

## **Celene McNeil – Healthy Hearing & Balance Centre (May 2018)**

**Anne:** Celene McNeil is the Director of Healthy Hearing & Balance Care, Bondi Junction. Celene is a fully qualified audiologist holding a bachelor of applied sciences in speech and hearing obtained at PUCB Brazil, a Masters of Audiology and a PhD in Meniere's disease from Macquarie University in Australia. Celene has been working as an audiologist in Australia since 1989

### **How long have you run your Healthy Hearing practice?**

Healthy Hearing and Balance Care was opened in September 2003. We are celebrating 15 years this year.

### **Why was Meniere's the chosen topic for your PhD?**

Meniere's disease always intrigued me since my student years in Brazil. I immigrated to Australia in 89 and worked as an audiologist with Prof Bill Gibson at his Newtown private rooms, initially at the Medical Centre in Carillon Avenue with the late audiologist Dr Charles Pauka and then in Missenden Road.

Many of the patients who came for audiological assessment had Meniere's disease. As an audiologist, one of my biggest frustrations were the inability to help these patients to properly manage their hearing losses. Attempts to fit them with hearing aids with technology available in the early 90's had almost always failed.

The problem with the hearing loss in Meniere's disease is the variation that occurs in the hearing levels. The hearing is better some days and worse at other times. There is no pattern or any means to predict this fluctuation. You can fit a hearing aid in the clinic and it sounds great for a while but then the hearing changes and the hearing aid is no longer helpful and the amplified sounds may become too loud, too soft or distorted.

I remember back when the first multi-memory hearing aid became available and I thought they would be the answer for these patients. I knew that hearing fluctuated in Meniere's disease so I thought we could set different programs on the hearing aid to address this fluctuation. I was soon proved wrong as it is not possible to predict the pattern of hearing fluctuation based on clinical audiograms, as I subsequently found during my PhD studies.

In the early 2000's a new concept in hearing aid programming became commercially available. This system had been developed for audiologists to fit hearing aids in remote areas with no access to proper audiological equipment. The new system had dual functionality as it allowed a hearing test to be performed by connecting the hearing aid via a cable to a portable battery operated machine. It was like the hearing aid turning into headphones and the portable machine turning into an audiometer. This machine used the results of these hearing tests to automatically program the hearing aid for the given hearing loss.

I started using this system with some of my patients with Meniere's disease with excellent results. I fitted the hearing aids in the clinic for the hearing loss at the time, gave the patients the portable equipment and taught them how to test their own hearing and to program their own hearing aids

when their hearing suddenly changed. I also made sure they signed a disclaimer as this equipment was designed for professional use only!

The satisfaction of these patients with their ability to hear well again excited me to embark in a PhD study under the supervision of Prof Phillip Newall at Macquarie University.

As part of my PhD study I used this system to collect hearing test results of 90 patients with Meniere's disease performed at home by themselves, 3 times a day for a period of 8 weeks.

These results have been published in different peer reviewed journals showing that there is fluctuation in the hearing levels in all 3 stages of the disease; that this fluctuation is mostly unpredictable and not always correlated with changes in the other symptoms of tinnitus, ear fullness and vertigo attacks.

**Many have never heard of Meniere's disease. Briefly, what is Meniere's disease?**

Meniere's disease or Meniere's syndrome is a complex clinical entity which has been disrupting the lives of those affected and puzzling health professionals for centuries. It is a progressive disorder of the inner ear emerged by fluctuating symptoms of hearing loss, aural fullness (blocked ear), tinnitus (noise in the ear) and vertigo attacks. The symptoms are provoked by an imbalance of endolymph fluid in the inner ear but the cause of this imbalance is still debatable and seem to differ amongst individuals. The order of appearance of these symptoms is also variable amongst sufferers. The disorder usually, but not always, progresses to a permanent loss of vestibular and cochlear function in the affected ear. The episodes of vertigo attacks tend to subside as the vestibular loss becomes permanent. The hearing loss and tinnitus become more severe in degree as the disorder progresses and aural fullness tend to disappear when cochlear function becomes permanently impaired.

Initially patients look for help to stop the vertigo attacks as they are by far the most distressing of all symptoms. Once this symptom is under control they start noticing the effects of tinnitus and hearing loss in their quality of life.

**It has been said that hearing aids are of little or no help for those with MD. Why do you think that MD sufferers have this misconception?**

Unfortunately, to this date we still hear doctors advising that hearing aids won't work for Meniere's disease. There is still this misconception that they do not help. Even though more than 10 years ago my published research had shown that hearing aids can be very effective in Meniere's providing the stage of the disease and the level of hearing fluctuation has been properly diagnosed.

The protocol to fit a hearing aid for patients with a hearing loss due to Meniere's is very different than those used for hearing losses by other causes. The reason some people still do not receive adequate benefit from a hearing aid is because their hearing loss fluctuation has not been properly assessed and addressed.

At Healthy Hearing & Balance Care we have helped hundreds of patients with Meniere's disease to improve their hearing. More than 15 years have passed since my original success with a hearing aid system for Meniere's disease and technology has made incredible advances over this time. These

days almost any hearing aid of every manufacturer can be suitable to a patient with Meniere's providing the fitting follows the appropriate protocol.

There are also many apps available for patients to test their own hearing to assess fluctuation but this, of course, needs to be conducted under professional guidance.

Unfortunately evidence shows that it takes up to 17 years for new research to be accepted and applied into clinical practice. This may be why the misconception is still around. Many have not caught up with the research...

In my experience patients with Meniere's benefit from hearing aids and the results help to improve their hearing ability, reduce tinnitus perception, reduce stress and improve overall balance.

**At what stage of Meniere's is it recommended that an MD sufferer visit an audiologist?**

Whenever tinnitus, ear fullness and/or hearing loss is noticed it is worth seeing an audiologist for at least a baseline hearing assessment. To have a relationship with an audiologist is fundamental for the well-being of patients with Meniere's disease. The audiologist will help to monitor the symptoms and liaise with your ENT specialist or neurologist when vestibular symptoms become out of control.

**Sufferers have learnt that what works for one does not necessarily work for another. Any comments?**

The old say "everyone is an individual" is the best answer to this question. Even more so when dealing with Meniere's as the disorder has different stages and affects people differently. It is mostly impossible to predict a pattern of symptom fluctuation for one single individual never mind across several... Everyone has a unique experience and there is a lot of trial and error before one finds what really works for them

**Do hearing aids help with balance issues?**

The short answer is yes, especially when you have a hearing loss in only one ear. A hearing aid does not prevent vertigo attacks of course, but it improves overall sense of balance by providing acoustic awareness of the surrounding environment. On the other hand, a hearing aid which is not properly fitted may provoke a vertigo attack as it can stir up the audio-vestibular organs after many ears of sound deprivation.

**Is it true that you can live more comfortably with tinnitus if you wear a hearing aid?**

Absolutely! One of the reasons tinnitus is a major bother is because of the hearing loss. The worse the hearing the louder the tinnitus is perceived. The more silent the environment the louder the tinnitus is noticed. Hearing aids amplify surrounding sounds to their appropriate levels so that instead of hearing the tinnitus you hear the environmental sounds you are meant to hear.

### **Does the hearing fluctuation stop at some point for MD sufferers?**

As far as hearing fluctuation goes we can divide MD in 3 stages. Before my PhD we believed that at stage 3 there was no more fluctuation but my study clearly showed that hearing levels continue to change throughout the patient's life. In stage 1 the hearing drops and fluctuates at the low frequencies but returns to normal in between attacks. In stage 2 hearing fluctuates at the low and mid frequencies but never returns to normal levels. In stage 3 hearing still fluctuates all across the frequencies but at a much lesser degree so that some people may not even notice these changes.

### **How helpful are hearing aids for MD sufferers with issues like mumbling, background noise, loud environments, phones, TV and radio?**

Current hearing aid technology is designed to help in all these different situations. To perceive someone as mumbling, to have difficulties to follow a conversation in back ground noise, to have difficulties to hear on the phone, radio and TV is a sign of a hearing loss full stop. These difficulties are not exclusive of Meniere's disease. What is exclusive of MD is the hearing fluctuation. The hearing levels are unstable and the prescription of amplification needs to change accordingly for the hearing aid to be effective.

Hearing aids are very helpful to improve hearing in most situations although they do not restore normal hearing. As mentioned before, patients with Meniere's disease can benefit from hearing aids to improve their hearing ability providing their levels of fluctuation are properly addressed.

### **You have said that self-programmable hearing aids help those with Meniere's. Is this a problem for those who are not technologically minded?**

Yes, this may impose a problem but not impossible to overcome. Technology surrounds our lives and motivation "moves mountains". I had many patients who never used a computer before but were able to learn to test their own hearing and to program their own hearing aids under my guidance with the help of a friend or family member.

The problem arises when people wait for too long to seek help with their hearing. And this again is not exclusive of patients with Meniere's disease. It is much harder for an elderly brain to adapt to changes. Hearing aids promote significant changes in brain plasticity and the older the brain the less plastic it is. Unfortunately we still encounter patients in their late 80s who refused to wear hearing aids for many years and when things really become out of control due to the progression of the hearing loss they decide to try hearing aids. Waiting for too long may mean too late. Not only the brain may not be able cope with the new sounds but also poor manual dexterity may not allow learning to manipulate a new device.

As a rule, the earlier one attends to a problem the easier it is to resolve it.

### **There are so many hearing aids on the market. Taking cost into account, how do you decide which hearing aid is suitable?**

Most hearing aid manufacturers provide similar products with slight variations which are mostly gimmick. All hearing aids have a proprietor hardware and software that allows the clinician to

program and adjust the hearing aid to an individual hearing loss using a computer. The distinct factor is the difference in levels of technology within each manufacturer. The same manufacturer can make from a very basic to a premium model. The difference in cost is based on the levels of technology. The different levels may or may not provide an advantage to an end user.

An experienced independent audiologist is able to advise the best option for your individual needs after appropriate assessment.

**Have you worked with any bilateral MD sufferers?**

I have many patients with bilateral MD who successfully wears hearing aids in both ear.

For the great majority MD starts in one ear only. It is not clear how many patients develop MD in both ears. Conservatively, it is estimated that 30% may develop the disorder on the opposite ear.

I also work with a number of patients with bilateral MD who no longer benefit from a hearing aid and proceed with cochlear implantation. Cochlear implants by-passes the damage in the cochlea and provide hearing via electric stimulation of the hearing nerve. These patients, like the ones with hearing aids, need ongoing audiological support to ensure optimal hearing at all times.

**From an audiologist's point of view, what is your advice to sufferers?**

I advise patients with MD to learn to manage their hearing and tinnitus early in the process. The cluster of symptoms can be very distressing, especially the vertigo attacks. Sufferers, understandably tend to focus on the vertigo and neglect the other symptoms until much later when they are well established. My experience shows that those who seek audiological help earlier have a greater understanding and consequently better control of their symptoms which significant improvement in their quality of lives.

**Do you need a referral to make an appointment?**

A referral from a GP or from a medical specialist to Healthy Hearing & Balance Care will attract a Medicare rebate on audiology and vestibular tests.

**Are your fees covered by a medical fund?**

Depends on the fund. Most give a rebate towards hearing aids and some also partially cover audiology consultation.