Ray’s story – life as a carer for June, who is living with dementia

My wife June was diagnosed with front-temporal dementia when she was 65 years, she’s now 72 years old. In hindsight, I suppose I noticed slight changes in June’s speech, probably when she was about 62 years old. She would sometimes miss out words, and at other times she couldn’t actually get the words out that she wanted to say. I asked the GP for a Speech Therapist referral and that started the ball rolling. Through the Speech Therapist, June was referred to a Geriatrician, and after some testing she was diagnosed with dementia. At that time I didn’t know anything much about dementia and I remember thinking “Oh my God, Alzheimer’s !” We wanted to find out the type of dementia June had. The geriatrician had connections with NeuRA Institute, and we ended up going there. The Institute had the technology that could determine the type of dementia. We went and June had all the tests and she received a diagnosis of fronto-temporal dementia, with Progressive Primary Aphasia (PPA).

I now know that there are a lot of different types of dementia, not just Alzheimer’s. But during the early period, after the PPA diagnosis, the biggest help was for me was that we were put in contact with a local nurse, associated with Dementia Australia. This nurse would set up meetings which people with dementia and their carers could attend. At that time of June’s diagnosis, four couples attended these meetings, (use included) and we met twice a week for a few weeks. Each time we met, the four carers went into one room with one nurse and the four people with dementia went with another nurse. For me, talking to the other carers was so important. From these conversations I started realising that there must be hundreds of cases of dementia and any two people with dementia never, ever present the same way. That’s the first thing I realised! Even though there are commonalties, each person is still an individual with their dementia. With the more meetings I went to and hearing the stories of other carers, I started getting a few ideas about how different carers approached different problems. As carers you get together and pick each other’s brains. That was really helpful, especially in those early days when things are so unfamiliar.

I can recall around the time of June’s diagnosis that her understanding of what was being said to her was fine, but her speech was starting to decrease. In this initial period, the progression of the symptoms was very, very slow; but over the last couple of years, I have noticed that the changes are speeding up. I think one of the worst parts of living with someone with dementia is watching your partner getting worse over time and realising that the things which they could once easily do, they no longer can. For example, I notice in the last 12 months that June can’t to blow out candles anymore. She just couldn’t figure out how to do it. I ended up blowing them out for her, but I was so surprised because I hadn’t thought about her losing the ability to do that. So, you start to notice those little things that change as time goes on.

In addition to June losing her words, the most obvious change that has occurred over the last 8 to 12 months is that June’s memory has really started to decline. I find myself saying things over and over, but she can’t remember. So, as a carer you develop strategies to help you get through the day and to keep the other person feeling independent as much as possible. This is really important for me and June. I think June can still read words; she seems to understand some words better if I write them down rather than if I say them to her - so that’s what I do. When I want her to make a decision, I write down the two possibilities and she can cross out the response she doesn’t want or point to the one she does. We’ve previously invested in all sorts of things to try and help June communicate. We had this application on the iPad and if you clicked on certain pictures it would say the words. But this wasn't overly successful and June only used the app twice or three times. Figuring out the best way to communicate with June is a constant *eenie, meenie, minie mo*. If one strategy doesn't work, I try something else, which may work for a little while and then I have to try something different. I am constantly moving through a process of trial and error. Because June can't speak now, I'm always asking myself, *"does she understand?"*, "*do I need to try something else*?"

Being a carer is an exercise in patience. It does get very, very frustrating at times. I try not to lose my temper which is very difficult, at times it's difficult to maintain your patience. That's why my shed is so important, I can go out there for a break. I'm fairly handy, I fiddle-diddle around. I have quite a lot of tools and I build furniture. When something in the house breaks down I never throw it away unless I have a look first to see if I can fix it. The other day June came to me with a gadget in her hands that she had pulled apart. I think she had tried to clean it and couldn't put it back together. I repaired the thing, it took me a while, but I did it. It's important to realise that as a carer you need to be able to take your mind off things, it gives you a break, so you can let off steam.

As June has lost her ability to talk, it has become more challenging to help her stay connected with her world. I have found that the iPad is quite good for June and she spends a lot of time these days on it and she reads all the posts on Facebook. Recently, she showed me on Facebook that we had storm warnings in our area. After reading the posts we were both thinking *"oh my God all these storms are coming"*; so, I was off like a rocket, I was locking things, securing things. Then, I took one more quick look at the post and I noticed that there was a little blue date beside the post that said 2016. I then figured out that the message had been reposted and was about three years old!! Of course, June didn't realise this either. But these are the little things that we deal with. But the iPad is one of the few things that keeps her connected with others and to a certain degree with me. When June gives me something to read on the iPad, I suppose it's almost like a conversation without words. She seems to enjoy looking at the posts on Facebook and every so often she wants to reply a post. I figure out what she wants to say and I always write out the reply on a piece of paper and let her copy it on the iPad. I do this because I believe that as long as she can type out the reply by herself, she should – I'm trying to keep her doing things as independently as she can for as long as she can. In saying that, I'm not always sure how much June understands of what she reads on the iPad from one day to another, I think it varies.

Of course, June's frustration increase as the dementia progresses, because she can't tell people what she wants; she can't easily tell me what's wrong and it's very upsetting for her. It has also become difficult to involve her in decision making processes as her communication ability has declined. One of my sons has suggested that we move closer to him. I've been trying to get June to somehow communicate with me, whether she wants to move or not. I don't want to push her into a decision, and she might not be happy with the decision I make - because I can't discuss it with her. It would feel absolutely terrible if I made that decision and if things didn't work out. But that conversation is a work in progress. My son thinks it would be better for us to move closer to him, because at present we don't have anyone coming in to help out with June's care. My son and his wife live over an hour's drive away and they both work fulltime and have busy lives. I don't do respite, and I have made that decision. which I can handle for the time being.

We did get an entitlement from the Government which could have been used for respite but that ended up being a big drama. Overall, dealing with the government can be very challenging. I first got a letter saying that we had been approved for the top-level care. At the time I thought *"great, I've got this service available if I need it*" and I filed the letter away. But then other letters started coming from the Government saying *'if you don't start using the entitlement, we'll take it away'*. They did eventually take it away. So then when I tried to make contact with My Aged Care to talk about it with them, the staff wouldn't talk to me. They said they would only talk to June. But because of her dementia June couldn't talk with them, which I tried to explain! This went on for 12 months. Finally, one of the members from Dementia Alliance Group in Kiama helped me, and I eventually got our entitlement back, albeit a smaller one. But that whole debarkle with the Government was very frustrating. To make sure I used the entitlement, so I didn't lose it again, I got an emergency alert button that can hang around June's neck, and I also used the funding for doing a bit of gardening and maintenance around the house. The difficulty is that June doesn't want anybody to come into the house to provide care and I need to respect that as well. But I've decided, as a compromise, that this year I'm going to start asking a provider to send a carer around occasionally so that June gets to know them and if the need ever arises, we have someone else that can come and sit with her or take her for a walk.

I find that as a carer you do become more isolated as the dementia progresses. Even I talk less to June because she really has difficulty understanding now. I'm getting used to not being able to talk with her as much. Prior to the dementia we used to go on a little holiday a couple of times a year and June also had a good small group of friends from her nursing days who she would see. But as the dementia has progressed those friendships have largely dropped off and June finds is difficult to travel now. She is also more reluctant to see people socially, because she's lost her ability to talk. Unfortunately, at times she tends to get left out of the conversation. I know I am guilty of this sometimes, because I can still forget that she can't just talk and so sometimes conversation happens around her but without anyone talking to her. Sometimes people are very good and extra patient to communicate with June and give her time, like our friends who live near us. But we've had people, for example, wait-staff at restaurants say "*Come on make up your mind, where are you going to sit*?", but because of her, dementia June can't make up her mind and I don't want to rush her. I could spend maybe five minutes trying to get her to decide where she wants to sit, and people get impatient because they don't understand. But thankfully, there are people out there that will actually talk to her and they are not worried whether they don't get an answer. It would be nice if that level of understanding and patience was more widespread with people in the community. It's important for the community to understand they need to be patient with people who have dementia. It's the only way things will get better, not so much for me but for June. I can get a break, June's can't, she's got this dementia all the time. I think a truly dementia friendly community would be where people in the community smile at June or anybody with dementia and make her feel that she is being recognised for who she is.

June is still able to do things that she enjoys. She irons - ironing was always one of the things she liked. She irons everything. She'll stand for an hour or two, twice or three times a week, on the veranda and she irons away. She still does a bit of gardening; she likes to grow a couple of tomatoes and because I like radishes she always grows me some radishes. We can still do things together, we do a lot of sudokus. I photocopy the sudoku out of the newspaper and enlarge it and we do the same one. Although I know is it getting harder for June these days, but it gives us something to do together. We have a little competition with the sudokus. I ask *"did you manage to do this one?*", she says "*No*", so I say, "*You can pinch a couple of numbers off me then*". Oh, and she pinches them alright!

I do other little different things that we enjoy. For example, I get the toast in the morning and I break a piece in half and I hold them up and move them around and ask "*which one do you want*?" We'll have a little bit of a giggle about that. And then she might take one half of the toast and puts it on her plate, and I put the other on my plate. Then she decides to swap them over. It's these little things that you try and maintain. In the mornings, June usually gets up before me and she potters in the kitchen and puts out some stuff for breakfast. The most important thing for how the day starts off is that I've got to give her a little hug and we have a little smile. Then we walk to the window and we look at what the weather is like. You know, everyday life still goes on regardless of the dementia.

June was always very good at sewing and knitting. The last time she tried to knit, was over a year ago, she tried to knit a little baby's outfit, because we had a new granddaughter. She kept coming to me with the knitting and the pattern but I could barely understand it. The pattern would read 'pearl one stitch, drop one stitch' and so on. We managed it, I would often count the stitches for her, but it took ages for her to knit this little tiny outfit, but we got there in the end. I have to be careful because things like sewing, knitting and cooking are her domains and rightly or wrongly she can get upset with me if she thinks I am interfering. For example, I buy the bottles of this tomato sauce to have with pasta and I just add extra ingredients to the sauce. I chop up a couple of sausages and add them. But whenever we cook the sauce I say to June, "*Don't boil it, you don't need to boil it, we just need to heat it*". But she gets quite upset because she can't understand why we don't need to boil it. So, in the end she boils it and I just have to quietly move the saucepan aside on the hot plate to get it off the heat. If she notices, then she gets upset and asks why I moved it. But overall, I try to negotiate these sorts of things and sometimes you just have to let things go. For example, for breakfast I say "*You do the toast and I'll cook some bacon and couple of eggs*". But often what that means is that I have to end up eating six pieces of toast. She starts off early and she cooks all this toast, she probably forgets that she's cooked so much and and then if I say, "*I don't want any more toast*", she gets upset because she has cooked it all and she doesn't like it if I leave any behind. So, I eat it – you make compromises. Our days are made up of these little things.

Even though June can't talk anymore, we have photos of amazing trips we went on that we sometimes look at. Most of the time these days June mainly digs out pictures of her family from the very early days. Her father, mother, sisters and so on. She really enjoys seeing our kids and the grandchildren - she loves picking up the new grand-baby for a little while. I think it is important that we go on a regular basis so she sees the baby and the rest of the grandchildren. She finds joy in this. For us there is another important thing; when we go to bed at night we practically go to sleep holding hands and that's important. It is those little moments that are most meaningful.