

DEMENTIA ADVOCATE SPEECH/OR ARTICLE FOR PUBLICATION

AIMS:

1. Use the story of our dementia journey to educate the audience on how best to cope with the challenges to be faced when caring for a loved one with dementia.
 2. Share the knowledge I gained on how to best navigate the complex government aged care system and get the best help and support.
 3. To encourage audience members to have a conversation with family members about end-of-life decisions and question whether they would support changes to VAD to include dementia sufferers.
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Today I am going to share the hard lessons learnt during the worst three years of my life. It's not easy for me to open up about these very private and difficult times. You may well ask why am I'm doing this? Well, here's why:

Right now, one in ten people over the age of 65 in Australia are living with dementia and the number of cases is expected to double over the next 50 years.

It's now the leading cause of death for Australian women and the second leading cause of death for all Australians.

Around 1.7 million Australians are currently involved in the care of someone living with dementia. Many, like me, end up caring not by choice but by circumstance. I cared for my mum who passed away from Alzheimer's and hers was a slow gentle decline over 10 years. When it's your life partner it's totally different and I was nowhere near ready to deal with the pain of watching John slowly succumb to this dreadful disease.

I would not have come through it without two wonderful ladies, Louise and Kerri Ann.

Louise was there for me every step of my carer journey and bore the brunt of my anger, frustration and despair. Now, when I have stepped down from the FTD support group to focus on navigating my new solo life – she had other ideas.

Kerri Ann founded a special Facebook Group just for people caring for their partners.

Here, I had access to a brain's trust of people in the same boat and, in this forum, we tell it like it is - not just how the professionals seem to think it should be.

So, when she posted this as I was wavering about becoming a dementia advocate it clicked into place. So, for me, today is all about Paying It Forward as a survivor. - and believe me some carers don't make it through – living with constant stress and anxiety is a killer.

Everyone's journey is different. In our case, due to the rarer type of dementia John had, he never accepted his diagnosis and literally fought everyone involved in his care every step of the way.

Some of the things we endured certainly won't be easy to hear. But, in spite of this we did manage to create some very special memories and, looking back now, I no longer beat myself up about the mistakes I made.

This is the pre-dementia John many of you will remember. He had 80 wonderful years and was always – what shall I say – a typical Alpha Male. Leader of the pack and fearless in his approach to life.

He had so many projects on the go it would have taken him at least five lifetimes to complete them all.

Luckily, we had discussed our end of life wishes, so I knew what he wanted if he no longer had quality of life. He told me not to worry about it because, if he started “losing his marbles” he would just slip off the back of our boat, dive down to the ocean floor and hold his breath until he passed out and floated away. I wish I had been able to give him that option.

In 2018, John had a knee replacement operation at Hollywood Hospital. The operation went well but he had a really bad reaction to the anesthetic and was delirious afterwards and took much longer than usual to recover. Five years later, his geriatrician told me that this should have been an early warning sign of changes within his brain that warranted further investigation at that time.

There were changes but at no time did I associate them with dementia.

For instance, his driving became increasingly aggressive and dangerous. Our last trip to Europe we had to replace wing mirrors on the hire car twice. He was also having difficulty reversing and launching our boat- something he had been doing brilliantly for over 50 years. He quickly accrued 12 demerit points and would not let me drive him until he finally lost it for a year for driving while under suspension.

Even more unsettling were the changes in personality that I put down to “Grumpy Old Man” syndrome - made worse because he was losing his freedom.

He also became very critical of people and world events. John was always outspoken and really enjoyed a good debate but a big warning sign I missed was the lack of empathy that crept in. He lost the filters that we all need to temper our words so they do not upset others. Sadly, in that pre-diagnosis year, we lost a few friends when they were upset by the way he would get angry at me when I was trying to help him.

It's common for dementia sufferers to be at their worst with the person closest to them. With me, John also became suspicious. He seemed not to trust me anymore and thought I was taking his things, hiding money away etc. Actually, the only things I was hiding from him were the car and boat keys!

Notice I haven't mentioned anything about memory loss! He could still remember dates, specifics of varied historical events and recount stories in great detail.

I am sure a lot of you still think, like I did then, that the symptoms of dementia are mainly short-term memory loss, repeating phrases and words, and repeatedly losing things.

In August 2021, I had to call an ambulance when John developed a urine infection and became totally incoherent and un-manageable. He had to be sedated for his own protection after being placed under guard at Joondalup Emergency Room.

After a week recovering in hospital his discharge papers included a note from the treating doctor to his GP that he had been referred to the Joondalup memory clinic for a full cognitive review.

It was at this point that I should have asked a lot more questions as the speed of deterioration escalated and that appointment was still a long way off. His GP did not think there was anything wrong with him and was a bit non-plussed at the referral.

I now know that most GP's have very little dementia training and it's important as we get older that we find a really good GP and, for couples, try and go to the same one so you can get seen together. John would not allow me to go in with him and "had his GP fooled."

Three months went by and I was getting worried as John was due to get his driving licence back without any medical review. I was a regular caller to the Memory Clinic and eventually had to get loud to get him seen threatening I would hold them accountable if he got back behind the wheel and caused a major accident.

The diagnosis when it came was brutal. Fronto Temporal Dementia – behavioral variant – one of the more challenging types to manage. No cure – no treatment – no way out. Likely to be too late to sort out the vital documents if we didn't have them in place – which we didn't.

An up to date will

Enduring Power of Attorney

Enduring Power of Guardianship

Advanced Care Directive

We had only one of the four – the wills - and those were written back in the seventies.

Critical for us at that time was to find some way to persuade John to appoint me as his Enduring Power of Attorney before he was considered incapable of managing his own affairs. This was not easy but I did manage to get one with the help of a good friend and an understanding chemist. I was so lucky that at that stage he could still sign his name.

At that time, I didn't think I would need the guardianship as I was John's next-of-kin. That was not the case. When he went into care, I had to go through an onerous court process to become his legal guardian as this was insisted on by the Nursing Home.

I never got a signed Advanced Care Directive for him and then found myself having to make the decisions as to what I thought was best for him at a very emotional time.

Death is something we are all going to experience and as families we need to talk about our wishes before something like this happens. It's just not fair for us or our kids to be forced to make these difficult decisions without guidance. Needless to say, I now have a very detailed Advanced Care Directive that is very specific about my wishes so Pirelle will not have to deal with the guilt that comes from putting me into care and withholding medications or life extending treatments – she knows my wishes.

Our family home was precious – a source of joy for decades – huge trees, fish ponds, a moat, big backyard swimming pool and big rooms crammed full of art and memorabilia. Now everything about it was a potential hazard and the complete opposite of the type of living space recommended for dementia sufferers. There were steps everywhere, open stairs, an unfenced deep back yard pool, no rails and an open drop from the second-floor interior walkway to ground level. The Occupational Therapist who visited just kept sighing.

Yet the home he built was so very precious to John – he had his man-cave and art studio out the back and loved his garden – so we accepted the risks and decided to stay put as long as possible.

One of the good things I learnt is that there is actually a lot of support and help available out there but it's a tricky system to navigate. My first port of call was to Dementia Australia via their helpline. They have a wealth of information free of charge to access. After the first call when I read the symptoms of Fronto Temporal Dementia online from their help sheet it was like a light bulb going off in my head. Now, I had to learn fast how to deal with it.

Louise became my coach setting up a series of six zoom calls. Mostly it was just her and I and we worked through what would help in our case. Learning how to care for someone with dementia and keep them safe, while still having a meaningful life, is an almost impossible balancing act. I describe it as like living that great Brad Pitt movie "Benjamin Button" – your husband's brain is misfiring and he's regressing backwards at an alarming rate leaving you to deal with a recalcitrant toddler in the body of a grown man.

First in home support came with a visit from both a Dementia Support Australia Nurse and the McCusker nurse. Their job was not practical help but for them to observe and give me ideas on how to deal with a dementia sufferer. A great thing to come out that first visit was six complimentary visits by an art therapy company who tapped into John's artistic abilities and helped him create some beautiful paintings and a collage. I also bought a GPS smart

watch so that I could keep track of his whereabouts and talk to him. She also told me about the Continence Aids Payment from Medicare which at that time was around \$600 a year.

Next, we tackled the government agencies. I registered both of us with My Aged Care the gateway to all government support for seniors. At our first in home assessment, we got no practical help as John was physically still able to do things for himself but they did tell us about Centrelink's Carer Allowance that was not means tested so after filling in some forms and getting the GP to sign them I received \$70 a fortnight carers allowance that allowed me to get some gardening help. I also got codes that enabled me to access subsidised respite care for when I needed a break.

The Commonwealth Home Support Scheme is definitely the best one for self-funded retirees like us, as the cost contribution is manageable and much less than under a Home Care Package – the rules on this are changing very soon so keep up to date with the new Support at Home arrangements.

My first blessing came in the form of a guitar playing amputee named Ivan. Ivan would come for two hours each week while I went to my yoga class. He would either sit and chat or sing to John or take him out for a drive. It's called social support. Ivan was great and the two of them got on really well – it did make me laugh that I had to go and clear the pathway down to the house so Ivan didn't slip and when the two of them walked into a café the waitresses would treat John like the carer and rush to help Ivan instead.

Next, when it was becoming increasingly unsafe to leave him alone at home, CHSS added more respite one day a week in the form of a day centre run by Community Vision at Woodvale. This was really helpful. They would pick John up by bus at 9.30 and return him at 3.30pm –giving me time to keep appointments and enjoy a much-needed break from the constant stress and worry about what John would get up to alone. He would constantly hide things away, re-arrange his wardrobe – all over the bedroom floor, wander off down the street or stand by the car trying to get in.

The stress wasn't too bad in the beginning as he was still able to shower and dress himself. I was determined to try and keep him with me per his wishes and set about making sure we did everything we could to stay connected and get out as much as possible.

Everyone thought I was nuts when I added a new puppy to the mix but Suzie was a blessing and kept John entertained and our home filled with laughter.

One of the difficult jobs was selling our beautiful boat "Sweet Freedom" and our four-wheel drive as I had to remove the temptation they presented. It cost \$850 for a special driving assessment so that someone other than me was responsible for taking away his driving licence and skipper's ticket.

I started using "white lies" to keep the peace. Little ones like the shops aren't open yet or it's a holiday today to deal with the incessant requests to go somewhere.

Often, I would give in and drive John any and everywhere even when he couldn't tell me where he actually wanted to go. It let him still have some measure of control. One day we drove down to Spearwood in driving rain to get to a printer he couldn't find and got caught up in a flood on the freeway.

When he wanted to leave a friend's place before we had even lit the barbecue, I put him in car and drove around for about 10 minutes then headed back to theirs saying – look here's Dave and Maries let' call in and say hello. He then happily got out of the car and went back to re-join the barbecue.

He loved his grandkids and they were great with him. But we could only manage short bursts before he would get distressed. They taught me a lot about how to get a reaction out of him as they had great fun leading him around the house finding things and going through his books with him.

We kept going out to lunches/dinners with or without friends as often as possible and had a short getaway in Esperance that was his last flight

Things that kept him active and engaged were mini golf, virtual reality race car driving and picnics outdoors.

I was told at that time that we didn't need an ACAT (Aged Care Assessment) as that was only needed for nursing home care. That was wrong – respite providers request an ACAT assessment to decide if they can provide the level of care needed. When we did apply after things at home went downhill fast, we had to wait nearly 12 months. By then he was regularly refusing to shower or change clothes for days on end and was incontinent. With dementia things can change fast. Dementia Australia stepped in again and told me what I needed to do to make the ACAT assessors realize the urgency of our situation. You have to talk about your worst days and make sure they know you are not coping alone and urgently need professional help in the home. In the system, priority assessments are always given to in-patients. This happens because doctors can see that it is unsafe for the patient to be discharged to their own home yet they urgently need the beds. I am told that as many as 1 in 4 inpatients in hospital in Australia are suffering from dementia, they tend to stay twice as long as other patients and are a challenge for nursing staff.

Our first disaster struck a year into the caring role when I slipped on wet grass and fractured my shoulder. It was then I discovered that “respite care” is almost impossible to get in an emergency.

I could not look after myself one-handed let-alone care for someone else. It took 8 days and hundreds of phone calls by Carer Gateway and myself to find a respite vacancy. I had to rely on the help of my family and friends who were marvelous driving me around, bringing food and taking over the running of our household.

John eventually spent 2 weeks in respite in Fremantle Aegis Care and although it was necessary it certainly added to his confusion. He packed his case and tried to escape to come

home every day until they took all his stuff out of his room and kept it in their office. A locked Dementia Ward is unsettling for both residents and visitors.

Nursing Homes are so full now many of them are not offering respite at all. I discovered later that there are small private cottage respite centres that can be booked for less than two weeks. My first holiday respite came with a 4-day trip to Dunsborough while John stayed at this beautiful Hills Cottage.

It's expensive – nearly \$1,000 a night from your Home Care Package or if you are lucky, you may get it from Commonwealth Home Support for a co-contribution of around \$120 per day. It was the best value we got from our Home Care Package and John loved it there.

As Self-funded retirees you have to pay an extra means tested fee on top of the regularly Daily fee of \$12.75 when you move up to a Home Care Package. The extra amount you will have to pay is determined by Centrelink and you have to upload all your income and assets for them to work out how much they will bill you. The extra fees can be as much as \$13,680 a year.

By this time John's mobility was affected and we were reduced to a wheel chair for outings.

Using a wheel chair served two purposes. It meant we could go to outdoor venues and parks but it also helped manage behaviors as by this time John was a bit of a kleptomaniac so shopping was a nightmare. Having the wheelchair meant we could keep a close eye on him and people recognized that all was not well and were much more understanding. Dementia Australia have cards that you can hand out to wait staff or shop assistants that explain the person you are with suffers from dementia. I used these a few times.

Sadly, the personal care issues just did not go away, no medication helped. The anti-psychotics seemed to make him more hyper or sedate him to the point where it was not safe for him to move around the house or go up and down stairs.

I began putting John's name down for permanent care in October 2022. The HCP care workers could not manage him even with my help. I eventually got approval for a lovely Dementia Support Australia nurse whose normal job was to teach carers in nursing homes how to manage resistance to personal care. She and I tried together for five days in a row to get John changed, dressed and showered without success. It really brought home to me the impossibility of our situation. She reluctantly agreed that I needed to accept it was definitely more than a one-person job. His first care plan in the nursing home required 3 staff to be present to do what I had been attempting at home alone for the past year.

One hard lesson I learnt is that nothing moves fast in this system unless you turn it into an emergency. I had already been told that if I ever felt unsafe or just could not go on, I needed to go to a room I could lock or outside the house and call 000 asking for both police and an ambulance to attend. Being admitted to hospital is the best way to fast-track transition to aged care. I didn't use it but John was really not getting the care he needed from me.

Those last 7 months he was at home were a nightmare. I could never relax, was not sleeping well and constantly on edge and flying off the handle in frustration. It was also really lonely. There is no longer any meaningful communication and, try as hard as you like to separate the behavior from the person, I still ended up screaming and shouting. The monthly support group meetings and Facebook rants helped a bit by giving me a forum to vent and share my frustration with others but there were no answers this time.

The guilt and distress that comes with finally accepting defeat and putting your partner in a home is horrible but it's an absolute necessity. John's stay was just five months but it was a blessing and I wish I had done it sooner. His dementia was so advanced by then he really didn't understand what was going on so was not as distressed as I feared. The best thing was that I was finally able to become his wife again. Now other trained people were the ones taking care of his bodily needs and doing a much better job than me. I could finally get the rest I needed and was able to be fun, positive and patient when I visited. I still had the job of advocating for his care, but my main focus now was on just spending time with him and making what final memories we could.

I even took the opportunity to do my bucket list trip to Africa in September that year. I sorely needed recharging knowing that he safe enabled me to escape. At that time, we could still take John out and have special family time.

In fact, Pirelle my daughter, managed to get him to Cirque D'Soleil while I was away. A great feat – I don't know how she did it but I am glad she did. You can see just how engaged he is. And accessing a companion card means that the carer goes for free.

When I got back from Africa, I did notice some significant changes. John was sleeping much more and was hard to wake up so I spent a lot of time just being there watching TV while he slept peacefully. Then he began sleep through meals and had to be fed. I was not sure if it was the medication being used to calm him or if he was reaching the end stage.

Luckily for him, he did not follow the normal long slow decline of people with dementia in care - some of whom linger for years when their quality of life has long gone.

On 23rd October staff reported that he had a choking incident and was having difficulty swallowing. I knew this would precipitate an ending as I had already specified, he was not to be tube fed.

Within a week he was being hoisted to and from bed and confined to a Princess Chair and sleeping most of the day.

He did wake up when we visited on Halloween but it didn't get quite the reaction we expected. I think I knew then that his fight with dementia was finally coming to an end.

What I didn't know was that the assurances I got that the nursing home had excellent palliative care arrangements were not going to work for us. It was a system failure not the fault of anything done by the nursing home staff who were amazing.

So began the most difficult last fight as his medical advocate. I was beating my head against a brick wall of a system that, yet again, cannot deliver vital services promptly in a crisis.

John's medical care was under the visiting doctor for that home who only visited fortnightly and had just been before John's choking episode.

Nothing prepared me for the sharp learning curve over the next 12 days. After our Halloween visit, I started asking about palliative care and was told he was not ready for that yet. A week later he was referred to Metropolitan Palliative Care Consultancy Service but died before they had even responded to the referral and could not be reached outside normal office hours. He died without being seen by a doctor at all.

So began my fight with the system that was breaking my heart. John had stopped eating or drinking and therefore could not take his oral medication. This meant he had no pain relief and no anti-anxiety medication.

The only option open to the nursing team to be able ease his passing was to get their GP to prescribe the usual end of life support medication via a phone consult. This he did on a Friday afternoon. It meant at least the onsite team on duty over the weekend now had access to a combination of morphine for pain relief, Midazolam for anxiety and Buscapam which helps dry up phlegm and assist with breathing that could be given by injection.

I was astonished to discover, however, that these had been prescribed PRN which means "as needed". This meant that the nurse on duty had to be called and make a visual assessment of need at each 4 hourly interval and if he was not visibly in pain or thrashing around, they were not supposed to give it to him. The one nurse on duty was responsible for medication for every resident. She was not present when the carers were waking him and manhandling him to turn him and change him or the sheets etc. so, she could not see how distressing this was for him.

As I said before, John had never been afraid of anything but now he was lying there totally helpless and I could see the abject fear in his eyes whenever they had to move him. It broke my heart. I could not bear it and begged them to just give it to him every time. It just didn't make any sense to me. Before this he was being given pain killers, anti-psychotics and anti-anxiety medications multiple times a day Now, when he was slowly starving to death without food and water and unable to speak how could he suddenly no longer be anxious or in pain?

I also began a quest for outside help researching other private palliative care providers and calling every help line – all to no avail. The palliative hospital linked to the MHC service answered the phone but said they could not send anyone as it was a different department.

My only other option was to call an ambulance which would mean he would have been taken to a hospital emergency room and that would be even more traumatic. So, we stayed put and I began what I called the final "exorcism of the demon dementia."

I divided his room in two. On one side was my angry office and research centre – complete with lap top, notes, food and drink for me and my mobile phone. Oh! and a blood pressure

monitor brought from home. Yes – that was for me not John! It was mine that was through the roof by then.

On the other side was our family area. His favourite music was on repeat. Suzie was on the bed with him and close friends came to say their goodbyes and talk to him in short bursts when his eyes would flutter open.

Saturday evening, I went home showered and changed into a pretty dress and returned determined that we would see this through to the end that very night. When I walked in, Pirelle remarked on what was I was doing all dressed up. I said I didn't want the last time your dad sees me to look a mess. She laughed and said "Mum – you can be sure what he's actually going to think is 'Where's she off to next - all dolled up like that!'"

The medical advice is that hearing is the last sense a dying person loses and you should reminisce and talk to them constantly. So, we chatted about everyday things and good memories. The online advice was to tell them you love them and it's okay to go but you can only do that for so long on repeat. I did my best to wait it out but was so distressed watching and waiting that it actually took two calls to the help lines for me to resist the temptation of a soft pillow. My last call connected with Elspeth who had come to our home in the beginning and she was my savior. She asked me to describe how he looked in detail and reassured me that it would not go on much longer as his breathing was very shallow and gasping and his feet and hands were turning blue.

As an aside - I now have in end of life wishes that if I get dementia and am at end stage I want to be sedated. I also have - although I doubt it will be possible in my lifetime - that I want access to VAD even if I have dementia. Why can't we say now while we are still of sound mind that when we reach a certain stage in dementia which is a terminal illness that we wish to access VAD. We can give clear instructions about the stage of dementia at which we wish it enacted and have the safeguard of two medical practitioners agree we have reached that stage.

We treat our animals much better than our loved ones in this regard.

I am telling this most painful part of our journey in detail because I really don't want any of you to have to ever have to suffer that level of distress.

Please make sure you inform yourself properly about their process for end-of-life care when selecting a nursing home. Ask about the availability of palliative care there and whether it is available 24/7. If you have to choose one that outsources to a third party, please make sure you keep a prescribing Geriatrician outside the home itself – don't rely on the Home's GP. Keep up your private insurance so you may at least have the possibility of a direct ambulance transfer to a palliative care ward if your loved one goes into a quick decline like John.

In the end John's final passing was peaceful – I had sent the nurses away saying I thought the end was near. Suzie had been sent home to Pirelle's as I was scared, she would bark when the carers came in and wake up the whole wing. She had been so good but when they got

to her house her two dogs came rushing up and scared her so she finally released all the pent up wee, she had held for hours all over Pirelle and their front room.

By 2am we were peacefully alone together holding hands with a John Denver favorite playing and I swear when he opened his eyes wide as he took his last breath, they had lost that milky film and were absolutely clear and bright without the fuzz of Dementia. I actually jumped up – pumped my fist and yelled out “Yes”. Luckily, the care staff didn’t come in right then as they would have thought I had lost my mind!

But imagine my surprise when I called them in to confirm he was not breathing, I said “I suppose we will finally get a doctor to come out now it’s too late to be of help. New lesson there – apparently that’s not the case. It’s not necessary and we were asked to call our chosen funeral home. Glad I didn’t know that when I was contemplating the pillow option.

Fittingly, although it was a really hot night – the heavens opened and there was a mini thunderstorm when we walked him out on a gurney for his final journey that was a big crack of lightening and Pirelle turned to me and said “Even the sky is raging at the loss of such a great man!” By that that time, for both of us, relief had replaced grief - the battle was over and John was finally free.

Slide ashes

We followed John’s wishes - no formal funeral rather a celebration of life with good friends sharing stories over a meal – one here and one up in Sarawak. Last November, a year and a day after his death we were finally ready to scatter John’s ashes at one of his favourite spots, Carnac Island. It was a beautiful finale out on the water. Pirelle and the kids snorkelled. The seals looked on. We ate jam and cream donuts, drank a toast and John was finally just where he wanted to be.

Phew, looking back, I know I made a lot of mistakes – but then again - I kept at it and did the best I could with the knowledge I had at the time. Please don’t put your head in the sand and think it will never happen to you. Take action now and get as much as you can in place. I don’t know about you, but my brain tends to go to mush when I am in the middle of a crisis.

SO PLEASE GET THINGS DONE NOW

Get those vital documents in order – Wills, Enduring Power of Attorney, Enduring Power of Guardianship and End of Life Wishes. Then discuss these with your family so they know where they are kept and what you want to happen if you can’t make decisions for yourself.

Register with My Aged Care and see if you are eligible for services now.

If you are caring for someone - you are eligible for a Carer’s allowance from Centrelink – every little helps.

If you are already caring don’t be afraid to use the option of calling Triple 000 and police to get immediate help.

Research and waitlist respite and permanent care early and don't forget to ask specifically about their Palliative Care arrangements.

I sincerely hope your journeys will be smoother than ours but if they are not – then remember you are not alone – use the help lines.

Let me end by sharing my thoughts on access to Voluntary Assisted Dying for Dementia Sufferers.

It is my sincere hope that Australia will follow the lead of Quebec in Canada and **expand the eligibility criteria for accessing VAD to include dementia sufferers who have expressed their wish for VAD prior to losing capacity.** Everyone should be allowed the choice to Die with Dignity.

I sincerely hope your journey is easier than ours.

But if it's not, please know this—**you are not alone.**

So, reach out, speak up, and do what you need to do to take care of yourself, so you can take care of your loved ones.