Are you beginning your search for information on Meniere’s disease? Have you been diagnosed as having it, but are unsure how the doctors came to this diagnosis?

In other words, how do they know it is Meniere’s disease?

Well, the honest truth to the last question is........they can’t be sure. You see, a Meniere’s disease diagnosis is a diagnosis by exclusion. What the doctors do is listen to all of the symptoms that are being experienced, and then proceed to rule out any other cause.

Some call it a “wastebasket” diagnosis. Take all the possible causes there are, and throw them away, one by one, until all you have left is Meniere’s disease.

But what exactly is the criteria for diagnosis?

First, the generally accepted rule for vertigo (and I mean true vertigo- I’ll get to what that is in a minute) is a minimum of 2 separate spontaneous episodes, each lasting more than 20 minutes. That is the guidelines from 1995. In 2015, an international committee met and decided to clarify that more by saying “more than 20 minutes and less than 24 hours.” I am not sure what exactly
was clarified with that word change. I know of some with Meniere’s that have vertigo for more than 24 hours. But I digress…..

The important aspect of this criteria is spontaneous. They can’t have a specific cause that brought the vertigo on. It simply happens. The reason they need to be considered spontaneous is the fact that the most common form of vertigo is BPPV: positional. You move, you spin.

Spin. That brings me back to vertigo. Vertigo. Not “dizziness”, not “lightheaded”, not “woozy”, but vertigo. Vertigo is the false sensation that either you are spinning, or the world around you is spinning. It is a hallucination of spinning. It is rotational spinning. It can be right to left, left to right, forward to back, back to forward, clockwise, or counter-clockwise. It can be any of these, and it doesn’t need to be consistent. It can vary from attack to attack. The only thing required is that it must be rotational.

Vomiting optional.

Next, you must have a recorded hearing loss, particularly, a low to medium frequency hearing loss. The 2015 guidelines make an improvement is this criteria. These guidelines state that your “thresholds must be at least 30 dB HL worse in the affected ear at two contiguous frequencies below 2000 Hz.” This is an improvement over the 1995 criteria that simply states you must have a hearing loss recorded at two different times. That criteria says nothing about the type of hearing loss and nearly all agree that “classic” Meniere’s disease shows hearing loss in the low frequencies first. The hearing loss need not be permanent at this stage. It simply needs to be verified on 2 occasions.

So how bad is a 30 dB hearing loss? Normal hearing is typically in the range of 20 to 30 dB. That would put the measurable level for Meniere’s at 50 to 60 dB, minimum. It can be much, much worse than that, but it must show up as a “reverse slope” hearing loss, with the low tones showing loss, while at the same time, the higher pitches may be normal.

Third, the criteria states that you must experience “aural fluctuations”. These fluctuations may occur in hearing, tinnitus, or pressure in the ear. Sometimes all three. These must be able to be noticeable enough to tell the medical professional that you can tell the difference. They must also happen within 24 hours of an attack. Either side of one will do.

And the fourth criteria that is needed to finally come up with a diagnosis of Meniere’s disease is that all other possible causes for the symptoms have been ruled out. That is the reason for all the testing. There may be a tumor pressing on the nerve. There may be a deep seated ear infection. Perhaps allergies are the cause. The list could be quite extensive of the other possibilities. It would also be a good thing if something else is found, and treated.

Most of the literature I have come across shows the need for all 4 of these criteria to be met before getting the diagnosis of Meniere’s disease. Some of the sites state that without 1 of these four, they will only say “possible” Meniere’s. Less than 3 and it becomes “questionable.”

I don’t know about you, as you were reading this, but as I was writing it, I was checking them off as I recalled the early days before diagnosis.
Vertigo? Check. Not the first attack, but certainly soon to follow. And I had no problem getting to two. I am not sure that any of my early attacks reached the 20 minutes of actual rotational vertigo, but I had no problem having the effects last for up to 24 hours.

Vomiting was optional.

Hearing loss? Check. I have had so many audiograms in 23 years I believe I could wall paper a room in my house with them. And every single one (until my hearing completely crashed) showed the classic reverse slope hearing loss. Mostly I was in the 60 to 80 dB range in the low frequencies while having normal hearing in the high. It got so bad in 2013-2014 that, if I answered the telephone at all, I would ask for a woman to come on the other end of the call if it were made by a man. At least then I had half a chance to hear what was said.

Aural fluctuations? Check. Not only was my hearing generally lousy, it changed. Sometimes hourly. This was actually a bit of comic relief for me. Not so much for the person talking. It was quite common for me to ask someone to speak up and a few moments later ask them why they were yelling at me. My hearing wasn’t the only thing to fluctuate. The tinnitus would, and still does, change. It changes in both intensity and pitch. I have days I hardly notice it, and others it could drive me mad. Some days it is a low buzz. Others a high pitched one. And on the really special days it may start out a really low buzz and go all the way up through pitches before settling in at the low buzz again. I have even had the privilege of having it buzz in 4 part harmony at the same time. The same fluctuations happen with the pressure. Some days it is nearly painful. Other days I hardly notice any pressure at all.

And lastly, have all other possible causes been ruled out? Check. Balance tests too numerous to count. CAT scans. X-rays. 3 MRI’s (that I recall). Blood work. And any other testing that may seem needed. I was even sent off to a Neurologist when being diagnosed bilateral. Yup, a brain surgeon. He looked at my MRI’s and asked me why the ENT sent me to him because my films were clean. Nothing he could do for me.

So, if you are in the early stages of getting a diagnosis, or have been diagnosed, but never knew how they came to this conclusion, I hope this blog sheds a little light on the process it takes to get to a diagnosis of Meniere’s disease.

Dennis

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1 International Classification of Vestibular Disorders (Lopez-Escamez et al, 2015).