

Brain Tumour: A Survivor's New and Ever-changing Way of Life

By Pauline Wood



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Pauline Wood is a registered (non-working) occupational therapist, a Tai Chi instructor, and a brain tumour survivor. Before entering the world of occupational therapy, Pauline worked backstage as a stage manager, a company manager, and producer in live theatre productions in both Aotearoa New Zealand and the United Kingdom. Changing direction in 2009, she began studying for a science degree at Massey University and this led to an interest in traumatic brain injury. However, direction changed again, after a friends' introduction to occupational therapy. Pauline graduated as an occupational therapist from Auckland University of Technology in 2017. Although passionate about working with people who had acquired brain injuries, she initially worked with mature adults experiencing cognitive decline and problems with balance.

Life is a rollercoaster, especially when unforeseen challenges arise that are completely out of your control. It seems the only thing you can count on in life is change. Still, how you manage unexpected life altering events is your choice.

After completing under graduate studies, and feeling like I was on the right path as an occupational therapist, I started studying for a postgrad certificate with focus on vocational rehabilitation at Auckland University of Technology (AUT). I remember feeling a lot of fatigue, and back pain for which I was attending a physio regularly. Around March/April 2018, I developed a consistent headache and was living on pain-killers until they became ineffective in reducing the pain. I was unconsciously exhibiting other types of symptoms (easily distracted, suddenly laugh loudly) which I put down to work/study-stress.

However, my world completely changed on 6 October 2018 when I was (unknowingly) diagnosed with a brain tumour (meningioma, grade 2, in left temporal lobe). I was scheduled for emergency surgery the next day and upon regaining consciousness after the operation, the surgeon informed me what had happened and why.



My first thought was "this is a gift, being on the other side of the health system as a patient/client, finding out about support systems, rehab, groups..." Still, when he showed me a CT scan of 'Bob' the tumour they had removed from my brain, I was shocked, it was the size of a navel orange and had pushed my brain to the right-side of my skull. My thought processes went into a tail-spin, I felt completely confused. Damage to the Wernicke area of my brain had impacted my cognition and as a result of aphasia, my difficulties included:

- Reduced ability to speak and move my jaw (because of the latter, I could only eat soft food).
- Identifying objects (my name for a rainbow was umbrella).
- Inability to read writing or to understand what health professionals were saying at times.
- Fatigue after 10-15 minutes of engaging in any activity engagement (e.g. eating breakfast, having visitors).
- Regularly fainting in the shower.

All of these issues were a challenge because I lived at home alone. My mother was in full-time care with cognitive decline. Hospital staff who aided my recovery included: Nurses, surgeon, registrar, occupational therapy, physiotherapy, speech language therapy, and social welfare.

Rehabilitation Journey

Being open and honest with myself and others was, I believe, one of the best things that helped my rehabilitation journey. For example, in the intensive care unit, the speech language therapist sent a message to AUT to inform them of my situation and advise of my need to temporarily withdraw from post-graduate study. Antony, my brother, helped me to fill in forms required by Work & Income New Zealand because I could not understand them. He also gave the occupational therapists and physiotherapists information on where I lived, the terrain, and access for

transport. This was needed for in-hospital rehabilitation to help me return to living safely and independently at home. Referrals were sent to a community occupational therapist and speech language therapist for acute rehab (three months). My discharge notes included the following prohibitions:

- I was not allowed to return to work for 12 months.
- I was not allowed to drive for six months.

Antony and Elena, my sister-in-law, took me home. The first thing Elena did was to shave off my hair (we had discussed this in hospital). Surgery had left me with a bizarre haircut, and I found it liberating to shave all my hair off.



I wore colourful scarves when going out for about two years so my head wouldn't get cold. The week I returned home was close to Halloween but there was no dressing up and no scary make-up needed for me as my head scar was frightful.



Knitting as therapy.

During the first three months post-surgery (Nov-Jan 2018/19), a number of things occurred. These included:

- Discovering Headway: Brain Injury Auckland. This organisation runs a number of support groups and social activities across Auckland. I started running weekly Tai Chi class's mid-2019. They still continue today as a hybrid class (onsite and through zoom).
- Developing double vision (left eye) from fatigue. Through this I discovered what Orthoptists do regarding eye movement rehab.
- Applying to AUT to continue postgraduate study in semester one, 2019. As I wasn't working, I felt activating neuroplasticity on the left side of my brain could certainly help with my long-term rehabilitation.

I was well supported by AUT staff and disability services during post graduate study. However my challenges included:

- Not being able to be around a lot of people.
- Walking up and down a flight of stairs unaided.
- Reduced ability to talk vocally.
- Light and noise sensitivity.
- Easily distracted and overwhelmed by many things.
- Cognitive fatigue.
- Poor understanding of how to do research as reading and processing information was difficult.

Still, postgraduate-study helped my rehabilitation with neuroplasticity and learning about my 'new-normal'.

Additional support I received from AUT included:

- A desk and computer in a secure PhD room on ground level with 24hr access. There were six spaces in there, and only one or two people around at a time. The space, quietness, and being able to leave study material behind, meant that I was able to plan my days with and away from study.
- Library staff assisted in re-educating me on how to find research material and referencing whenever help was needed.
- Disability services assistance included: a recording pen and pad for taking notes during lectures; a light sensory acetate to place over computer screens to reduce blue light; and referrals for counselling.
- Lecturers listened, gave me extensions on top of extensions, and were always willing to go above and beyond when needed.

Moving On

Life has thrown many challenges my way since October 2018. Some of the main ones include: My mother passing away end of March 2019. The support I received from family and friends was incredible yet, my memory of the funeral is fuzzy. When AUT suggested I wait and return to study in 2020, this freed up 2019 to engage in many activities that pushed my capabilities beyond expectation. Importantly, it and gave me time to be

my own occupational therapist. For example, meaningful activities that year included:

- Driving to Wellington to attend a Level 2 Concussion training session.
- Attending a Brain Injury Convention held at AUT City Campus.

Covid-19 in 2020 was challenging yet enlightening equally discovering how useful zoom could be was very helpful. Still, August put me back in hospital to have a lower right parathyroid tumour (benign) removed. Recovering from the anaesthetic felt like I had returned back to zero in brain function. Thankfully, being aware of fatigue warning symptoms in regards to driving a car meant I took the bus, or stayed at home if travel was not needed. Even today, when feeling tired and given warning signs (zombie state), I ask myself "am I safe to drive?"

Upon concluding postgrad study end of 2021, I focussed on Tai Chi and started giving classes in the community, one step at a time. (In mid-2019, I had become a registered Tai Chi Instructor for Qigong for Health, and Tai Chi for Arthritis (for falls prevention). My interest was also piqued when a website kept coming up advertising Concussiondoc, which focussed on traumatic brain injury rehabilitation in Canada. Being an inquisitive occupational therapist, I had a look and found the underpinning research and active support that is given fascinating. Anyway, short story is, I sent them my story and was surprised to receive an email from Dr Cameron Marshall (CEO [physio]) who wanted to speak with me. I have now run a Tai Chi class since 2022, every two weeks over zoom, on Tuesdays at 4.15pm (Eastern Standard Time). Each class is recorded and able to be accessed in their resource section.

Also during 2022, I applied for a full-time therapy assistant position at a brain injury rehabilitation service that works with people following a traumatic brain injury, and advised I was only able to work part-time. About a month later, I was informed the position had been taken however, they would like to meet and have a chat with me. Consequently, I started work as a volunteer therapy assistant for two hours every

Saturday morning and needless to say, this helped build up my work capacity. At the time, I realised that cognitively, I could maintain full capacity for about two hours before my brain function started to decline.

Bobs Return

After being in remission for four years BT 'Bob' came back (I found out just before Christmas 2022). I am currently being monitored and my next appointment for an MRI is in November this year. Possible treatments include: radiation, surgery, and maybe a sprinkling of chemo. Finding out that 'Bob' has returned, has had an interesting impact on my emotional well-being among other things. In thinking about the next set of challenges you might ask, what has this got to do with occupational therapy. I can tell you - EVERYTHING!!! The short answer: Become your own occupational therapist!

About Easter this year (2023), as a result of consistent self-rehab, I came to realise that my brain function is improving (now good for three hours before it starts to decline). Plus, I finally felt able to inform the company I work for that 'Bob' is back. Despite this recurrent diagnosis, and in acknowledging the work completed in the volunteer capacity, I was unexpectedly offered permanent employment. I am now a therapy assistant for three hours on a Saturday morning. Even today, I am unable to comprehend how far I've come on this journey.

In conclusion, I am pleased to advise that my achievements since becoming a brain tumour survivor include:

- Being a registered non-working occupational therapist.
- Graduating with a Health Science Postgraduate Diploma which focused on acquired brain injury rehabilitation.
- Becoming a registered Tai Chi/Qigong Instructor (running four to six Tai Chi classes weekly (including Canada).
- Practising as a therapy assistant with my colleague, Aarushi (a second year occupational therapy student).

Finally

Thank you again x 1000 to everyone who has helped me during this incredible journey. What's next for me on this 'new normal' adventure:

- Continue embracing the roller coaster following brain injury.
- Support and listen to people on the chronic acquired brain injury rollercoaster.
- Share information on support/rehabilitation services.
- Increase Tai Chi class content.
- Come up with more adaptable activities for use in therapy.
- Write a book to share my experiences.

Most importantly, be grateful, remember to breathe, live in the present, and keep smiling.



Photo taken by Stacey Mowbray of Headway.