Graham’s story - Life as a care partner for Robyn who is living with dementia.

I suppose my awareness of dementia came about when Robyn’s mother, Dulcie, was alive. She died in 2015 at age 91 and had Alzheimer’s dementia for about 10 years. She was widowed in 2004 and continued living by herself in Glebe. In 2005 we went on a cruise with her during which we became aware of some serious memory issues. Through the Mind and Brain Institute of the University of Sydney she was diagnosed by a neurologist as having Alzheimer’s Disease. She came down to live with us because she wasn’t coping very well. Within a couple of months, we got her into the local retirement hostel, first on respite, then permanently soon after. Dulcie’s Alzheimer’s presented quite differently to, Robyn’s dementia.

My awareness of my wife’s cognitive impairment probably emerged around 2010, although in hindsight there were clearly some issues earlier. Robyn was a School Counsellor for most of her career. She changed schools in 2004, when we moved from Moss Vale to Culburra Beach in New South Wales. She had been a member of a support group of counsellors in the Campbelltown area. I remember, when she left that group, they gave her a gift of a pen and letter opener set and inscribed on it was, “World’s Most Forgetful Psychologist.” So, I think maybe there were early signs. Robyn continued to work part-time until I retired from being a church minister in mid 2010.

By 2010/11, at age 63, Robyn was needing help with remembering things, particularly in giving accurate information in medical appointments. We moved to our retirement home in Gerringong, New Sotuh Wales, at the end of 2011. At this time, I had to take more responsibility for general household management, because Robyn’s ability to remember things was getting worse. In 2012, I arranged for an appointment with the same neurologist at the Mind and Brain Institute who had seen Robyn’s mother. By this time, it was apparent that there was something wrong with Robyn’s memory. She wasn’t formally diagnosed with dementia until about 2013. It took a while to get a diagnosis. Then later, after a some scans, Alzheimer’s Disease was diagnosed.

When Robyn got the diagnosis of dementia, I think she was in denial for quite a while. We would go to the neurologist but he would talk to me separately to help me to manage the situation. I think he did not want to alarm Robyn. My response to Robyn’s diagnosis was probably one confusion and uncertainty, not knowing a lot about the course or progress of dementia. But subsequently, I read a lot about dementia. I started reading books and articles and online materials. I probably educated myself more than anything else. I also attended some educational programs that Alzheimer’s Australia (now Dementia Australia) ran. These sessions were helpful - just to hear people share their stories, and recognise that everyone’s dementia is different - even though there are common elements. When you become a carer, it’s really about understanding how everyone’s story and experience of dementia is different.

For some time after the diagnosis Robyn was still able to cope with lots of things, she was still driving - probably until about 2013 or 2014. She got lost occasionally, she’d ask the same questions over and over again, and I learned how to cope with these changes. We kept doing things for as long as we could. We’ve been involved in Sing Australia here in Kiama which she enjoys. We’ve also continued to travel, as we have always enjoyed that. We have a daughter in Alice Springs. We’ve visited her every year up until 2017. We’ve also done a couple of other trips since 2013. We did a river cruise in Europe, Budapest to Amsterdam. We also took other holidays to Lord Howe Island and New Zealand. Robyn doesn’t remember any of the holidays not, but that probably doesn’t matter because she had a good time. She enjoyed it while she was there. We’ve got photos, so we can show her them. One of the things that the care workers who visit her do is go through our photo albums and talk about her travels. Unfortunately, travelling has become more difficult and we no longer travel. In particular public transport is difficult for Robyn because she is restless much of the time. Over time, I took up more household duties. I'd started cooking probably 10 years ago and I enjoyed that, and slowly bit by bit, I took over responsibility for our life. It's important to realise that it didn't happen all of a sudden, the change in my role was more gradual.

I think it was really through the involvement with the Dementia Friendly project in Kiama, Southern New South Wales, that Robyn and I started to "come out" about Robyn's dementia. Caring for someone with dementia can be quite isolating but being part of the Dementia Alliance in Kiama, has been really good. We were involved virtually from its beginning in 2014. At the time, I was the secretary of a local residents' association in Gerringong and when an invitation came about the start of the Dementia Friendly Project, I said, "Look, I'm happy to represent the precinct at the Dementia Alliance." I thought it was certainly something I could do, because I was interested in the project and dementia. I went to an initial Dementia Alliance meeting, and somebody said, "Oh are you coming back tomorrow?" So I returned the next day and Kate Swaffer was speaking to a small group of people living with dementia and their carers. During this meeting somebody asked me whether I had a home care package. I had no idea what they were talking about, no idea at all what a home care package was. In actual fact, we didn't get an ACAT[1] assessment until the beginning of 2015, so that was about two or three years after the diagnosis. It's not like you get the diagnosis and then get told by someone "this is all the support services you will need".

Once I found out about the home care packages and Robyn was assessed, we were offered a level one Home Care Package[2] which gave us a minimal amount of in-home support. Robyn started going to a day care program, but it was mostly frail aged people and wasn't the sort of stuff she was interested in. At this time, she was only in her mid 60s and younger than all of the other clients at the centre. Within a month or so we got her into another day respite service which suited her needs much better. But the level one package didn't really give us the support we needed, particularly with transport, because it was only an hour or two a week. Robyn's ACAT assessment was reviewed in March 2015 and we jumped up to a level three package with a different provider. This has provided us with much more support.

Since Robyn's diagnosis there are lots of things that we had to learn how to deal with that we would never have previously contemplated. Little things, like places having not adequate signage for Robyn to find the toilets. Robyn would also accidently lock herself inside the toilet cubicle and she couldn't figure out how to unlock the door to get back out. This was a real issue for us at one point, because I'd then have to go and find somebody to get Robyn out of the ladies toilet. Now, we use accessible public toilets all the time. But it is the practical things, like signage and locks, that you have to understand about when you become a carer. Those little things can become big things and can completely change what your day is like – it can go from being quite clam to very stressful. You learn to be patient and to take time to do things carefully. I also had to learn not to put expectations on Robyn that are unrealistic, because she actually just can't do some things anymore because of the dementia. I think it's also important to try and not get frustrated because and I've found out that there's no value in arguing because you won't win.

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[1] Aged Care Assessment Team. For further information see: https://www.myagedcare.gov.au/publications/acat-assessments-english

[2] For further information about Home Care Packages see: https://www.myagedcare.gov.au/help-at-home/home-care-packages

As a carer, you also get good at learning how to deal with change over time as the dementia progresses. For example, we were getting a carer to come in each week and take Robyn out for a coffee, or go for a walk, as well as some home help cleaning and household chores. While that still continues, Robyn doesn’t tolerate too much activity outside the home, because her agitation has increased over the last couple of years. As the dementia has become more advanced Robyn can’t do a lot of the things she used to and she now has more trouble engaging with people. The one thing she does still enjoy doing is walking. She can walk on our deck she loves to walk around and around and around. But if I leave the front door open, she’ll walk out on to the street. Robyn has done that a couple of times, so I’ve got to make sure she is secure, just for her own safety. We go for walks around the block or a walk up on the headland and she enjoys that. She can’t verbally interact much anymore, but sometimes she’ll say a word or two. We still go to church and that’s probably the main activity that she copes well with. For example, when we go to church, sometimes she can sit right through a service, but sometimes she won’t. At our church there is a secure yard area. I make sure all the gates are locked, and she can wander around in the open, and she’s quite happy. She still enjoys engaging with people at church. People will talk to her and compliment her on her earrings or dress or something and she obviously enjoys that. My church community is quite caring and accepting. Another activity which has been excellent, is that Rotary in Gerringong have been running Dancing for Dementia for the last 18 months. They run it for about five weeks at a time. Last Friday there were probably 60 or 70 people there and we danced around for a while. Robyn is happy to shuffle around for about half or three quarters of an hour. There are a couple of other things that spark joy - often a smile from me and going walking.

About three of four years ago I did lose Robyn in a large shopping centre. It was Easter Saturday and lots of people around and she suddenly disappeared. I went past a few shops but couldn’t find her. So I thought I’ll do a lap around Target and then my phone rings. It’s a friend from church. And he said, “Where are you? I’ve got Robyn.” He was on the other side of the shopping centre, about 10 minutes’ walk away and she’d walked all that way up there. So she wears now a Safely Home bracelet, if she does get lost for some reason. But I generally try not to let her out of my sight. But these are the things that you have to learn to deal with and you have to be more aware of. Overall, I find she’s best at home, she’s calmest and less distressed when she is at home.

I have people from our home care provider coming four days a week to help look after her, so I can go shopping or be involved in other social things. Otherwise, it can be very isolating being a carer and it’s a challenge at times. If I want to go out of an evening it’s hard to get home care workers to come at night, so that I can still be involved in some of the things I like doing. Being a full-time carer at times is tiring and that’s why it’s nice to have carers coming in several days a week to actually take some of the load and it helps to keep to her at home. I think if you were trying to manage by yourself at home, you wouldn’t last all that long. My aim is to have Robyn at home as long as I can manage with her. At times it is lonely because things we used to do together like going to movies, going to concerts or other musical events are gone now, because it’s too difficult for her. So I try to keep involved with other things - I run a men’s bible study group. But for me one of the things that’s been good is to be part of a whole network of people through the Dementia Alliance Group. We usually have a picnic once a month, we also have a morning tea and this is important to keep connecting with people - mutual support is really important.

It’s hard to sum up what it is like caring for someone living with dementia in a few words, but here’s just a few points:

- Be open and honest with people about what it is like.

- Use the resources available to help you care well - books, videos, conferences, support groups

- Make the most of each day and each opportunity - don't think too much about the past - don't try too much to plan the future. Dementia - and life - are unpredictable in many ways - and we are not in control. Accept it with grace and patience.

- Don't try to do it all by yourself - find the help and support you need to live life to the full - despite setbacks and disappointments

- Stay involved with family, friends and community groups and activities. Life is about relationships - make the most of them.

Graham Fairbairn