

## **Dianne and Bilateral Meniere's**

It is hard to put timeframe on my MD because I had acute vestibulitis and I was also in a car accident. The accident resulted in a sore neck but not requiring treatment.

It started when I went in for surgery on a totally unrelated matter and when I came out of the anaesthetic I had an extremely painful neck. Over the next three days I experienced vertigo, vomiting, tinnitus, diarrhoea and poor balance. The vomiting became so bad I could not move my head. I noted hearing loss in my left ear. A month later I was referred to an ENT and after a series of tests I was diagnosed with Bilateral Meniere's disease.

### **Hearing Loss and Tinnitus**

I was diagnosed as bilateral almost immediately as all the symptoms were all on both sides.

There is some difference though e.g. the tinnitus is much worse on the left side but I have a mix of sounds. The left side I can identify up to four different sounds at times e.g. cicadas, ocean roar, a high-pitched screech. The right has only two sounds - cicadas and roar. At times the level is so high it is impossible to function. I call it 15 out of 10. It is to the level of jet engines. You cannot think or concentrate. Your only focus is to get rid of it. At these times, no matter what time it is, I take half a Temaze sleeper and go to bed. Usually after a deep sleep the noise level has lessened.

A hearing test showed I was profoundly deaf in the left ear and decreased fluctuating hearing in the right.

After hearing tests, I have had several aids including one with a cross transmitter. This allowed sound to be sent from deaf side to hearing side. The hearing aids have been of limited success. I have hearing loss on both sides. Profoundly deaf left ear with fluctuating hearing in right ear.

An audiologist suggested a cochlear implant for the left ear. I have given it some thought but am really concerned at the permanence of the device. I need to do more research on its success re MD

### **Balance**

My balance also is worst at times on one side. I find I usually stumble to the left but it affects both sides at its worse. I have had several falls from the poor balance resulting in broken bones on two occasions. I use a walking stick especially if my balance is poor, especially at night when visual clues are poor.

## Work

Due to the continuous vomiting and diarrhoea and tinnitus in both ears I had to give up fulltime work as a nurse. I cut back to part time and tried to find a path that would allow me to continue as a registered nurse and be flexible enough to give me the space I needed to manage MD. I went on part disability payment due to MD.

My employers allowed me to work the hours I wanted to but I knew this couldn't continue so I started to explore different avenues. I then became a tutor and module marker at a local TAFE college. Unfortunately, due to my inability to hear the students (in spite of hearing aids and their assistance) I stopped the teaching and concentrated on the marking and this ended in 2014.

## Management

- **Medication** - At the onset I was on Serc and a diuretic for about three years with little effect. However, I keep Serc and Prochlorperazine tabs for a severe attack. I don't take anything now
- **Vestibular rehabilitation** - unfortunately it caused more attacks with little noticeable improvement in balance.
- **Cognitive behavioural therapy** – this helps me cope with the tinnitus as well as the overall impact
- **Exercise Physiologist** - to improve core strength to assist with balance. I went into a severe attack as soon as I tried to balance.
- **Low salt** diet
- **Reduced caffeine** - no coffee but have two drinks a week with caffeine
- **No alcohol**

## Impact

The hardest part for me is the hearing loss. I miss hearing the conversation around me, especially my family. In particular I have two disabled grandchildren who have speech problems so it's important that I hear them.

I go out as much as possible. I will not allow MD to limit my social life. I go to noisy clubs in large groups even though I cannot hear what people are saying. The alternative is to sit at home! I choose to do what I want and suffer the consequences.

I can no longer dance, work or contribute to the community, as I don't know how I am going to feel. The stress of having to meet a deadline or commitment will bring on an attack. I have problems with large shopping centres, the lights, glossy floors, music playing and noise.

At times it all becomes too much especially the noise, falling over in front of people and the hearing loss.

## Looking forward

I want to stay on top of it I continue to do what I love:

- Going out in groups
- Art sessions each week
- Mahjong three times a week.
- I go to the beach and enjoy the tranquillity, especially alone as my MD does not affect anyone else's enjoyment.
- I like to walk but unfortunately due to other medical conditions cannot walk too far. In the summer I do Hydrotherapy and African drumming
- I use audio books at times (but not a lot as this may trigger the tinnitus)

I would love to be involved in the healthcare industry even as a volunteer but am reluctant to do so because of major attacks, vertigo, hearing and balance loss.

It is a daily challenge for all of us whether unilateral or bilateral. I deal with the symptoms as they happen and really try to give it as little of my day as possible. When it all becomes too much, I have used behaviour therapy with some success.

At the moment I am under the care of a very supportive GP, as I have not long moved to Sunshine Coast. However, I am in the process of finding an ENT specialist with MD knowledge.