



‘I might lose all my memories one day, but that wouldn't keep me from making them.’

— Sarah Ockler, *The Book of Broken Hearts*



Brain Activities

There is a multitude of resources available on the internet and in hard copy form, that depending on your age, are designed to keep the brain active. By utilising what doctors refer to as ‘*cognitive reserve or neuroplasticity*’, I hope by regularly keeping my mind active, I will be able to rewire it, by creating new pathways for nervous impulses to travel throughout my brain.

However, it is very difficult to locate brain exercises that are specifically designed for people with Alzheimer’s Disease. It is for this reason that I try to keep everything very simple by buying the *Daily Telegraph* paper during the week and the *Sunday Telegraph* over the week-end. By programming my Perx App, I usually spend between 1 – 1.5 hrs each day, from Monday to Saturday, completing

- **Sudoku** – Rating Difficult
- **Target Master** – in this exercise you are tasked with making as many words as possible, containing at least four letters or more. Of the 9 letters you are given, the letter in the centre must be present in all of your words. A target is then set for you in order to gauge your performance.
- **Simon Shuker’s Code Cracker** – Usually, you are given the identity of two letters. After placing them in the control grid, you are then required to use your knowledge of words to determine the identity of the letters that go into the missing squares.

On Sunday, I will read the paper and if I’m feeling like a challenge, I will attempt the **Samurai Sudoku**. Other than that, I will then go back through the week’s papers and complete one or more of the following other activities: **Wordfit, Double Cross, 5 x 5 and 9 = 6**.

Under the resources section of this website, I plan over the next few months to develop my own series of Brain Activities that hopefully will be useful for those that have diagnosed with Mild to Moderate Alzheimer’s Disease.

Meal Preparation

Cooking is a great example of a goal that can be achieved on a daily basis. It requires a great deal of concentration, focus, patience, problem solving and decision making to follow a recipe, in order to change a list of ingredients into something that is edible. If the meal is then shared, it is not hard to understand why this activity has such a ‘*positive effect on your sense of self-worth and value*’.

(<https://www.leeclarion.com/2020/the-mental-health-benefits-of-cooking>)

Although I used to enjoy cooking on a regular basis, I have found, since my diagnosis, that it is a lot more challenging to remain focused and follow complex recipes. It is for this reason, I have now levitated to cooking a range of straight forward, easy to prepare meals.

As I find that most recipes don’t really cater for people with a mental disability like Alzheimer’s Disease, I’ve set myself a goal of re-designing and creating a new type of cookbook that is more dementia friendly. This will focus on providing recipes that have already assigned specific tasks/activities to the person with Alzheimer’s Disease (Assistant). This would include activities such as sorting, washing, measuring, chopping, adding and mixing ingredients. I hope to have the first cookbook available for purchase on my website by the start of November this year.

Music Therapy

Music can have a range of positive effects on your mental health, as it stimulates the formation of dopamine, which is part of your brain's pleasure-reward system. This occurs because the broad areas of the brain that are linked to your musical memory are relatively unaffected as this disease progresses. (Cuddy et., 2012 and Jacobsen et al., 2015). It is for this reason, many studies have found that, music, whether you are listening to it, singing along or playing an instrument, can improve your mood¹⁴ by reducing stress levels¹³, agitation and anxiety¹, provide inspiration, incite warm feelings, soothe and delight people in all stages of dementia.

Every day, I try to listen to as much music as I can. If I'm driving, I will always switch the car radio to Nova as I find listening to the *'Fitzy and Wippa'* in the morning and afternoon is very entertaining. Their down-to-earth attitude to life, mixed with a great array of music, provides a real positive influence on my mood. When I'm at home doing some research, I will log into the *Moove&Groove* website and using my headphones access a range of songs from artists and bands from my past, such as U2, Eagles, Cold Chisel, Midnight Oil, Bruce Springsteen to name a few.

Socialise with People

Being socially engaged is a very important aspect of human nature. Not only does it provide mental and intellectual stimulation, it also allows you to connect with people who care about you and it makes you feel heard. Studies have shown that cognitive decline is associated with poor social relations^{5,6}, such as those experienced with loneliness and isolation. According to Hackell (2019), a decline in social engagement, is associated with a range of adverse neurobiological changes such as *'faster cognitive deterioration, changes in memory, identity and mood'*. Whereas, Fratiglioni (2004) has found that being able to social with people, increases your cognitive neuroplasticity, mental resilience and reduces psychological stress.

From my perspective, even though COVID-19 has introduced many changes into our lives, we should try on a regular basis to access as many avenues as you can, so that you remain socially connected to your family, friends and other members of the community.

Mindfulness Practices

Mindfulness, involves the teaching of a series of attentional and emotional skills that enable you, in a non-judgementally manner, to deeply experience and enjoy the present moment¹⁴. According to Wong et.al (2018) there are both formal and informal mindfulness practices. In formal practices, attention is paid to breathing, bodily sensations, arising feelings, thoughts and pleasant/unpleasant events¹¹ while informal practices involve *extending such attentiveness and awareness to everyday activities such as mindful eating and walking, and doing mental exercises such as reading and solving puzzles*.¹⁴ Although evidence is emerging that links the practice of mindfulness to changes in the brain, such as *'positive effects on brain volume, grey matter concentration and brain functional connectivity'* (Luders, 2014), there is no evidence to suggest that this might also cause a delay in cognitive loss. Chisea et al. (2011) and Larouch et al., (2014).

From my perspective, I find that by practising mindfulness (whether it is formal or informal) on a regular basis, has provided me with a number of benefits, such as reducing my stress, improving my mood and overall well-being. This in turn has caused my quality of life to improve, as I am now feeling that I am able to manage and cope better with the demands of daily life.

Setting goals

Setting goals is a life-long process that changes with time. It is a powerful process for *'thinking about your ideal future, and for motivating yourself to turn your vision of this future into reality'*.

(<https://www.mindtools.com/page6.html>)

Provided they are designed correctly, I have always found goal setting to be a highly motivational experience, as they allow you to focus on what you want to achieve in an ideal situation. In doing so, they allow you to believe in yourself, as you move forward, setting up strategies which not only reinforce each step you take, but they provide the motivational energy you need to keep going. It is therefore, very important to take time to celebrate each small step that you have made.

After I returned from Japan last year, something changed in me, as I had adopted a mindset that was now centred on what I wanted to achieve in my new life. That is, by choosing to fight, I wanted to become the first person to survive this disease. Even though I understood from the very start, that the achievement of this goal was too high a mountain to climb. It did, however, provide me with a platform from which I was able to re-set my life goals so that they were now in line with my current diagnosis. For me, goals need to be like electromagnetic waves – they must be self-perpetuating. As soon as you accomplish one goal you need to start looking for the next goal to conquer, until you reach where you want to be.

With this in mind, the goals I set in April this year, as part of my NDIS plan are as follows.

- To improve my relationships with family and friends
- To return as a volunteer Life Saver
- To remain as independent as long as I can
- To write and complete a submission to the Royal Disability Commission about my story

Since then, I have added the following additional goals

- To set up my own website where I could show by example, the importance of remaining positive (positivity) in the way that I choose to manage my Dementia and Alzheimer's Disease.
- To work towards becoming an effective advocate

Regular Routines

Following my diagnosis, I soon realised the importance of establishing a regular routine around the different aspects of my life. Initially this included dressing, grooming, oral hygiene, showering, shaving, reading the news on my i-phone and even driving to and from the family restaurant. As time passed, I have extended my daily routine to include specific times for Stretching/balance/coordination and brain training activities. I even walk my dogs around the same block 2 – 3 times each day, in the belief, that one day they would be taking me for a walk rather than the other way round. More recently, I have moved all my medical appointments to a Tuesday so as to avoid any clashes.

To help me manage my daily life, I have programmed everything that I need to complete each day, into my Perx App, as it provides me with helpful reminder whenever a nominated activity is due to be completed. This includes activities such as taking my medications, recording my weight and mood, completing my brain exercises and walking 4,000 steps. This App, is proving to be a great success for me, as I regard its *'points and reward system'* as a great motivational tool, especially on those days when I'm feeling 100%.

Under resources, I have included a Weekly Routine template that can be easily assessed and downloaded. This template was created by Matt Donovan from Empower Exercise.

Webinar Sessions

Studies have shown that participation in webinar sessions leads to a *'decrease in isolation, increase in social support and ability to accept the diagnosis, cope with symptoms, improved quality of life and enhanced family commitment'*. Given the changes that have occurred with COVID – 19, and as a member of Dementia Alliance International and Dementia Australia, I am regularly involved in webinar sessions on a weekly basis. These sessions provide me with opportunities where you I can share personal experiences and learn from others, while fostering engagement and socialisation.

Mental Stimulation

Studies have shown, that activities which stimulate thinking and memory, have been found to build up your cognitive reserve, due to the increase in the number/strength of the connections between your brain cells. Different ways of mental stimulation might include: reading newspapers, books and challenging material, discussions of current events, solving puzzles, playing board games, playing music, dancing, cooking etc.

Needless to say, on a daily basis, I take advantage of every opportunity that becomes available, in order to stimulate my brain and strengthen the memory connections in my brain. For example, when I'm working in the family restaurant as a waiter, after writing down everyone's order on my pad, I will only use my memory to enter all of the details into the POS machine. Before, I send it to the kitchen, I will cross check everything that I have entered and make any changes that I need to. On a busy night, then would happen at least ten times.

When I need to go to Woolworths to buy anything for the restaurant, I always carry a list with me. Before I walk into the Woolworths store, I will look at the list and then place it in my pocket. The next time I look at the list, is when I'm just about to line up and pay for the items that I have collected.

Internal Foraging

As animals search or forage for food for survival, we also tend to forage through our minds, especially at times of uncertainty or unpredictability. Cognitively, when we are foraging, we are activating specific areas of our brains, as we are searching our memories, relying on information that has been stored, as we learn and make decisions. From my perspective, I do of mental foraging during my early morning walks each day. As this is a time when I think ahead, not only planning and prioritising what I need to accomplish, but also trying to predict possible future outcomes and scenarios.

Let go and Declutter

Clutter is referred to *'anything that you don't need or use that saps your time, energy and space'*.

<http://www.nus.edu.sg/uhc/resources/articles/details/can-decluttering-lead-to-better-mental-health#:~:text=Clutter%20is%20anything%20that%20we,also%20be%20mental%20and%20emotional.>

Besides calming the mind, research has shown, that the act of decluttering helps you to focus and free the mind, allowing you to think and work efficiently. It therefore, helps to reduce your stress levels and has a positive impact on your overall health, happiness and well-being.

<https://www.domain.com.au/living/5-mistakes-people-make-decluttering/>

My willingness to declutter my life and home environment, reflects my understanding that this disease, has, and will continue to impact on my life as I once knew it. In order to cope with these progressive changes, I will need to re-evaluate my life so that I can 'let go' of my past dreams, hopes and aspirations. Only then will I be able to make the necessary decisions concerning which items will be beneficial and those items that need to be removed, as my new life evolves. In this respect, decluttering goes well beyond just removing a lot of unwanted objects from the home.

Self-Education

After coming to grips with my diagnosis, I felt a strong desire to *'transform the unknown into the known'*¹⁵. That is, I embarked on a journey where I wanted to learn everything I could about this disease, including its history, causes (risk factors), symptoms, progression and available treatment options. While the countless books, journals and articles that I read, provided me with a lot of information, it also left me with a large degree of uncertainty. According to Wilson et al (2005), the term uncertainty has been found to be associated with *'anxiety, worry, and difficulty in adapting to new environments and culture'*, I wanted to know why no cure has been found for this disease, just a range of drugs that can provide relief for some of the symptoms. This was despite the huge amount of time and money that has been spent in the last 30 years. I therefore, experienced no 'joy' just 'disillusionment', as I came to understand the answer to this question, Wilson et al (2005) refers to this as the *'pleasure paradox'*.

However, things started to change for me at the beginning of this year, with my enrolment into a clinical trial, coupled with the people I met from Dementia Alliance International and the impact of COVID – 19. I say this because I came to the realisation that it might be possible to manage my Alzheimer's Disease in such a way that I could extend the accepted trajectory of the life expectancy of this disease. As a result, I shifted my focus towards researching what new methods, interventions and strategies are being discussed and put forward throughout the world on this topic.

What you are reading on my website, represents a culmination of this research.

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