

My Vertigo Story

The first time I experienced vertigo, like many others, I had no idea the disorientation and crazy loss of movement control that others may have tried to describe, could actually really happen to someone. It was 1984, I was in the last academic term of my physiotherapy degree, a healthy, fit mother of 2 children, just living the hectic life most young families would understand. I finished a usual school day, picked up the girls, and returned home to start dinner. I felt a little tired and run down, so meal was simple, quick and get everyone off to bed.

Waking the following morning, things seemed not great, but it was trying to get up that had the room spinning, over whelming nausea but 'bouncing off the wall' to stagger to get to the toilet, to avoid vomiting elsewhere. Somehow the girls got to day care and I managed to bring a bucket close to the bed, where I spent the entire day vomiting. A call to the doctor (my paediatrician in the USA), who prescribed a scopalean patch, stuck to the mastoid bone, behind the ear, stopped the nausea/vomiting instantly. It was then that the disorientation was obvious. I simple could not find a vertical posture without holding onto something. As long as I was still in bed, things seemed OK but moving was impossible. There was no pain, no fever, nothing else to complain about, as long as my eyes were closed and I didn't have to stand up.

Eventually, 4 or 5 days later, I saw an ENT (audiogram showed a right ear hearing loss) and the neurologist, across the hall. The diagnosis was brain stem encephalitis. Bed rest and it should resolve. Not easy but doable. Luckily I had taken mid-term exams and done well. 2 close friends would tape the lectures on one day, come by and study for an hour or two, while I listened to them talking. Then the following day I could play the tapes and at least not fall too far behind. I was unable to read, or walk straight. I half-slept most of the day and night. This continued for a month. I had double vision and wore a patch to read or walk. I did get back to school for the week before finals and somehow passed. The end of the term was mid-December and I had a further 5 weeks to just be Mum to a 5 year old and 2 year old, Christmas and all. It was 6 months from the start to being back to full function and doing all that was my usual roll before. My Physio degree had 3 six week pracs, in hospital and private clinic setting, which I managed and did graduate in June of 1985, thinking all was behind me.

This was not to be the case. 'Normal' lasted until April 1987 (by which time I had a 3 child, 11 months old) and woke just as the first time, feeling not right and violently ill by the time I could stagger to the bathroom. Called the neurologist, from the previous episode and was admitted to hospital for a week, many more tests and this time was diagnosed with an arterial-venous malformation (AVM) in the brainstem, near where the CNVIII (hearing and balance nerve originates). No real treatment, as before, double vision, disorientation and extreme fatigue lasting several months. This time the recommendation from the Dr, was "live a stress-free life" and hope it does not happen again!!! They should hear themselves sometimes!! In the meantime my husband's job was becoming more international and we made the decision to come to Australia (from the USA) My neurologist thought, your only a 14 hour flight from LA, so if something happen you fly back to USA. So with no real help from doctors in LA we made the move and once settled, place to live, children in schools, I began to learn about the medical situation in Sydney.

I feel that it was a blessing to come here. Firstly it made me be proactive to research the system and how I could be involved in finding the best care from my condition, which already had 2 different labels. Secondly, there were doctors willing to investigate until the problem was correctly identified. Naturally that led to the best solution. It was a process and it took time but I eventually was referred to Dr Michael Besser (neuro-surgeon) at RPAH. He thought it was a brainstem cavernous haemangioma in the brainstem (small vascular tumour) and he suggested surgery. I was well, and had been for over 2 years since the last bleed, so I was not keen. I told him I would like another opinion. He gave me three doctors' names and I had consultations with all of them. The first was Dr McLeod, head of neurology at the medical school in University of Sydney, he was conservative and said no surgery, at this time. One for and one against. The next was Dr Michael Morgan (neuro-surgeon), just return to Sydney from the Mayo clinic in USA, he did a further angiogram and suggested the surgery is easier before I have another bleed, which he felt would be very likely. The last consultation was with Dr Kevin Blessel (neuro-surgeon), he presented my case at the neurology-radiology rounds at St Vincent's hospital and everyone in the room agreed with Dr Besser and overwhelmingly said return to Dr Besser and have him perform the surgery, which I did (Dr Morgan was the co-surgeon).

It was a long journey, with a lot of fear and uncertainty, which anyone experiencing vertigo will relate too. Thankfully, Dr Besser found exactly what he suspected (brain surgery to remove the tiny tumour) and, after another few months' recovery for the surgery, I have been very well (a small residual decrease in balance) since. No more vertigo, no further episodes.

I was very fortunate the original problem (small hemorrhage into the brain stem) was resolved completely, no chance of vertigo could return, unless a different problem occurs. The surgery left a small residual deficit to my balance. I have slow, down beat nystagmus most of the time. The brain compensates and I do not recognise or "see" this eye movement, unless I'm over tired, stressed or sick (at those times it might be more noticeable). There is no treatment or medication that changes this. In the day to day it means I'm not good at reading signs if I'm moving in the car or walking. I don't always recognise faces (at a distance) unless they speak to me. I have always been active and I think this helps the balance not to deteriorate more/faster than age would account for. I do yoga once or twice a week, walk regularly (3-4 times a week) at least 1 hour.

Like everyone, every day I get older and face the same challenges (which means less hearing and less balance) but hope that I can continue with an active life style for a lot more years to come.