

Paul Talintyre - Ménière's Story (June 2018)

Shortly after starting a new job on the railways in 2002 I noticed some hearing loss in my right ear followed by some vertigo attacks a few days later. I was referred to an ENT in Hornsby and following the usual MRI scan and so on, I was diagnosed with Ménière's Disease.

What happened next wasnot much at all and I learnt much later that it is quite common but my Ménière's disappeared for over 7 years. NO symptoms at all but I continued on a relatively low salt diet.

A few days out from Christmas 2009, I then had some hearing loss, again in my right ear, followed by a large vertigo attack on Christmas Day. This attack was far longer (around 5 hours) than any I had experienced all those years ago and thus began the first of many long and sometimes nauseous attacks. These attacks continued occasionally over the following 3 months and then it all disappeared again for 9 months. For this period I was prescribed Moduretic, as well as Stemetil for the nausea.

In December 2010 the attacks came back and never really left me from then on. I found that if I had not been too careful with my salt intake, it would usually involve in an attack. I monitored and recorded every attack to try to determine ways to lessen the severity and frequency. As a keen cyclist, I managed to ride regularly through this period and I consider that the exercise helped with my general wellbeing - physically and mentally. However, I soon learnt that if I overdid the exercise (and occasionally I did) an attack would usually follow.

This level of self-management continued until my birthday (57th) in July 2013. On this day I had my first drop attack, falling off a bed end to the floor whilst watching the Tour De France on TV late that night. I put this attack down to inappropriate food, and excessive noise after a party in a restaurant and tiredness related to shift work. The next day I had another one while crossing a road with my wife and made it to the ground only gently, fortunately she was hanging on to me. It was now time to be more serious and do something about it. My wife contacted Whirled Foundation in Victoria and they suggested Prof W Gibson could be a good professional to see. I ceased work and obtained an appointment with the Prof in late July. The Prof was the first ENT that I had seen since originally being diagnosed with Ménière's some 11 years earlier. I was prescribed Serc which I remained on for the next 4 years with different levels of dosage and also experimented with higher water consumption. The Prof suggested that I was obviously towards the burn out stage of my Ménière's Disease. How long this period was to be would be anyone's guess.

Due to job regulations I did not work for 7 months. However, I returned to work with the Prof's approval in February 2014 and remained on the job for nearly 2 years until December 2015 when my Ménière's became much worse. This second period off work was much longer and again I required the Prof's approval to enable me to return to work. This came in April 2017, once the drop attacks had ceased for a period of six months.

At the time of my drop attacks it was suggested I have Gentamicin injections. This would have reduced or eliminated these attacks but I chose to ride it out as my balance was still very good and I knew it would have compromised my cycling and old age balance. I had a total of 16 drop attacks from July 2013 to Sept 2016. I hit the ground on 5 occasions including coming off my bike, fortunately at very low speed and once whilst driving. I was very lucky not to break any bones as a result of these attacks but I certainly took some skin off.

Since returning to work the dizzy attacks I experienced were very rare and lasted only 20-30 seconds. They were very mild or hardly noticeable at all and have now disappeared completely. It has been nearly 7 months since the last of these dizzy spells and whilst I have next to no hearing in my right ear, I thankfully consider my Ménière's Disease has run its course.

What do I think helped me in the management of my disease? :-

In July 2012 I stopped having any alcohol.

In July 2013 I cut out caffeine where possible and would only drink decaf tea and coffee.

I tried to eliminate stress as much as possible.

I tried to get as much rest and sleep as I could. This is quite difficult as my job involves shift work and explained why, during the times off work, I was much better.

Fantastic love and support from my wife.

Where to now? :-

I plan to retire from the workforce late this year.

I now occasionally have a meal out that is higher in salt than home cooked meals and also a little alcohol. However, I know that reducing these luxuries will always be better for my long term health.

I now have hearing aids which help with tinnitus and the hearing loss.

I no longer take Serc.

I plan to ride my bike as much as possible.

Paul Talintyre