

Anne Elias: January 2022

In 2015 I started feeling unwell and was constantly complaining of blocked ears, sinus like symptoms, hearing loss, pressure in the head and a blocked nose. It drove me crazy.

I think we all remember our first Meniere's episode. My first one was in a restaurant. My partner wanted me to meet a colleague of his who lived in our area. Well let me tell you, I made a huge impression! Not long after we met, I made a grand exit. Unable to walk, I was supported by my partner who hailed a taxi. It was the shortest taxi ride of my life as I lived only a couple of blocks from the restaurant.

The episode lasted six hours during which time my world was spinning with the added bonus of the vomiting. It was horrible and all I wanted was for the spinning to stop. I had put this experience down to food poisoning and got on with my life.

As it goes, these episodes continued regularly and fear set in. After trips to doctors and ENT, it was recommended I have an MRI. I was later diagnosed with Meniere's disease.

In a funny sort of way I was relieved as I finally found out what was wrong with me. I accepted the diagnosis of Meniere's, filled out the prescription of Serc but had no idea what impact this would have on my life.

As the days passed my fear grew. I was afraid to move or leave home. I lived in fear of another episode. I was extremely down and felt very sorry for myself.

Luckily I have a supportive partner. He dragged me out of the house so that I could breath some fresh air and to be in another environment other than being surrounded by four walls and a roof. He took me to the local park where we just sat. In time he was able to help me get some of my confidence back.

One of my biggest problems at that time was facing up to the reality that my world had changed. In my pre-Meniere's world I was very active. We cycled, swam and bush walked. Being a culture vulture I was out seeing film, galleries, theatre and going to live concerts. Then it all stopped.

During this period I couldn't manage going to a supermarket, a shopping centre, noisy restaurants, loud music venues or cinemas. Working on my computer was a huge problem and I stopped working and driving.

This inactive life was a struggle and did not sit well with me. After many down days, I had had enough. I couldn't stand myself any longer.

Mr Google connected me with Whirled Foundation and I have never looked back. Micky who ran the foundation was my first great support. I asked after a support group but unfortunately there were none in Sydney at that time. I believed from

my experience that there was a huge need for this kind of support so I started the Sydney Meniere's Support Group. I can honestly say without the support of the members of this group, I would not have managed.

Regarding medical treatment, I started with Serc 1 x 3 per day for a couple of years then stopped. I took Stemetil only in emergency. I went on a very low/no salt diet. I stopped drinking coffee and drank the occasional glass of red wine.

No matter what I did, the beast kept coming back. I had to cancel concerts and theatre shows, I stopped exercise, rarely went to restaurants as they were too noisy and too difficult to find somewhere with low salt cooking. The most difficult part for me is not driving and letting people down. I am tired of telling people I am unwell, especially at the last minute. I often feel like a hypochondriac, especially if someone says "but you look so well".

My first drop attack was in London. I was sitting in a chair in hairdressing salon. In a split second I felt like I was falling off a cliff like I was rolling over and over. I had no idea what was going on and I was so scared. I apparently screamed, and next thing I know I was on the floor. Although this happened in a split second, it felt a lot longer. It was the most frightening experience of my life.

Life continued with too many attacks, too many dizzy days, too many nausea days, and too many inactive days. I had had enough. I wanted some of my old life back.

After reading and talking to other sufferers and giving a lot of thought to it, I had my first gentamicin injection in May 2017 followed by vestibular physiotherapy. Some weeks later I had a hearing aid fitted in my Meniere's ear. With all this in place, I started feeling human again.

I decreased the Serc and eventually stopped taking it. Life was great for many months and so I challenged myself to a seven-day hike through the Great Ocean Road National Park. It was fantastic.

After the walk we were relaxing at a beach town where I had another drop attack and symptoms of dizziness started coming back although the balance was fine. I had a third drop attack at an outdoor concert but I was not sure if that was because of the music or the crowds as I was one minute standing then I was on the ground surrounded by lots of people.

Five months later I had my second Gentamicin injection and the dizziness lasted for some time. However, both times I saw a Vestibular Physiotherapist afterwards and that put me back on track. Although I had ongoing dizzy days I have never had a spinning episodes and managed to get some normality back into my life.

What now?

I still get days where I am dizzy and I honestly believe that is stress related. Generally I am living a fairly normal life. I try to look forward, challenge myself and stay as fit and healthy as possible as that helps with my stress levels. Yes "stress" is unfortunately something I am still trying to manage.

I will continue with my no/low salt diet, low caffeine intake, drink a glass of red from time to time, keep fit and try to challenge myself no matter how big or small that challenge is.

I would also like to mention that I was a candidate for Gentamicin two years after diagnosis as my hearing loss went down quickly.

I often ask myself whether Gentamicin was a good idea? For me, yes it definitely was. I ask myself whether I regret it down the track? Maybe/Maybe not but whatever happens to this body of mine I am going to make the most of my life while I can.

STAY DIZZY FREE