

## C.5 A Carer's Story #1: Karen Gurney



Photo taken 5.5.2018

### Dementia Carers Journey

My dad was diagnosed with Alzheimers in May, 2017. He was 76. My mum was 69.

There were 3 major things that happened that led me to organise an appointment for mum and I to see his Dr to discuss what was happening that ultimately changed their lives forever.

In January March 2017, mum and dad took their caravan to Queensland to have a holiday and to attend a wedding. During the time away, dad was driving and crossed to the wrong side of the road, into oncoming traffic, to make a right-hand turn. Luckily the oncoming traffic slowed so there was no accident. When mum questioned him about what he'd done, he couldn't see that there was a problem. How else was he to get into the road?

Another time on the same holiday, dad was ordering 3 ice creams. When mum asked why, he said one for her, one for him and one for his mum. His mum had passed away about 25 years previously.

The third thing that happened was in their caravan one evening. Dad was sitting on the bed, getting teary. When mum asked him what was wrong, he replied that he didn't know where his wife was. He couldn't find her. Mum asked him who she was then. He said that she was an imposter. He didn't recognise his wife of nearly 50 years.

When they returned home, mum, dad and I went to see his Doctor. A memory test was done, as well as an MRI, and the diagnosis was Alzheimer's. He had to relinquish his driving license as his score on the memory test meant that, by law, he wasn't able to hold a driving license any longer.

I'm the eldest of 3. When I told my younger brother and sister about dad's diagnosis, we all wondered why we hadn't seen the signs before. Why didn't we pick up that there was something wrong? We all came to the same conclusion or realisation. We thought that what was happening was just dad getting older and his personality getting more pronounced. When we looked back over the past few years, we could see that the signs were there but we hadn't realised. The literature says that it's often in hindsight that you see the first signs of dementia. That's what happened with us. We came to the conclusion that it was probably about 5 years prior to his diagnosis that changes had begun.

The diagnosis is 2 edged. On one hand, it is hard. There is mourning and grief. Mourning for the life that had been planned and hoped for, mourning that the person you know is changing and things aren't the same as they used to be and will never be that again. Mourning for the relationship that you've known that is now going to be different.

On the other hand, having a diagnosis is good. It helped us to understand what is happening to dad and gives us access to information and support. A diagnosis changed how we relate to dad, but for the better. An example to highlight this happened in January of 2017. Dad was getting the van ready to go away on their holiday and to the wedding that I mentioned before. It had just been to the mechanic and everything was ok. Dad, however, was convinced that he needed to pull the wheels off the van to check the brakes. Mum hadn't succeeded in convincing him otherwise, so I thought I'd have a go. Dad would often listen to me when mum had no success. Dad and I were discussing leaving the brakes alone. The discussion in their driveway got louder and louder. We ended up yelling at each other, which wasn't a normal occurrence. I felt like I was talking to a brick wall. Nothing I said was getting through. I thought he was just being stubborn and obstinate. In the end, dad yelled that it was his van and he was going to check the brakes and I couldn't stop him. That's where and how the conversation ended. Had I known then that dad had Alzheimer's, I would have approached things in a very different manner. It would have had a much better emotional outcome for both of us.

The journey we're on sees us constantly learning and changing how we do things. Some things will work one day that won't work the next. We've found that some friends and family had withdrawn from mum and dad, which was hurtful for mum, more so than dad who wasn't aware of what was happening. I discovered that people didn't know how to handle the diagnosis and what to say or do.

For some, it was a reality check. This wasn't happening to their parent's friends; it was happening to their friends. That meant they were getting older too. Being patient with them while they work through what dad's diagnosis meant for them was hard, especially for mum. Some friends and family have said that they spoke to dad and he was fine. There was nothing wrong. They don't see the day to day struggles. The late night phone calls to Health Direct to see if it was ok if dad didn't take a particular medication or how to stop him from doubling up. One night he was convinced he hadn't taken the tablets and wanted to take more. Mum had seen him take them but he wouldn't listen to her. People don't see the challenges with meal times, the time it takes for showering, getting dad into bed, having to plan and think ahead to avert possible problems, the confusion and agitation.

There are some things that I have found helpful on this journey. I've listed them as Do's and Don'ts.

#### DON'T:

- feel like you're on your own in the journey. Others have been through the journey that dementia is.
- feel like you SHOULD be able to cope. It's a hard gig.
- feel guilty about it being hard, about how you're feeling towards the person and the disease
- compare yourself to others and their journey. It can be destructive to look at others and think "They are coping so why can't I?", or "My husband/wife isn't cooperative like that." Instead, look at what others might be doing and see if there is something they have tried that might work for you. Take the positives from someone else's experiences as that can help with where you're at. Some things may work, and some things not. You won't know unless you try.

#### DO:

- let friends know what is happening
- give people suggestions on how to interact with the person with dementia. With dad, it was things like go with the flow during a conversation as it often jumps around from topic to topic and it's hard to make sense of it; if he laughs, laugh with him; if you can enter the conversation by finding something to share, that's ok
- get help from others
- doing something physical. For mum and dad, it's push bike riding. Mum leads the way and dad follows. He has independence and they can ride into town to pay bills or have a coffee. The need to balance on the bike is also great for his brain and will often calm him when he's agitated. (Sometimes getting him on the bike can be tricky.)
- keep doing things for yourself
- use the services available eg. Respite Day Centre, local Dementia Support Group

- accept the new reality, as hard as it is
- accept and ask for help
- have someone go to appointments with you. It's good to have an 'extra brain'.

We know things will deteriorate and they have in 12 months. But find the person that's still there, because they are. You just might have to look a bit harder. Enjoy the time you have with them, in whatever way you can.

Karen Gurney  
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