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Life with Meniere's Disease

Before you judge me on one of my good days, you need to understand what one of my bad days is like.

Tinnitus - imagine having a headache caused by a fire alarm ringing or a bee buzzing in your ear continually for a long period of time. You can't hear anything but that fire alarm or bee - It drowns everything else out.

Vertigo - Now imagine yourself as really drunk or with the flu at the same time as the fire alarm is going off. Now imagine that with these two things, you'd be dumb enough to get on one of the super roller coasters that does loop-de-loops or the amusement park rides that spin in two different directions at the same time. I'm not that dumb, but unfortunately I have no choice in feeling these sensations.

During one of these vertigo attacks that can last from several minutes to several hours if not days. I can't keep food or water down, I can't walk, and in order to get out of bed to go to the bathroom, I have to crawl like a baby on my hands and knees. The movement makes me so ill, if I'm able to crawl back to bed, I'm covered in sweat from exhaustion. Otherwise, I keep a pillow and a blanket at the bottom of a linen closet in the bathroom so that I can pass out lying across the bathroom floor. I end up sleeping for days after one of these attacks, only getting out of bed to go to the bathroom or to get something to drink, if I think I can keep it down. I have to call my family to see what day it is when I wake up. That is, if I can hear.

You see, this disease while playing havoc with your balance and equilibrium, also reeks havoc with your hearing. It wouldn't be so bad if the hearing loss was constant and predictable. But no, one day I can hear conversation fairly OK, and the next I can be virtually deaf, then the next day I can hear again. The hearing loss can fluctuate, but is usually progressive, and many with the disease end up severely hard-of-hearing or deaf.

Even on a daily basis, your mind is so confused by the signals its getting from your ears that your balance sucks. You run into things constantly because you can't balance well enough to avoid walking into things, or your mind is telling you the object is a couple of inches from where it really is. I don't know whether to laugh or cry when someone teases me about being such a klutz. I could make the Keystone Cops look graceful.

I also have days that my coordination just doesn't seem to be together. I'm carrying something, and all of the sudden I drop it because my brain seems confused as to whether my hand is really attached to my body. I sometimes miss a step and fall because of the feeling that my legs are not quite part of me and I have to focus on them to realize they are there. Apparently this happens because the part of your brain that recognizes parts of your body as belonging to you is the parietal brain lobe and it sits right above your ear, so if the nerves around your ear are inflamed, it can press on this part of the brain, or send the wrong signals to it (I'm not quite sure

which), and you can lose coordination.

Ironically, the few high frequencies I don't seem to have a hearing loss in can sound extremely loud, unbearably so. When a baby cries, an alarm goes off, or a microphone gives off feedback, I'd be willing to climb up a wall to get away if I thought I could make it. This symptom is called recruitment.

The disease also plays tricks on your vision. For some strange reason, the nerve that goes from your inner ear to your brain also controls some of your eye movement. Your eyes can twitch or bounce constantly, making focusing on objects, much less print, extremely difficult at times. Your eyes tend not to be able to "track" movement at the same speed, giving you double vision, and a bad headache.

You can get confused easily and your memory and concentration aren't reliable. It's what some people with the disease refer to as "brain fog". Many of them originally were afraid that they may have a brain tumor or Alzheimer's because it can sometimes get so bad. Finally they find either a doctor whose very knowledgeable regarding the symptoms, or they happen to ask someone else with the disease, and find that this too is a symptom of this blasted disease.

Now try to imagine living with this disease never knowing when one of these periods of tinnitus, vertigo, hearing loss, double vision, lack of coordination, recruitment, disequilibrium, or "brain fog" is going to hit, or how bad it will be. At least with being drunk or riding an amusement park ride, you know what's causing it, and you can make the choice not to do it again. With this disease, there's very little warning if any for these attacks, you don't know what's causing it, and there's no cure - only devices, surgeries, and some medications that can somewhat help alleviate the symptoms. And some of the surgeries are so radical, you think they came from a horror movie about a mad doctor. My ENT surgeon won't even perform any more surgery on my left side, since I have the disease in both ears. He's concerned about what would happen if my right side became worse than what my left side is now.

Understandably, anxiety and depression seem to go hand-in-hand with Meniere's for many sufferers. We often ask how much worse can this disease get? For some strange reason, doctors aren't very willing to give out worst case scenarios.

Now decide if you think I'd be able to do the same things you do on as punctual and regular of a schedule. For me, there's no way. I'm being up front about my limitations. I try the best I can at living up to my full potential. Could if you were in my shoes? They think now that Van Gogh suffered from this disease, and he cut off his own ear trying to escape it.

Yet on my not-so-bad days I may look like a totally healthy, able-bodied person. You ask me "why can't you bend down - pick it up - lift it - drive - get a job - walk without a cane" Its because I know these things can either bring on an attack - I couldn't do them on a regular schedule because of the symptoms - or if I did do them, I could put myself and others in jeopardy if I should have an attack. You have to realize that

with my friendship, love, dedication, and loyalty comes the fact that I can't decide when I'm going to have a bad day, and the more stress I'm under, the more likely I will have a bad day.

So, please don't judge me unless you've been in my shoes."