Life Rebalanced Live 2023

CENTRAL VESTIBULAR DISORDERS

***This transcript may contain errors.**

[Danielle Tolman, DPT] Welcome and thank you for joining the Vestibular Disorders Association for our third annual virtual conference life rebalanced live. I'm Dr. Danielle Tolman and I'll be your host alongside my partner Dr. Abbie Ross. We are vestibular physical therapist with balancing act rehab members of the board of directors and self proclaimed vestibulo-holics.

[Abbie Ross, PT, DPT, NCS] That’s right. And today we are going to learn more about central Vestibular Disorders. We'd like to thank VeDA staff, donors, and volunteers for the countless hours they have spent preparing this event. We're so pleased to be able to put on the live event at no cost to our attendees. Now if you do wish to purchase the event after it's live, we will have it available for purchase for $55. And the best part about that is all $55 Go directly to VeDA and help them support their continued programs to spread vestibular awareness.

[Danielle Tolman, DPT] Let's take the time to give a shout out to our sponsor this week, the James D and Linda D. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology. Jim Hainlen was the inspiration for this conference having hosted his own in person conference for patients with vestibular dysfunction in 2018, and 2019. We very much appreciate his continued support. And on another note, if you have questions you'd like to ask during a live event, feel free to type them into the q&a tab on our app.

[Abbie Ross, PT, DPT, NCS] Our topic today one more time is understanding central Vestibular Disorders. Vestibular Disorders are often thought of as inner ear problems, and that is true for many people. But there is such a thing as central vestibular dysfunction and while both can coexist, it is important to understand what central vestibular dysfunction means and how it is treated.

[Danielle Tolman, DPT] So without further ado, we are very excited to introduce you to today's speaker, Laura Morris. Laura has 25 years experience and Vestibular Disorders. She specializes at Elmhurst memorial hospital in the Chicago area. Thank you so much for joining us.

[Laura Morris, PT, NCS] Thank you. I'm happy to be here today.

[Abbie Ross, PT, DPT, NCS] First, can you please define what central vestibular dysfunction is and how it differs from peripheral vestibular dysfunction?

[Laura Morris, PT, NCS] I'll start with the peripheral system. The peripheral vestibular system is encompassed by the inner ear itself located just outside of our brain cavity and the nerves that travel from that inner ear into our central nervous system. Do you want to pull up the picture? (shows diagram of inner ear and brain) The rest of the Vestibular system is located in the brain from its connection into the brain stem you have a myriad of connections that travel all over the central nervous system. There are more connections in the central system than there are in the peripheral system. We consider any of the connections between the brain to the cerebellum and then up into the cerebral cortex, which is the main body of the brain. There are also connections that travel down into the spinal cord that helps us with balance and spinal control. All of that is considered the central Vestibular system.

[Danielle Tolman, DPT] Now, how does the peripheral vestibular system connect and communicate with the central nervous system? Is it all in just one place? Is it diffusely through the brain? What does that connection look like?

[Laura Morris, PT, NCS] The inner ear sends signals from that structure into the brainstem, and there's a central location in the brainstem called the vestibular nuclei, and that is where all of the connections from the inner ear travel. And from there they dispersed all over our brains and into our spinal cord.

[Abbie Ross, PT, DPT, NCS] So there are some hot topics when it comes to central vestibular dysfunction, as you know. Can we start by diving a little bit more into Vestibular migraine, for example?

[Laura Morris, PT, NCS] So there are several Disorders that we know about and deal with frequently that involve the central Vestibular system, but one that is frequently involved is that of migraine. Migraine as a condition affects our brain in a variety of different areas depending on each person. For instance, some people have migraine that don't have any Dizziness. Other people have migraine that includes Dizziness as one of their symptoms. A migraine headache or a migraine phenomenon affects a variety of areas of your brain. It can be primarily located in the occipital lobe, and those persons often have visual associations with their migraine. Other people have more parietal and temporal lobe and frontal lobe involvement and may have different symptoms based on that. Depending on what area of your brain is affected will reflect what symptoms you have with your migraine event. And because the areas in our brain are so diffuse where the Vestibular system projects, it often can have an effect on Dizziness that way. In addition, the migraine can actually affect the brain stem or the base of our brain where those nerve endings happen in our brain stem in the Vestibular nuclei and have a very direct effect on Dizziness there. It really is dependent upon where the brain is affected.

[Danielle Tolman, DPT] That would make sense why we see such a range of symptoms and reactions to different treatments. There are a lot of different areas that can affect and create some overlap in symptoms, and some patients can have completely different types of migraines that avoid the Dizziness or just have the visual dysfunction. it can be a very complicated rabbit hole to go down.

[Laura Morris, PT, NCS] And the other thing that happens is migraine can change over time. Some people have migraine for much of their life and have never had Dizziness associated with it. And then over time Dizziness can be one of the symptoms that develop as that migraine changes where the neural activity is in their brain. I've had many a person say, but I've never had Dizziness before with my migraines. Why is this happening to me now? And it's just because a different area of the brain has been affected.

[Danielle Tolman, DPT] I have seen that in patients as they enter perimenopause or hormonal shift. It starts to digress into these more chronic episodes of dizziness. That sounds very much in line with exactly what I see here

[Abbie Ross, PT, DPT, NCS] So migraine is considered one central Vestibular disorder. Can you list some others that we would consider more central?

[Laura Morris, PT, NCS] Another large group of patients that we see with essential Vestibular disorder would be those who have Persistent Postural-Perceptual Dizziness or PPPD. We see Dizziness with Parkinson's disease, with multiple sclerosis. Wheezing Dizziness -- and those two populations especially have become much more studied recently in their effect on the Vestibular system. We also see Dizziness with concussion, brain injury, when it has affected the cortex and those Vestibular connections as well. Those are the big ones.

[Danielle Tolman, DPT] I'd like to touch on that Persistent perceptual postural dizziness. This is something that can arise from other Vestibular dysfunctions. What does that look like centrally?

[Laura Morris, PT, NCS] PPPD is such an exciting time in studying that condition because we have been learning more and more about how exactly does it affect the brain chair mat when I first started doing this, we saw lots of people who had these sorts of conditions, but there was never any hard evidence about what exactly was happening.

Over time, what we have discovered is that the brain actually changes into atraumatic traumatic or precipitating event. The precipitating event can be a medical event that causes Dizziness. It can be a psychological or psychiatric event that causes Dizziness, a very significant anxiety condition or crisis that develops. Or it can be a Vestibular condition. Regardless of what starts this process, what happens over time is that we have a specific reaction to that crisis event and we develop behavior associated with that. So this traumatic event causes a great amount of anxiety, a great amount of distress, and we changed how we behave in response to that.

We become more careful. We become more cautious about how we move and when we move. And we pay a lot more attention to what's happening around us in order to manage our own environment and our own postural control here overtime that changes how our brains perceive and manage our own postural control and our own movement and those changes in the brain become hardwired, become our new normal around that. So what we have discovered with advanced imaging and a lot of really cool research is that we actually start paying more attention to our visual system.

We enter into this sort of fight or flight state where we are paying attention visually to everything happening around us at all times. And our brains pay less attention to our body awareness, the sense of our feet on the floor, the sense of where we are in space and less attention to our Vestibular systems, or to the input being projected from there. And the result of that is then that we don't feel safe. We don't feel comfortable moving through environments. And it actually changes our ability to move through an environment. Our spatial navigation. So getting from point a to point B changes hardwired in our brains.

And we have been able to see that with advanced imaging techniques that have shown us that the brain actually changes. The good news is, the brain can change back. And that's where we can come in. And that's the great hope around this condition.

[Abbie Ross, PT, DPT, NCS] That is great news, and that is why we have jobs. You brought up the visual system and how you may become more dependent on that. If you become more dependent on your visual system, what types of activities throughout your day might be especially provoking?

[Laura Morris, PT, NCS] Good question.

When anyone becomes visually dependent, relying more on our vision than we are on our other body awareness or our inner ears, it doesn't necessarily affect how we move around our own homes, our familiar environments, because we already know what's happening there. And so that's not so bad. But when we enter into the community, when we enter into unfamiliar environments where we are having to look around and pay attention to everything that is happening -- grocery stores, even just outside moving around if there are a lot of pedestrians -- I'm in Chicago, you know. It's a busy place. When we are visually scanning to look around to make sure we know where we are in space, because we are also using that to help balance ourselves, we feel off balance when we are in those environments. It makes us feel unstable because we are too busy trying to look around to make sure we don't trip and fall on something or run into someone. And our visual system just can't do everything. So anytime they are out in the community, when we are having to use our visual systems to scan makes us feel much more destabilized.

[Danielle Tolman, DPT] I have a lot of patience that struggle at the beach because they have the wind coming one way, the waves coming another way, people walking around, dogs, especially in the soft surface of the sand, it drives people crazy. That and golf courses, too. But also it sounds like this issue of sensory reweighting. The brain is putting more emphasis on things that it doesn't normally put it and puts this on can be an issue. And this can be transcribed into other diagnoses beyond PPPD?

[Laura Morris, PT, NCS] Absolutely sure it is something we see often in migraine. It is a very common problem with migraine. See it often with people who have chronic concussion, mild traumatic brain injury conditions. Certainly it's not Unique only to PPPD, but we will see it with other conditions as well.

[Danielle Tolman, DPT] We have talked about treatment. It sounds like this is something that we could potentially work on with exercises or therapy. We have a lot of patients asking, Can you do therapy for central vestibular dysfunction? So it sounds like there are some things that we can address. And how does therapy address the symptoms? What do we do with these exercises and what's happening to make us feel better to help us recover a little bit from the symptoms from Central vestibular dysfunction?

[Laura Morris, PT, NCS] So that's the great news. We have things that we can do to help these conditions. We have known for a very long time that when the brain has changed in its organization of sensory information, when the brain has become more visually dependent and less dependent on our inner ears, less dependent on our sense of where we are in space from our bodies, or somatosensation or Proprioception, that disorganization can be reorganized. We call it sensory reweighting, as mentioned so what we do is we, in treatment, work to decrease that dependence on vision, increase that awareness of where our body is in space, both by somatosensation and by the inner ear, so that those levels are a little bit more normalized, so that when you are out in the world trying to use your vision for what it is meant to do, you can do that without feeling destabilized.

To do that, we work with exercises and tasks that require you to use your somatosensation more, that require you to use your inner ear more, and that requires you to use your vision less. Any situation where your vision is busy or absent in the case of eyes closed so that you can pay attention to those other sensations.

[Abbie Ross, PT, DPT, NCS] Broadly speaking, are there differences in how you approach someone with a peripheral disorder versus a central disorder, aside from considering the individual aspect?

[Laura Morris, PT, NCS] Yes. And it's hard to make generalizations around these things, but by and large, trends that we tend to see are that if you have a simple inner ear dysfunction, peripheral inner ear dysfunction, when you get dizzy, you are dizzy in the moment. And then when you stop, the disease pretty much settles down pretty quickly. With central disorder, sometimes that Dizziness will actually ramp up after you have finished and those symptoms stay at a heightened state for a little bit longer. So it may take more patience between activities in order for those symptoms to settle back down. There can be more nausea, so we may have to manage that nausea better. And in the case of migraine, we can trigger migraine events if we are not careful. So there is more care and caution in treating those conditions in such a way that we don't ramp up symptoms too high or make them last too long.

[Danielle Tolman, DPT] We have a couple of really good questions.

Somebody had asked, is it ever too late to be able to do therapy for central dysfunction? They have a central issue, they did therapy and rehab for 10 plus years. Can they still benefit from treating central dysfunction even though it's been chronic for a very long time?

[Laura Morris, PT, NCS] Excellent question. The brain has an amazing ability to recover. One of the abilities that we find is that somebody who has a central Vestibular condition can fall into those patterns over time of avoiding things that make you dizzy. Who wants to be miserable all the time?

So if the grocery store bothers you, overtime you're not going to want to go there. You will send your kids. You will send your spouse. And what can happen is that your world can get smaller because of that if you start to avoid all the things that bother you. Conversely, by pushing that envelope a little bit, by working in therapy to broaden your horizons a bit by exposing yourself to a little bit of things that are bothersome, you can reverse some of that. And the other thing that I often find is that if you can do some therapy that involves improving your own wellness, that also helps.

Because the more you avoid things that make you dizzy, the less you are moving. And the less you are moving, the less well you can get. By addressing both those things, you can make changes far down the road.

[Abbie Ross, PT, DPT, NCS] Really good point. I talk about the other things involved in rehab, like wellness, getting good sleep, diet, exercise. When it comes to rehab -- and let's say the grocery store is problematic -- is there another way to get exposure to that type of environment without actually going to Costco. Excellent question.

It is difficult to expose yourself to visual motion by having to drive to the grocery store only so you can spend 5 minutes and leave and come home. That's problematic from a logistical standpoint. There are several ways in which that has been addressed over the years. And what we know is that exposing yourself to visual motion in other ways can translate to those other visually rich environments -- the grocery store, restaurants, bars, dancing places, whatever you want to do. By exposing yourself to visual motion at home, you can work up to going to those places that might be logistically difficult. So we often use exercises that involve movement with backgrounds that move and are a little bit challenging.

We might also use videos on a screen. You can play any sort of video that causes movement on a screen. You can start with smaller screens, work toward big screen TV's with a fast action movie or Mario kart or anything that causes that movement. I sometimes have adolescent patients who like to play video games and have been told not to. And the parents are happy about that because they don't want their kids playing video games. And then I come along and I say, why don't you play some video games? And they're like, no! But any motion will help you tolerate being in those visually rich environments better. We definitely can use those to our advantaged.

[Danielle Tolman, DPT] Is there a space for virtual reality in realm of rehab? We've gone from having to use really expensive equipment to being able to use cardboard. Is there a space for that for patients with central issues and in rehab?

[Laura Morris, PT, NCS] There have been millions of dollars actually spent on this exact concept here and what we know is that virtual reality is very fun and super cool and interesting for many people. And is actually -- there has not been a study yet that has demonstrated that it is more effective than what we can use that doesn't involve virtual reality.

So traditional therapies, movements on a 2D screen like we've been talking about. Having said that, many people find it much more pleasurable to use virtual reality and do something fun with it than to watch something silly on the screen here so it has its place, and it's definitely worth considering. If you don't have it available, all is not lost. There are other things we can do to address the same thing. One thing that is challenging about central Vestibular patients is that if you are very visually dependent and if visual motion bothers you, some of those virtual reality/augmented reality modalities can be very destabilizing. So you have to be cautious about introducing them and for how long you use them. And I would argue that if you have a central vestibular problem, to do any of those modalities standing can be a safety concern if there isn't anyone around to help you. Because you can get so involved in the scene that you are watching that you are not as aware of where you are in space. Even in my own experience, I was in a virtual reality thing where there was height involved. And then they jumped from the height. And I literally went to my knees because it was so realistic here and it made me sick as a dog. So it is one of those things that you need to be careful around, depending on what the environment is and what your postural situation is at the moment.

[Abbie Ross, PT, DPT, NCS] Echoing our talk from yesterday that dosage really matters. You as a patient have to give your therapist feedback so that they know how to adjust your program here it reminded me of a Whitney-ism, which is: do what you enjoy. It's what you enjoy and what you're going to participate in, then by all means. I want to talk about for co-occurrence of a peripheral disorder and a central disorder.

Can you talk about how we approach treatment for those?

[Laura Morris, PT, NCS] There are times when we see with mild brain injury where you may have had damage to the inner ear itself and you've got a brain injury on top of that that would be considered a mixed bag of both central and peripheral. Occasionally you can have sequential injury where you have had a neuritis or something that has affected the inner ear itself, and on top of that you have migraine. That would be another example of where you might have two conditions at the same time the cause both a central and peripheral involvement.

It is harder to recover when you have more than one thing going on. And it doesn't mean it's impossible, and it doesn't mean we haven't seen really good outcomes in people who have both a central and a peripheral condition. But it does make it more challenging, because we rely on our brains to help make sense of what is happening in the inner ear. And if what we are getting from the inner ear is dysfunctional and our brain itself is dysfunctional, then it's hard to recover from that. But not impossible.

[Abbie Ross, PT, DPT, NCS] Another example is migraine and BPPV, we see together you also touched a couple times on the duration of care and how the expected duration may be a little bit longer. What if you have that patient was anxious to get better and get back to work or just feel normalcy again? How do you talk them through that? What motivational speech do you have to help patients?

[Laura Morris, PT, NCS] I'm not a patient person in my own life, so I can identify. And even when I have had minor injuries, it seems like it takes forever to recover. And that's hard. It's really hard. And so I will say – in my own personal story, I had a very long recovery from COVID. So I have experienced in a small way what it's like to take a long time to recover.

And so often I can say with some empathy, yes, I know what it's like, and it is hard. But unfortunately, you can't make recovery happen any faster than it's going to happen. You can do due diligence to address it and do your exercises as consistently as you can to set up your body for healing as well as you can. But the body is going to heal in the time it is going to heal. And unfortunately, we just have to be patient with that process one of the things that happens sometimes with anyone who is trying to recover from a Vestibular problem is that we get anxious to get things done and overdue here you have a good day, you feel good that day, and so instead of doing the one or two errands that your therapist has told you to pace yourself and not do too much in a day, you do four things.

Because it's got to get done, right? I'm a mom, I have a job, I have to get everything done. And so you overdo. It sets you back, because it takes you a couple of days to get back to a place of healing again. So I try to really encourage my patients to try to avoid that, just because it can then set back your recovery. It's so hard. I'm not good at it, and I know that we all have experienced overdoing it from time to time. But if we can keep an even keel and try to set ourselves up for the best recovery and the best healing, then that's all we can do.

[Danielle Tolman, DPT] We had a good question in the queue here is there anything somebody can do that would make them less likely develop PPPD on their journey to recovery? That's a tough question, I know.

[Laura Morris, PT, NCS] That's a good question, and I'm going to tell a story around that to answer it. During the height of COVID, a dear friend of mine had a terrible Vestibular neuritis, double terrible. She was hospitalized for a few days. She really was quite impaired and then she went home here being a dear friend and knowing what I do for a living, she was in touch with me I was trying to walk her through what she needed to do.

She was in California and I was in Chicago, so I looked up who was there to help with her recovery. And it turns out that the person that was there that could help her with recovery was only seeing patients virtually. And so I said -- actually, my friend said, if she's only seeing patients virtually, why don't I just see you? So I set out to help my dear friend, and we took her through her recovery from her problem and then over the summer, as she was coming out of her impairment from her peripheral problem, she had an incredibly, terribly stressful summer -- really very stressful. And the result of that was that she slipped right into a PPPD pattern, even though I had done everything in my power to make sure that didn't happen to her, it didn't matter. She developed it anyway. So we can't always predict. She did all the right things. She really did. But she's a perfectionist, she's very high functioning, she is a type A personality and just sort of went at life all holds barred that summer, and was also in a very stressful situation. And it developed regardless of anything. We did all the things right, and she still ended up there. So sometimes it happens no matter what you do.

I have patients, they say what could I have done differently? You don't know. Will say that there is a tendency with people who have developed into PPPD to attach a lot of anxiety into that, and that can be what triggers this whole thing. And so developing other ways of managing anxiety and not intentionally becoming hypervigilant around your symptoms can be a way of addressing that. You can't tell somebody, well, don't worry. For god's sake, my whole life has changed, and I'm dizzy. That's not effective. Anytime any one of us has been worried, if someone says don't worry, it has zero effect. So I would argue that it's very difficult to predict, and it's very difficult to prevent that from happening.

[Abbie Ross, PT, DPT, NCS] This story reminds me of a talk we had that was specific to migraine, but I think it extrapolates to other Vestibular Disorders, and that you have a threshold. And perhaps without that stressful summer, the anxiety, and everything else going on in her life, she might have been fine. Because all the things added up to put her over her threshold, she had symptoms. I like thinking about it that way because patients often say, I came home and watched a film on my big screen on Monday night and it was fine.

But on Friday night when I tried that, that was after a long work week, and you didn't sleep, and you had a glass of wine, and all the things added up to then be a problem. I like to tell patients who know your body best. But it takes time to learn what's too much, what's too little. And that can change.

[Laura Morris, PT, NCS] Our physiology is not static. Especially with migraine, when you are talking about triggers, something that was a trigger months ago may not be trigger now. Other things may be more prominently involved now. It's the same with many things -- our predisposition, how our physiology is at the time, allows us to tolerate or not tolerate a lot of things.

You may think, OK, I got it down. I can watch a movie here that's good. But no, you're really tired, maybe you didn't hydrate well that day. That affects your physiology, and that affects your ability to tolerate things.

[Danielle Tolman, DPT] We have a question -- neuromodulation used to be a big thing for managing migraines, such as vagus simulations. Could you go into how neuromodulation might help with migraine or the central dysfunction that is going on? Or hard to say?

[Laura Morris, PT, NCS] We think that by stimulating those nerves in a more consistent way that we actually changed how the nerves behave. And so over time, with that regular low level stimulation, which means how the nerves behave appears and then hopefully changed how they discharge when there has been a trigger. So that's the theory behind them. And some people find it to be incredibly helpful. Some people find it not to be helpful at all. And especially when it comes to migraine, everything about migraine is wacky and different. Every patient is different, how they respond is different, triggers are different, symptoms are different.

We know that there are some central pathological changes that happen that are consistent. But what each person responds to is very different. I have had many a patient who finds it very powerful and a wonderful tool to help them. Hopefully, that answered your question. I get excited, and then I realized, did I actually answer?

[Abbie Ross, PT, DPT, NCS] We do that too, we go off on tangents. But we're pretty focused today. We touched on PPPD earlier, but it's more symptom specific. Do we typically see spinning vertigo with a PPPD diagnosis?

[Laura Morris, PT, NCS] We think of spinning Vertigo as coming more from direct inner ear Disorders.

With almost any of my patients, if they get dizzy enough, if they are exacerbated enough, they can experience spinning Dizziness with any central disorder. It's really how our brains are perceiving that information from our inner ears and in some cases an experience that here the other thing that can cause a real true sense of spinning Dizziness is anxiety and panic attacks. And so if you are in the middle of a panic attack, that Dizziness can also feel very much like spinning. So even though that's not a typical thing that we see with PPPD, you may see that with somebody who is very exacerbated or if they are experiencing concurrently anxiety and panic while they also have PPPD. You don't have to be terribly anxious, but they can go together.

[Abbie Ross, PT, DPT, NCS] Is there a correlation between PPPD and dementia?

[Laura Morris, PT, NCS] Thankfully, no. We have seen no long term effects of developing any type of dementia.

[Danielle Tolman, DPT] It may be brain fog for some patients, a temporary brain fog.

[Laura Morris, PT, NCS] There has been lots of concern about whether it changes cognition over time, and there is no evidence to say that that has happened. With any chronic condition -- headache, PPPD, migraine -- it's hard to think. It's hard to process. Even times when I am particularly tired, it's hard to think. If I am perimenopausal or menopausal, it's hard to think. There are lots of things that cause that brain fog that don't end up developing into permanent cognitive changes, thankfully. But in the moment, it can definitely cause an inability to utilize our brains well for cognition work.

[Abbie Ross, PT, DPT, NCS] I couldn't agree more on that. When it comes to providers, one of the things through this week has been a multidisciplinary approach. Who would you see if you suspected you might have central Vestibular disorder? What kind of caretakers might be on your team?

[Laura Morris, PT, NCS] Some of that depends on where you are and what providers are around. Generally speaking, a person to consult would be a Neurologist. There are some neurologists who are very interested in Dizziness, and there are some neurologists who that is really not that thing. Like any other practitioner, there are those of us who love this stuff and do it all the time and others, orthopedic physical therapists, who don't know much about Dizziness at all. It's the same when Neurologist. Some are very interested in migraines, very interested in Dizziness, and some are not at all. So there is variation and experience or expertise and Dizziness. But by and large, a Neurologist would be the first place to start.

[Danielle Tolman, DPT] We have a couple of questions in the chat hovering around the same question, how do I know if I have a central issue or a peripheral? There are some differences between what a patient may feel and what shows up in testing. We listen to a patient's history, we listen to a patient talk about what they are experiencing.

[Laura Morris, PT, NCS] That's a big question. If you have direct involvement of the inner ear, we have Vestibular testing that tests specifically for that. Unfortunately, in some cases the central Vestibular diagnosis happens when that peripheral system is good. We have tested the peripheral system. It's fine. This patient clearly still has Vestibular issues, and so some may be coming from the brain instead. And so we can make inferences that way. For the diagnosis of PPPD, that diagnosis is primarily clinical based on the patient's report of symptoms, based on behavior that we see, based on the sensory organization that we have assessed, that does not involve the inner ear itself. And then also, what we may see is that clinical diagnosis of migraine.

So a patient already has a diagnosis of migraine and we've been able to look at this episodic dizziness that can develop and match that up with the migraines. Some of it double dashed I wouldn't call it a diagnosis of exclusion, but we have ruled out that the inner ear is damaged. And then also we can look at concurrent – if somebody has involvement in either brain injury, moderate and more severe brain injury, MS, things like that where we can use imaging and see some changes with that.

[Danielle Tolman, DPT] A lot of patience with central dysfunction are initially frustrated because they undergo all that testing and it all comes back great. And they are like, I'm not great.

[Laura Morris, PT, NCS] And if you do not have practitioners that are well versed with managing central conditions, you're left with, you must be fine, because your inner ear is fine. But they are really not fine. And that is an unfortunate thing. I think that over time we have done a better job of educating Vestibular therapists, educating the medical community. There is more understanding of central vestibular dysfunction. But it is really not a widespread given. If you go to your local ENT and get Vestibular testing and your inner ear is fine, they may not know what to do with your next.

[Abbie Ross, PT, DPT, NCS] This question returns back to some visual dependence. Do you have any tricks or tips for people who are working on their phone or computer a lot and have issues with that screen time?

[Laura Morris, PT, NCS] Yeah. 2 things happened with screen time. Actually tolerating the screen time is hard. It's hard to watch that visual motion, scrolling on your phone or scrolling on the computer. God forbid you've got two screens going and you're having to go back and forth. That in itself can be exacerbating. The one thing that I often encourage people to do is increase the font size on your phone and on the computer in order to make everything a little bigger.

It decreases the amount that's on the screen, and it also decreases the eye strain involved. That can sometimes be helpful. I often will encourage people to maybe not use their phone if they can. Try to switch from their phone to an iPad or their phone to a computer so that everything is just a little bit bigger here if you're really having a difficult time on your phone and you have to be out and about with your phone, try not to be walking, moving while you were trying to use your phone. Either stop and stand, lean nonchalantly against the wall while you are on your phone, or sit if you can to help to decrease the symptoms here the other thing that can happen with using your phone or using your computer is if you have been sitting and on the computer for a long time, sort of focused, and then you get up to move, it can be really exacerbated or a bit, just because your visual focus is so different. And so sometimes what I will encourage people to do is when you get off the computer or off the phone if you have been on it for a long time, stand up. Take the moment to take in your surroundings, to refocus that visual field to what's around you before you start moving so that you aren't so destabilized by going from that small screen to a larger environment.

[Danielle Tolman, DPT] We have another question about concussion asking to expand on the relationship or comparison between post concussion or Vestibular disorder. What does the treatment look like for those?

[Laura Morris, PT, NCS] I'm stopping, because I could talk about that for the next few hours, so I will try to keep it brief. Concussion is really synonymous with mild brain injury. It is an illness that happens in the brain that is mild in nature. We consider it to be an acute condition. It should recover very quickly. The vast majority of people with concussion recover in about four weeks time, three weeks time if you are an adult, and a little bit longer if you are a younger person. So we expect that recovery to happen pretty quickly. If that recovery doesn't happen quickly, then we consider that person to be in a – of what we might call subacute or protracted recovery from that condition. And that can go on for a few months, so about a three month period of time. The term post concussion syndrome is one that is a little big gray, and one that I am not super fond of. And that's my own opinion. But it's typically thought of as being anyone who has had a condition -- their concussion symptoms have lasted longer than about three months. That's sort of the unofficial definition.

And that post concussion syndrome is whatever you haven't recovered from. So that could be you have chronic headache, chronic neck involvement, neck pain, neck dysfunction. It could be that you have chronic fatigue and problems with endurance and those sorts of things. And it could be that you have chronic Dizziness. And that chronic Dizziness, I would argue, we can give a diagnosis based on what that Dizziness is like. Is that Dizziness post traumatic Vestibular migraine? Is that Dizziness because of an actual peripheral problem, which is much less common but can happen? Is it because someone has developed into something that is more like a PPPD presentation? So I would argue that post concussion syndrome just means that you're having symptoms longer down the road. So let's address that instead of giving it a broader term. I hope that answers your question.

[Danielle Tolman, DPT] I hope -- I think that puts a spotlight on central Vestibular disorder it is hard to make this conversation easy to generalize from. There was a lot that can vary between person to person, but there is still hope. There is a lot that we can do to improve life.

[Laura Morris, PT, NCS] That's the great thing about working in this field. Over time we have learned so much more, we know so much more, and we have been able to hone in on what we can do to improve upon these conditions. it's not easy, it's really, really not easy, and not quick. But with the right plan and with good lifestyle choices, you can set yourself up for a really good recovery and healing. Doesn't mean you're going to be 100%, but we can get you out doing what you need to do in the world.

[Abbie Ross, PT, DPT, NCS] I think this is a mic drop moment.

Thank you so much for coming. Awesome questions from the audience. Please keep them coming. Thank you, Laura.

[Laura Morris, PT, NCS] So grateful to be able to discuss this stuff with you. It is my great love.

[Danielle Tolman, DPT] We can tell. Thank you, thank you. Talk again soon. Let's bring Laura and on up here, hello.

[Laura Cala] How amazing was that? Such a perfect opportunity for the patient panel to come in and discuss.

Hi, everyone. Welcome to day 4. My name is Laura. I am based in Australia. My diagnosis is Vestibular migraine. Today we have Pooja Rawal and Jennifer Warner.

I'm going to hand it over to Jen to give a little bit of background about diagnosis. If you have questions, post them in the q&a, and I will be monitoring the chat as well. Hi Jennifer. How are you doing?

[Jen Warner] Hi. I'm good. Normally people call me Jen, but Jennifer is fine. I was only diagnosed with vestibular migraine in 2021. Upon moving to Chicago, I lived with recurrent BPPV since about 2011. And it was always just sort of dismissed as Oh, you know, I guess you're here, you know, BTCD comes and goes, Don't worry about it, don't worry about it. And despite the fact that I had a long history of suffering from really terrible headaches that were actually sort of located in my neck, I was never officially given a diagnosis of migraine. Except for one time, 25 years prior chronic five years ago, I had an episode of lost vision in my eye. And in my right I went to the ER and after a lot of evaluation, I told myself Oh, we think you're having an ace of Belgic migraine, which is a migraine with aura, but nobody did anything about it at that time. And they just sort of sent me on my way.

And so years tick by I would get these neck headaches. And it was just never treated. Everyone just assumed it had something to do with my neck I was sent to and from PT. And then you know 2011, I had my very first episode of BPPV. So fast forward to 2018, December 2018. Where I, you know, as happens for me, it all BPPV always comes in the middle of the night, I woke up with what I thought was BPPV. And, you know, I did my Brandt Daroff exercises that had been given by one of my providers, which was not helping and things just kept kind of getting worse. But I didn't actually go see this particular PT at that time I was living in Seattle. I just kept trying to work through it.

I'm a psychotherapist and a clinical social worker. Just like God, I feel awful, and it was lasting for a month and I just I felt like I was you know, kind of walking on foam. I finally went to a neurologist. And he said, Oh, okay, you know, maybe you're having all the departmental syndrome. You know, that's what it sounds like... (technical sound issue)

I'm sorry this is taking a long time, but I am sure it takes a long time to get diagnosis. My Neurologist at that time thought that maybe she's having a Syndrome come up but they kind of dismissed it, and as December ticked on, I started to feel a little bit better, wasn't having positional Vertigo anymore, but eventually they did a whole battery of Vestibular tests, and they said everything is normal and sent me on my way. While I continue to not feel well, it just sort of lasted.

And I moved to Chicago, and that was in 2021, and we were here in Chicago for maybe a month, and I woke up one morning, and I was like ohh my lord. My school felt like it was crushing into my neck. I thought I was having a stroke. It was that bad. Everything was spinning and it was terrible. And I knew because of my history of this that I needed to contact Vestibular PPPD, but I had only been in the city for three weeks, and I finally found his Vestibular PT. She worked for a month on what she said was Bilateral BPPV – 2 Canals, in both ears – and then she said I think you're having this Vestibular migraine and BPPV – It's sort of interesting. So I did hook up with an auto-neurologist here in Chicago, and he did the usual battery of Vestibular testing, and he said everything seems generally normal. Maybe you have

Vestibular neuritis, it's hard to say. Maybe it's a Vestibular migraine. So that's where I was left. The diagnosis is now officially Vestibular migraine. It's taken awhile.

[Laura Cala] People are saying, how often do you hear, it’s all normal? And you know it’s not normal. So there are sort of similarities coming and going, but I would love to hear more. I’ll pass it to Pooja. She's going to tell us a little bit about her journey, and then we'll crack on into the questions.

[Pooja Rawal] Hi, thanks for having me. And once again, it took quite some time to get diagnosed. One of the first times I had an episode, I would describe it like I -- someone slammed the brakes in the car, and I move forward, but I wasn't actually moving. And I started out my primary care doctor and worked my way through everybody, ENT, allergists, cardiologists, you name it. I did Vestibular physical therapy three times a week, and everything was coming back normal, which I guess is good in a sense, but it was also really terrifying because what I was feeling was very real and initially when just kept telling me you have anxiety coming you're just stressed, your life is stressful, and I'm like nothing extra stressful has happened to me, so it was just that dismissal of, well it's anxiety, it's anxiety.

And then I finally saw a neurologist who was like, at the time, he diagnosed me it: atypical migraine with aura, and that's really all he could say. And I started on the usual typical migraine medications, like tryptoline ones and I don't even remember what the rest of the meds were, like triptans and all those. But nothing was working for me. And this took -- I would say the first time I saw it help was around 2018 or 2019, and I don't think it was until about end of 2020 that I had an official diagnosis of the atypical migraine, and my Vestibular migraine diagnosis didn't actually come until about a year or two after that, but I believe it was the end of 2020 when I switched Neurologist.

Someone recommended my current into becoming and she saw me and was like, ohh you have Vestibular migraine. Duh. Duh. And it was -- since I've been with her, it's been just much better. She really listens to me and hears me out when I talk about what prior treatments I've done, and I'm sure, just like all of you, we've tried probably 8 to 10 minimum before we land on something that helps us manage anything, and so it was quite a long journey. I guess time wins. It doesn't seem that long, but when you're working and everything, and I had to take FMLA, and I had actually started a new job that I had to leave because I was too new so I couldn't qualify for FMLA.

My old job thankfully took me back and I immediately went after FMLA because they knew that was the situation, but the PPPD kind of came a little later, kind of recently, I would say last year, and it kind of just went hand in hand -- the vestibular migraines trigger the PPPD, and while things are getting better to manage, every time I have an attack, it almost feels like it's the first time I'm having one, and I have to remind myself, wait a minute, you've done this thousands of times where you know what happens next, and you're OK, and a part of it is giving myself a pep talk to not make the attack even worse, because if I start to panic, then I also have -- it gets worse, and I'm sure all of you have experienced that too.

[Laura Cala] There are so many things there that correlate with my own journey, and I think there's a lot of people in the chat that are also sort of agreeing. Is so interesting. It's that notion of there are so many different things to try, there's that continuous -- your Neurologist said it was a Vestibular migraine. That's exactly what happened with my therapist.

That leads me on to my next question, is had you ever heard the word Vestibular before? Because I certainly hadn't when I went to my therapist and he said you have a Vestibular migraine. And I was like, well I've had a migraine for as long as I remember, and similar to what Laura spoke about in the previous session, he explained it to me like a chameleon. Chameleons can continuously change in your migrants can continuously change. But I'd love to hear how your initial experience is just with the word Vestibular and when you were in the process of getting diagnosed, what were your initial onset thoughts, and what was going through. Over to you Jen.

[Jen Warner] That's such a great question. I had heard the word Vestibular. I've been dealing with chronic illnesses since probably 2007. POTS, Ehlers Danlos Syndrome, and I had kind of become a little bit of a zebra. I had always been a pretty healthy person, and in 2006, a lot of things changed, and I ran the new York city marathon and everything changed right after that. So it just kept getting new diagnosis of things like pre malignant blood disorder, and I had heard Vestibular because even though Dizziness wasn't necessarily my presentation, there was always something that was along the way because especially with POTS, you can have Dizziness with POTS. But it wasn't until 2011 when they mentioned Vestibular to me, and I was like that makes sense. I also as part of my work, my work because of this has become with people who are living with complex chronic illness, so as part of that I had heard it, but my understanding of it was actually pretty scary back then, because no one could explain to me why I was suddenly having these episodes, and there was always so much nebulousness and dismissal around you've got all these things wrong, and maybe it's your Vestibular system, and maybe it's your autonomic nervous system is just wonky.

I remember one of my doctors said that I had a deranged immune system, and I was like you're making me deranged, and my immune system. So I've heard and had to learn, and I'm sure like so many of us end up having to educate ourselves come out that's fine line between educating yourself and frightening yourself, because you start to read about things and it can become quite frightening. I'm not even sure when and how I learned the word, but it came out in one of these experiences. I'm not sure if I answered your.

[Laura Cala] No that's wonderful. How about yourself?

[Pooja Rawal] I had heard Vestibular probably in college biology or something like that, so I knew Vestibular had to do with ears and balance and things like that, and really the only thing I could -- prior to this, when I heard the word Vestibular, I would think of Vertigo. And that's about it. And then I heard the word migraine prior to this, and I would think of really bad headache, and things like that. So when I was first -- by the time I went to my Neurologist and she said Vestibular migraine, I had felt like I already heard the migraine diagnosis, but with my first Neurologist, he diagnosed me with atypical migraine with aura, and I was always like no I don't think so.

I don't get headaches, I just don't, and I was like are you sure it's a migraine? It took me a long time to accept that you can have a migraine without a headache and it's still a migraine. And so when I really started to understand Vestibular migraine, it was like OK, your migraines have Vestibular symptoms and when I started to look at it like that, it all kind of just clicked and made sense. But when I first heard the two words separately, it's like are you sure it's me?

[Laura Cala] That's fantastic and I guess let's take it one step further. When I tell people I have Vestibular migraine, or that's what my diagnosis is, obviously close family and friends see you initially struggle. I know back in 2016 for me, it took a good three years before -- no four years before I was given my diagnosis, so when I turned around and said -- when I finally got it and said I have Vestibular migraine, everybody was like oh so you have a headache? Well they just didn't know, and just as if it was no big, just take an advil and everything will get better. Obviously initially, because I had been given so many different diagnosis from general anxiety disorder, and I'd gone to every other specialist, and as I put the words together, I thought how could this be migraine? For me, I settled on the migraine part of it I said are you sure it's Vestibular migraine? So, I'd love to hear how you explained your disorder to other people.

[Jen Warner] That's another good question Laura. I think this is true for all of us again who are living with complex chronic illness, particularly Vestibular Disorders, they're so hard to explain to people, and Vestibular migraine is for whatever reasons especially hard to explain to people, and I still struggle with it so what I will say is it's a migraine that doesn't necessarily have to have a headache associated with it, though for me my headaches will often end up triggering my Vestibular episodes. But that creates Dizziness and sometimes Vertigo, and in my case, that Dizziness and Vertigo will go from being a central issue to a peripheral issue because I will wind up with positional Vertigo based on the otolith, so it's complicated, and most people will look at me and say OK so -- it's like trying to explain any of the other things that I mentioned like Ehlers Danlos Syndrome or POTS or dysautonomia in general, or other things in general. There's such a glazing over that happens for people where they can hear one thing and then they sort of stop listening, and then I don't know if anybody else has experienced this come up but they get very anxious, and I don't know if that's because I'm a therapist and they don't want to see it, but it's almost like they start to feel dizzy and don't want to hear it anymore when they start thinking about it, and it suddenly becomes about them. So I just stopped talking about it right so I do my best just by kind of breaking it down into chunks, you know migraine, in Dizziness, and sometimes Vertigo, so that's where I left it.

[Laura Cala] And the chat is agreeing as well. It gives that notion we're almost like because we can say it so confidently now, well that's what I have and I'm managing I'm dealing with it and yes I still have it, but it's really that notion of I had one – someone had written it in the chat now that I explained I haven't neurological condition because it's easier, it can become somewhat exhausting to have to go and explain it to someone I don't think is open to really understanding without giving advice. What have your experiences been like?

[Pooja Rawal] Pretty much the same. I think anytime -- this is my just my personal thoughts come up but I think anytime you have an illness that you can't physically see, the person in front of you if you've never experienced anything like that come up they're just not going to get it. Or unless they have first-hand experience dealing one on one with somebody who has experienced it, so I love my friends dearly, but I have explained to them 1000 times what Vestibular migraine is, and still they just call it a headache and stuff like that, but I totally get it because even if I look at my diagnosis sheets with my medical providers, it's often listed as headache, and if you ever go to the doctor and you see what conditions you have come up oftentimes they just write it down as headache, and sometimes I'm like do I correct them or do I not? And is even worth it?

I like just saying, like that one person that chats saying, I have a neurological condition that it makes me lose my balance, and it's chronic, and I never know when it's going to happen. And that's how I explain it. Obviously I'm pretty sure like most of us, we can kind of tell when an attack is coming on, but I think for the general population, when they're hearing it, it's just best to explain it like that. I think otherwise it just gets dismissed, like are you sure you're not having a panic attack?

I think I know I -- I think I know what I have, so thank you for trying to help me, but like I said, unless you have something, like you have a cast on your arm or you're working with a limp, I think that people mean well, but if they can't see it, then it's hard to relate. That's all.

[Laura Cala] Absolutely. And you pick your battles don't you? I had a question about earthquakes triggering migraines. We don't have many earthquakes in Australia, so I haven't experienced it, but Jen how about yourself?

[Jen Warner] That's such a great question. I grew up in new York city, and not a whole lot of earthquakes obviously in new York city except in 2011 when I was working at a clinic. This is long before I was diagnosed with vestibular migraine or really even migraine except for that one time 25 years ago. What we did have -- I was working at a clinic in Brooklyn, and there was a very mini trimmer, and what was so strange about that day -- because I think I had had maybe one episode of PPPD, but I dismissed it as all of my doctors had but the day that that happened, it was really strange.

I had been in the bathroom, and I didn't feel any of the shaking, and I came back into my clinics office, and all these things were on the floor and my colleagues were sitting on the floor nervous, and they said did you feel that tremor? Here's the thing. I remember feeling really nauseated. Like, nauseated, a little off balance, and not knowing what it was. And I was like, I don't feel anxious about that. I didn't even feel the tremor. But there was something about it. And we're talking about it -- you can't even call it a earthquake because this was the mildest tremor, but I absolutely do think double that it's just like barometric pressure where there are changes in your environment, and how can there not be? That's my experience.

[Laura Cala] Absolutely. Pooja have you had a similar experience?

[Pooja Rawal] I have not. I live in upstate new York, so we don't really experience earthquakes, and prior to that I lived in new Jersey, so I've never really experienced anything like that. But just imagining it, I can see how it can definitely trigger. The ground is mooting beneath you, and what other trigger could be bigger than that for a Vestibular episode of any kind? But otherwise I can't really speak to that.

[Laura Cala] It's one of those things as Jen said, and I know we certainly spoke about it earlier in the week, and it's sort of something you can't really control, but it's something you have to manage your symptoms with.

We do have a few questions coming in in the Q&A which is fantastic. We'll switch across to another question. Marcelo has asked, have you seen any correlation with treating your upper neck to reducing Vestibular migraine chemic in my case, my pressure in my neck and migraine pain have always correlated, and I do think a lot of that is connected with my Vestibular. I do things like yoga to ground and reposition, and I do try -- if we work with a computer, so I do try to always consciously get up and move around as to not load extra pressure. Jen, how do you manage that?

[Jen Warner] Another great question. And it was such a relief when I finally had Neurologist who were listening to this issue with my neck, because again my migraines usually center themselves somewhat usually in the back of the skull, but entirely in my neck. It's awful and excruciating, and it goes into my eyes and my jaw. So yes, absolutely dealing with my neck issues, but that's been largely through -- while I've had some PT, but PT for me, and this is you, can kind of trigger neck pain, which can activate a migraine, which can activate Vestibular symptoms, but two things that have been super helpful for me has been botox for a migraine treatment, so I've been luckily enough to have a Neurologist for that, and insurance covers it, and the other thing is actually rescue meds, so neurotech ubrelvy. I will take those, and technically they don't take Vestibular migraine, but if I notice that I'm starting to get neck pain, I will immediately take neuretech or another pill, it calms my pain which settles the Dizziness for me, and again that’s not always. There are obviously some variables come up but that's been very helpful for me.

[Laura Cala] Wonderful. Pooja, how about yourself?

[Pooja Rawal] I also experienced a lot of neck pain. I have a congenital fusion there, so already it's quite tense back there, but with my migraines, same thing. It's almost like I can feel everything kind of tighten up, and I also get botox for migraine. And every time they come to do the shoulders, they mention that your shoulders in neck area are rock hard. And I just explain that I'm not tense. That's just how it always is.

And so I found relief with botox for migraine. It took me quite a few rounds I've had rounds just for some reason that don't work as well as other other rounds, and then I also do acupuncture. I find that that helps a lot. And just the rescue meds as well. For some reason for me, the neurotech didn't work, but ubrelvy really works for me, so same thing. If I start to feel it I will take one, and I also did a gamma core device that is a vagus nerve stimulator, and I should be better. But the preventive part of it sometimes I miss one or two here or there, but in terms of rescue, that has been really really helpful.

And I know that all three of those, botox, acupuncture, vagus nerve stimulators are all very expensive, and so I'm lucky that my insurance does cover the botox and the acupuncture, because the acupuncture is done as a referral through my Neurologist, and so that way I am able to just pay my copay for that. But the gamma device is quite expensive, so I do have the budget for it, but I can understand that for everybody that's not an option. I don't know what else I would recommend to help with neck related pain – massages I guess. I don't really know. These are just the things that worked for me, and I know that neck stiffness does play a huge part in it.

[Laura Cala] That's wonderful. Jen did you have something to add? Thanks so much for sharing.

[Jen Warner] I always wanted to try gammacore, apparently it's contradictory for people with heart conditions and other things as well as being expensive, although I'm thrilled to hear that it's been helpful for you, because I've heard that for other people. My Vestibular PT here in Chicago, who thankfully takes my insurance, also does something called dry needling, which is similar to acupuncture, but also different.

When there's acute muscle pain, it has been a real life saver, so if can't -- if you're lucky enough to have a Vestibular PT, you can ask if people are in for dry needling. I would only go to someone who is a PT and really understands the body or another medical professional who does come up with training is very helpful to you.

[Laura Cala] That’s great Jen. I know we've talked about some other alternative treatments like botox, but Jen and Pooja have any of you tried injections for your Vestibular migraine? Can I pass that to you first?

[Pooja Rawal] So aimovig has been offered to me, and some as ajovy, and there's a new one that's like got an infusion I don't recall the name right now, but all three I personally have turned down. I'm just not ready to try that yet. And I say that because I find that my migraines are fairly managed well with what I'm doing right now, so I still have about 5 or 7 attacks a month come up but I can usually predict when they're going to happen plan accordingly, and recently my neurologist -- I saw them last week, so they told me that with one of the meds you can take it now as a prevention so if you know you're going to have an attack -- my attacks I've learned are generally around my cycle, so I can kind of predict when it's going to happen, and I can take your ubrelvy as a prevention. I also do eye drops as a rescue. But ubrelvy is kind of like my heavy hitter. I know if I have something to do and I can't miss it, I will just take the ubrelvy because I know it's going to take care of it. As far as the injections come by I personally don't have any experience with it, and I chose not to take it because I was afraid of having a reaction, and it's something that you inject and it will last for a month, so I think you have to discuss your own individual needs and comfort with your provider, and so I know two people who take it, and have had excellent results, they don't have vestibular migraine. They have your typical migraine, and they have had phenomenal results with it. So that is why I even considered it in the 1st place, but other than that I have not taken any of those.

[Laura Cala] That's wonderful insight, how about you Jen?

[Jen Warner] I have not tried it. It's been offered to me, and I'm very similar in that I get 5 to 7 a month around menstrual cycle, and they're fairly predictable, but I don't take it for a couple of other reasons, which is because since I have pots which impacts -- it's an autonomic nervous system issue, but aimovig and vyepti -- because they're CGRP inhibitors, and they can create constipation -- in fact I have a psychotherapy client who had taken aimovig and had severe constipation as a side effect. But because it can impact digestion, and I already have issues relating to dysautoanomia impacting my digestion, it was decided it wouldn't be safe for me, because as Pooja explains, it has to wear off, so there's no way to reverse it if you start to have complications and again, it's very individual when talking to your doctor about it. But that's why I didn't take it.

[Laura Cala] Thank you for the insight. We've a couple of questions that are coming in with the Q&A and on the chat, what has been the best treatment plan for your Vestibular disorder? Whether it's what you're currently doing now, and if that includes a combination of a lot we talked about, whether that's acupuncture, supplements, diet, medication. What does your treatment plan look like at the moment?

[Pooja Rawal] So this might be a little long winded, but initially I did the heal your headache elimination diet just to get rid of any triggers that might be food related, and I did have a couple that I was kind of eating regularly, so I still follow that.

Maybe not as strictly anymore, but then I get botox for migraine, and I tried to do the gammacore every day for prevention. I do acupuncture once a week, and I do eye drops and pills, and the gamma core device. I think with the combination of everything -- and I manage my stress levels, not to go back to the beginning when they were saying you have anxiety because of stress, but I do find that if I have an attack and I stress myself out about the attack, my attack will last longer. So when I say I manage my stress levels come out I just mean would I know an attack is coming on, I focus on the attack as opposed to how long is this going to last and why me? Well for a long time when I had an attack, I was wondering why is this happening to me and what did I do? I would be very dramatic about it. It was very scary and nobody ever listened to me, but now that I know what's going on, I have an excellent Neurologist who I can message on a portal and she will get back to me right away. I have an excellent acupuncturist who I can text message right away and say I think an attack is coming on, can I get in imac and so I would say finding -- it's a long journey to find out what works for you, and like I said, it's not just one thing I have a couple different things in my toolkit that I use to prevent and to treat, and also having providers that really listen to you and are there for you, and kind of respect you like you respect them is really really important. Because I can tell you my prior Neurologist was brilliant and great there would be times that I was having an attack and I just couldn't get in touch. There was one time that I had an entire class for two weeks, and I was just being passed around. It was just the way their office worked. And so that was very frustrating. This is what's working for me, and I don't know if it would work exactly for you or anybody else, but you'll know when it works. For me, it wasn't like -- I wasn't even conscious of I was getting less and less, it was like I was was just living more of a normal life again and I started to realize, wait a minute, I can drive here and I'm not worried about having attack while driving? Because that was always one of my biggest fears. I wondered what it would happen if I was about to lose balance and I'm on a 5 lane highway. What am I going to do? That would make me more depressed, and when my triple D was really bad, I couldn't even cook or make stir fry because the colors of the vegetables and stirring them and all the little pieces would trigger an attack and I started to realize, wait a minute, I can cook again, or can do this again. And for me that's how I realized it was working. I didn't have one day I mean an attack in one day I wasn't coming in I was like this is with working. It was a very slow and gradual process. And that's also kind of why I'm hesitant to even try other options, because why mess with a good thing? I'm fine with the five to seven attacks a month.

[Laura Cala] That's wonderful thank you so much for sharing that. I love how you explain that there's so many layers, and you find that things that work for you, and you add them to your toolkit to help you manage those future attacks. Jen how about you? What does your ultimate treatment plan look like?

[Jen Warner] I have to say that affexer has been very helpful me. I was a little bit hesitant, and I'm sure everyone hears about how hard the medication is to come off of and etcetera. But when my Neurologist had said this is one of the only antidepressants we know has some effect on Vestibular migraine, I thought OK. And that has been an absolute game changer for for me. That was wonderful for helping with Vestibular symptoms. Again, it's not a cure all, but it was very helpful. When I am having an episode of BPPV that has been triggered by a prolonged period of migraine, obviously Vestibular PT, but neurotech and ubrelvy are great. I have found some dietary triggers, but diet doesn't seem to be a huge trigger for me, there are the obvious ones, so I really avoid those things. But then also dry needling has been helpful, botox has been very helpful, and then meditation. It is very helpful for me, as is exercise. Exercise can be very very scary, it's almost impossible to do when you're in an acute flare, but any kind of movement and just reminding your body that it can move has been key. And maybe I'm biased because I am a therapist to come up but I think therapy is very helpful too. so I have my own therapist to talk to about this, because I'm in the process of living with complex mental illness, and there's no shame in it, but you do need somebody other than your partner or family members to talk to you about it, and I think that's the wonderful thing about organizations or meetings like this where you can talk to somebody and say, I'm totally freaked out today, and they can say we get it. Then we get through that.

[Laura Cala] Thank you so much for sharing that. I know myself -- I initially went on a diet, which I for the most part follow, and when I don't follow it, it's more self inflicted anyway, so if I had red wine or pizza, I'm more likely to have an attack when I got to 70% under control, that was when I was put on effexor, and that changed the game, and I know for some people it doesn't work, but for me it changed my world. Going back to the Q&A, there's a question that's coming from Tanya.

And she says, when you feel an attack coming on, what is your first symptom, and are there symptoms are there times you can stop your symptoms from progressing further? I'll hand that one over to you Pooja first to kick us off.

[Pooja Rawal] I feel an attack coming on, sometimes I can catch it quickly and stop it, but oftentimes, usually it's around my cycle like I said, and there's nothing I can do to prevent my cycle until I go through menopause and so I know at those migraines are going to come and be bad, and they're going to be difficult. And so I can't stop those.

Once or twice, my medications haven't worked, and I just need to lay down. If I have something planned, say there's something in the future, I will try to plan it around my cycle. If I'm making plans for something, I'll make sure that I'm not gonna be running through an airport or flying on a day that might coincide with something like that, because those types of events are already triggering for people with Vestibular migraine, and the change in air pressure and things like that, and fluorescent lighting is one of my main triggers, so I have to be very careful even about things like that on a day to day.

I used to be embarrassed, but I don't care anymore I will wear sunglasses in the store or do what I have to do, and sometimes I'll do it at a doctor's appointment or something which I think is kind of funny because you're at a doctor's office treating migraines and you have all these fluorescent lights, and I'll just say I get migraines and have to keep my glasses on. I'll just say something like that but sometimes I can stop them, and sometimes I can't. I kind of just go through the same process as always. If I feel it coming on, usually I think a part of it because I have become very mindful and in tune with my body, and I feel like I have now become a person where I can sense a very minor change in my body, and so for me that helps me identify that something might be happening. so for me prior to an attack, I might have a bowel movement change. Just something very minor. And now I know wait, wait a minute, I'm gonna have a migraine in a couple days. I open up my app for my cycle, and I make sure, and here we go here we go. And then I take my medication ahead of time, or a couple extra gamma core sessions I don't necessarily take another pill at that time. Ubrelvy I wait, even though I can take it as a preventative, I've only done that twice so far. usually I wait for the first attack come out right it feels like the grant has been pulled out from under being, and I will take it right at that point point .

Usually it tends to work, but sometimes it doesn't.

[Laura Cala] That's really helpful. Jen, how about yourself?

[Jen Warner] I'm a therapist and I see people every day on screens all day, so sometimes I have a standing desk and if I get the feeling of the store they'll dash the floor starting to go, and I started to get nauseated and my neck starts to spasm, I just can't stop this session. In fact, I have had to work through a lot of these, which have been difficult, but it's really starting to get bad, the first thing I will do is I will take a ubrelvy or azertac, and the next thing I will do is drop my shades, and I will put on my migraine glasses or any of my glasses that have blue light blocking tech, and I make sure my screen is as dim as it possibly can be without being dark, and I will make sure not to fixate here, so again lowering my light, taking a preventative, and if I'm really starting to super gross because the nausea can get fairly intense, I will position myself on my couch and be slightly elevated and put a warm compress on my eyes, and put an ice pack on my neck, and do all the other things that I mentioned as well, and really try to make sure to do some diaphragmatic breathing. I really try to notice any areas of tension and relax my body that way, but for me cutting down on visual stimulation is very helpful, and you probably noticed that I have my little stadium cup of water. I always have ice water with me, so staying hydrated Hydrops is really important.

[Laura Cala] That's really helpful. so let's move on to resources that you looked into initially appeared I know we sort of spoke about how sometimes there's a fine line, and it is scary and I remember how at the beginning how scary it was reading about things come up but I remember when I found VeDA. When I found David's group on Facebook, it was everything all in one spot. So for me that was absolutely huge. Jen, what were your experiences like finding the resources especially as a therapist? Where did you go originally? And Cynthia is sharing some fantastic things on the chat ask questions come up, but how did you initially go about going down the rabbit hole of all things Vestibular and knowing what was credible and what wasn't?

[Jen Warner] That's a great question. I would say that both VeDA and social media and Instagram was very helpful in finding people that had the hashtag of Vestibular migraine, and that was helpful. Doctor Timothy Hain, who is now since retired and has been replaced by doctor Marcello here in Chicago, -- they're very well known. They have a website called Dizziness and balance, it's a wonderful resource for all things Vestibular. It is the most comprehensive resource come and that's what I limited myself to. And I ended up seeing one of the doctors in Chicago but I know someone else, but he's very fond of information, so that website is what I relied on.

[Laura Cala] Wonderful. And now Pooja, how about yourself?

[Pooja Rawal] For me come on I must have just been googling something, and I found out about Alicia's blog, and I just clicked and it happened to be on the page about her journey come on I was reading that, and I was just like, there's somebody else in the world who has experience other than me come on I remember I immediately got on Instagram, and I found her Instagram page and added her, and I messaged her and I told her you just changed my life. Just to know that there is somebody else out there that had gone through this was just so validating, and reading her story was just like come on this is me it's me. Of course there was differences come up, just to have that was amazing on Instagram -- once you add one person have you started to get recommendations of everybody else, and I was just like yay.

[Laura Cala] It's the best feeling. I was the same. I remember finding Alicia and I messaged her straight away, and I was just like, -- I couldn't believe it. I was reading online, and being so far away, I was like there's somebody that understands exactly what I'm going through.

It's so incredibly validating to have these conversations, and even listening to people talking in the chat, it's the whole community of people that just get it. You don't have to put up barriers or cut it down small. It's a whole community of people that just understand. And there are some questions coming in about the Facebook groups groups we mentioned. Pooja did mention the dizzy cook, and Cynthia has a question, and I put those links in the chat, so have a check on there and give them a follow here I'm gonna go across to one of the questions on the Q&A. Amy has asked, what do you do when all fails? Do you stay at home? I know for me, that's just not possible sometimes. When Jen says, when you're in the meeting of meetings -- when you're in the middle of meetings or at work, or there are things that you just need to get done, sometimes it's a measure of pushing through and filling with it afterwards I know similar to what Pooja had said before her, much of mind happens around my cycle, so I plan accordingly to that. Jen, what about you?

[Jen Warner] For me, if I'm out, I'm just going to be really compassionate with myself and say here we are here I'm not gonna be enjoying my plans if I try to go out.

It's gonna be miserable in the stimulation is gonna be far too much. Getting in the car, public transportation, lights, sounds, smells, it's just going to work work if you're having an attack kind of like your body is giving you a signal, and it's saying please slow down. It's OK and I am as type a as the next person. I'm a full virgo. And sometimes you just have to rest, and that's really OK. And I've learned that. I feel like this condition has taught me so much about self compassion and also what it means to listen to your body.

Your mind talks in words and your body talks in sensation. when your body is talking to you, you really have to listen.

[Laura Cala] Yes I love that. You just said that's perfectly Pooja, how about yourself?

[Pooja Rawal] I'm an attorney, so if I have a court date and I'm in front of a judge, I can't stop. I also have a duty -- I work for the government, so I have the duty to the state to represent them properly. I can't just throw a case because I'm having an attack. I can think of 1 very clear time I was having the worst attack right in the middle, so we couldn't stop, and we couldn't do anything. I couldn't even get medication out of my bag and wait for it or nothing and so I was stumbling over my words and losing my words.

That's how bad the attack was. Sometimes when I have a really bad attack, it's hard for me to get the words out. And it went on the record, but I had to say, excuse me please. Just give me a minute while I gather my thoughts come I'm having a migraine attack. I find that just being honest like that, most people aren't going to be like, what? How dare you. They'll just be like, OK, and understand. Another time was quite recently. I have PCOS, so sometimes it's hard for me to predict my cycle. I don't get that typical 28 day cycle. I rely on a lot of other things within my body to tell me that the migraine or my cycle is changing and my migraines are coming on.

I remember I was just at brunch with a friend, and I already cancelled on her two times prior, and so I was not going to cancel this time, and I knew that I was going to get a migraine. So one of my medications that I very sparingly use is a benzodiazepine, and it's called klonopin I'm sure a lot of you are familiar with it if you've experienced Vestibular migraines I just took one right at the table, and it's fast acting, and it helped me manage some of my symptoms and get through, and even enjoy myself a little bit before it ended.

A lot of it is just powering through when you don't have a choice, like I said previously, if I do have a choice, I try to plan things around my cycle. It kind of sucks, but that's just my new normal now. And so I don't even really think of it as a burden. But if there's something I really want to do or I have to do, I'm not going to let my diagnosis and my attacks take that away from me if I can have anything to say about it.

[Jen Warner] Can I add one thing to that if that's okay? As Pooja was saying, as an attorney or even as a therapist, I work with -- my clients have PTSD, and traumatic stress, but absolutely you do have the duty to show up for your clients and work, and in both our situations, that's necessary. I too am honest on my website, and I'm honest with my clients about the fact that I'm living with health conditions. I do not abuse that privilege of taking time if I need it. In fact I've only ever done that once when I was having what I thought was a stroke back in 2021, and it was not really, but it was awful, but I think when it's social time that I might be able to stop down and not do, I will do that for myself I really do feel like it's important to give oneself permission to do that.

And if it's work, it's tricky. Sometimes you absolutely cannot. And sometimes like in my case, there can be a modeling of, I am not feeling well today, and if you see something in my expression you are correct, but I am fully here with you, but in the interest of transparency, I want you to know, in that honesty as Pooja said is very important.

[Laura Cala] Wonderful. Goodness, we could think -- talk for hours about the subject we've only got a few minutes left, but perhaps to close off we could give a piece of advice for someone who's trying to understand their Vestibular disorder, especially for those who are feeling frustrating and looking for answers.

I know in the chat, there are people who are asking how they can come and see you, Jen, but maybe you'd like to mention how they can get in contact or whether or not you want to post that in the chat later. My message as it has been for most of the week, and I mean as both of these wonderful women have shown, it just takes that perseverance and patience, and finding something that works for you, and when it comes to trying to understand, I still am learning to understand, and I've had my symptoms onset from 2016.

So it's forever a journey, and you just need to be open to learning and adjusting, and it will get better. And you will be able to continue going forward. We're stronger than we think we are. Jen, how about you?

[Jen Warner] I don't think I could say it much better than you just did Laura, but I would add to that that there's about -- information is power. So it's the more education you have. By the way, that's like reliable information from organizations such as this one or the dizzy cook, where you're really reading something that's reliable.

Really allow that information to soak in. I know that for myself, a lot of the fear was tamped down. Not all of it, but tamped down by knowing what was going on, and knowing I was not going to die, and this was probably not going to last forever, and it would be pretty and pleasant for a little while, but almost like turbulence in an airplane, it's not comfortable, but what are you going to do? You've got to ride through it. And at some point you're going to hit some blue sky and you're going to land, so it's really about normalizing for yourself and recognizing this is scary for right now, but we can get through it.

[Laura Cala] Perfect. Cynthia shared your website on the chat, so for those of you who are asking for it. Pooja how about?

[Pooja Rawal] Both of you have said it so well, the only thing I would really add is that if you're at the beginning of your journey and you're here walking come out that's huge. That's a huge thing that you're doing right there. And if you're frustrated because you're not some results or anything yet, just keep going. I know how upsetting it can be here every medication you have to try for six months, and it's not going to work, and then you got another one, and another one, and just keep going.

You will find something, and when you do, you will start to get your life back. Just keep going. That's all I can say. And try to surround yourself with people that validate you and support you. I also wanted to mention this prior come up but I forgot. Therapy is huge. It's huge because you cannot burden your spouse or your partner or your children whoever is in your immediate circle you can't burden them with this. It's extremely overwhelming and unfair to that person. They can support you, yes, I have a therapist as well, and she is amazing, and when I first started seeing her and I was going through all this and I was having difficulty managing at work, I was seeing her two to three times a week just to figure out how to get through things.

And now I see her once every couple weeks, it's just something she says to me all the is put a, give yourself grace, remind yourself that you have a chronic condition.I have a couple other conditions too. When I start to get frustrated -- I have a 2 year old, and all these moms, especially in Instagram, and they're so toxic and up to all these fantastic amazing things and I'm just having a tax and this condition and that condition, and this is all I have to step snap myself out of that and say wait a minute, no, my daughter is healthy and loved, and as soon as she sees me she says mommy, and those are the signs and indicators. But I think having that great therapist to remind me when I'm not able to do it myself is very important.

Just keep persevering and keep going it will get better. It's almost too recent for me how frustrating and everything I felt, and how now I'm sitting here with a smile on my face talking about it, but I can promise you, it was not that long ago, and those feelings are still very much in the back of my mind. Just keep going to your you will have a treatment plan that works, and you will find providers that will help, and you'll find a community like this that will just hold you and support you.

[Laura Cala] I love that I can listen to both of you for hours, thank you so much ladies for joining us today, and thank you for joining us online here big thank you to Cynthia and all the volunteers. Cynthia shared some absolutely amazing resources that we've been talking through thanks again to James D and Linda B and the Discovery Fund, and the University of Minnesota Department of Otolaryngology for sponsoring this conference. As a reminder, you get lifetime access to the recordings and transcripts of the entire conference at vestibular.org/LRL-recordings you can make sure that the information of this event remains free by making a donation at vestibular.org/LRL-donate.