

One day in December 2000 I awoke to violent vertigo, vomiting and an unusual pain in my back which had been present for a few days. Thankfully the GP made a house visit, gave me a Stemetil injection and when I asked her to check my back she told me I had shingles. After a few more attacks of vertigo and vomiting spread over the next year I was diagnosed with Meniere's Disease based on my symptoms and an Ecog test. I was in my forties. A low salt diet was recommended and Serc and diuretic were prescribed.

For the first 8 years when I had these attacks I suffered severe vertigo, nausea (the slightest movement would make me retch or vomit), urgent bowel movement at the onset of the attack, full ear (left only affected), low tone hearing loss and tinnitus (initially spasmodic but non-stop from 2004 to present, at times both a high pitched sound and pulsating tinnitus in unison, at other times just the continuous high pitched sound). A cluster of Meniere's attacks in 2009 brought on two additional sensations, that of chronic imbalance and hyperacusis.

Standing and talking to someone became difficult and standing at the bus stop waiting to go to work was not easy with me shuffling around to maintain an upright position. When I spoke to the ENT about the imbalance he told me that the balance function in my ear had been affected due to the Meniere's, to think of both ears as jet engines with one engine not functioning properly, hence the imbalance.

Since 2009 I find it hard to recall a day during which I have not had this sensation of imbalance which at times makes me feel as though a vertigo attack may be imminent. I know I am not functioning in a normal way. I am conscious of my movements, such as turning, bending or getting up and going down, for fear of doing a "wrong" movement and also walking too quickly which may set the vertigo off. To date luckily I have not had a drop attack.

I still get Meniere's attacks and the vertigo (full on, then subsiding and alternating between both) can last for 24 hours and the nausea for a further 24 hours. "Recovery" in the sense of being able to do things like house cleaning and shopping can take up to a week after the attack.

The Dexamethasone (steroid injection) into the affected ear has been tried on three occasions with vertigo on the evening after two of the occasions. Gentamicin has been recommended but I do not want to lose more balance in the affected ear or lest the other ear down the track gets the Meniere's as well.

I use the Meniett device, take Cinnarizine (Stugeron) and try to follow a low salt diet to try to ward off attacks. I have also consulted a balance physiotherapist who has given me exercises to do. I was told these would not prevent a Meniere's attack from happening but would assist in quicker balance recovery after an attack.

I mentioned above that at the same time as I had a Meniere's attack in December 2000 I also had shingles. Co-occurrence or some correlation no one can say for sure. An eminent physician in the Meniere's field has talked of Meniere's patients perhaps getting the shingles vaccine. I am considering this. Something in my body is causing the fluid to build up and whether it is possibly the zoster virus, which causes shingles, being stimulated or becoming active who knows.

My hope is that researchers will soon come up with some definitive answers for why the fluid builds up in the inner ear and to find a “cure” for this wretched disease. Perhaps I am past the stage of benefiting from a “cure” but hopefully for the newly diagnosed one will become available soon before their Meniere’s progresses to the stage I am at.

I feel any relief from my chronic imbalance may only come from a balance device or implant to restore the equilibrium of both ears. I am therefore hoping that budding inventors, innovators, scientists, researchers etc. will take up the initiative and fast track a device in order to reduce or eliminate the chronic imbalance.

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