

Maureen's Story.

My husband was a dedicated teacher, who took great pride in the achievements of his students. He advised and supported their parents as well, often keeping in touch many years after they had been at his school. He played sport and was very involved with community service clubs and our church. He took on office bearing roles in these organisations- at National level with Apex and State level in Rotary. He had been diagnosed with sleep apnoea at 60 yrs old and used a breathing mask very successfully. He took early retirement at 62yrs old.

It has only occurred to me since I began compiling this story, that the first signs of dementia may have been as early as 60yrs of age. He would often talk of travels we had done together but speak as though he had travelled without me. I felt hurt, but when I challenged him he seemed genuinely surprised that I had been with him. So I would let it go rather than embarrass him in front of others. However it may have been the start of dementia.

When he was 65yrs old he suffered a stroke and had 2 stents placed in arteries of the heart. It was then, that I became aware of real changes in his behaviour. He was very good at remembering names of former students and their parents, as well as teachers he had worked with over the years. He took pride in his memory. If he could not remember the names of people that would stop to chat with him in the street, or at club or board meetings he was very upset with himself. He knew he SHOULD be able to! I think it caused him to feel ashamed. He resigned from Rotary and other clubs, I believe, because he felt he was falling short of his own expectations.

When we were at gatherings of either families or friends, where multiple conversations would be happening, he would suddenly disappear to the bedroom saying he was tired! I began to realise his brain could not cope with the multiple stimuli of several conversations. For instance, I found it was better if the TV was off, when I wanted to talk to him.

At 68yrs old he tested positive to cognitive dementia. His frustration with himself increased as he could not name/or remember items in the house and where things were kept. He would ask half questions such as – “do we have....?, where is.....? I found it was not helpful to try to guess the rest of the question, all I was doing was reinforcing that he couldn't remember. I struggled with the fact that I couldn't help!

I did learn to avoid using the word “remember” as much as possible. Instead of ‘do you remember..?’ I would try to make a statement such as “we went to (place name) in our caravan”

Since his nature to help people was still strong; he was always wanting to help me around the home. I found I needed to give clear instructions – eventually it became one at a time, even for easy tasks. For example, I encouraged him to make the coffee, dry dishes, help make the beds, help load the washing machine and preparing vegies for meals. However I still needed to ‘supervise’ unobtrusively, especially in the garden, otherwise my plants could be pulled up as “weeds”!! His need to ‘help’ caused some embarrassing moments for me, like the day he asked a delivery man at the supermarket if he could help him unload his truck!

At 73yrs old he was diagnosed with Alzheimers. I was inundated with information and brochures about support and care that was available for us, and all the different facilities and groups that provide them. I felt bombarded by representatives from these different groups, not really understanding which I /we needed or which would be appropriate for us. I felt I was making decisions without having time to absorb the info or understand how it would help us in particular!

The first support we were granted, was that he would spend one day a week at a respite day care centre specifically helping Dementia sufferers. He was picked up and returned to home.

He settled into the routine with less negativity than I expected! However, often when he returned home, he would tell me that he felt it wasn't doing him any good and we should cancel it! I could hear 'the school principal' talking!! I found he needed to be distracted at these times, otherwise he would continue to get more agitated. So I would suggest we go out for a drive and coffee together -which generally worked! It was something he had done regularly for 'shut-in' friends he knew.

I was also aware that he would forget things fairly quickly, so we would return home and he had forgotten about the day care. I learnt that if I didn't engage in, or prolong discussions, but used distractions, it wouldn't agitate him so much. There were occasions when it didn't work and we'd be in tears. When that happened it seemed to resolve things - but didn't feel good!

I remember the day I became aware that I could no longer let him go anywhere on his own. I had organised to meet him outside the newsagent after he went in and bought a paper, but he didn't appear. He had gone out the back door of the shop to the car! When I finally found him, my stomach was in knots. He was so worried about where I was that we both exchanged angry words. A terrible silence - I made an apology, knowing I would be within sight of him from then on!

Another incident that indicated I needed to adopt a new routine, was when he 'lost' his wallet on two occasions. I realised that he probably left it on the counter when buying the paper-I would let him go into the shop himself to get it. So we retraced our steps and fortunately found the shop owner had it. That was a timely warning! I removed important plastic cards, and most of the paper money from his wallet. If he saw 3 to 4 notes (\$5) in it, he would think that was OK. If he realised it was 'only' \$15, I would say we can use the bank card for other things!

He always loved travel and would just turn down a road saying "let's see where it goes". I did a lot of impromptu drives - either to settle his restlessness or satisfy my need to 'escape'. They began as afternoon drives (2 hours), however, they became shorter as he got worse. I learnt that we could be turning around after 5 mins!

He used to play bridge and other card games and was good at Scrabble. For awhile he could play some games on the i-pad with some instruction from me! However his concentration became so short, that he was really just watching me !

I was often asked 'how did I cope'? I understood what happens to the brain because of Alzheimers and reasoned that the slow demise of the brain's function was like slowly reverting to childhood . The brain was unlearning and the person didn't have control of what their brain could do! If I was to help my husband as well as I could, I figured it was I, who needed to change my expectations of what he could achieve and do, as he couldn't! For most of his illness he still had expectations of what he felt he should be able to do, and most of his angry outbursts were directed at himself, and how he felt he was failing himself and me. To witness these moments was the cruellest thing I had to do.

My faith in God also helped me, in that I could feel vulnerable and helpless, but not weak, alone or 'hard done by'. Life has its highs and lows!

The two things that I like to 'indulge in' are the garden and art. The weather determined when we could be in the garden, but I needed a carer for my husband if I was to take up art classes again. One of the most valuable supports once he was diagnosed, was that I could have someone come for an afternoon and either stay at home with my husband or take him out for a drive and coffee. This allowed me to go to Art class for the afternoon! I was

immediately aware of how stressed I had been getting and how wonderfully indulgent 3 hours of art class felt!

The day care centre also offered respite over a weekend, which I booked on several occasions – it allowed me a weekend free of caring for him. I was able to visit family in Melbourne. I was also made aware of ‘temporary respite care’ that was available to us as well, and used it on one occasion for 2 weeks. It was not a good experience for him or me. He spent all his time packing his case and trying to leave and I felt terrible because he was so disoriented and alone. I was glad I took the advice of not visiting more than once a week, as I would have brought him home! In hind sight I knew I had really needed it, and benefited from the break. I learnt that I needed to find out more about the facility we booked, if I wanted to use extended respite again – and for permanent care!

The other support came from my daughters who lived close to us. They visited on a weekly basis to see dad, but were willing to be involved when a hospital visit was needed etc. I knew about ‘Sundowners’ behaviour, where agitation and restlessness increases as evening approaches. I used the distraction ploy, but sometimes it wasn’t enough and I was at my ‘wits end’.

On one occasion he woke up at 7 am really agitated and it continued for 8 hours. He was continually getting up & wanting to ‘do something’ but nothing suited him, going back to bed, up again within 5 - 15mins; until by 3pm I was at screaming point. I called for help from the daughters who organised a roster between them and I was banished! I was not ‘allowed’ back until he had gone to bed at 8pm and was asleep!!! What a gift that was!

It was the constant restlessness that ‘got under my skin’ most, as I could not organise a routine for myself! I knew his behaviour was not his fault, but if distractions didn’t work, eventually my feelings of helplessness would cause me to burst into tears in front of him. (I was successful at hiding them most times). This actually seemed to help us both – it defused our tensions! But again not what either of us wanted!

As his condition deteriorated I had a nurse come in to shower him twice a week, which he accepted better than I expected. However he ‘blotted his copy book’ one morning when he let fly at her with more expletives than I’d ever heard him utter! It was very embarrassing for me, even though the nurse was well aware these behaviours can occur. I was really pleased to be able to get him to have his shower!

I had learnt that as a carer I needed to be familiar with the permanent nursing care that was available to us, AND be ‘on the lists’ of those places. Thankfully we had done the ‘hard yards’ and it was just waiting and hoping that a bed would be offered. I also knew he did not want to go into any type of care permanently! He made that clear - even the day care centre!

About four years after his diagnosis, we accepted the offer of a permanent bed. A year earlier we had turned down an offer as we were still coping, but this time I knew I had been waiting for it to come – I had reach my limit!

I still felt guilty and very distressed by his pleading to ‘come home’ and took the advice of staff to limit my visits to one or two a week at the start. I think he too, recognised that he had to be there – and gradually stopped asking to go home.

However he never really settled as he could not cope with the behaviours of other residents – it often distressed him – so he spent more time on his bed (or some-else’s!) to avoid them. He became incontinent which created more stress and embarrassment for him.. I had only had one episode of incontinence at home, which was so embarrassing for him, I was glad I didn’t have to witness others!

His abilities to communicate – find the right words- also decreased, so it was hard to know what he was feeling or doing! The staff were a great help as they could relate many incidents of conversation and when his sense of humour showed through. There were several times when he ‘presented’ to the staff in the ‘principal’ role, checking up on his staff – he

was always caring for people! However I couldn't get him to talk much at all, and really felt like 'an outsider'. I learnt that I needed to talk with the staff, who could relate occasions when the true Allan would show through!

Our GP had talked with us once he was in permanent care, as to what our wishes were about 'end of life' issues. The daughters and I were grateful to have had this discussed and be prepared. He also visited him regularly and monitored medication. He knew we had agreed that he should not to resuscitate and in the event of a fall or infections, that he be made comfortable. He gave us regular reports which helped confirm what we felt was happening- that he was rapidly declining. He only spent 6 months in care before he died.

One thing I was very pleased I had done, was buy a plot at the Crematorium. He often asked if his funeral would be at our church, which I affirmed for him. However he had also asked if we had a plot at the Crematorium whenever we passed it to go to the daughter's place. We had agreed on purchasing a plot but as he grew worse I didn't bring the subject up again with him.

. I knew I needed to buy one so I could say 'yes', if he asked. I included the daughters in looking at and choosing, a grave site suitable for us both. I knew it would not be easy for them but I believe it was a good move! Part of the journey we had to take!

The irony of it all was that he never asked about a plot or the funeral again!

He died a month short of his 77th birthday, but we did make our 53rd wedding anniversary.

We had the Cremation service, for family and close friends, first, and then a memorial service at the church, to give thanks for his life. It was a fitting tribute to him; with 250 people attending from as far back as our University friends. Vale Allan.

My 'ALZHEIMER'S' work of art.

I enjoy my art classes , it is a creative release of stress and energising for me.

Allan had been put into permanent care during the term and at the end of that term, our art tutor instructed us that we were NOT to bring pictures or photos that we could "copy" next term! She wanted us to come with an 'idea' for next term. She explained that it could be something that we thought about a lot.

For me that was easy! ALZHEIMER'S was at the front of my mind all the time!! But how to depict it? Suddenly I heard the start of the word "AL". That's what I always called my husband! Then I saw the word "HE" in the middle and "ME" near the end. It was meant for me!

I used the word Alzheimer's with those three words slightly larger than the other letters but reducing in size, as well as falling away towards the end of the word, -to indicate his reduced brain capacity –and where I felt I was in the scheme of things!

I used vibrant colours around 'AL' to indicate his colourful and involved life, which faded around the 'HE' as his awareness decreased; and became grey/white around the 'ME', in an attempt to convey the world that was his reality as the disease progressed.

Normally I am very slow to complete work, however this was completed, using pastels, in three sessions! It was extremely cathartic for me and my testament to the man I knew and loved.