



## **Review of Health Technology Assessment in Australia (HTA Review)**

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The objective of the HTA Review is to recommend options for improving process efficiency and reducing regulatory burden for Commonwealth HTA processes to facilitate medical innovation without compromising timely and affordable patient access to medical services and devices that:

- are demonstrated to be safe, effective and cost effective; and
- deliver improved health outcomes and value for money.

### **What is Meniere's Disease and its personal impact on Australians**

No cure. I found my heart sinking and all I wanted to do was surround myself with family and be very quiet. I don't have to remind anyone who is reading this of the sheer disbelief and amazement that any illness can have so many aggressive facets. I now had reasons for the falling over, getting lost in the dark, the vomiting, exhaustion, screaming ears and so on and so on.

Meniere's disease or Syndrome is an unseen, chronic, debilitating vestibular neurological condition. It is caused by a build up of excess of fluid in the inner ear, which affects the balance and hearing mechanisms of the ear. It can occur in one or both ears. It is not a well-known disease in the community, but for individuals experiencing attacks, it is life changing and disabling.

The ABS reports that Meniere's disease affects 1 in 606 Australians.<sup>1</sup>

There is no known cure.

Living with vertigo (dizziness, drop attacks), tinnitus (ringing in the ear) and fluctuating hearing loss (often not knowing the cause), can be physically and psychologically devastating. It often leads to depression, isolation, low self-esteem and

mandatory lifestyle changes. It can severely limit one's chances of employment and ability to participate fully in community, family and social life.

I don't think it all sunk in at first. In fact I know it didn't because when I got home with my scripts, brochures and test results I had no idea that life as I had known it had changed forever. On reflection there had been very subtle signs in the doctor's rooms... The change in the expression on the audiologist's face, as he explained the results.

An early correct diagnosis and access to treatment options can lessen the long-term effects of Meniere's. One such option is micro-pressure therapy.

### **This submission is about the opportunity for Australians to access the Meniett™**

#### **AAO-HNS Policy Statement about Micro-pressure Therapy for Meniere's**

The equilibrium Committee of the American Academy of Otolaryngology – Head and Neck Surgery (AAO-HNS) and the Board of Directors of the AAO-HNS issued the following policy statement in March 2008:

<sup>1</sup> Australian National Health Survey 2004-5 ABS

“We find there is convincing and well-controlled medical evidence to support the use of micro-pressure therapy (such as the Meniett device) in certain cases of Meniere’s disease. Micro-pressure therapy is best used as a second-level therapy when medical treatment has failed. The device represents a largely non-surgical therapy that should be available as one of the many treatments for Meniere’s disease.<sup>2</sup>

In 2005 the Medical Services Advisory Committee (MSAC) commissioned the National Horizon Scanning Unit to provide advice to the Health Policy Advisory Committee on Technology (Health PACT) on the state of play of the introduction and use of the Meniett™ alternating ear pressure device.<sup>3</sup>

The report noted there was... ‘No “gold standard” for the treatment for Meniere’s disease currently exists. A number of treatment alternatives are available that include non-invasive and conservative treatments such as dietary control, symptom control with antimetic agents, administration of vasodilators or medical ablation. If conservative treatment fails, surgical treatment may be considered and may include procedures that are either non-destructive or destructive to auditory function.

In summary, Meniett™ appears to benefit most, but not all patients in terms of reducing the number of vertigo episodes. It is difficult to ascertain if treatment with Meniett™ has a positive effect on the hearing levels of patients. It appears that treatment with Meniett™ would have to be continued in the long term for a sustained reduction in symptoms and as yet the longest follow-up study is 18 to 24 months. Long-term use of Meniett™ may be associated with adverse events associated with long-term implantation of tympanic tubes such as infection and the need for regular replacement of the tube.

It is noted that goal of this review is to recommend options for improving process efficiency and reduce the regulatory burden regarding medical innovation (such as medical devices and procedures) without compromising timely and affordable patient access to medical services.

The Meniett™ device was removed from Schedule 5 of the prosthesis list in February this year as it no longer met the criteria of a prosthesis.

The cost of the Meniett device is \$5,000.

Removal from the schedule meant that patients with private health insurance cover were no longer able to not access a rebate and that is a concern. Meniere’s is an invisible condition that comprises disability (hearing loss and vestibular loss with debilitating illness.

We strongly advocate that the Meniett must be available as a choice of a recognised treatment option for Meniere’s disease.

It is noted that one of the listed important features of a effective HTA systems are

- promoting patient access to cost effective health technologies that positively impact on health outcomes
- achieving value for money from investment in health technology in the context of limited health care resources
- keeping pace with international best practice

Meniere’s Australia applauds the Government for implementing this review across departments and looks forward to a streamlined system.

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<sup>2</sup> [www.entnet.org/Practice/micropressure.cfm](http://www.entnet.org/Practice/micropressure.cfm)

<sup>3</sup> [Meniett%20Horizon%20Scanning%20Report%20Final.pdf](#)

Att: Personal story of living with Meniere's and the benefit of the Meniett

## The Silent Terrorist

Married for 3 years and just started my own accountancy practice, I had my first child of four and the second one was on the way. Everything was just right. We were a happy family!

Early in April 1989, I was invited to a fun trip on Port Philip Bay on the tall ship the 'Alma Doeple'. I never got sick while at sea; I love fishing and I am out there as often as I can. However, at the end of this trip I was quite dizzy. I could not work out why I got so sick as the weather was fine and the sea was calm.

**'... dizziness... buzz noise in the right ear...surroundings spinning...severe vomiting '**

The next day I went for my normal walk on the beach and started getting light headed again. This time the dizziness was accompanied by a buzz noise in the right ear. This noise was quite annoying and never left me, except it varied in intensity.

Later in the month celebrating Easter dinner, I suddenly felt my surroundings spinning. I had to hold my chair and could not stand up. This was accompanied by severe vomiting which lasted at least half an hour.

**'...they couldn't pin point what caused the problem... '**

I was taken quickly to the Williamstown Hospital where I was checked but they couldn't pin point what caused the problem. I was sent home, but for the rest of the day I was sick. That was the day I experienced my first Meniere's attack although I did not know what it was at the time.

**'... confirmation of Ménière's...'**

A few weeks passed without any problems and I concluded that it might have been a virus. However to my surprise I experienced my next attack while at work. Once again, it started with dizziness followed by projectile vomiting. At this stage I knew I had some issues. Visits to my doctor did not reveal much except she felt it could be Meniere's disease. I requested a referral to see an **ENT specialist**.

I consider myself to be a very positive and ambitious person. However with these attacks, I felt hopeless and down. The fear of another attack was real and I wasn't sure how to cope.

The ENT Specialist did some of his own tests; he believed that I had all the symptoms of Meniere's but to make sure he sent me to the Alfred hospital for other tests. These revealed some degree of tinnitus, loss of hearing and...*confirmation of Meniere's*.

I was given the news that there were no cures and had to live with this silent terrorist. The disease progressed to burnt out level. This means severe dizziness without the vomiting. Over the next ten years I had to cope with the disease, continue to grow my practice, be a father of three girls and a boy and try to have a normal life.

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## **'Meniere's now ruled my life. It made me a prisoner'**

In 2003, my marriage of 18 years collapsed. Stress and worries made my Meniere's worse. In the last 3 years I was **afraid to go out**. I was afraid to drive as I had attacks while driving. I stopped going to the gym and as a consequence I put on a lot of weight.

I enjoyed ballroom dancing and even that had to stop. I was away sick more often and got behind with work. The whole world was collapsing. I did not care whether I lived or died. From being independent, I was now relying on other people for help. I was scared living on my own at home. Being on 8 stemzine tablets a day made me drowsy. I was at the lowest point. I felt my life at 47 was over. Meniere's now ruled my life. It made me a prisoner.

## **'A machine called the 'Meniett' was my hope'**

I got on the Internet on several occasions to learn more on the disease and in February 2006 I came across a glimmer of hope. A machine called the 'Meniett' ([www.meniett.com](http://www.meniett.com)) was my hope.

My morale was up and for the first I felt there was some light at the end of the tunnel. I discussed this matter with my ENT specialist who explained that this procedure does not necessarily help everyone but it might work for me. I suppose he did not want to put my hopes high. I had nothing to lose except constant dizziness. I was willing to try it. In June, I was admitted to a day procedure at the Freemason's hospital.

Well here is the good news! Since the procedure and the **use of the Meniett for ten minutes a day, I have not experienced another attack**. I am now doing something to reduce my weight, I've started to go out a bit more and plan to commence ballroom dancing again. In addition, I have not taken one stemzine tablet for the last six months.

I believe I have won the war against this silent terrorist. I am once again in control of my life. Since then I have expanded my business through a merger, taken my family on a cruise, am driving and go out without the fear of an unannounced attack.

**Don't ever give up.** Take calculated risks and don't stay in your comfort zone. It's only the end of the world if you want it to be. Give the 'Meniett' a go, it might change your life. It has changed mine. There is nothing to lose except the constant dizziness and the feeling of being sick.

**Joseph – Meniere's Support Group Vic member**

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