Written by Colleen Fitzpatrick

Dementia – a real life challenge

My husband and I are now in our mid 60's. We are no longer middle aged – we are officially 'young old'. Have you noticed how many birthday cards make bad jokes about ageing? And how many of those jokes have to do with being forgetful and, by implication, dementia?

Talking to friends and family, dementia often features in our conversation. Sometimes we hear about a person's parents who have it. I don't mind that but only if the parent is in their mid 80's or 90's. It's more challenging if the parent is younger than we are! Other times we hear about a partner or a sibling who has dementia. Several of our friends have been diagnosed with dementia and they are able to share with us what they are experiencing.

Ann and Timothy

My friend Ann has dementia and she has agreed to share some of her story with you. Before we start, though, please be aware that Ann does not want you to feel sorry for her – she says that she does not know anyone who wants to be treated differently than the way they were treated before the onset of dementia. She does want you to be aware of some of the things that might help you when you engage with a person who has dementia.

This is Ann's story:

I am a 62 year-old wife to Tim and mother to 4 adult sons and a daughter-in-law. I was a former nurse, nurse administrator and more recently coordinator of programs for the aged and for people with dementia. Things have really changed! Only a few years ago I was helping develop and implement social programs for people like myself with dementia.

At the end of 2011, I started experiencing memory problems, and the next year I was given a diagnosis of younger-onset dementia – quite likely Alzheimer's. I was 59. I was numbed by the diagnosis. I thought of my family and the changes we'd face. To say that Tim and I were shocked is an understatement. We both had a fear of the future. Privately I doubted the doctor's diagnosis. I knew that doctors have been wrong with their hasty diagnoses in the past.

Before marriage I had been employed in a variety of senior nursing positions, including as a Nursing Advisor for the Health Commission of Victoria. After being a full-time mother for 18 years, I re-entered the work force in 2006. My roles have involved working with people who had disabilities including dementia and assisting them to stay at home, to reconnect with their community and to provide support for carers. During this time, I worked with Alzheimer's Australia on a couple of projects. I read about neuroplasticity. I saw the importance of maintaining a healthy body and an active memory, and the need to support carers.

I guess I've always been a bit of an idealist and a tad judgemental. I thought I knew pretty much what would be of help for people with dementia. These well-intentioned assumptions have since been challenged by my own struggles with dementia. I remember encouraging a man in one group to do Sudokus. I couldn't understand why he couldn't manage the easiest ones. I now understand that even if he had been good at them in the past, he may well have lost the interest, let alone the ability, to do them anymore.

There were a number of signs that alerted me to problems with my memory.

At work:

- I started to keep numerous note books simultaneously. I'd copy from one to the other and get muddled and increasingly confused.
- I started to forget the names of work colleagues.
- I acknowledged I had a problem, but thought I was just forgetting a couple of things, or I had too much work to do.
- I attended a work meeting, and asked for a copy of the paper that was being discussed, as I'd never seen it. When I was shown the article, my hand-written notes were all over it.
- I had been good with numbers. Now I found I couldn't remember or understand from one day to the next how I had done my calculations.
- I had difficulties with rosters, budgeting, financial reporting and report writing.
- Work became stressful.

At home I was finding simple things a bit harder.

- I needed to write lots of lists.
- I had to concentrate harder on simple tasks. I needed a plan to wash the floor. I kept forgetting which bits I'd already done.
- I found it hard to hang out the washing. I'd get muddled and hang clothes across 2 lines. I got lost finding the opposite edges of sheets.
- Following recipes became difficult. I needed to refer to the ingredients and method much more frequently.

When I received my diagnosis, my work manager and colleagues were very understanding and supportive. However, I resigned soon after my diagnosis.

In order to help stay socially engaged, and to contribute in the community, about 2 years ago I became a volunteer at The Hutt Street Centre (Adelaide) for homeless people. I love my volunteer work. I am there a day or so each week. The staff are terrific. Not only do I feel a keen sense of satisfaction, but I also feel appreciated. I'll do anything that is needed. I work in the day centre and I also help with data entry. There are days where things fall into place and I have the odd day where I think it might be better to go home. They are aware of my memory problems. The woman I am working for is kind and patient. She will explain the same instructions day after day if needed. There are no time expectations. I take my time, I am thorough and I enjoy the work. Working there makes me think about how hard it would be to be homeless and have dementia. I encourage organisations who use volunteers to take on people with dementia. We have skills and insights to offer.

In general I have problems with the following and my memory problems do fluctuate:

- I have started to get my words muddled. I called high heel shoes 'shoes on stems', and I use 'thing' a lot. I use my hands to help describe things.
- I have taken clothes from my wardrobe that I'm sure I've never seen before.
- I forget where household items are.
- I find I have bought the third lot of a grocery item that I already have, but I have forgotten the item I really needed.
- Sometimes I need to photograph where I have parked the car in car parks.
- I have some balance issues and I have a bit of a tremor. I get embarrassed carrying a cup of coffee to my table at a café, especially when I have the shakes.

- I have become more literal in my understanding of language. Sometimes I have trouble following the sense of abstract conversations.
- I still try to manage my own tablets – I don't want to give up my control of them. But I've tried to get a script made up weeks before it was due.

I find that my interests and hobbies have changed or been adapted so that I can still enjoy them.

- I love cooking. On one occasion I put a cake in the oven and then found the flour in a bowl on the bench. Out came the cake, I added the flour and back it went into the oven! OK, the cake was a bit flatter but no one complained. I do 'tried and true' recipes more. My family enjoys my mistakes! They make references to Leticia, from 'The Vicar of Dibley' who added strange ingredients to her cooking!
- I find it hard to follow the plots in movies and books. I used to enjoy crime and thrillers. I now read non-fiction books that don't rely on page-to-page memory. We watch more documentaries on TV.
- Embroidery is far more challenging. I loved doing detailed needlework. Now I can't follow the instructions. I try embroidery that doesn't rely on counting or detailed charts. And the same for knitting. I keep it simple and read instructions frequently to check. I constantly have to undo mistakes.
- Art work has become more difficult. I have started doing Zentangle. This involves small doodle type drawings. Some patterns are available for copying, but now some of them are too difficult for me to replicate. This is a relaxing activity with an aspect of meditation. It doesn't matter if I shake. I have also started using colouring in books.
- Sudokus are hard now – I used to be good at these. I find it a struggle to do the very easy ones. But I keep trying.
- Tim and I enjoy crosswords and cryptic crosswords. We do them together. Words are harder for me to find, and my spelling is deteriorating, but we find it fun.

Other things I've noticed about having dementia are:

- I've been embarrassed trying to figure out the correct money to pay for something when shopping. On one occasion the shop assistant ended up taking the correct coins from my palm. A bit confronting.
- There are things that I am finding more difficult such as doing up my apron and working the machine to print the ticket that indicates who is next at the supermarket.
- When I was working I couldn't understand why some people with memory loss became worked up about an appointment in the coming week. Now I can empathise with them.
- I have to keep a detailed diary. I record all contact details, addresses, phone numbers, passwords and codes, where I had relied on memory in the past. I can't remember our home phone number or car number plate.
- I get tired easily.
- I find it more difficult to make conversation at social occasions. My social skills were quite good. Now I have to work hard at being socially engaged. Occasionally I fudge.
- I know that people mean well, and I don't take offence, but it is not helpful when they say, "You seem OK to me", or "I forget things like that too", or "Oh, I do that too".
- It would be easy to withdraw. Sometimes it is hard to make the effort.

I appreciate dementia friendly communities. Clear signage, labelling and directions are a great help and there can be more of this. Dementia friendly activities and courses would be a great help. More awareness and consideration for people with dementia would be appreciated. I recently had to visit the dentist and he knows about my dementia. I felt comfortable because he knew about treating people with dementia. I subsequently found out that he had literature in his surgery about understanding people with dementia and the elderly.

I am fortunate to have informed and patient doctors and specialists, and have my memory issues identified at an early stage. Seeking ongoing help and assistance from qualified and trained nurses and aged care facilities is a great help.

Thank goodness for my family and our sense of humour! Thanks to Tim who I have been happily married to for more than 30 years. He is loving, understanding, caring and supportive. Tim and I have been open and honest with our family and friends from the start about my memory problems. We share what is going on and pass on relevant information - mainly from the Alzheimer's Association.

My hope is that my family and I continue to learn, grow and laugh in the future, and that the future is long and peaceful. Although we can't be certain about the future, we know that God holds the future and us in His hands.

Despite my memory issues and having a 'likely diagnosis' of Younger Onset Dementia - Alzheimer's, God works in mysterious ways. I have, it seems, some insight into my issues. As a result, I have been invited to speak about my dementia at a variety of public events. I presented and helped develop a communiqué recommending legislative changes for increased funding for dementia support in the community and health care and residential services. By sharing my story, I hope to achieve two things: to help reduce the stigma and myths about dementia in the community, and to provide information about dementia in an objective way. I pray that other people with dementia can share their story too and receive God given support and reassurance.

Raymond and Delia

(Not their real names)

My friend Delia's husband Raymond has Lewy Body Dementia. He has had it for a number of years and is now in a residential aged care facility. Delia cared for Raymond at home until it became physically impossible for her to continue to do so.

One of her coping strategies was and continues to be her use of Facebook. Through it, her friends are able to track Raymond's high points and the challenges that he and Delia need to address. We have journeyed with her through his lessening ability to manage daily routines and his increasing confusion. For some time, he was able to stay at home while attending a day centre where there were activities and care was provided.

Every now and then Delia posts a message sharing her sadness or frustration about what is happening. This medium provides her with immediate support from her circle of friends and family at home and overseas. Messages of encouragement and offers of prayer support flood in.

Over the years, I have been conscious that Delia sees Raymond's illness and all that is associated with it, as a challenge. With the support of her family and friends she was and is able to meet those challenges and to retain a positive attitude as Raymond's condition deteriorates. Recently, we were having a cup of coffee together and I asked Delia about the role faith is playing in their journey. I know that both Delia and Raymond's faith has been an integral part of their lives. Raymond has now lost his ability to respond to prayers or hymns or rites that were once so familiar and important to him. This is another loss to grieve, but Delia knows that he is still a child of God and that God's promises remain relevant for Raymond and for her. She continues to go with Raymond to the worship times at his aged care facility, and he is happy to be there with her even though he appears to have lost the ability to participate or to realise what is going on. She looks forward to heaven and the resurrection when they can be reunited and he will be whole once again.

Something else I have noticed in my chats with Delia is the very active role that she takes in Raymond's care – she has needed to monitor that he receives his medication regularly (an important factor in managing his condition) and she is involved in taking him to appointments and encouraging him to keep active. She has also advocated strongly for his personal care to be managed appropriately in accordance with his physical limitations and to maintain his dignity.

Not everyone is as blessed as Raymond in having a caring spouse to visit and support them. It is not unknown for people to be admitted to an aged care facility and as their ability to respond diminishes, or their family members become frail themselves, they become more and more isolated and lacking in social contacts from outside of the facility. Caring people make a difference to someone with dementia.

If not a family member, a caring nurse or volunteer can make a difference to someone with dementia, even by simply visiting and being with them. Maybe you could be visiting a friend or relative who is now in a facility and who could be socially isolated.

Nancy and Maureen

(not their real names)

I recall hearing about Nancy who had been in an aged care facility for some time. She had no visitors, and her dementia had progressed significantly. She did not respond to the carers or staff in the facility. Nancy was allocated a volunteer visitor, Maureen, who came and sat with her and talked to her for some time without a response. After several such visits, Maureen decided that Nancy was not aware of her presence and not able to respond. Maureen explained that she would not be coming back and said 'good-bye' to Nancy and got up to leave. As she walked to the door, she heard a frail voice say 'You don't know what it means.' Maureen continued to visit Nancy until Nancy died. Maureen knew that Nancy was aware that she was there, and was able to provide contact and to hold her hands and massage them and to share with her in increasingly simple ways.

Attitudes

'Come Lord Jesus be our guest and may these blueberries (or red wine, vegetables, or anti-oxidants) do their best' could well be the correct version of our usual family prayer before meals. We're told that there are some things that are supposed to be good for us including blueberries, tomatoes (rich in anti-oxidants, whatever they are), and various vegetables. We tuck into them virtuously hoping that they will stave off the unpleasant consequences of the ageing process. Then of course there are the things that we're told are not so good for us including saturated fats, chocolate, and caffeine. We enjoy these on the quiet or apologetically, hoping that we can continue to dodge the physical and mental deterioration that accompany ageing.

Ageing can present an amazing set of things to worry about as the signals start appearing to herald the certainty that I am not going to live forever. Various family members and friends are showing signs of slowing down, and there are visible changes to their thought processes. I was shocked recently when one of my close family members commented on the fact that my short term memory had let me down yet again.

The message is clear – ageing is not going to go away. Everybody who eats blueberries is going to die. And dementia is not going to go away in the foreseeable future. I guess it is up to each one of us to determine whether any life event including ageing is seen as a loss, threat, challenge or perhaps an opportunity. And how we view the event will determine how we deal with it.

Facts

A couple of years ago the Australian Bureau of Statistics came up with the following:

- By 2050 there will be close to 900,000 Australians living with dementia. Over 60% of people with dementia live in the community.
- 2.6 million Australians provide unpaid assistance to older people or those with a disability. 29% of these are primary carers; that is people who provide the majority of the informal help needed.
- By 2050 we will need an additional 500,000 aged care workers (Australian Institute of Health and Welfare (AIHW) 2012).

Diagnosis

Dementia is more than occasional memory loss or taking longer to remember things. The only way to determine whether a person has dementia is to undertake a full psychological and medical assessment. A diagnosis of dementia should lead into a discussion about what the future holds, and options that are available along the way.

One thing that I have noticed is that when people are diagnosed with a condition that is life changing, some will want to share with family and friends every bit of information along the way. Others who have been close to us have gone through lengthy diagnosis processes, and maybe even some treatment before they are ready to tell us. There is no right or wrong way. Each of us has the right to determine who knows what about our lives and to determine at what point our personal information can enter the public domain. Sharing information implies that some steps have been taken on the way to absorbing and accepting it.

I believe that the discovery that you have a life changing condition carries with it a loss and as such, there is some associated grief to be addressed. However, grief is not finite and its path is different for every person in every situation.

Hope

Is the diagnosis of dementia just a slippery slope into oblivion and death? I don't think so, and I know that Raymond and Delia don't think so nor do Ann and Tim. Ann has shared with me that their hope is their faith. They trust in God that he will continue to be with them and to help them on their journey.

The journey may not be easy, but there are good times to share and memories to create and to recall. With a sense of humour, there may be opportunities to appreciate the absurdity of some experiences! It's also possible to develop an even keener appreciation and love for family members. You may discover deep wells of patience that you did not know that you had.

And throughout it all is the promise that our loving God is there with you and you are in the palm of his caring and supportive hand. God does not expect you to theologise or perform amazing works but receive and trust in his unfailing love and presence in your lives. God does this by giving us his Holy Spirit to always be with us and points us to the eternal love of Jesus Christ. Nothing can separate you from Jesus' love, not even a forgetful mind, dementia, or even death. God will never leave you or forsake you. He is always there. God remembers us, even when we can't remember him.

"I am sure that nothing can separate us from God's love—not life or death, not angels or spirits, not the present or the future, and not powers above or powers below. Nothing in all creation can separate us from God's love for us in Christ Jesus our Lord!"

Romans 8:38-39 (CEV)

Resources

There is so much to learn and know about dementia. One of the best places to start is the Alzheimer's Australia website: **www.fightdementia.org.au** or call them on **1800 100 500**. As well as good information, there are fact sheets that cover important topics to help people who have dementia as well as carers, family and friends.

There are also local support groups for those who have dementia and for their carers and for family members. Participating in such groups ensures that you are able to share your experiences with people who are going through exactly the same as you and receive their encouragement and support.

Introducing the Author

Colleen Fitzpatrick is allegedly retired, but her survival plan includes involvement in a range of committees and volunteer activities including membership of the Committee for Lutheran Aged Care Australia – a gathering of representatives from aged care organisations from around Australia. Colleen was the Director of Lutheran Community Care in South Australia and has also worked with other government and non-government organisations. Colleen enjoys spending time with her husband, her 2 adult children and 3 amazing grandchildren.

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You will find more booklets, DVDs, and other helpful resources at **www.lutheranmedia.org.au** or call us on **FREECALL 1800 353 350**.

There are booklets on topics relating to illness (such as cancer), relationships, suffering, depression, anxiety, aging, parenting, conflict and communication.

face 2 face
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