I have dementia. But dementia does not have me.

Dementia Advocate Valerie Schache of Ballina is living with dementia. Here, she shares her thoughts on how to live your best life, beyond diagnosis.

“I have dementia. But dementia does not have me.

I am as yet ‘untagged’, in the sense that it still has not been determined which of the 130 types of dementia I actually have. The diagnostic process has been a slow one, particularly as I keep confounding the experts with my cognitive reserves.

I suspect I have Alzheimer's 3 Toxic -it mimics Lewy Body and FTDbv. I'm one of a new generation of people living with dementia who are doing so productively, by staying in work for example, and taking steps to remain physically well and socially engaged. This is, in part, thanks to the many support services in place.

I know I don’t look like I have dementia. People tell me this a lot. Where the intent is kind and it’s said as a compliment, I accept it as such and proceed to try and simply educate about the condition. If the intent is unkind, I’ll morph into a pit-bull terrier with lipstick and fight to make my point.

Whatever dementia this is, it successfully cleared my contact list in days, by frightening off dozens of family and friends ... ironically, just when I needed their support the most! The stigma and lack of understanding around this condition also led to me stopping doing a lot of the group-based activities I used to enjoy.

I’m not exaggerating when I say Dementia Alliance International (DAI) and connecting with a younger onset dementia counsellor saved my life. Suicide ideation started to rule my life with clever ways to ‘have an accident’, ensuring my insurance policy would be paid out in full, and an open coroners finding. To survive the first twelve months after a diagnosis without appropriate support means these thoughts are not uncommon. It was only my love for my family, who I know would never recover from the grief if I took that path, that forced me to find an ongoing way of dealing with what I perceived to be a very bleak future.

Through my association with DAI, I'm online and inform other members of the best practice and life skills that have helped me, and offer constant encouragement, especially to new members reeling from the diagnosis of a terminal disease and the stigma that results in ‘exclusion by ignorance’. It is great to be able to spend time with people who just ‘get it’, and to feel as though I can just be myself. Yes, our brains are damaged. Yes, we are different on the outside to what we once were. But we are still the SAME person on the inside, and should be recognised as such. The DFC movement nationally and locally is essential too.

DAI has been so vital to me, that all Christmas gifts, birthday presents and funeral bequests will now revolve around making donations to the organisation, so I can do my bit to support a group making a massive difference with such limited funding. Its the only organisation run by people who are themselves living well with and beyond dementia -our motto is “Nothing about us without us!”

The public can do its bit by becoming better informed. Become a Dementia Friend - get the badge. Don’t be part of the problem. Be educated and aware, and always be kind. It’s the Aussie way to look out for your mate, even a non sober mate with their cognitive abilities being temporarily impaired. As you are kind, tolerant and understanding of that mate, please extend your mate with dementia the same inclusive courtesy and dignity.

So what does this look like? It’s pretty simple, really. Greet me in the same way you did before ... with a smile, a hand shake or a hug. Don’t ignore me. Include me! Invite me to be part of your world. Sometimes I will say yes, while sometimes I simply won’t be able to. But either way, I love to be asked.

Even at the end stages of the disease, the person with dementia can still be meaningfully reached with a touch, a song, a prayer. During my career as an acupuncturist physiotherapist, I worked in a hospice, and as a consultant to a local nursing home. I have therefore seen what it takes to be there for a person’s final journey and support their grieving families.

My brain has limited battery power and so I have to prioritise where I expend it. I need to pace myself and rest more. I was a ’workaholic’ with family friends work and the numerous committees I have been involved with. -all without the need for a diary! Connected iPhone and Siri helps me now.

Since the dementia, I have started to get ‘brain fag’ ... it’s a bit like the way you feel after a big exam. That’s when I know to take a step back and stop pushing myself for a bit. I distinguish between ‘brain fag’ and ‘brain fog’ by saying that, while brain fag is fatigue, brain fog is a thick blanket that covers and distorts brain function, and is one of the things that led me to seek help in the first place.

Me and my husband of 47 years had been noticing that things weren’t right since 2013. When investigations started, my self reporting was not initially believed. Upon diagnosis in August 2015, the physician went white with shock as he announced I had dementia. I, however, felt vindicated.

I started on Aricept . It cleared the brain fog within days and lit me up! I’m an adrenalin junkie and I had the ride of my life — the fact that it was given so early in the disease progression has meant it has, and continues to be, extremely beneficial. It even lifted my Mensa-type brain from an IQ of 90 back up to 121!

I'm now under a functional integrated medical doctor with specific , precise supplements / exercise and emotional mindfulness.. Recently I was found to need a CPAP machine as my brain O2 driver is damaged - I now at last sleep soundly. I've previously had specialists assume I must have some sort of underlying psychiatric disorder. 'Change nothing!' is my bestments latest comment - I'm eight hours ahead of the disease but it is enough to thrive.

Aside from the drugs, I have developed a number of strategies. For instance, I fast for 12-16 hours every night, with my last meal being at 6.30pm, bed by 10.30pm and breakfast after 8.00am. I believe burning fat energises the brain, meaning no fade or fog ... and my clothes fit better! I also avoid the toxic SIX whites – flour, sugar, rice, milk, salt and margarines -white untouched.

Knowledge is power and so I'm researching, asking, attending online webinars ... I continue to have a burning 'need to know'. I have also presented and submitted posters and have a paper on 'Who cares for Whom'

I have a VVCS Counsellor to whom I vent regularly. I also have my zoom 'dementia family' who understand and to whom I don't have to pretend.

Since retiring from work, I have established a popular Facebook group known as, 'Val's Journey - Dementia is a word - Not a sentence', to provide a supportive online community and as another means of sharing some of my extensive useful knowledge.

My advocacy work is something which has improved my quality of life immeasurably. I'm now part of the Dementia Australia Advisory Committee; advising on the government-funded Dementia-Friendly Communities program, which aims for individuals organisations and communities to educate themselves Visit www.dementiafriendly.org and complete the course and get the badge.

I am blessed because my family and friends support and enable me. For other believers, you will understand when I say I walk in divine health with the mind of Christ. I continue to work really hard at staying well. Today is the PRESENT, and I intend to suck the marrow out of life, not just endure it. I have a great exuberant life! Yes, I have dementia, but dementia doesn't define me. Dementia does not *have* me.

I would urge anybody in similar circumstances to visit dementia.org.au for a one-stop-shop of dementia information and details of the available support services.