

You Are Not Your Diagnosis: Living Well with Chronic Vestibular Conditions

These are some of the questions from the 2026 Life Rebalanced Live virtual conference, answered by VeDA volunteers who are vestibular healthcare professionals. Disclaimer: This is not intended as medical advice. Please talk to your healthcare provider before making changes to your treatment plan.

Q: I have had BPPV and continue to have migraine with aura and vestibular migraine. PT for imbalance and dizziness by a very skilled clinician was invaluable. I continue to be very active in a variety of ways. What are the best ways to keep up on PT vestibular home exercises? Are some practices or exercises better than others?

A: Hi Marilyn. I am a long-time vestibular PT and health coach. I usually recommend to my patients that they put a reminder on their calendar, out 6 months or 12 months from their last visit with me, to check in with me and schedule a reassessment and tune-up for their exercise program. Whether it's 6 or 12 or something in between depends on the individual case. The main point is that they need a check-up. Just like the dentist and the PCP. I would reach out to your PT and see if you could schedule something for the reason of making sure you are doing the right things currently for your vestibular health. If you were my patient, I would be thrilled that you wanted to do this. Hope this helps., Sarah Conover PT, MHPT, CHC

Q: How do I find a competent therapist to help me deal with the anxiety and depression that accompany the fatigue, vertigo, hearing loss, headaches, sensitivity to light and noise that I live with?

A: Mental well-being is often glossed over when you have a chronic condition. I have found therapy and psychological interventions (biofeedback, imagery, mindfulness) support my mental health...therefore, improves my neurological disease status and outcomes. Resources for finding a mental health professional are available through the American Psychological Association and organizations whose purpose is to support people with a chronic condition. Sending positive energy...here's to finding the "right fit"., Kelly Amspacher, MSN

Q: Vestibular disorders are often considered invisible illnesses. How do you best explain it to others so they can try to understand what you're going through?

A: As a person with chronic intractable daily migraine as well as vestibular migraine, I feel the stigma of migraine. Depending on the situation, person, and social environment, I share that migraine and my associated vestibular signs/symptoms are part of a neurological disease. For the vestibular aspect, I explain how my vision changes (double, blurry, 3D, poor depth perception). Usually, there's an understanding or respect for vision disturbances. I also use the analogy for my balance problem as "riding a wave" or being in a row boat...usually people can relate to motion sickness. The bottom line is that unless you have the condition, you "just don't get it.", Kelly Amspacher, MSN

For many of my patients, I use this analogy: "Imagine going blind in one eye suddenly. That would make things pretty tricky at first, but the brain will adapt with time. It turns out that we have balance sensors in our ears, and I've gone 'blind' in one ear, and now my brain has to learn to adapt."

Make sure to get nerdy with people so they can realize that the body has not just 5 senses!, Anthony Veglia, DPT

Q: Beyond the standard responses of drink more water, avoid sodium, or take Meclizine before doing something that might affect our "normal" functionality,

are there any other strategies you can recommend for doing activities that you know before it starts are going to be a vestibular challenge (e.g. flying, rapidly traversing/driving quick elevation changes, cruise ships, etc.)?

A: Just like helping someone move a couch, it's not so much what you do the day of, it's what you have done weeks and months and years leading up. A person who never lifts weights is not going to be ready to move that couch without risk of injury.

Vestibular therapy exercises right now can help you build up a tolerance for activity, travel, and the rest of life so you're ready for anything. The brain needs challenge to reach a higher level of dizziness threshold., Anthony Veglia, DPT

Q: I have autoimmune/paraneoplastic cerebellar degeneration, which presents with vertigo, occilopsia, double vision, hearing loss, and gait and balance issues. Sometimes life gets very overwhelming. The vertigo and occilopsia is the worst when shopping. Any suggestions?

A: Here is an article on "supermarket syndrome" that might help:
<https://vestibular.org/article/coping-support/living-with-a-vestibular-disorder/visual-induced-dizziness-supermarket-syndrome/>, Cynthia Ryan

"Fear of the Marketplace" or Agoraphobia is a very common complaint with many vestibular issues, but it is treatable! As is oscillopsia. Tasks like VOR exercises and VOR Cancellation exercises can be quite helpful towards these complaints. VeDA's YouTube channel has a video on these topics made by me, actually., Anthony Veglia, DPT

Q: How do you know when it's safe to drive?

A: Here is an article with guidelines on whether it's safe to drive:
<https://vestibular.org/blog/should-you-drive-with-a-vestibular-disorder/>., Cynthia Ryan

Q: How to overcome exhaustion. It's so frustrating. Also, get a tremor, muscle weakness, and a bad headache. Does anyone else feel drunk?

A: These are not rare complaints with these diagnoses! The biggest ingredient to this recipe is graded exposure: steadily and repetitively perform the activities that are bothersome and increase symptoms. The more the brain can be challenged, the more that the brain can adapt. It is exhausting for the brain to feel off-balance or feel drunk, so the more that the symptoms are reduced, the less exhaustion will be present., Anthony Veglia, DPT

Q: What are some strategies to navigate social and daily situations when you don't "look" sick but you feel like everyone thinks you are drunk because you stumble and slur your words?

A: Since vestibular disorders are "invisible," it is difficult to be in these situations. Suggestions include conveying your disorder in a way that's comfortable for you, and your signs/symptoms, educating people on the nature of your "presentation" so you can actually have others support you in the identification and management tools. You will feel less "under the microscope" and more supported., Kelly Amspacher, MSN

Q: How are we to get help when all of our vestibular conditions are very different and have different causes?

A: For sure, it's frustrating to feel like there isn't one best answer for help. This is why it's so important to have a provider(s) who is experienced and can get you the help that is best for you. In my over 30 years of being a vestibular PT, I have learned so much from my patients, and even though there are individual differences, causes, etc., there are similarities. , Sarah Conover PT, MHPT, CHC

Q: I do all my exercises for Meniere's and VN, I walk, and go to the fitness center 3 days a week for over 90 mins. I'm exhausted all the time after work or exercising, and have no energy for my personal life. I rest, meditate(30+ years), and do breathing exercises. Any suggestions for balancing maintenance with personal life?

A: Dr. Daly was just talking about pacing. You might consider whether you are overexerting yourself for where you are in your recovery. It sounds like you have great coping strategies - exercise, meditation, rest - but maybe try a different "dose" of exercise, less, or a different type, that doesn't drain all your energy.,
Cynthia Ryan

Consistent activity matters, especially to increase overall endurance in the presence of these symptoms. It is tiring for the body to have to work harder to maintain stability when it used to be automatic! However, listen to the body. If there is an exacerbation of fatigue more than typical, take a day off from exercise to allow greater recovery. After all, it is the recovery when the body actually improves, not during the exercise itself., Anthony Veglia, DPT

Q: Please touch on when you do get the courage to ask for help, and when you ask, it is turned down. I think it is important that the people you believe would step up may not.

A: It's a challenge for each person to find the "place to be" when you are comfortable asking for help. As we learned in today's session, needing to set expectations is critical. I have found that I received the help I was wanting if I had a priority list. That helped me focus on my expectations vs feeling disappointed, frustrated, and alone. Also, I have learned that people are tentative about offering help due to their own fear of physical pain and discomfort. People in my life shared with me that they were under the impression that I "had it together". Therefore, it

was not always recognized that I have a chronic disorder, and physical support was a necessity., Kelly Amspacher, MSN

Q: Sometimes I'm fearful that too much movement when symptomatic can worsen my dizzy/nausea symptoms. Is movement suggested for vestibular recalibration, and should I push myself to move despite the fear?

A: Movement is an important part of vestibular therapy. Dr. Daly recently talked about pacing - push past the fear of movement, but don't push yourself beyond your limits. Dr. Stross suggested trying things one at a time, not all at once, so you can tell what is working and what is not working for you., Cynthia Ryan

Q: How do you layer your therapies so you don't go backwards? Where do you start, and then know how to add? Example, if you need vision, vestibular, physical, spine, cervical strengthening, trauma, EMDR, and communication/social.

A: As a full-time vestibular PT, my goal is to make the routine for exercise as simple and quick as possible. My goal is NOT to have to keep coming in every single week forever. Get a few homework exercises that are

- A) challenging
- B) tolerable
- C) scalable

The last one is important. If the exercise is to move your head left and right to provoke mild dizziness, then you can gradually scale it up to be a little faster, a little faster, a little faster.

You don't need an extra visit for me to say move your head slightly faster than before. That way, we can spread our appointments and make the process more digestible.

Tell your therapists to make things simple and scalable so that you can address all your needs together!, Anthony Veglia, DPT

Q: Has anyone with PPPD had experience with general anesthesia? If so, did you have any problems? I am very nervous to move forward with a procedure because of how the anesthesia might affect my brain.

A: Everyone responds to anesthesia differently. Talk with your ENT or neurologist about what to say to your surgeon and anesthesiologist so they can take your vestibular problems into account. Also, remember that you may decompensate after surgery, which can cause your vestibular symptoms to flare, so be careful reintroducing movement after your surgery.

<https://vestibular.org/article/what-is-vestibular/the-human-balance-system-vestibular-compensation/>, Cynthia Ryan

Q: Are vestibular issues considered a "disease"?

A: A definition of "disease" is: a disorder of structure or function in a human, animal, or plant, especially one that has a distinctive group of symptoms, signs, or anatomical changes and often a known cause. Vestibular disorders fit that definition in that they are real, physical illnesses, which may affect the structure of the inner ear and/or the nervous system., Cynthia Ryan

Q: People understand if you say you have an illness they have heard of. If you tell them you have vestibular issues and explain what your symptoms are, they look at you like you have two heads and are making it up to "get out " of

participating in something. Suggestions on how to properly explain what this is would be greatly appreciated.

A: "Imagine suddenly losing vision in one eye. That would make things really tricky for a while, but you would learn to adapt. We have balance senses in our ears, and I went 'blind' in one ear, so I'm learning to adapt to the new set of senses."

These are the kinds of analogies that I use with my patients to help explain their diagnoses, and they can be helpful for family or friends.

Also, the biggest shame is that the body is talked about in terms of 5 senses, not the 16ish that we actually have., Anthony Veglia, DPT

Q: Has anyone used hearing aids for the loss of hearing from Meniere's Disease? Being unable to hear conversations affects interacting with people daily.

A: Tinnitus can be helped by masking protocols with hearing aids, but it depends mostly on the cause, and sadly, Meniere's doesn't see a huge difference with masking compared to other causes., Anthony Veglia, DPT

Q: Will PT exercise help if my inner ear has been damaged due to cisplatin?

A: Yes, vestibular physical therapy is really addressing the brain, where all balance and orientation must come from. Whether an ear is damaged from infection, medication, injuries, surgeries, etc., the brain is capable of adapting through repetitive challenges with vestibular rehab exercises., Anthony Veglia, DPT

Q: Are all vestibular issues chronic?

A: Not at all, fortunately. Certain diagnoses, like BPPV, can happen once and then never again. Others, like Meniere's disease, can cause symptoms for years or potentially the rest of a lifetime, while others can resolve over a few months, like vestibular neuritis. The most important thing is that function can be restored even if there is still an underlying diagnosis., Anthony Veglia, DPT

Q: Can you travel on a plane when you have Meniere's Disease?

A: Yes! Meniere's disease is typically not affected by small changes in barometric pressure, like air travel. However, motion sensitivity and motion sickness can be worsened by Meniere's, but that does NOT mean that major vertigo attacks will be triggered by travel., Anthony Veglia, DPT

Q: Will there be talk about vestibular hypofunction with permanent vertigo 24/7? I have zero balance nerve on the left side and only 35% balance left on the right nerve. It seems like most people talk about flare-ups and temporary recovery. My life is 24/7 dizzy when standing, walking, or bending. Uneven ground is everywhere and hard to manage. I would love to hear how others cope with this version of vertigo.

A: I've had patients with both ears involved, and even complete loss of both, and the strategies remain the same, but can take a lot of time and repetition. With my patients, that's actually something I spend a good chunk of time on, showing patients where they were when we began, and retesting them again to see where they have improved, where they still struggle, etc. Dizziness and imbalance can be so intangible, but there are ways that we can help quantify these. However, the biggest thing is FUNCTION. Can a person get back to the life that they enjoy and be productive overall? That's what matters most for therapy., Anthony Veglia, DPT

Q: How many people, like me, have the overlapping symptoms of vestibular and nervous system disorders? Usually, they feed off each other as well. It is a new learning process, but also some of the therapies overlap as well and help both areas.

A: The vestibular system is very much a part of the nervous system, and many nervous system diagnoses cause disruption of vestibular awareness. Having treatment for each aspect is helpful, and at the end of the day, FUNCTION is the biggest thing. Getting back to the things that a person needs to be able to perform and back to the things that a person enjoys is what matters most.

Neurologic diseases, like MS for instance, are not curable, but with treatment from both a neurologist and a physical therapist can get to both the underlying disease and to help improve function.

To answer your first question, no, it's not too rare at all. Many people can struggle with both elements at the same time., Anthony Veglia, DPT

Q: I share many of the symptoms that all of you are describing. Could the panel address Binocular Vision Disorder? Often misdiagnosed or not diagnosed due to the similarity of symptoms with VM, PPPD, etc.

A: This can take a team! Having a good set of doctors around you, including vestibular PT, ENT, neurologist, and eye doctor, can all make a big impact on the full picture. The big thing is that 85% of diagnosis is just taking good history, so find the provider that can get into the fine details of your symptoms., Anthony Veglia, DPT