



Managing Ménière's Disease

Laboratory of One

Understanding How Ménière's Disease Affects 'You'

By

Mark McGee

A friend of mine likes to say that everybody is “a laboratory of one.” I agree. We are all ‘unique’ individuals. Yes, there are some similarities and commonalities, but we’re still unique. That includes our experience with Ménière's Disease.

Technically speaking, you need a formal “diagnosis” to say that you have Ménière's Disease (MD). Many people have vestibular issues without having a diagnosis of MD. I developed tinnitus in one ear, then the other ear, and visited doctors to see what they thought. I even had slight dizziness when climbing a ladder, standing on a chair, stepping down from a stage, etc. However, no doctor diagnosed me with MD. In fact, no doctor even mentioned the word to me.

I learned about Ménière's years later when my mother received her diagnosis. I didn't know it at the time, but I've since learned that her two brothers and five of my cousins also have or had MD. Ménière's is known to run in some families. I spent as much time with my mother as I could toward the end of her life and witnessed what Ménière's can do to some people as they age.

It wasn't until I experienced multiple bouts of spinning vertigo and nausea about a year-and-a-half after my mother's death that I began to think I might also have Ménière's. A friend recommended a great ENT and we began the process of going through medical tests to find out what was happening (e.g. hearing, vision, multiple MRIs of head and brain, balance testing, strength testing, posturography, echocardiogram, ENG, VNG, VEMP, etc). I received an official diagnosis of Ménière's Disease from an ENT, confirmed by an Audiologist and a Neurologist. I received a diagnosis of Cervicogenic Vertigo from several DPTs, confirmed by a DC with a speciality in Orthospinology Upper Cervical.

I've talked with other people whose experiences were similar to mine, but also those whose experiences differed. It's good to remember that each of us is a "laboratory of one."

I've spent years sharing with people on a variety of Ménière's forums and have seen the variety of ways people enter into the world of MD. Some had no warning before their first full vertigo attack that eventually led to a diagnosis of MD. Most said no one else in their family had MD. I've learned to learn from other people with MD, but not compare my experience with theirs. We are unique. Each one of our stories is special and should be heard and respected.

Vestibular Diseases

I'm a journalist, not a doctor or scientist. What I've done for the last several decades is research subjects and interview experts for news stories, series, articles, books, eBooks, and documentaries. That's how I'm approaching this series about Ménière's Disease.

If you are a veteran of MD, some of this will be familiar. If you are new to MD (bless your heart), you may find some of this information helpful. One of the scary things about 'early' Ménière's Disease is not knowing what's happening to you. It's also scary for family members, friends, and co-workers who wonder why you're so sick at times, and whether you have something that will potentially kill you.

The good news is that Ménière's itself is not a fatal disease — but —

Ménière's disease isn't a life-threatening illness, but it can affect quality of life. People who have this disorder may struggle with symptoms that happen without warning, come back time and again, and may disrupt their daily lives. [Cleveland Clinic](#)

Ménière's Disease, also known as “idiopathic (or primary) endolymphatic hydrops,” is one of many vestibular diseases. **Vestibular** simply has to do with problems of the inner ear, especially as it affects balance — “of, relating to, or functioning as a vestibule; of, relating to, or affecting the perception of body position and movement” (Merriam-Webster). Doctors who specialize in vestibular illnesses include ENT's and Neurologists.

Vestibular dysfunction is a disturbance in the body's balance system due to an insult to the vestibular system of the inner ear, the central nervous system

processing centers, or both. National Library of Medicine

Because I'm a journalist, I ask lots of questions in what we call the "gathering" phase of developing a story. That includes observation as well. The second phase of journalism is the "confirming" phase. That's when a journalist goes through the process of confirming the information he/she gathered. The third phase of journalism is the "reporting" phase. That's what I'm doing in this series of articles. I've spent years gathering and confirming. Now the time has come to report about what I found. What the reader, viewer, or listener does with the information is up to them.

I learned that the percentage of patients who visit ENT's and Neurologists can be as low as two percent (2%). I thought it would be much higher, so I asked what other vestibular disorders doctors deal with in their practices. I discovered that the list of vestibular disorders is larger than I had imagined. Here's a list of some of them in alphabetical order —

- Acoustic Neuroma
- Acute unilateral vestibulopathy/vestibular neuritis
- Atypical Meniere's Disease
- Autoimmune Inner Ear Disease
- Benign Paroxysmal Positional Vertigo (BPPV)
- Bilateral Vestibular Hypofunction
- Bilateral Vestibulopathy,
- CANVAS Syndrome
- Cervicogenic Dizziness
- Cholesteatoma
- Cogan Syndrome
- Concussion & Traumatic Brain Injury (TBI)
- Enlarged Vestibular Aqueduct Syndrome (EVAS)
- General Vestibulopathy
- Labyrinthine Infarction
- Labyrinthitis
- Mal de Débarquement
- Ménière's Disease
- Neurotoxicity
- Otosclerosis
- Ototoxicity

- Pediatric Vestibular Disorders
- Perilymph Fistula
- Peripheral Vertigo
- Persistent Postural Perceptual Dizziness (PPPD)
- Pets & Vestibular Dysfunction
- Presbyvestibulopathy (PVP)
- Secondary Endolymphatic Hydrops (SEH)
- Superior Semicircular Canal Dehiscence
- Third Mobile Window Syndromes
- Tinnitus
- Vestibular Migraine
- Vestibular Neuritis
- Vestibular Paroxysmia
- Vestibular Toxicity (Vestibulotoxic)
- Vertebrobasilar Insufficiency

I will admit that learning about all of the different types of vestibular disorders that people deal with gave me a new appreciation for the folks sitting in the same waiting room as me — especially when I learned that my illness, Ménière's, was an extremely minor reason for people waiting to see doctors. 98% (or less) of the people in ENT and Neurologists' waiting rooms across the country were there for reasons other than Ménière's.

Ménière's Diagnosis

According to the Mayo Clinic, an official Meniere's disease diagnosis needs to include the following —

- Two or more vertigo attacks, each lasting 20 minutes to 12 hours, or up to 24 hours.
- Hearing loss proved by a hearing test.
- Tinnitus or a feeling of fullness or pressure in the ear.

The National Library of Medicine has similar wording —

Patients with a definite Meniere disease, according to the Barany Society, have:

1. Two or more spontaneous episodes of vertigo with each lasting 20 minutes to 12 hours
2. Audiometrically documented low- to medium-frequency sensorineural hearing loss in one ear, defining and locating to the affected ear on in at least one instance prior, during, or after one of the episodes of vertigo

3. Fluctuating aural symptoms (fullness, hearing, tinnitus) located in the affected ear
4. Not better accounted for by any other vestibular diagnosis

Ménière's Theories

What causes Meniere's? I found that while there are lots of theories, nobody in the medical community knows for sure. What? How could a disease be named and known about for 160 years and no one in the vast medical community know for sure what causes it? Excellent question.

Medical experts can describe Ménière's disease with some precision, but when it comes to a cause?

Many theories exist about what happens to cause Ménière's disease, but no definite answers are available. [National Institute on Deafness and Other Communication Disorders](#)

The exact cause of Ménière's disease is unknown, but it's thought to be caused by a problem with pressure deep inside the ear. [NHS Inform](#)

The cause of Meniere's disease isn't known, but scientists believe it's caused by changes in the fluid in tubes of the inner ear. Other suggested causes

include autoimmune disease, allergies, and genetics.
HealthLine

The exact cause of the disease is unknown. Better Health Australia

The exact cause of Ménière disease is unknown. It may occur when the pressure of the fluid in part of the inner ear gets too high. Penn Medicine

Although the cause is unknown, Ménière's disease symptoms are due to increased volume of fluid in the inner ear. ENT Health

The cause of Meniere's disease isn't known, but doctors think they understand how the symptoms of Meniere's happen. WebMD

I've also had that same information confirmed personally by several specialists.

As if not knowing a 'cause' was enough to hear, I heard and read this —

There's no cure for Ménière's disease, but your symptoms can be managed with treatment. [NHS UK](#)

Managing Ménière's

That's why I called this section of my Substack, "Managing Ménière's Disease." The cause is unknown and there is no cure. However, there is something we can do — learn how to manage the disease to the best of our ability and cope with it. That includes learning your "triggers" and best "treatments."

I'll get into that more in the next Managing Ménière's Disease newsletter.

"... rejoicing in hope, patient in tribulation, continuing steadfastly in prayer." Romans 12:12

Here's to hope!