

Evelaine's Story – Carer for Ron, living with dementia

Ron and I have been together for 60 years and the thing about Ron is that he was an extremely curious man. There are so many things he's just so accomplished at. From when I first knew him, he made his own fishing lines for trout fishing and his own trout flies. He's also been very curious about the world and how it worked. He has books on geology, books on fly fishing, books on the universe. In fact, he has books on just about anything you can think of. But Ron's biggest passion was flying aircraft, it's all he ever wanted to do. He was on the land with his father, who was a grazier until he was about 25 years old. After that he left and went to the Royal Newcastle Aeroclub to fly. Subsequent to that he started a new flying school at Cessnock and then to NASA at Cessnock, then PNG to the South Pacific Aeroclub and was the chief flying instructor up there. Then, he went back to NASA and then down to Albion Park in the early 80's, to the flying school there and then he had his own flying school for a while. His love for flying and teaching people how to fly meant that Ron was important in many people's lives through his work. He taught Gaby Kennard to fly, she was the first Australian woman to fly around the world. Then recently he was visited by a first officer in one of the big airlines, who came to thank him for teaching him to fly. As a token of his appreciation, the first officer gave him his wings, which was really special.

As for me I was an oncology nurse and I'm a people person. I was really blessed with my work that I could go out and see people in their homes. So, for example, if there was a child dying, I could sit with that child, or anyone, if I chose to. If I thought there was a need for something I would try and meet that need. In my role I started a painting therapy group for cancer patients. It was supposed to be only for six weeks, just to help the patients regain some control over their lives; for them to feel valued. That was 20 odd years ago and it's still going.

Ron and I both worked until we were about 70. I didn't think that Alzheimer's would be one of the things that we would have to share together. Perhaps I should have done, because Ron's sister died with Alzheimer's. As I think back now, I recall, a number of years ago being concerned about Ron thinking "he's just not interested in the same things." He was interested in so many things. He would usually be reading five books at a time and I noticed the reading was disappearing. The magazines that we were ordering weren't being read. He was also withdrawing from the Men's Shed, which he absolutely loved because he was learning new skills. He always did woodwork and he had a beautiful desk that he had partially made, but

then all of a sudden, he just stopped working on it. Other things about daily life changed as well, Ron was obsessive about making sure the bank statements were in order, all the bookwork and money was organised. But slowly these things became less important. But it didn't click! I now wonder whether it's because I don't want it to? It wasn't until Ron had major surgery a little over four years ago, in 2014, that we realised something was wrong. He was in intensive care for about a week after the operation. He was very confused and following that, the confusion didn't improve. So, he was assessed and had all the scans and saw the gerontologist. And was diagnosed with Alzheimer's. While the diagnosis provided answers to some of the changes I had noticed, and always you've got comfort in answers, at the same time it was difficult not being sure of what was ahead. It's funny how you can be a nurse and still not be aware of all the dimensions of dementia.

After the diagnosis, there is this feeling of being lost and helpless, most carers are fairly shattered or numb and not quite sure what to do. Carers need to know who they can ring and find out what services are available. Dementia was something Ron didn't want to talk about and didn't acknowledge. When we were told the diagnosis it was as if he didn't hear it. So there's been little or no communication about what we're going to do or how we're going to deal with it or how we're going to work together with it. So it's been a very isolating situation for me.

Over the past four years there's been lots of sadness and lots of watching things disappear. As the dementia progresses, as a carer, you start gradually letting go of all the things that you did, and everything that you were involved in like travel plans, trips to Sydney, visiting family, going to see films, the things that you just normally do as part of everyday life. For example, my sister was down visiting she said, "What do you want to do while I'm here?" I said, "Oh, I'd just love to go to a film because I haven't been to a film for so long." But we couldn't sort the times out, because I can't leave Ron alone now. I also used to run relaxation classes, one night and one morning a week and I have had to stop doing that also. So it's an enormous change.

Being a carer is isolating in two ways. One is that you're withdrawing from all the things that you were involved in socially. And the other is that you no longer can communicate with the other person that has dementia and say "what are we going to do about this?", "What do you think about this?" You don't have that person to help make decisions. You have to make the

decisions yourself and they multiply. I'm really trying to downsize, gradually, quietly, but I can't say to Ron for example "what do you want me to do with all your old lecture notes and books?", because I'll probably find him just sitting worrying after the conversation. Making big decisions like moving house are difficult because I can't ask him or bounce ideas off him about how he would feel. There are still things about this house that are very important to Ron. Our dining room window looks out over the harbour and every morning – every time Ron sits down at the dining table he can see the lighthouse on the point. He'll often comment on the traffic that is parked on the point, "oh, there are only three buses out on the point. I wonder what all those are doing?" or "Oh, there's a lot of cars there today, why are they there?" So, I've been really reluctant to make the decision to move because even though he doesn't go near his work shed anymore, and he's stopped doing anything in the garden, he's still that sitting at the dining table and looking out the window in the morning and that's important in his day. So I'm trying to make the most of those things that remain important to Ron as long as I can.

I'm also trying to look ahead and anticipate the more difficult times in the future and trying to be prepared. That's why I did the Understanding Dementia MOOC. I thought, "I'll do that to help me to understand and be prepared." I'm also a member of the Dementia Alliance Group [DAGS] in Kiama. When the group first started I thought, "oh, I should go and get involved" and that's important to stay connected with people. I also find that some of the online social media forums are really good for getting ideas that are helpful to managing aspects of the caring process and also for feeling a sense of support. If you are online, you can build up a relationship with other carers because you are all in the same boat. When you are reading the forums often people will write "Oh, I didn't realise that" or "I didn't realise that particular thing was happening to other people, I thought it was only me." So that's really important for carers to understand that their experiences are often shared by others.

For the most part I plan my days around Ron and I've either got to get going and get a lot of things done before 9.00, or I put up with things until later in the day. Usually Ron will be up by 9.00am. He'll go and shower and shave. Which is really lovely and I'm so grateful that he's still doing that himself. Then he'll sit at the dining table and he has a nebuliser for his lungs and because he's diabetic he has his sugars done and then pill and potions and breakfast until about 10am. It's easy to forget that it takes a lot of energy for someone with dementia to do things; to get up and do daily living things. As the dementia progresses, as a carer, you realise that you just can't get things done like you used to. I did start taking Ron to a day respite group.

A really lovely group of people and a lovely group of carers. It was really wonderful because it meant I could go and actually do some things that I needed to -like shopping or other appointments. But Ron hated it. He didn't want me taking him somewhere where he didn't know people. So even after three visits, it still was uncomfortable for him and he didn't like playing games. One day I picked him up from the respite and I said, "What have you just been doing?" He said, "kicking a bloody ball round the floor". He's never played games, he's not a games person and he didn't enjoy it. But the other difficult part of this is that I find accepting care for myself is very difficult because, I've always been the one who has been there for other people.

Living with someone with dementia you have to have a different way of looking at things and you sometimes just have to laugh, even when things are tough. Take for example the leaf blower. I loathe leaf blowers, absolutely loathe it, but it's one of Ron's favourite tools. And of course, you can't have a leaf anywhere. In the garden we've got a Norfolk pine on one side of the yard, and a Norfolk pine on the other and they're 30, 40, 50 feet high. But they drop needles. And Ron will go outside and say to me "I only cleaned them up yesterday, I've got to clean them up again." So he goes off to get the blower and he connects everything up and this would happen every day. Also, we have what I call the grand canons alongside our footpath. The grass doesn't get to the footpath, because Ron has a cutter and he cuts along the grass edge. So we end up with a trenches – the grand canyons. Then he blows the trenches out of course, with the leaf blower, so the dirt goes everywhere too. But you have to laugh. Nurses are good at black humour anyway, it's sort of just another derivation of that, I think.

We also had to laugh about the case of the missing mustard. That's about two months ago. I cooked some corned meat and Ron likes mustard on it, but it had to be Australian mustard. The next day, I went to get the mustard for some leftovers. I was going to make him a sandwich. Do you know where the mustard went? It was not where it should be. And I looked in every drawer and every cupboard that I could possibly think of in the house for two months. I thought, oh well, this mustard's going to be pretty strange by the time we find it. In the end I found it under the sink. I would have opened that cupboard door every day to put rubbish in the bin and to get the detergent out. And there it was sitting on top of another little bottle so that has become a family story. Where's the mustard? Who cut the mustard?

There are some things that you also need to make choices on and that you just have to let go of. For example, Ron's got problems with his swallowing so the fluid goes into his lungs. So I've got to be really careful, because he had a series of pneumonias. I was told to give him thickened fluids. He was really patient with me giving him this awful thickened tea. He'd say, "is it going to be normal tea? Or the other stuff?" I tried it for about two or three months and then one day I thought "this is ridiculous, for a country man particularly, a cup of tea is so important and the tea was awful." So you make choices, we stopped with thickening the fluids. It's quality of life or risk and sometimes you have to pick your battles.

My big battle is with the car. Ron was always fastidious about our cars. They had to be clean inside and out. And they had to be fuel in them, the windows cleaned – everything had to be just right. So Ron says "I'll clean your car", every time we go to get in and I tell him "Oh no, don't worry, it's okay." The other day, the water for the windscreen wipers ran out and I said, to Ron "I've got to put water in". So the minute I put the bonnet up, he was there at car. I said to him, "you don't need to check the oil". But he's got to check the water; got to check the oil. And I really lose it, but then I remember, those things were so ingrained in him as a pilot, to check everything; you do not get into an aircraft unless you've walked around, touched everything, you make sure absolutely everything is perfect. It's ingrained in him these tasks, but it took me ages to realise that. But you also have to be always thinking about how you are going to respond when more difficult questions come up. Like, "where is mum and Dad?" or just this morning, Ron came out and said, "Oh, I don't know what to do," and I said, "If you can tell me - can you tell me why you're anxious?" He said, "I've just got to get an aircraft". So I said, "You know, the really good news for you today is you're retired and someone else is going to worry about that," and that worked well and he replied "Oh, okay. All right then."

I'm trying to keep Ron connected to the present as long as I can and to help him cope with the changes he is experiencing. I have photographed everything that's in the kitchen cupboards and then I blew up photos and laminated them and put the photos on the outside of each cupboard. The photos help him know where things are, the cups, the mugs the saucepans. So the whole kitchen's got photos all around it. I've also blown up and laminated photos of all the kids and the grandkids and the great grandkids. And I've also laminated a lot of photos special events and of flying events. So there's a whole rack of photos that I can put out for Ron to look at; different ones each day. But some days he will look and some days he won't. But he does enjoy looking at the photos of the grandchildren. So while we can, we keep doing that.

They're the things I'm hanging on to, because I know they are going to disappear gradually as the dementia progresses.

There are still things that we can share together, but I do worry that I don't give Ron enough stimulation. I told one of my friends "I'm feeling awful because I can give him superb personal care. But I feel I'm not doing enough stimulation, I can't – I've run out of oomph for that." But Ron will happily sit and listen for hours to David Attenborough and Brian Cox. He loves anything on the universe and space and we can go over the millions of David Attenborough episodes. When Ron is watching them he'll say to me, "oh, look, I haven't seen this before, look, you've got to come and sit down and listen to this! This is really, really interesting!" In fact I've probably seen it about 10 times before. So I'll poke my head in and have a listen. Sometimes I'll sit and watch. If it gets to about 6.00 in the evening I might say "oh yes, I'll come." I'll bring a glass of wine and sit down with him. Other days I will say, "would you like to go for a drive? We'll go for a magical mystery tour." And we'll go all up around Jamberoo and around the stone walls. And we re-do the same trip all again. Sometimes we stop for some coffee somewhere and Ron says, oh, I haven't been on this road, never been on this road. We might have done it the week before though. He'll say "I wonder how long those stone walls have been there?" So we can talk about them together. Often he'll ask can we have fish and chips? So quite often, about once a week, we go and get fish and chips and we go and sit somewhere near the water and he really appreciates the harbour and the view. But it can get monotonous and each day I get up and I think – another day of the same. But then I think, "oh no, you never know, you might not get fish and chips today, you might have a sausage roll." So there's still things we can do together and I hang onto those moments. Another thing that is really important to me is that Ron still never gets into bed without, saying "thank you for putting up with me, I love you," and kisses me goodnight. He says it every night, he will not miss it. I'm really grateful for that because I've still got that. It's really special and so you hold on to those precious moments.

I'm really also grateful that I have got a background in nursing. Looking after Ron is like an extension of that. But being a normal human being, the frustrations are still there. When Ron gets aggro, or when you get really frustrated, sometimes you do just have to think, "okay, I need to step back", whether you go to another room or you take a deep breath. But it's not something that you know straight away as a carer. I think it's a process of adjusting and becoming seasoned. But you do have to be flexible and be reassessing every day how things

are. Some days start well and then they go downhill, some days start badly and then they improve. I find that when I step back and reassess and start again, just little things can bring about an improvement in Ron. Things like a kiss or a hand hold or a back rub.

But what I find most upsetting is when he gets distressed or frustrated and says to me “I’m useless” or “I’m hopeless”. That’s difficult for me to hear and I reassure him and tell him “what’s happening is you’ve got some damage, you’ve got cells that aren’t working properly in your brain, and it’s your memory. So it’s not your fault. You’re not responsible for what’s happening.” So I try and just reinforce, “You’re not responsible, it’s not shameful, it’s something you don’t have any control over. This is something that happens to one in four people our age.” I tell him “you are still a smart man, you are still the same person; you still have all these wonderful skills, but some parts of your brain are damaged so it’s difficult for you to use them.” So I try to help him make sense of what’s happening and it’s just part of what you do when you care about somebody, and you don’t want them suffering. I also think as a carer you can be quite protective of that person. I probably still step in and bridge the gaps in conversation with other people if I think Ron might get hurt. So you are quite vigilant in that way. But overall that vigilance, of wanting to help, wanting to fix things. There is a constant alertness and awareness that sits inside you. It’s really central to how I react and how I feel being constantly on the alert - it never goes away. And I thought even if I’m away from home and I’ve got my phone in my pocket, the alertness is still there sitting. Every day you’re alert to every movement, every sound, every change of direction or mood of the person - it’s 24 hours a day. But in the long run it creates a calmer atmosphere and he is not distressed and obviously that’s of value.

I think one of the most important things for the future is somehow or other being able to get the broader community to see that someone with dementia isn’t responsible for what’s going on, for what they’re thinking or not thinking, or what they’re doing or not doing. That the disease is what’s happening to them. I think there is an enormous amount of work to do for the community to understand that dementia is not something shameful and it’s common and that it’s alright to admit that it’s part of your life. Perhaps most importantly, people need to be understanding, and not devalue the person with dementia and don’t treat them as if they’re not there. They’re still inside.