



The Ménière's Years

Part 1

Coping and Hoping

By

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I've spent several months sharing information about Ménière's Disease, drawn from a wide variety of medical and health organizations. I hope you have found the research helpful. You can either read [individual articles at this site](#), or download free eBooks with all of the [research articles here](#).

Coping or Managing?

When I started the Managing Ménière's Disease 'section' last June, I almost titled it 'Coping with Ménière's.' I even built a graphic for it, but changed the name to 'Managing Ménière's Disease' at the last minute. Naming a 'Section' of a newsletter is challenging because you want the name to reflect your precise reason for doing it. Are we 'managing' Ménière's or 'coping' with Ménière's? I also thought about 'Living With Ménière's,' but that name was already being used for a Ménière's forum.

I've spent several years reading many Ménière's forums and believe the answer includes all of those ideas. We 'cope' the best we can as we 'live' with the disease, 'hoping' that we might find ways to 'manage' it.

It's a new year, so I want to look at the research for 'coping' with and 'managing' Ménière's in a slightly different way in 2024. We have a substantial amount of research available on the Internet even though Ménière's is listed as a 'rare disease' that has no known 'cure.' Diagnosed Ménière's is estimated to be only about [0.2 percent of the U.S. population](#). The world-wide number is estimated to be less than that — [0.012 percent](#) of the population.

The second article I wrote in the series last summer was titled — '[Laboratory of One: Understanding How Ménière's Disease Affects 'You'](#)'. Even though there are many 'commonalities' among people with the illness, each person is unique. Our experiences are often different for a variety of reasons. The combination of the rareness of Ménière's and the uniqueness of each person diagnosed with the illness makes any commentary challenging — and sometimes controversial.

Experts and Experience

Whether you've had Ménière's for two months, two years, twenty years or longer, you can learn a lot from the experts (e.g. doctors, scientists, pharmacists) and from your experience and the experience of others. That's one of the benefits of online Ménière's forums. People who are new to the illness can share their thoughts and concerns with people who have years of experience living with Ménière's.

There's an upside and a downside to online forums. I've been involved with forums for almost 30 years. I remember when we used to call them 'message boards,' 'bulletin boards,' 'groups,' and 'online communities.' Those names are still used, but 'forums' is what I see most often now. They cover just about every topic imaginable. The upside includes getting to know new people with their thoughts and opinions on the topic, along with finding help and support when needed. The downside includes the potential of being 'attacked' for your posts or comments, a lack of strong rules and good moderation to control the community, along with the possibility of getting bad information or advice. Read the rules

carefully to make sure you agree with them, and watch to make sure moderators are enforcing the rules. If you feel uncomfortable in a particular forum, you can leave and look for others that are more to your liking.

If you've found a couple of Ménière's 'forums' with a friendly atmosphere, good posts and comments, good rules, and good moderators to enforce those rules, that's great. You can learn a lot about Ménière's through those forums. Keep in mind that what works for some people may not work for you. I recommend noting the information someone shares about a treatment that worked for them, then doing two things: your own research and discuss it with your doctor.

That leads us to the 'experts' who help Ménière's patients. Many people who begin to have some of the symptoms of Ménière's talk with their family physician. That's a fine place to begin. You might talk with them about whether your symptoms could be Ménière's. They may do some testing of their own or refer you to an ENT or Neurologist. Getting a diagnosis for Ménière's is pretty specific, so following the advice of a specialist who understands the disease is helpful in the early

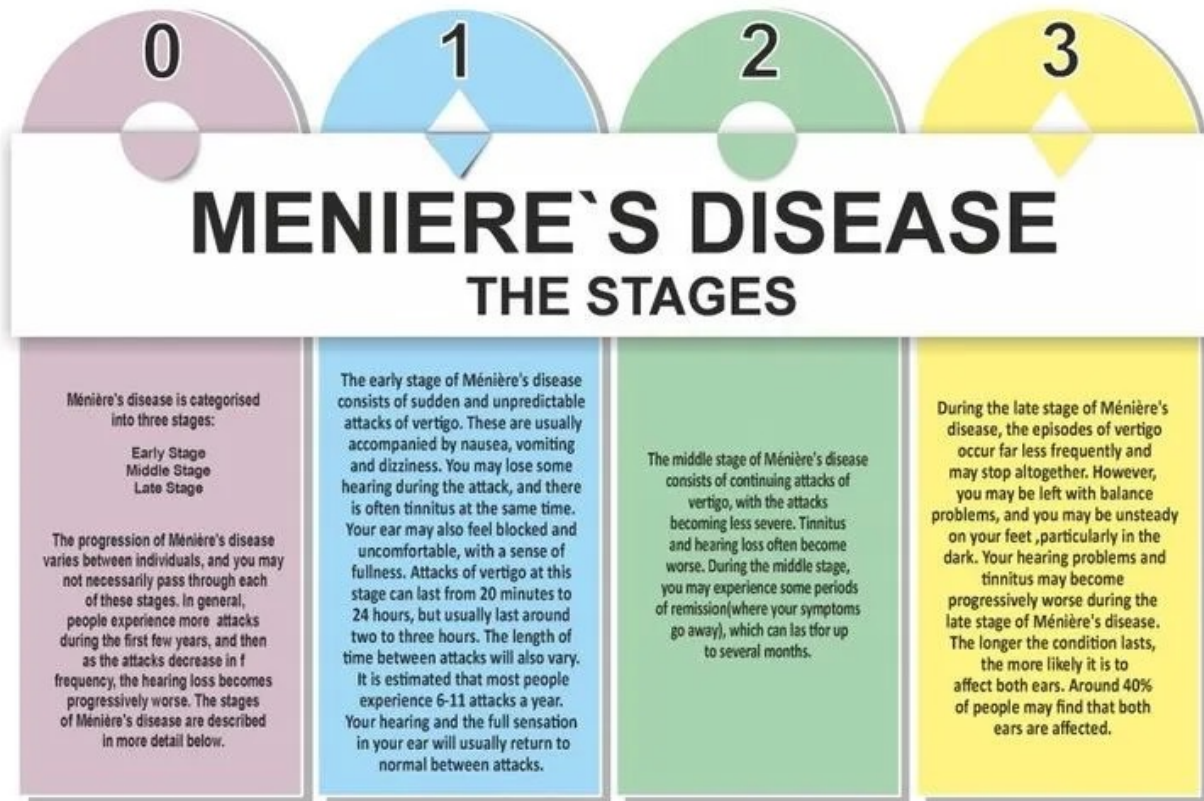
stages. It may help you be more successful in managing Ménière's through your life.

The Ménière's Years

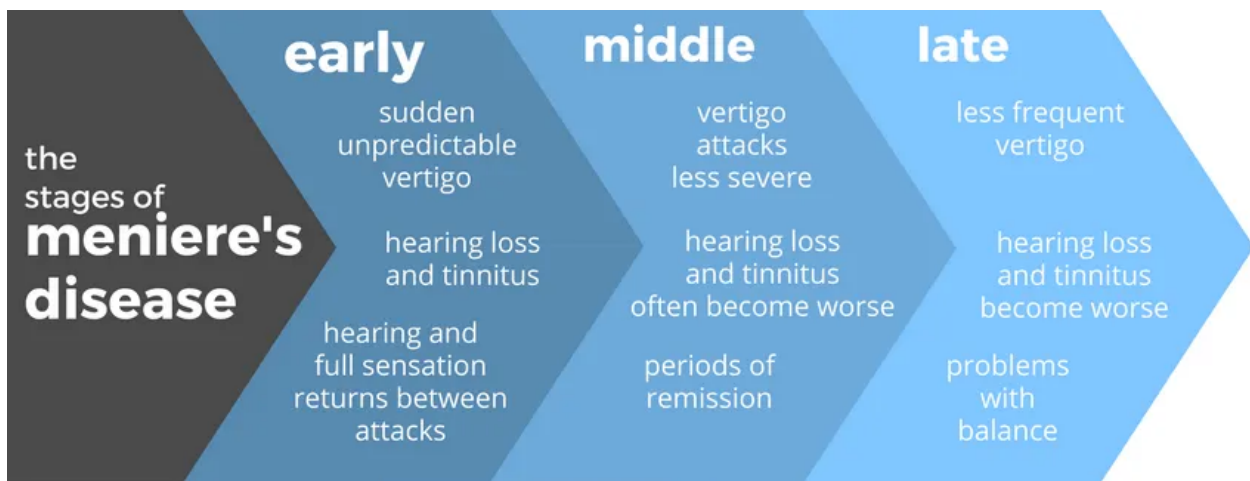
The reason I named this new series, 'The Ménière's Years,' is because many experts believe we will deal with the illness the rest of our life. By saying that I don't mean that the symptoms we experience in the early days of Ménière's are the way it will always affect us. Medical experts often speak of 'stages' of the disease, but not everyone follows those stages exactly.

I've used these graphics about the various **stages** of Ménière's in past articles, so let's look at them one more time

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[Courtesy](#)



[Courtesy](#)

I have talked with scores of people about their experience with Ménière's, including several in my own family, and not everyone has followed the three or four-stage guidelines above. Remember - everyone is unique, a laboratory of one. Look at the charts and do your own research. Talk with your doctors and let them know how things are changing for you (if they are). The combination can be of great help in both 'coping' and 'hoping' with Ménière's.

Ménière's - Heavy or Light?

One member of my family who has had Ménière's for many years says her doctor told her she had 'Ménière's light.' Her symptoms are not the same as mine, which tend toward the 'heavier' side of Ménière's. She seems to be on a similar Ménière's path to her father, while my path is similar to my mother's experience. My mother and her father were sister and brother, yet their experiences were different. They had another brother with Ménière's whose experience was different than theirs. Their mother, my grandmother, also had Ménière's, but her experiences were different than some of her children. Some of my cousins with Ménière's have varying degrees of symptoms, leaning toward the lighter side.

I share that with you just to say that even people in the same family can have varying experiences with the disease. Their symptoms may have started in early adulthood or many years later. Their symptoms may have gotten worse through the years, stayed about the same, or even improved. Some of the improvement can come from medical interventions, which is

why we see doctors with expertise in Ménière's. We're looking for an improvement in our 'quality of life' (QOL).

We'll look at other life events that can affect your 'Ménière's Years' 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!