



Someone still lives inside the body of the mind
that is overcome with Alzheimer's.

Source unknown



It's okay to stumble

I have always believed that it is a part of life to stumble, trip or fall, especially when you decide to move out of your comfort zone and attempt things that really matter to you. It is for this reason, when I decided to set new life goals after my diagnosis, I accepted that along my journey there would be many bumps, when things don't go exactly the way I hoped or planned for. For me, it reminded me of the past, when I was attempting to parallel ski. If I wasn't stumbling or falling into the snow, then I wasn't trying hard enough. Luckily for me, the snow was soft enough to cushioned my falls, so that the only thing that was bruised was my ego.

While I was growing up, my father taught me, the most important thing you do when you stumble, was what you decided to do when you got up. As this will be a test of your character and what will separate you from everyone else. I believe this message is aptly conveyed in the following quote:

"I'm a fighter, I will not give up. I will stumble and I will fall but I will stand back up. It might take me longer at times but I will stand back-up and keep fighting" Source unknown

Random Acts of Kindness

For me, kindness is a behavioural response that is linked to your ability to feel compassion and empathy for others. When you are kind to others, not only do you feel connected to others, but there is also a release of neurochemicals, known as the '*feel-good chemicals*',² that makes you and the recipient of your actions, feel better. As a result, end up creating positivity all around you.

Where possible, I always try to do random acts of kindness every day. These can be as simple as always giving way to others when I'm out walking my dogs, saying hello to strangers to more meaningful examples such as when customers come for dinner at the family restaurant, I always try to make sure that everyone has a good experience by splitting bills, providing special wines at realistic prices, providing young children with a dessert at no extra cost, or candles/sparklers if a special occasion is being celebrated.

Recently, two events have occurred which are indicative of the impact that acts of kindness can have.

- **Quote from Sarah T**

'Bill is a family friend, who I met through the South Curly Surf Club. When speaking of my difficulties about choosing which university courses to pursue after high school, Bill generously offered to run a few career counselling sessions with me. We had multiple career sessions which then turned into chemistry tutoring – all of which were extremely beneficial to my learning and confidence in approaching higher education. Bill was incredibly helpful, patient and understanding. He helped me explore all of my options and set expectations about what HSC exams, results and university study would entail. Bill has been an amazing mentor, dedicating hours of his time out of pure kindness, and I am incredibly grateful for his support'.

- For months, a couple used to come to the restaurant in the afternoon and sit quietly sharing a drink. When I learned that Frank had Alzheimer's Disease and his wife, Denise, was his primary carer, I used to spend a lot of time with them, discussing the challenges that they were facing and how they were managing the myriad of demands that this disease places on you. Then, all of a sudden, they stopped coming to the restaurant. After about three months, Denise returned to the restaurant with three of her close friends, and I learnt that she had just recently decided to place her husband into aged care (due to the advancement of his Alzheimer's Disease). In our discussion, I told Denise I believed she had made the correct decision. As they were leaving the restaurant, she approached me and asked me *'How do you know that I made the right decision?'* I thought for a while, before I told her that I had also been diagnosed with Alzheimer's Disease, and when the time came, I hoped that my wife would also have the strength to make the same decision she had made. With tears rolling down her cheeks, she gave me a big hug and thanked me. Recently, I had the opportunity to re-live this event, when Denise returned to the restaurant, with her daughter (Mandy) and grandson, John. It is with her permission, that I have provided this recount and the following comment:

'Bill's advice at this time, gave me a lot of reassurance that I was doing the right thing, even though deep down I believed I was failing my husband'

Acts of Kindness also work both ways.

Recently, I was presented with my own 'hello' t-shirt. Based on the slogan *'if you don't say hello you will never know'*, Tony Staunton initiated this idea as he wanted to build a 'community atmosphere' amongst the local people who were walking along the South Curl Curl promenade, by inviting everyone to say 'hello' to each other. In the last 5 years, Tony has only given out t-shirts to those people in his opinion *'who do good and contribute to the community so we are all happier, healthier and stay connected'*.



Enjoy the Past

Starting with your short-term memory, memories of your past-experiences are slowly taken away from you as this disease progresses. Therefore, providing the opportunity to rekindle these memories, can leave you with a strong sense of feeling valued, as you recall and talk about those past events that are important to you.

The reason why I included this ***'leaf of positivity'*** in my tree, was that I wanted to be constantly reminded of those past events in my life that had given me so much pleasure and enjoyment. To achieve this, I commandeered my son's old room and changed it so that it now contains many of the items from my past that I value. For example, on the wall, I have put the photos of my son winning the Champion Lifesaver event at the Branch, State and Australian Surf Life Saving Carnivals and a series of framed Japanese wood block prints. I have also included a range of photo albums that cover different stages of my life. While working at my desk, I have a set of headphones which I use when I'm listening to music. On top of the cupboard, I have placed the three stuffed monkeys I brought back from South Africa, a Japanese Samurai sword set and ceramic pottery that came from China.

In setting up my room, I wasn't looking to improve my cognitive ability. It is simply a means of improving my overall well-being by decreasing my stress and boosting my mood.

Appreciate Nature

Especially during summer, I regularly spend a lot of time between North Curl Curl, South Curl Curl and Freshwater beaches. This involves either walking along the beach, swimming in the rock pools and surf or just sitting on the sand, enjoying the sun, talking with friends and reading a newspaper. As a newly built walking promenade now connects the headlands of each of these beaches, it is a great way to step back and appreciate the uniqueness of nature, especially early in the morning and when the sun starts to set in the afternoon.



Although, it tends to be a rarity these days, too see the whales and dolphins frolicking in the water is enough to take your breath away. Likewise, the splendour of watching the waves roll onto the beach, the early morning rays of sun light reflecting off the water, the surf spray hitting you in the face when the wind is blowing off shore or just hearing the noise of the birds in the background, is an exhilarating way of appreciating the beauty of nature.

Becoming an Advocate

My first experience at being an advocate occurred in January 2008, when my father's dementia became so unmanageable, that my mother needed to leave the family home, as he refused to be placed in an aged care facility. In the months that followed, as divorce proceedings were initiated, it was then left to Peter and myself, to not only to act as his primary carers but also to defend his rights during a long and bitter settlement process. Which, has still divided the family, even to this day.

Following my diagnosis of Younger Onset Alzheimer's Disease in August 2019, and my subsequent completion of an 8-week dementia course with Dementia Australia a few months later, I became interested in joining the Dementia Advocate Program that is run by Dementia Australia. More recently, after enrolling in a clinical trial, I have become very passionate about this role. I say this, because where I have been extremely fortunate to respond so positively to this novel approach, I believe it is now my responsibility, to continue as an advocate for those who are less fortunate than me.

My role as a Dementia Advocate has been both varied and extremely rewarding, as I feel that I have been able to give others a voice by being able to speak up for them, expressing their views and opinions, both verbally and in written form. To date, I have been asked to complete surveys, questionnaires, comment on draft documents and to attend webinar sessions to express my thoughts and views on a range of issues. More recently, I have been asked to offer my opinion on a range of new innovations that have been reported in the media. As a result, I believe that I have personally grown. Not only has it improved my confidence and self-esteem, but I feel that what I have achieved, and will continue to do in the future, will be of help to others who are less fortunate than me.

Organisations

Following my diagnosis of Younger Onset Alzheimer's Disease last year, I decided to join Dementia Australia so that I could attend their 8-week program and learn about how best to manage this disease. This was an extremely beneficial experience, as I met and became friends with a great group of people who were also facing similar challenges, issues and demands that I was encountering. As I was so impressed with the way this program was run by Robyn and Sian, I decided that I wanted to continue my involvement with this organisation as an Advocate. This was important for me as it allowed me to keep in touch with everything that is happening across Australia at the grass roots level.

In my search to find overseas conferences that would give me insights into past, current and future treatments on how best to manage my diagnosis, I came across the legendary name of Kate Swaffer, as CEO of Dementia Alliance International. This is a non-profit organisation that is run by people with dementia and membership is only open to people with dementia. After reading about their amazing achievements, I decided that this was the organisation that would give me the global perspective that I was looking for.

I would, without hesitation, recommend anyone who has been diagnosed with dementia to become a member of both of these organisations.

South Curl Curl SLSC

I included this leaf, because it reminds me of so many past memories and experiences. This summer, will mark my tenth year at the club. From the time my kids were nippers at the club, I have thoroughly enjoyed the mateship, friendliness and the inclusive community atmosphere that this Club has extended to my family. Despite my absence from active patrols, the Club through its members, have been extremely supportive of me in the last five years. Perhaps my greatest memories, has been working with brother Peter, when we both coached competitors in an event known as Champion Lifesaver. Over a period of 6 years, our competitors won two Australian Titles and 9 NSW State titles, with a total of 59 medals overall. Not bad for a club that is nationally recognised for its champion rowing teams.



This picture shows Termite's U/23 Boat crew enjoying a well-earned dinner at our family restaurant – The Bored Monkey.

Earlier this year, the U/23 South Curl Curl rowing team were selected to represent Australia in the Trans-Tasman Surf Life Saving Rowing competition. Not only did they win their division, they also beat home the New Zealand Open crew.

An amazing achievement.

When our father passed away in 2012, Peter and I, decided to sponsor a surf lifesaving boat. This boat was christened the 'Charlie Kuhn' and it carries the Yeates family emblem with the words 'In loving memory of William Yeates Senior'. After an absence of 5 years, hopefully with the approval of NSW Surf Lifesaving, it is my goal to return as an 'Active Volunteer Lifesaver' during the 2020/21 patrol season. Obviously, with the limitations that Alzheimer's Disease places on me, my duties and responsibilities will need to be restricted. I am looking forward to achieving this milestone, under the support and guidance of Craig Blake (Club Assessor) and Patrol Captains (Paul Torrington and Steve 'Doc' Hall).

Aromatherapy

I decided to include Aromatherapy as one of my *'leaves of positivity'*, because I had read about the effects of using two essential oils (extracted from Lavender and Melissa Balm) to provide a sensory experience that is known to improve your overall well-being. There is no evidence to suggest that aromatherapy improves cognitive function. As a result of my literature search, I decided to initiate a three-month trial, that involved using Lavender (by diffusion) in my office. Apart from making my office smell extremely nice on a daily basis, I found that the smell of Lavender has had a real calming effect and my mood overall has improved. As I have experienced no adverse side effects, I have decided to continue using aromatherapy for the remainder of the year.

Restaurant

In April 2018, my twin brother, Peter, his son, Joshua, and myself decided to enter the field of hospitality, and take over 'The Bored Monkey' as a family run restaurant at Narrabeen on the Northern Beaches of Sydney. Initially, I regarded my involvement in the restaurant as an excellent way of managing my depression. Although my main job at this point in time was cleaning, ordering and re-stocking the fridges, I found that I now had a purpose and a responsibility to focus on. With the months rolling past, as my mindset and outlook on life started to improve, I wanted to start to undertake different responsibilities, but I was always under the care and supervision of my nephew, Joshua. Following my diagnosis of Younger Onset Alzheimer's Disease and subsequent involvement in a clinical trial in late 2019, my whole attitude and involvement in the running of the restaurant took on a completely different perspective. This occurred, because the restaurant provided me with a unique opportunity to test out a strategy that I had been working on in terms of managing my Alzheimer's Disease. The results of which you are now reading about.



Despite the many challenges and demands that we have faced over the past two years, the restaurant has prospered under the tutorage and leadership of my nephew, Joshua. However, due to the impact of COVID-19, our landlord has now decided to return our weekly rent to its original status. As a result, we will have no alternative but to permanently close the business, as the current level of seating restrictions will not allow us to pay all of our staff wages, meet our rental commitments and still make a profit.

Early Morning Walks

Getting up early every morning, just after sunrise, to take my two dogs for a walk has been extremely beneficial for me. Not only am I creating a healthy routine (my weight is finally under control), but I feel that this activity is making me more energetic and alert throughout the day. As I often use this time to think ahead, planning and prioritising what I need to accomplish on a daily basis, there is a real sense of achievement attached to this leaf.



As sleep disturbances are common in people who have Alzheimer's Disease, I researched the effects that Bright Light Therapy can have on the amount of quality sleep, and learnt that the aim of this Non-Pharmacological Intervention is to '*stimulate the cells in the retina (back of the eye) that connect to the hypothalamus*'.¹ By using the early morning light to activate the hypothalamus, the same time each day, I hope to establish a normal circadian rhythm that will give rise to a better pattern of sleep.

To date, this intervention has been extremely successful for me as the quality of the sleep I am experiencing is well worth the effort.

Deep Spiritual Experience

In February this year, a very dear and close friend, Sam Papandrea, who was aware of my diagnosis at the time, organised for a recognised faith healer to hold a special 'Healing Mass' at the Mona Vale Catholic Church. After much deliberation, prompting from Sam and reflection on a previous text message that an ex-student (Rina) had sent me, I decided to attend this Healing Mass at the last minute.

I think of Jesus as being the greatest example of someone who changed the world.

I have accepted Jesus as my Lord and Saviour. I pray you will too.

From the moment I sat down in Church I knew something was different, as I quickly became mesmerised by a picture of Jesus that was hanging above the altar. Just as the healing ceremony started, I was asked by Sam if I minded being one of the '*catchers*'. To my utter amazement, I must have caught at least a dozen people who, as soon as they were touched by the healer, fell to the ground in a semi-conscious state. It was when I caught my last person, that I felt something mysteriously pass through me. The closest description I can think of, at the time, was that it like a surge of warm energy passing through me. It was at this point I started to believe that my goal of becoming a survivor of this disease was no longer in the realm of being an impossibility. So strong was this experience, I organised and spoke to Fr Peter Jones, who is Head of the Augustinian Order in Australasia. The name of this leaf reflects my understanding of what happened that night.

Clinical Trial

I knew from the outset, that the only chance I had of ever achieving my goal of becoming the first person to survive this disease, lay in gaining access to a new experimental drug. This of course meant finding, enrolling and meeting the criteria of a clinical trial that was based on a new approach to the treatment of Alzheimer's Disease, as I was convinced that all previous trials that were based on the beta amyloid and tau hypothesis, had already exhausted every possibility. Based on instinct and my own research, I decided to gamble my life on an approach that viewed the progression of Alzheimer's Disease as an inflammatory response. As I was literally placing 'my life on the line' with this decision, I wanted a trial that had no placebo's and if the drug happened to show any potential, then I wanted to be guaranteed continual access to this drug after the trial had finished. Luckily, for me, my twin brother, Peter, was able to locate such a clinical trial that was being run by KaRa MINDS in Sydney, which met all of these criteria.

Having never participated in a clinical drug trial before, I was naturally quite apprehensive, possibly due to the large degree of uncertainty that surrounded my life at this time and the risk that I was taking. However, this quickly changed from the first time I met Laura (receptionist at the front desk) and has been constantly been re-enforced on a weekly basis, by all of the staff who work at KaRa MINDS. Not only is there a genuine feeling of empathy and willingness to help every person, but the quality of care that is being offered is exceptionally compassionate and person centred. In my opinion, this is largely due to the leadership that is being displayed by A/Prof Kathryn Goozee and the leadership team she has personally selected to work with. In my discussions with Kathryn, she clearly has a vision which is articulated extremely well, as she is able to empower all of her staff, to actively support and nurture it, through the daily operations of this wonderful organisation.

From a personal perspective, I believe that the only way a cure will be found for this devastating disease, is if, more clinical research is conducted throughout the world. Where everyone is waiting anxiously for a cure to be found, it will only become a reality, if people are prepared to become involved in clinical trials. I recently read an article that stated that 80% of clinical trials never get off the ground because there are not enough people volunteering to become involved in clinical trials. Where I understand and accept the logistics that are involved in participating in clinical trials, progress will be slow and limited, unless this shortage is addressed. With the knowledge that no new drug has gained FDA approval for nearly 20 years, and the projection that by 2050, there will be over 100 million people diagnosed with this disease throughout the world. It is not hard to understand why I believe that this is a real issue that needs to be addressed.

"The first survivor is out there but we won't get there without you"

Source: The Alzheimer's Association.

Bibliography or Reference List

1. Hanford, Nicholas & Figueiro, Mariana. 2012. Light Therapy and Alzheimer's Disease and Related Dementia: Past, Present and Future. Journal of Alzheimer's Disease. JAD 33 (4).
2. Sreenivasan, Shoba & Weinberger, Linda. 2017. Why Random Acts of Kindness Matter to Your Well-being. Psychology Today.