

Triggers and Treatments Part One

By

Mark McGee

In the mid-1880s, the physician Prosper Meniere was studying hearing loss. Through his research, he found people with an odd blend of symptoms occurring alongside hearing difficulties. The constellation of symptoms is what physicians identify as Meniere's Disease.

It's a condition affecting about .2 percent of the population. If you're wondering why you never heard of Meniere's, it's because the disorder is not only rare, but it's an invisible, chronic condition. Menieres.org

Meniere's is called a disease, but it really is a cluster of symptoms for which the underlying cause is unknown and for which there currently is no cure. American-Hearing.org

I've written before about how the medical community doesn't know what causes Ménière's disease. It can rob people of their self-control, their dignity, their careers, and eventually their hearing — and there's currently no cure. So, where do

we go from here? Are those suffering from the disease doomed to a life that's barely worth living?

Simple answer: NO. Life is worth living — even life with Ménière's Disease.

Living With Ménière's

The purpose of this Section of my Substack is to offer information and hope for people who suffer from Ménière's. I think the more we know about the disease, the better we can manage it. Some of the medical 'theories' about Ménière's include viral infections, genetics (family relationships), allergies, migraines, autoimmune reactions, changes in the weather, changes in atmospheric pressure, etc. — but still no "underlying cause."

According to the <u>Vestibular Disorders Association</u>, acute Ménière's attacks often include —

- spontaneous, violent vertigo
- fluctuating hearing loss
- ear fullness (aural fullness) and/or tinnitus

In addition to the above main symptoms, attacks can also include:

- anxiety, fear
- diarrhea

- blurry vision or eye jerking
- nausea and vomiting
- cold sweat, palpitations or rapid pulse
- trembling

Following the attack, a period of extreme fatigue or exhaustion often occurs, prompting the need for hours of sleep.

The periods between attacks are symptom free for some people and symptomatic for others. Many symptoms have been reported after and between attacks:

- anger, anxiety, fear, worry
- appetite change
- clumsiness
- concentration difficulty, distractibility, tendency to grope for words
- diarrhea
- fatigue, malaise, sleepiness

- headache, heavy head sensation
- lightheadedness (faintness)
- loss of self-confidence and self-reliance
- nausea, queasiness, motion sickness
- neck ache or stiff neck
- palpitations or rapid pulse, cold sweat
- sound distortion and sensitivity
- unsteadiness (sudden falls, staggering or stumbling, difficulty turning or walking in poorly lit areas, tendency to look down or to grope for stable handholds)
- vision difficulties (problems with blurring, bouncing, depth perception, glare intensification, focusing, watching movement; difficulty looking through lenses such as binoculars or cameras)

vomiting

People who have this disorder may struggle with symptoms that happen without warning, come back time and again, and may disrupt their daily lives. <u>Cleveland</u>
<u>Clinic</u>

Attacks can last from 20 minutes to 24 hours. They can occur with the frequency of many attacks each week; or they can be separated by weeks, months, and even years. The unpredictable nature of this disease makes managing it challenging. It also complicates the ability of scientists and physicians to study it. <u>Vestibular.org</u>

It can be exceptionally crippling for those who suffer from it. The symptoms of this condition are quite debilitating, particularly vertigo. It can impact the quality of your life negatively. Moreover, it can cause you to miss out on various important family, social, and work events. Mountain State Wellness

A Little Understanding Goes a Long Way

I've experienced most of the 'symptoms' listed above at some point in my Ménière's 'journey.' That's why some people call Ménière's one of the worst chronic diseases a person can experience. For people who don't suffer from Ménière's Disease, it's often difficult to explain the symptoms. It's like being on the worst spinning fair ride you can imagine, then getting off the ride and trying to walk without stumbling or falling as you search for a place to sit or lie down. I've also used the example of being on a boat in the middle of the ocean during a bad storm while trying to walk from stem to stern without losing your balance (or your lunch).

I also found a couple of graphics that have been helpful in sharing what it's like to have Ménière's —

I HAVE MENIERE'S DISEASE PLEASE DON'T BE DISAPPOINTED IF I

Often cancel our plans at the last moment

Am often too fatigued to participate in family functions, or I leave early

No longer talk on the phone

Seems like I am not listening because in fact I may not hear you

Lay on the couch all day – It's not laziness it's dizziness

Seems like I'm a different person

I would love to be my old self. The happy me the adventurous me. Each day I pray this illness goes away and I can retrieve my old self. Until then please understand.

Meniere's Awareness Project

Know the facts! on living with

Ménière's Disease

We give up careers we pushed so hard to get.

We fight everyday in a body that has no remorse.

We fight constant judgement that is not deserved.

We have limitations that control what we do.

We are constantly pushing ourselves harder everyday more than you realise.

We strive not to let family and friends down.

We are so tired beyond words.

We are sick of being sick.

We often find ourselves lost, alone and in isolation.

We get no support whatsoever, only the words that say

"GO LIVE WITH IT!"

Depression, Anxiety, Insomnia, Headaches, Nausea, Vertigo, Dizziness, Pain, Vomiting, Hearing Ioss, Tinnitus, Fatique, Balance problems, Aural Fullness.

"Ménière's Disease is a debilitating, chronic illness"

"All we need is your support, love and understanding?"

"Together We Can Make A Difference"



Having people in your life who support you through Ménière's is a great blessing. If you have that support, thank the Lord for it. It is truly a gift.

Triggers for Ménière's Attacks

While the medical community doesn't know the cause of Ménière's attacks, there does seem to be agreement about some of the 'triggers' of the symptoms.

I came up with an easy way for me to remember my 'triggers' and explain them to doctors and others who ask about my experience with Ménière's. I call it my 'MESS' —

1. Motion (turning head or body too quickly, turning from one side to the other in bed at night, standing up too quickly, sitting down too quickly, leaning over to pick up something, climbing up or down on a step stool or ladder, driving or riding in a car and having to stop suddenly, etc .. I asked my ENT and other specialists why motion affected me this way questions and they explained how the brain receives positional information from the ears and eyes and how Ménière's gives the brain conflicting information about my position, causing dizziness and other imbalance .. another problem is how the endolymph moves when the head moves .. the OHSU Brain Instituteexplained it this way — When the head

moves, the endolymph also moves, which causes nerve receptors in the membranous labyrinth to signal the brain about the body's motion. Endolymph buildup in the labyrinth can interfere with the normal balance and hearing signals between the inner ear and the brain. resulting in Ménière's disease. - Doctors also told me my brain was working overtime to keep me from losing balance or falling, even though all I had done was bend forward to pick up something, or lean to the side during exercise .. too much bending forward (usually 30 seconds or longer) would lead to an attack and/or fatigue .. I also found that going up escalators at the mall brought on extreme dizziness, another type of movement my brain didn't like .. I found I can use elevators as long as I stand in a corner with my back touching the wall .. it works okay unless the elevator is too fast or starts or stops too fast .. I was still able to teach martial arts classes during the first few years after receiving a Ménière's diagnosis, but it eventually came to the time when I was no longer able to move in ways that had once been very easy for me to do .. even my practice of T'ai

Chi, which is very slow and gentle, was eventually hindered to the point I can't do that any longer because of the turning involved, even though it's very slow .. the long walks my wife and I had enjoyed for years were curtailed when the motion of walking caused dizziness and fatigue .. I now walk with a cane and can walk for a few minutes at a time .. I can also stand for a couple of minutes as long as I lean on a cane, otherwise I struggle to keep my balance .. we even had to stop long-distant travel, which supports what my doctors told me might happen .. Ménière's is progressive .. things have gotten worse year after year as the disease moves through a variety of 'phases' .. I did have one doctor tell me that my Ménière's might 'burn out' after 10-15 years, so we'll see if that happens .. he said my hearing and balance would probably be affected negatively, but at least the vertigo attacks might not be as bad, allowing for travel and other similar activities to resume .. I'll address Ménière's 'burnout' in a future article)

- 2. Exertion (physical exertion lifting heavy objects, pushing or pulling something too hard or for too long, walking too far, working too long mental exertion working too long on a research/writing project, or talking too long to people in person or on a phone call)
- 3. Salt (not all Ménière's patients l've spoken to are sensitive to sodium, but many are .. doctors recommend we stay within a maximum range of 1,000 mg to 1,500 mg a day .. and not too much salt at any one time .. they recommended that we spread out the salt use across the day .. I had no idea how much salt is in food until I began looking at food labels .. look for products that have less than 100-150 mg of salt per serving .. if you REALLY want to eat something that has more salt than you know you should have, cut the serving in half .. you still get the taste, but might not have an acute reaction .. my wife and family are so kind to understand my situation and prepare 'special' no or low-sodium dishes for me .. I love that they add pepper, garlic, herbs, spices, and lemon to foods instead of salt .. tastes good but without the

dreaded 'attack' ... eating restaurant food is challenging because chefs use a lot of salt to make food taste better .. I rarely go out to eat anymore because even many 'low-sodium' dishes still have too much salt in them .. I was surprised to learn that just a pinch of salt is equal to 600 mg of sodium .. if I find myself in a situation where 'salted' food is all that's available at a restaurant or someone's home, I try to eat some food higher in potassium since it helps push salt out of my body .. or I drink a glass of water and eat a few bites of food while visiting with family or friends .. some of my favorite words in the English language are 'sodium-free' and 'no salt added .. I've learned to 'love bland')

4. Sugar (eating foods with too much sugar in them can lead to attacks .. I either avoid those foods or eat small portions .. the American Heart Association recommends that men should not consume more 36 grams of sugar per day, and women should limit themselves to no more than 25 grams per day .. however, most Ménière's organizations recommend much lower amounts of sugar

in your diet — A low-sugar diet can reduce dizziness. Meals or snacks with a high sugar content can cause fluctuations in the volume of body fluids, which may increase vestibular symptoms ... Tips for lowering overall sugar consumption include cutting the amount of sugar in recipes in half, substituting fresh fruit for sweetened baked goods, and possibly the use of sugar substitutes. Sprinkling a few currants or berries can help to sweeten up dish. Vestibular.org).

5. Stress (emotional stress, mental stress) — Stress and anxiety can be significant triggers for Meniere's disease sufferers. Understanding the relationship between stress, anxiety and Meniere's disease is crucial for managing symptoms and finding relief. Meniere's Disease Help — Being exposed to emotional stress increases the risk of getting an attack of Menière's disease during the next hour, and the hazard period is possibly extended up to 3 hours. PubMed .. there are things you can do to lower your stress levels (emotional and mental) that may help in the future .. I'll address some of those in the

Treatment sections in future articles)

6. Sounds (This is 'external' sound, not the 'internal' sound of tinnitus that most Meniere's sufferers experience ... some people describe their tinnitus as a 'ringing,' 'roaring,' 'whooshing,' 'buzzing,' 'humming,' 'hiss ing,' or even 'clicking' .. However, tinnitus, which affects about 15% to 20% of the overall population in our country, does not usually 'cause' a vertigo attack for Ménière's sufferers .. it's a 'sensitivity' to certain external sounds that can bring on an attack .. some of the medical terminology for this is 'acute acoustic trauma-induced Meniere's syndrome,' 'noise-induced vestibular dysfunction, 'hyperacusis, 'misophonia, 'and 'phonophobia' — Excessively loud noise can also induce perilymph fistulae and cause Meniere's disease to worsen. Dizziness-and-balance.com — I learned early on in my Ménière's experience that certain loud sounds, usually of particular pitches (high or low), were very uncomfortable and could bring on a vertigo attack if I didn't get away from the sound guickly .. it could be a

vacuum cleaner, a blender in the kitchen, ice falling from the fridge into a glass or bowl, a metal object falling on the floor, a leaf blower, a lawn mower, bush or tree trimmer, loud truck engines, sirens, etc .. I found that even the sounds in a restaurant or at a basketball game were often too much to take .. with granddaughters who play basketball for their school, I needed some help to be able to attend their games .. fortunately, their mother gave me special ear plugs (Ear Peace) as a present ... they are the kind of ear plugs where you can change how much 'sound' gets through to your ear .. I set the plugs for both ears to maximum and that has helped tremendously .. that falls more in the 'treatment' category, so I'll look at that in more depth in a later article)

7. Subluxation (several doctors diagnosed me with Cervicogenic Vertigo, also known Cervicogenic Dizziness, in addition to Ménière's .. I found that upper cervical chiropractic helps address that problem .. more on that when we get to the **Treatment** section)

- 8. Sleep (not getting enough sleep .. I sometimes can't sleep because of the dizziness, which makes symptoms worse .. better sleep, better day, is what I say .. I'll share some treatment ideas for that problem in future articles as well)
- 9. Sight (lights that are too bright, fluorescent lights in stores, strobe lights, flashing lights, viewing spinning or falling objects in person or on video, etc .. I close my eyes or look away from the light or sight and it usually helps .. if I'm in a store with fluorescent lights, I get in and out as quickly as I can)
- 10. Storms (many people who suffer from Ménière's say that approaching rain storms can cause minor or even severe attacks before the storm arrives .. that's been my experience for the past few years .. it usually begins with aural fullness in one or both ears, the tinnitus gets louder, and internal spinning begins .. I know it's time to take some 'rescue' medicine and lie down since it usually gets worse as the storms move through .. once the storms

leave the area, symptoms improve within 24-48 hours, depending on the size of the storm system)

I've added several other triggers to my personal list as I became aware of them. Those include caffeine, dehydration (not drinking enough water every day), seasonal allergies, trying to navigate in a dark room or space, and changes in atmospheric pressure (barometric pressure). I have an app on my phone that informs me when the barometric pressure drops more than two or three MB (millibars). I usually know before my app alerts me because pressure builds in my head similar to a migraine headache. I don't smoke or drink alcohol, but have read that those are also triggers for many Ménière's sufferers.

Everyone is an Individual

Not everyone with Ménière's will have the same experiences I've listed above. We're individuals — a laboratory of one as I've mentioned before. Also, having certain experiences with the disease now doesn't mean you'll always have those same experiences throughout your life. I've known people who get better, some who get worse, and some who seem to stay about the same for long periods of time. There are 'stages' or 'phases' to Ménière's that I'll address in the next article.

Whether you are new to Ménière's or have been riding that pony for a long time, you will discover what 'triggers' your attacks. Keep a list of them. It's a way to remember for yourself, as well as share with family and friends.

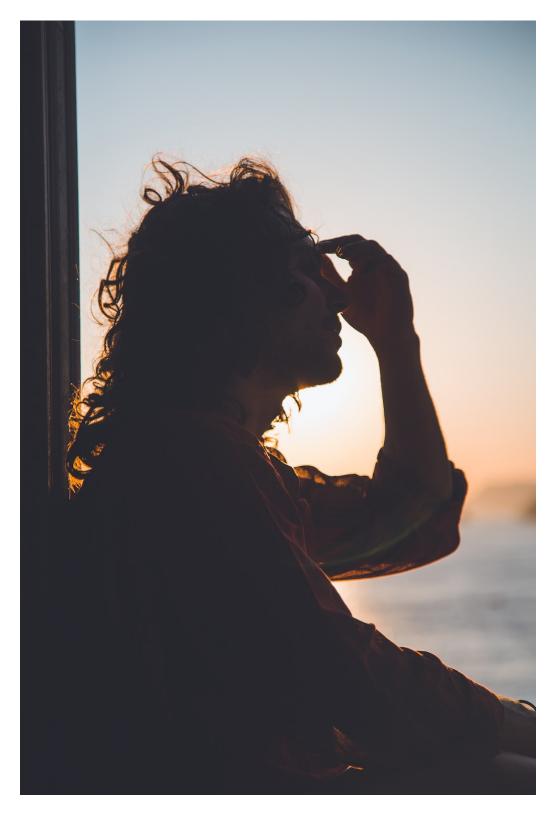


Photo by Matteo Vistocco on Unsplash

Managing Ménière's

I hope this post has been helpful to you. We're a very small group (less than 0.2% of the population), so we need to 'stick' together and help each other as much as we can. That's why I called this section of my Substack — **Managing Ménière's Disease**. The cause of the 'disease' is unknown, there is no cure, and it can get worse over time. However, there is something we can do — learn how to manage the disease. That includes learning our 'triggers' and best 'treatments.'

We'll look at the progression of Ménière's and some of the 'best treatments' 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!

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