

Life Rebalanced Live 2023

TREATMENT & REHABILITATION

***This transcript may contain errors**

[Danielle Tolman, DPT] Welcome in thank you for joining the Vestibular Disorders Association for day three of 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 therapists with balancing act rehabilitation members of VeDA's board of directors and self proclaimed vestibulo-holics.

[Abbie Ross, PT, DPT, NCS] And we've had a great first couple of days with Life Rebalanced Live. Our speakers have brought such awesome information. We've had great questions come in from our audience, you guys. So thank you. And we've had a great feedback and input from our patient panels. We'd also like to thank VeDA's donors, staff members, and volunteers for their countless hours in putting together this great event. And we're so pleased with their contributions to be able to provide the live event on at no cost to our attendees. Now we will have the event available for purchase for just \$55. Following the live event, you'll have access to all the presentations and transcripts and what's really cool about that is All proceeds go directly to VeDA for their continued mission and spreading vestibular awareness.

[Danielle Tolman, DPT] Before we start, let's give a shout out to our sponsor this week, the James D and Linda B. 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 this tubular dysfunction in 2018, and 2019. We very much appreciate his continued support. And on another note, if you have any

questions you'd like to ask during the live event, feel free to type them into the q&a tab. As we've seen many of you do already. We've got a great lineup of awesome questions for Dr. Whitney.

[Abbie Ross, PT, DPT, NCS] Absolutely. Our topic today for day three is treatment and rehabilitation for vestibular disorders. Although we wish there was one treatment that would address all the stimulator symptoms and all the stability disorders. I'm sure many of you know, that is just not the case. So finding an effective treatment for you can be a journey of its own. And it often requires a multidisciplinary approach, which we've heard from our first few days or first few speakers on day one and day two, and we'll certainly talk about today. It can include medication, it can include lifestyle modifications, it can include psychotherapy, and vestibular therapy, which will be one of our focuses in today's talk.

[Danielle Tolman, DPT] So without further ado, we'd like to introduce you to today's speaker, Dr. Sue Whitney. She is a professor in the Department of Physical Therapy and Otolaryngology at the University of Pittsburgh and is heavily involved in vestibular research, having authored or co authored over 180 articles. Dr. Whitney, thank you so much for joining us today.

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Oh, thank you very much for the invitation.

[Abbie Ross, PT, DPT, NCS] I still can't get over 180 articles. I mean, do you have time? It's awesome. Thank you for all your contributions to our vestibular therapy world. And we're just going to get right started with some questions. The first one we touched on in our in our introduction, and also we've touched on in day one and day two, but we'd also like your take on this, a multidisciplinary approach has been most has been proven most beneficial for positive outcomes for patients. Can you describe what a

multidisciplinary approach may look like for a person with vestibular symptoms?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Well, I can tell you what I'd like to see places. It's really nice if if you're in a community where people can share and by that I mean there's a physician, a neurologist, ideally, obviously, an ear nose and throat physician would be exceptional or otolaryngologist. Ideally maybe a nurse or and or a psychologist would be part of the team. Access to testing - I'm telling you the magic place that doesn't really exist - access to to an expert, for example, a vision expert that can help because sometimes the dizziness is caused by vision problems. And and really a groups that can work together and psychotherapist and or psychiatrist can sometimes be really helpful, because it's not one thing. Often what happens is that people who weren't nervous or anxious before can become anxious after having an inner ear problem. And we you need a team to try and put the package together to optimally help somebody living with dizziness, because it's very frustrating.

[Danielle Tolman, DPT] Sometimes having that team approach might be different in some places than others. In some places where you might not have access to these specialists, you might have an ENT or a therapist that you work with. In other places you might have one person across all of the disciplines that you mentioned paragraph .

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] What we know from the literature is that people from different areas get different treatment for dizziness. And that's a problem, because many people don't live in big cities and don't get the kind of care, which is a problem.

[Abbie Ross, PT, DPT, NCS] I think one great thing that COVID brought is access to providers across the world, even if it's just a conversation. Access

to providers can be really beneficial to this patient population. When would Vestibular rehab be appropriate to enter the picture?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] I think as early as possible. There are three studies that came out of France by doctor Lacour. What he has shown is that the earlier Vestibular Rehabilitation is started in people with Dizziness, at least if they have one ear involved or two ears involved, they get better faster period. And what he found was that if you saw people within that first one to two weeks, their results were better in terms of their outcomes as compared if they were seen between three and four weeks or after four weeks.

It does matter. Time is important. That doesn't mean that if you've had it for a long time you won't get better. It gets harder. Timing is really important part. A lot of people don't know about this, and it is important for the world to start to recognize that timing can make a difference in your recovery.

[Danielle Tolman, DPT] You make an interesting point about timing in that when you receive Vestibular therapy can be pivotal. Are there times when maybe it's not appropriate? We see a lot of patients complain that the Vestibular therapy made them feel worse. What would you say to patients who experienced that?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] There is a dosing issue and an intervention issue. Sure all of us have screwed up. yYu give a dose and it's a failure. But if you don't fix that as a physical therapist, then that's the problem. You don't have someone continue to do that. I gave too much, it didn't work, it wasn't the right exercise to do. I think we all have to learn from that. And a person living with the disease needs to really articulate that so that we know that we have screwed up and fixed it.

There are people that have such significant symptoms that I know that if we don't try some medicine and therapy that they are not going to get better.

There's a magic to recognizing where it's going to be a failure if you don't try medicine and also exercise. It's clear that exercise improves people's function. It's not real clear what's the best exercise, though. Movement is probably the most critical thing for anyone living with a Vestibular disorder.

[Abbie Ross, PT, DPT, NCS] Can we talk about a patient with maybe uncontrolled migraine activity? So they get a referral to physical therapy and it's too much too soon. Can you talk about the management for that type of patient?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] When I see someone who's headache is terrible, if I give them exercise, all I'm going to do is make them sick. Someone will say I have these migraines and the therapist kept wanting me to do more. And I'm pulling my hair out, ohh, goodness gracious. I would say stop, you need to get the headache under control, most likely with medicine. So I would refer you to a good doctor who would manage that. And then we could start. We could get into a walking program, some simple things. But until the headache is under some control, moving your head around or looking at, like the scene behind me (heavily patterned background) can really increase people's symptoms. You can't do exercise when you're too sick like that. It's too hard.

[Danielle Tolman, DPT] It can be very difficult to pinpoint the best exercise to do for patients because it is very individualized. Each patient is going to react differently. We have a question in Q&A that pertains to this. They ask, I know it's important to continue to do PT exercises throughout life even after you've been much improved. Is this unique to the individual, or are there certain activities that are a priority to include in a maintenance plan.

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Whitney's rule is do what you love, because then you will do it. If you love to walk, do it. If you love to bike, do that. If you love to go to the gym... What we see is, people can

decompensate. I've seen it many times where someone did very well with an exercise with their doctor, and they were very active in their job. And then they retire or got a promotion. That's what happened to one guy. He got a promotion and sat in a chair, and then he got dizzy again. When he started doing exercises again, he got better again. People can actually decompensate, meaning that the function you had when you were moving is good, then when you stop moving it isn't so good. I try to get people to do what they love doing pure if I can get them to do something they love, then they will continue the exercise.

[Abbie Ross, PT, DPT, NCS] I love that rule. I also like to put an activity that I want them to do with something they do every day. You brush your teeth every day. Do it while brushing your teeth. You drink coffee? Do it with coffee. Link it to a habit that they already have. We know that patients can decompensate and then benefit from another course of rehab. What about when patients come to you and want to know, how long can I expect to do this before feeling better? Is there a general rule of thumb?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] We have written about this, and lots of other people have, too. When it's a brain, it takes longer to get better. We know that people are more symptomatic if it's a problem with the brain then a problem with the ear. Whether it's the nerve that goes into the ear dash and part of when you look at prognosis and how long it takes to get better, there are things that people bring to the situation that affect how long it takes to get better.

If you have balance problems and you also have diabetes, those people are going to take longer to get better because they can't feel their feet very well, many people living with diabetes. If have bad vision to start with -- my husband has very thick lenses. If he has a Vestibular problem, it's going to take longer, because he can't see very well to begin with. Or if you are a worrier, people who have anxiety are going to be harder to treat. It takes

them longer because it's a factor that affects your recovery. There is a lecture I give to physical therapist, and I try to get them to understand that if people have certain factors that when they present, it doesn't mean they are not going to get better, it just means that they are going to take longer.

That is what people need understand. If you can't feel your feet or you have bad vision -- there are a huge number of factors that can affect your recovery -- if you expect to get better , because I have had patients go to the clinical guidelines and read them, and it says, I should get better in six weeks -- I say, in the real world, I don't see people that get better in six weeks. I think the physician may, because they typically only send people who aren't getting better to see me, the PT. Take home message is it doesn't mean you can't get better.

[Danielle Tolman, DPT] I think that is everyone's biggest fear, is that this is what the rest of my life is going to look like. We have a question. Can we Vestibular Rehabilitation help with central brain disorder A PT told me they couldn't help me because my dizziness was from a central brain disorder. But I've heard migraine patients say that VRT was essential for their recovery. So it seems like they're kind of getting some mixed signals, and they're a little bit worried that they're not gonna be able to come back from a central issue. Is this right? Or is this wrong?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] People can definitely improve with central issues. One of the hardest ones is a progressive Dizziness that is caused by the back of your brain, which is called your cerebellum, your balance center back there. If you have any remaining function, the physical therapist can help that.

People who have had strokes, it is very helpful. People with migraine and brain injury, people who have concussion, we know that it will help those folks, too. It takes longer, generally. And you may not -- depending what the

damage was, you may not get full recovery. That can happen. But you can get better. I can remember a video that came out of Hopkins years ago, with a man who was speaking about living with Meniere's disease. He said if you walk into there and they tell you they can't do anything for you, he says find another doctor, because there's somebody who probably can help you. Don't give up, because there is lots of new advances in this area that can help you with your balance or Dizziness problem.

[Abbie Ross, PT, DPT, NCS] This is a great segue. Aside from exercise recommendations as a Vestibular therapist, often what we are doing is educating and providing tips and tricks to leave living life more normally pure sometimes that involves lifestyle modifications. Can you talk a little bit about what lifestyle modifications would be appropriate for this patient population?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] I try not to make too many, because people need to live in the real world.

I used to do a lot of that. There was a time when I would have people wear dark glasses, and now I've been persuaded that I was wrong. And I really try as much as possible not to give them too many adaptations. You don't want that all the time, for example, if you are living with vestibular migraine. The lights overhead are just brutal. But you don't want to adapt so much that really aren't pushing yourself toward being able to do things more normally. So I try not to do that too much now. I used to do that a lot, and I taught that to people. But I think I was wrong.

[Danielle Tolman, DPT] So it sounds like there is a time and a place for these modifications. For somebody at the beginning of their journey, using modifications like light filtering glasses can be helpful. We also encourage patients to continue trying to get back to those everyday functions, so they are not hiding from the light so much, but getting it in small doses. Sometimes we can be reliant on those tools. What about consistency and

stress reduction? I think anybody can benefit from those. Those are things I also talk to patients about in terms of lifestyle modifications as well.

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Absolutely. That treats your brain and makes you happy. Happy brains are less dizzy than unhappy brains. Yoga can help. Tai Chi can help. And there are some really nice techniques you can use -- relaxation kind of exercises can really help. It is very stressful living with Dizziness, especially all the time. I feel so bad for people who have constant dizziness here just like constant ringing in the ears, that really is a terrible thing for people. So what I try to do is see if I can get them to refocus on the good things. What makes you feel good? Try to do more things like that. That can also kind of heal your brain and make you feel better.

[Danielle Tolman, DPT] We have a question in the Q&A. Are there any generally applicable and free self guided therapy resources available for people who don't have access to Vestibular rehab therapy, because maybe they don't have a diagnosis, a referral, maybe there's nobody in their area? Do you know of anything?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] I don't care but there are some apps that you can get that have exercises. Here's the problem if you're dizzy. When someone is a skilled physical therapist, they can't figure out sometimes the right dose for you, it becomes really difficult for you to treat yourself. Kerry Alvin is a Vestibular therapist I worked with for years, one of the smartest people I've ever worked with. He says to me, I'm not sure whether it's the exercises or if it's you that helps me get better. I think that it's both. There's the exercise piece. And we don't just treat the physical. We treat the mental. We are many psychologists in many ways. And we try to help heal the brain, too.

People talk about these models where we work not just the physical but we look at the psychological state, too. And I'm not a psychologist, but I'm smart enough to know that I have to treat the mind and the body to help people with Dizziness. And that's the piece that you miss when you use an app. I'm sure it will help. Movement helps. The more you move, the better you are going to be, as long as you're not super, super at the top list with your dizziness and headache period something that helps you figure out how to move and be successful -- when you get your feedback, people can't see sometimes that they are doing better.

And that's what we can do, is we can say, look, you did this this week. You did this last week. You are really doing better. And they say, no, I'm not. And I say, look at the data here. You are getting better. That's what you miss with the app there are apps that can show you how to do exercises you can try those. But part of getting better is interpersonal interactions that we have. That can be virtual or face to face.

[Abbie Ross, PT, DPT, NCS] It's so important in this field just having someone that listens to you as a patient. And that's what we do first thing, is we ask the patient a bunch of things and we listen. Sometimes in the first 20 minutes of the evaluation, you see them start to get better, like, this person understands me. It's amazing. A question from the audience -- should I see a physical therapist with Vestibular experience and training, or will any physical therapist help?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Personally, I think you need somebody who has a clue about people with Dizziness. There are a lot of similarities between Dizziness and chronic pain in terms of how people react to it.

I just finished a study where we took 30 physical therapists from around the US and asked them to make clinical decisions about exercise prescription.

What should you do? There were twelve people who had Vestibular problems. And they watched the videotape and gave them a paper report how they did. And what we found was my top performers who were most consistent with their responses were actually physical therapists who had worked in a large medical center or a multidisciplinary team. One of the first things you talked about is different types of care, and the answer in my mind is yes.

Those therapists were much more consistent in their responses. If you have the ability to choose -- some of you have no choice whatsoever, but with telehealth, you do have options. Depending on your state and what's legal on your state, if you can see someone with more experience you will probably have a different experience.

[Danielle Tolman, DPT] Seeing a good clinician who knows what they are doing makes all the difference in care. I think people watching today would wholeheartedly agree with that, having been through multiple diagnoses, received different approaches to treatment and care. I think everyone here is good at being their own advocate, educating themselves.

A lot of times Vestibular dysfunction is a lifelong thing. Keep creating your team at home and working with the clinicians that you felt most informed by and helped by to continue managing symptoms. In terms of other alternative treatment options, are there other things that people with Vestibular dysfunction might see benefit from, like acupuncture? Are there any supplements that potentially could help patients with their Vestibular dysfunction symptoms?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Whitney's rule is if it helps you use it, I've told people to try anything that they think might work. There's no evidence of hyperbaric oxygen is one that I am actually picking along because I haven't seen anything that works there. I've had people try a type

of needle that you use on the ear, I haven't seen many good results on that. But I never tell somebody not to try it. I have had some results -- it doesn't work for everybody, but sometimes those sea bands that people buy because some people get motion sickness, that helps with nausea. Sea bands you can get at your local drugstore for probably 10 to \$15. But be careful, because I had one person do it and she never took it off, and it can cause a wound on your wrist. So please don't wear it 24/7. But that's considered alternative, because that's a pressure point that came from China, that concept. Those things, for some people, work jerk the ginger and peppermint can sometimes help people.

I'm sure both of you have tried this, the ginger and peppermint can sometimes help people. And some people don't like one or the other, but it can help you know -- tea. Just even a piece of candy can sometimes help -- have peppermint candy or ginger candy for people whose stomach doesn't feel good. There was literature that says that it does help. People sometimes will take magnesium. And doctors will prescribe magnesium as a medicine for migraine. But you can get that in your health food store, too. There are doses of magnesium that you need to check with your doctor about that can help with headaches. There's lots of things that people try. And my rule is that if it helped me, keep doing it. But always let your physician know, because some of those things that you get from the health food store can affect what you take from a prescription.

So it's important to let all of your healthcare providers know not just all the medicines that you are prescribed, but also the ones you get from a store. In some countries you can buy anything. You can just go and buy drugs without a medical prescription, which is interesting. But here in the United States, it really is important. Your pharmacist needs to know everything that you take. One pharmacist. It's really scary what people are doing it, to save money -- if you get one medicine here and one medicine there because that is where it

is cheaper, you need one person to know everything, even if you don't buy everything from them.

[Abbie Ross, PT, DPT, NCS] I think we need a poster in our offices of all the rules so far. I want to get specific now. Now this was another pre submitted question from someone in our audience, but it talks about BPPV. And the first question, there's a couple with this. The first one is basically you have BPPV Benign Paroxysmal Positional Vertigo, you had some sort of maneuver, you're feeling better. Does this problem come back? Or is it fixed permanently?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] This is another Whitney ism. Alright. And that is that if you live long enough, you'll probably get BPPV. That's what I tell people. There is a German study that followed people out about seven years, and they found that it's about a 15% recurrence rate per year. So what that means in that fancy language means about 15 people out of 100 will get BPPV again in a year. If you go out two years, 30 people out of 100 will get it again. And if you go out three years, you're talking about 45 of those 100 will get it again. The problem is we don't know who is going to get it again and who won't. We can't predict that. One take home message is that you don't want to live every day thinking that you're going to get it again. You just want to live. So once it's fixed, just live well. Because you don't know -- you might never get it again.

I've seen people who had it at 20 or 30 and they got it again at 60. Some people can go a very long time, and other people can go a couple of months and they get it again. It's so frustrating. If you look online and it says 100% cure rate, why do I keep getting it again? It's really a hassle. For a lot of people, it doesn't always come back in the same ear and on the same side. And that's the thing that I worry about with people trying to fix it themselves, is you can get kind of stuck or jammed in. For some people it works great, and for some people who try to fix it themselves, it can be a problem.

[Danielle Tolman, DPT] So that sounds kind of leads into a question I had to follow up for that is if once somebody say they're a frequent flyer and this is something that happens to them, often, you would recommend that they get diagnose each time they have a recurrence, make sure that they're still working on the same year or the same canal in order to resolve that issue and make sure they don't complicate anything down the road by doing maybe a maneuver that wasn't appropriate, or for the wrong side.

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] There is a recent paper that talks about self treatment. They teach them how to do it through telehealth. But I read a rebuttal to that. There are concerns that all those people who did that treatment actually had already been diagnosed by a physician in south Korea.

And they only enrolled people who were willing to do it here it was close to 25%, which means one out of four people said I'm not comfortable even trying this. And then they used a questionnaire that they developed through -- artificial intelligence is a fancy word they used, but there is a computer questionnaire. It asked which side it was. It worked well, but there were a lot of caveats, because people were afraid to do this on themselves at home. If you look at an earlier survey, only 20% of the time it came back on the same side and the same ear.

I always thought it was the same slide, same ear, but that is not what the literature suggested in this trial where they fixed it and checked to see which side it was when they next came in. It's not always consistent.

[Abbie Ross, PT, DPT, NCS] We kind of touched on the next piece of this question here you have recurrent that may not respond to the same treatment that it did the first time. We all loved those unicorns that come in, you do one treatment and it works. But then you have patients that are not

responding to the maneuver that you are initially choosing. What to do next in those cases?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] I talked to a neurologist in Argentina recently. He told me there are 23 different maneuvers that are out there in the literature that can help you fix it. I have a big toolbox. If one doesn't work, I have another. If that doesn't work, I have another. If the third one doesn't work, I have another one. And that's the value of seeing somebody who has a lot of experience. Because my guess is that most of the local physical therapists that you might go to in a small community would have one option, maybe two if you are lucky.

If you were talking to three physical therapists that are highly skilled, we have more tools in our toolbox. If you don't get the results that you expect, you might want to find somebody who has more options to try and help you. I never give up, but there are people who give up. I think it's just ingrained in me that I will keep digging, keep trying to figure out how to help somebody. And that's the kind of person you want to find.

Even rural therapists as a consumer of care, you can say, I hear there's more options. Can you check them out? Because I can't go to the city. You can have them look at the literature to see if they can find something else that would help you.

[Danielle Tolman, DPT] One thing that is amazing about our discussion is hearing you, who has decades of research experience and time with patience, it's clear that we are always still learning. There is always some new study or surprise result that might affect how we treat our patients. We are constantly learning new things. I have a question from a physical therapist in the audience. Can BPPV be seasonal? And if so, which seasons are worse? Is there also any connection in the literature with dehydration as a cause for BPPV?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Yes and yes. I'm at a meeting right now -- I will answer the second question first, related to how dehydration. I've been asked that for years, I have always believed that it's true. The gal who did the lecture this morning said it. I looked up the reference. I couldn't find the reference yet, but I guarantee we can find that reference and post that. There is something out there that says that dehydration is related. And it's always made logical sense to me. There's some jelly and strings together hold it in place. If the jelly wasn't as jellish, then the crystals can fall out more easily. There is something out there, and I promise I will send it to you guys. You can figure out if somebody is interested how to post the reference.

The answer to the first question is yes. There are two studies. The father of neurotology in the united states looked at people in California and how often they had loose crystals. What he found was that in the springtime, they had more loose crystals than any other time. Then my friend did the same thing in south America. And he looked to see what the relationship was. Because their seasons are reversed in the southern hemisphere, he found the same thing. So he looked at radiation levels. Okay. And so there clearly is a relationship.

I had patience for years who would come in and say to me, every spring I have to come find you. I have the spins again. I say, I hear that all the time. I keep hearing it. There's something here. So there is something there. And what we think it is that the crystals are built in your body, and they have some vitamin D in them, calcium. And what happens over the winter is that most of us don't go outside that much, at least in the northern hemisphere where it's cold. We stay inside. We don't get all that vitamin D from the sun. So there clearly is a relationship. There was a randomized trial to look at whether if you supplement with vitamin D and calcium if you have less time between recurrences. That's the only thing that's been shown in the

literature to actually decrease recurrence. That makes it very clear in the paper that it's only in people -- they only saw that positive relationship and people who had low vitamin D and calcium. So please don't go out and take vitamin D and calcium without checking with your doctor. But also you need to have a blood test, so if you don't like blood tests, you won't know if you are low in vitamin D or calcium. Can give you a test and tell you whether you are low, and if you are, it is one of those things that can help. First question, is it seasonal, the answer is yes.

[Abbie Ross, PT, DPT, NCS] We had another question come in here, and I feel like we've all had this question from patients. You helped them, and then they say they're going to do this maneuver every day. Is that going to make it never come back again? What do you say to patients who want to do something everyday for the rest of their lives hoping that this doesn't come back?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] It doesn't work. Huminski and Hain probably 10 to 10 years ago at least, they actually got people like this person to agree to do it and it didn't make a difference. You can do it, but it's not going to make a difference with recurrence. So if it makes you feel better, go ahead. But it's a lot of time to do that. And, and my experience, my experience has been that sometimes you can not the crystal soft was doing it. So I don't actually tell people to do that at all. I don't know. Do you guys? Do you guys ever advise that?

[Abbie Ross, PT, DPT, NCS] No, but I do tell patients, if it feels good, do it. Do what feels good to you, but same answer that you gave here.

[Danielle Tolman, DPT] We actually had when I was in Maryland who would come in once a week because he wanted a maneuver done for every canal on both sides, just because he felt reset, and it helps him feel better. And although I've never actually seen active BPPV in him, it was something that

he wanted to pay for out of pocket because he felt great about it. And you know, if it helps do it, but that probably would be something I would have normally recommended for a patient.

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Insurance definitely wouldn't pay for that.

[Danielle Tolman, DPT] No. Definitely not. You know, we there, there are so many different types of dysfunction. And it's so hard. I wish we could take you on for another hour because we have so many questions coming in about all these different, different diagnoses. But I want to jump around a little bit. We have some questions about MdDS or Mal de Débarquement Syndrome. Is vestibular rehab helpful for this patient population? Or what does a treatment approach look like for somebody with mal de débarquement syndrome?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Nobody knows much about it. The only thing that seems to work is the training that doctor Dai has done. But that does not work for all people. I have sent people to New York to do it. I know other doctors who have sent patients to new York to do the therapy, which is pretty expensive. It sometimes works, but it is not the magic answer. One case was done at the medical center in San Antonio here one person was treated with the Dai protocol and did get better. But that isn't the answer for all people. And I've tried just about everything that I can think of, and nothing in my mind has really helped. I tell people to move. I can certainly tell people to exercise. I've tried all kinds of things, anything that anybody could imagine, and have just not been very successful. We have a lot to learn.

[Abbie Ross, PT, DPT, NCS] This is another diagnosis specific question, but I think this comes up a lot too. Can you talk about the vestibular therapists

role? The extent of that for patients with Ménière's disease? Does it change along the course of Meniere's? Or is it consistent?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] The new European guidelines state that physical therapy is helpful with Ménière's disease. I always think that I'm most helpful... if you don't have symptoms, what am I going to do for you? I like to see people early on, even if they are really symptomatic or asymptomatic to educate. There is so many things I think we can do, the relaxation, the diet, regular exercise, regular sleep. A balanced life really helps people living with Ménière's, and less stress. I know that some people say that dietary triggers aren't real, but I have some folks that as soon as they touch an anchovy, they are having a Ménière's attack. I know that for some people there are dietary triggers.

I like to go over those things with people to help them understand what it is so that it does not ruin their lives. When you have a Ménière's attack and can't predict it, that is awful. So there is a real role that even early on -- when people are asymptomatic, they don't need me -- but there are techniques that I have taught them that they need to do all the time to change their lives and to lead a healthier lifestyle and better living with many years.

[Danielle Tolman, DPT] A lot of times people with Menieres disease might have secondary diagnosis, and there was a lot of overlap with migrainous tendencies. Some of the studies are showing that a low salt diet doesn't necessarily help, but there are people who are more food sensitive pure there were some migraine patients out there that are triggered by foods, and there are some that are not bothered at all by food triggers. In that similar realm, what about Persistent postural or perceptive Dizziness? What percentage of patients recover close to their previous functioning? Is there a timeline, or is that very individualized as well?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] It's very individualized period it really helps if there is a Psychologist involved, or someone you can talk to. You've got to treat the whole body here. People are maladapted. They try to get better, but their brains didn't work that way. It's like, this is the path that might help you get better, but your brain went this way, so you have to try to get it to go this way to feel better. So that takes a team of people. But there are a lot of people getting that diagnosis. And when I talked to Dr. Stop, because we talk frequently, he's the physician at the Mayo Clinic who a-- he's a psychiatrist who came up with the criteria for the diagnosis. And he and I both feel very strongly that there are many people misdiagnosed with three PD that don't have it.

There are very specific criteria you have to meet to get the diagnosis. There are a lot of physicians that say, I don't really know what it is. And then the patients think they have it when they may not. So that is one of the concerns I have. Those folks who have PPD that generally need a multidisciplinary team to help them, especially if they have had the problem for a long time period.

[Abbie Ross, PT, DPT, NCS] Another diagnosis specific question here. It talks about Bilateral Vestibular involvement. Can you talk about the difference for what therapy looks like for Unilateral versus Bilateral?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] Sure. And it's not versus, it's how Bilateral you are. If you have remaining inner ear function, I can help you. I can still help you if you don't have any, but I can help you a lot more if you have a signal still in that ear. And what I've learned over time is that the strength of that signal is critical. If you think about the inner ear signaling as 100%, everything works great, if you've got 25%, I can do a lot more with you than if you have 0%. And the exercises that are given for people with weakness in both ears sometimes are similar, but there are specific things we can do to try to help regain function of what's remaining there. So I

always hope if you haven't had a lot of testing and stuff like that done, I go full force and assume that you have some inner ear function.

And I had that beaten into me by Dr. Clendaniel who's also a physical therapist, because I always said, if they are Bilateral, why are why am I doing these exercises? Well, they might still have some left. And now I am much more aggressive about trying to train any remaining function. Because if you have any remaining function, you are going to do better. And you want to optimize what you've got.

It's like hearing. Some people have hearing loss in both ears. One of the things as physical therapists that we do is talk about hearing loss. I'm not an expert, but we can send you to an Audiologist to make sure you preserve your hearing, too.

That's really important to protect it. If you work in a loud environment, you can get earplugs -- they cost money -- but you can get earplugs that filter sounds so that you don't lose more hearing.

[Danielle Tolman, DPT] One of my most exciting things is the Vestibular implant. I think it is so cool. Could you touch on that a little bit about what it is and how it is helping patients with Bilateral Vestibular loss?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] The group I am most familiar with is the group in Belgium and also at Johns Hopkins, although they are also doing work at Washington state.

It's working for these folks. They have gotten some really nice results. I have seen people who could barely walk who can now run on the treadmill, and their lives are better. It's not at the stage that cochlear could implants are, the ones that help you if you are deaf to hear. But they have really improved remarkably over the last five to 10 years. And they certainly give hope to all of us. So that is something to watch. Continued to watch that. And continue

to watch some of the stem cell work. There is some data in the animal research that shows that you can regrow some inner ear function in the nerve with stem cells. And that is pretty exciting for people who might not want to do the surgery. So there are definitely options.

[Abbie Ross, PT, DPT, NCS] Can you talk about gaze stabilization? What does that mean, and what do we do as therapists to address issues there?

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] It's kind of weird how this works, but there is a signal from your ear that makes your eyes move. And people don't get that because they don't understand why I'm looking at their eyes and I can figure out what's happening in their ear. What happens -- those of you who live with this certainly know -- everything can jump. And for people with Bilateral loss, things always jump if it's really bad when you when you move your head or the your vision jumps. And what we tried to do with exercise is minimize that jumping here for the idea is that everything jumps. I have exercises where what we can do is retrain your brain and minimize that so that people don't feel dizzy and they can see clearly.

[Danielle Tolman, DPT] Oh, man, we could take your time for another hour. But we greatly appreciate everything that you provided us today with his amazing information. I know our audience is loving and looking through our chat right now. And you are definitely a fan favorite.

[Abbie Ross, PT, DPT, NCS] One of ours too, by the way.

[Danielle Tolman, DPT] We way are fan girling over here. We appreciate just getting to sit and chat with you again. So we appreciate it. So so much. We are going to take this time now to pass it over to Laura and welcome our patient panelists. Dr. Whitney, thank you so much again, we really appreciate your time.

[Susan Whitney, DPT, PhD, NCS, ATC, FAPTA] You're very welcome. And I wish all all people living with to assume this a good life.

[Danielle Tolman, DPT] Thank you very much.

Oh, she's amazing.

[Abbie Ross, PT, DPT, NCS] I love her so much.

[Laura Cala] I am definitely a fan girl. How amazing was she?

[Danielle still Tolman, DPT] So great. Oh, I just amazing. We are so lucky and so privileged to have had her on as a guest this week. And we're excited to pass the torch to you and hear from your patient panelists.

[Laura Cala] I'm so excited to get them on. And I'm so excited to sort of hear how we can relate it to our first session. So thank you so much.

Hi, everyone, my name is Laura. For those that don't know me, I'm based over in Australia. I have vestibular migraine as well. And I welcome on our two special guests today, Lisa Thompson and Casey Dill. So I'm going to pass over to our panelists to tell you a little bit about themselves. And then we'll go into our treatment journey. Casey, can I hand across to you to tell everyone a little bit about your journey so far?

[Casey Dill] Sure I had chronic dizziness going on 13 years now. I developed dizziness when I was about 14 years old and it was a very long journey to get a diagnosis. Only just diagnosed at the end of 2021 with PPPD and also vestibular migraine. So over the time it took to get diagnosed I did a number of treatments and I saw a lot of different types of doctors, a lot of testing. Kind of landed me nowhere until more recently when I finally was properly diagnosed.

[Laura Cala] We look forward to hearing more about that journey. Lisa can you tell us a bit about your journey so far?

[Lisa Thompson] Thanks Laura. I probably had my first episode of vertigo around 2004 and then never experienced it again for about 15 years and then it started happening again and I started thinking, it's this weird thing that happens to me. But then it started happening more frequently and then I noticed hearing loss in the left side so finally after many months of denial, I went to a physician and I was diagnosed, I checked all the boxes for Ménière's disease you're I sometimes wonder if there's more going on because my symptoms. Casey I don't know if this happens to you and Laura, my symptoms are changing and evolving. I don't know if there's new things going on.

[Laura Cala] It's so interesting you say that as we've spoken over the last few days and hear from the patient panel, as you learn to understand your symptoms more you're able to almost differentiate and actually I guess our biggest thing is we know the big thing that is bothering us. Is that sort of what you mean?

[Lisa Thompson] Yes. And I notice this year my Nystagmus changed from side to side to circular. So just kind of different things. And I'm like, well, that will that's new. Okay, we're doing that now. So I'm just kind of different things, weird sensations in my head that happen that I don't know, that I've necessarily experienced before. I don't know if I'm just hypersensitive to it. Or if it really is changing and evolving because of maybe more hearing loss or, you know, who knows, or you know, something else that's going on that hasn't been diagnosed yet?

[Laura Cala] Absolutely, no, that is very interesting. There's a few comments coming in as well saying that people's symptoms have evolved and changed. But let's get into the crux of treatment. So I'm going to ask each of you what

treatment was originally recommended to you by a doctor or physical therapist, or were you recommended different things and what route did you choose to go down? Casey, can I hand over to you first?

[Casey Dill] Sure. It was a long journey to get a diagnosis. I tried a lot of different things over the years. The first thing that was prescribed was anti-anxiety medication. I was told I have anxiety, just do cognitive behavioral therapy and take antidepressants and that's all they could do for me.

Later on I did try Vestibular physical therapy. With two different therapists at different times and both times made me worse. I've tried a lot of different things and now I'm kind of more leaning into the mind body approach, full body as opposed to just medication or just physical therapy. Trying it all.

[Laura Cala] I love that attitude, trying it all. I said to people at the beginning of my journey that sounds so difficult, surely there's got to be a better system and I was like I will try anything that will provide me with some relief. As some of the panelists said yesterday, you've got to give yourself that grace and space to go through and experience and feel all of those things. That is so entirely relatable. Lisa, how about you?

[Lisa Thompson] When people say that it's so hard it is like, pizza or Vertigo?

[Laura Cala] That is my argument all the time. If you were diabetic or had broken legs and you make --that is my biggest thing. Just because you can't see what's going on with us -- I think that is the big thing that is hard for people to understand.

[Lisa Thompson] Until they actually see it happen and I have some friends that have actually seen it happen and then they are like oh.

One thing that stands out in my head was the first ENT that I saw who ended up leaving the room before he actually told me I had Meniere's disease and

the nurse came in and gave me a handout about foods, high potassium foods and I'm like, what is going on? I made him come back in the room and I said are you telling me I have a chronic disorder now that is going to affect me for the rest of my life? If so please sit down and let's have a discussion about this. He actually told me to stay off the internet. Yeah he was not my doctor anymore.

But less sodium was definitely something that was brought up to me early on, although it was not explained well or as extensive as it could have been and I learned about more with my own research. They did put me on -- the knee jerk reaction probably everyone in the audience today regardless of their diagnosis been prescribed -- I'm going blank.. the fluid in your ears, the diuretic, thank you. You know, that's like, you know, everybody gets that I have an allergy have a Benadryl? You know, I have a vestibular disorder have a diuretic. Still take that but not as much. A lot of experimenting, like Casey said, trying different things.

I do try to follow a low sodium diet. I found that exercise for me is key. If I'm not exercising, I'm more of a dizzy girl and that strange sensation, lots of different things, start coming up. I was a smoker, I quit smoking right after my diagnosis. I was not a heavy smoker but I was a regular smoker. Lifestyle changes and just kind of addressing the whole body again.

And my poor ENT, I told people before has to go into sales mode before he puts me on any drugs because I'm like what's this going to do? And in three months you're going to say now you need another pill because this is happening. It's hard for him to get me to take any drugs.

[Laura Cala] I know for myself I initially started with Vestibular therapy and then I moved on to the migraine diet which for me, I will always say that I controlled most of my symptoms by 75% without medication. And I know we will talk about medication later, but it was going on the medication that

knocked it on the head for me. For the most part now I've weaned off of that. Things are more normal I have more dizzy free days but in saying that, it wasn't just the medication as I continued to do what you said, I for the most part follow the migraine diet.

I do need to exercise just like you because I find if I don't exercise now -- in the beginning I couldn't because I was too dizzy but if I don't exercise now it's like a fog. A brain fog that happens and I feel heavy and I feel like it's my lightness at the same time. That has increased to walking and a slow jog. Let's talk about VRT and medication which we briefly touched on. Casey you were trying a few things, was VRT something you ever thought about or looked at and did it supplement with medication? How did that side of things work for you?

[Casey Dill] I did VRT twice around. The first therapist that I had, she didn't, I don't think she understood me and she was like a certified Vestibular specialist . I don't know what kind of certifications you need for that. She was very unsure about what to do with me I think. So that was a little bit off putting and made the process a little more anxiety inducing. I would ask her do you think I'm getting better and she would respond with, how do you feel? Well I don't feel good at all.

So eventually I stopped with her because I was exponentially worse. I stopped seeing her altogether and I moved on to doing a lot of the migraine diet, I did, I tried botox for migraines. I tried all the medications beforehand before insurance lets you do botox. For all of those things I never noticed a huge difference for me or I felt worse or some of the medications caused side effects that were worse than what I was already dealing with. I tried VRT again the following year with the different specialist, different office altogether. I had a more positive experience and they felt more understood, however, it still didn't help me.

It really didn't change anything for me and it made me feel more loopy and I would have to recover for days afterward which is obviously not the goal. VRT was not really friend – helpful in my journey – not to say it can't be helpful for other people just for me with PPPD I did not think it was the right thing for me and then my migraines were so uncontrolled as well. Doctor Whitney talking about if your migraines are too out of control VRT is going to probably make things worse with little head movements. I don't really care for VRT personally.

[Laura Cala] No, no. And I guess that's even as Dr. Whitney said, it's those trying those different things and because there were other factors – at least we can say you gave it a second ago and that is an applaud in itself. A secondary to that question before I go to Lisa, did you go down the medication route for your actual migraine the headache component of it and how did you manage that side of things?

[Casey Dill] I saw a neurology pain specialist and so we started first with the anti-seizure medication, that's the first thing they try. I had a horrible reaction to that so I only took it once and then we moved on to, I was already taking antidepressants and that was one of the treatments that obviously was not doing anything for my migraines so then we moved on to the injection, the CGRP blockers that one did cause side effects and we did not want to treat the side effects with more medications so we just went off of that and that's when I moved on to botox.

I did 3 rounds of botox and on the third round I had a really strange reaction to it. Could have been some light stuff, light stressors with that at the same time but I had weird flu like reaction to the botox and after that I was so dizzy and debilitated literally my whole life flipped upside down that day even though I had already been dizzy for so long. It got so much worse I lost my job because of all of it and could no longer even really take care of myself at home.

I kind of was on a new journey and figuring out what just happened and how do we come back from that. I found Vestibular Neurologist and he helped me a lot. We did a lot of different supplements as well as changed up some medications and hardcore migraines for a little while which now I just loosely follow the migraine diet. And now I am on another shot for the migraines and it's going a lot better for me. Even though the shots are very much the same I guess there are little nuances about them like the one that I'm taking now does not cause the same side effects that the previous one did.

[Laura Cala] I hope you know how amazing that is. You've listed off so many. A lot of people are probably thinking how did you get through that and how were you able to keep pushing forward so congratulations to you to be able to get where are you now and live to tell that story and be on -- I hope you know how strong and powerful we all think you are.

[Casey Dill] A lot of support from family, friends and the right people around you to help you get through it because it's really isolating and lonely especially when it's so bad you can't work anymore or you can't really leave the house. It can be really horrible for your mental health.

[Laura Cala] Lisa I can see you nodding along. Obviously you mentioned you've stayed away from medications in the past. Have you explored VRT? Explored the routes of medication? Can you tell us about your journey there?

[Lisa Thompson] I was, when I found another doctor to work with, and I was with a regular ENT in town, he did refer me to a Vestibular therapist, which I was clueless. I did not even know what that was or what I was doing. He explained it so I went. We did a lot of the head movement things.

A lot of walking with head movement. I've done yoga over the years and everything so standing on the mushy surface, you guys have all done that. I said so I felt like I did pretty good and he's like no and my friend that came with me to drive me, because we did not know what was going to happen,

she's like no you were like -- we worked a lot and we discovered through that journey that I instinctively did a lot of those things on my own when I had a Vertigo attack. I did a lot of standing, I know it sounds crazy. The worst thing I can think of is laying down and having vertigo.

I would stare out and I've shared this story before – I have a small window in my bathroom. So you are in the bathroom and I'm holding onto the windowsill and I'm staring at a tree that is way across someone else's lawn and across the street and I'm just staring at it and he and I talked a lot about the connection between eyes and ears. Doctor Whitney was talking about it also and I did not know anything. I did not understand any of that so we worked on that for a while. More walking and he was like we are kind of at a point where I don't know what else to do with you. Until you start, if you start feeling a lot worse or having new symptoms or whatever, I'm going to set you free little bird. You have some tools in your toolbox now and you know where I am.

Sometimes when I'm out on my walk I probably look like a crazy woman but I'm walking and I'm doing this (moving head side to side). And I've incorporated some of that into some of the yoga that I do as well. Oddly enough I like to do the head turning focusing exercises when I'm in a forward bend upside down. Other people I've told that too said that sounds awful but that's just what is working for me. I have a feeling that has a lot to do with my neck.

So as far as medication goes, I shared with you would put me on the diuretic. I weaned myself down to 1/2 of 1 a day. I would not recommend doing that without talking to physicians. I weaned myself down to taking a half a day. I take just over the counter. Barometric pressure is a huge trigger for me so I take Sudafed quite a bit. We also worked on getting me off ibuprofen. I was taking way too much so got me off that.

I'm trying to think what else do I do. Vitamins like Casey was saying. Some different things, B complex. I'm a big fan of ginger, ginko biloba, the basic kind of things like that. I have my emergency meds, my Meclizine, durmamine. When I was in the hospital – tell me if you guys have experienced this – when I was in the hospital once with a Vertigo attack, they filled me with benadryl. They were IVing me with benadryl. Maybe they just wanted me to go to sleep I don't know. It was very relaxing. When they are -- I use benadryl when I have an exceptionally busy day or when I'm in a full-blown Vertigo attack to the point when I think everything's going to stay down I will take a benadryl.

And then they also prescribed for me, you were talking about antidepressant. With my neck issues that I have, they prescribe amitriptyline and I was like a tricyclic antidepressant not so sure about that. As it was explained to me it can also be used to help block pain signals so I do take that every other night. That's kind of where I'm at right now. I still get, which is why I'm starting to wonder if there's a migraine component to this because I have a lot of neck and head issues and I was in a car accident several years ago and they say sometimes long past neck injuries can be a trigger for some of this stuff. We shall see.

[Casey Dill] I experienced a lot of neck issues. I assume it's a migraine trigger as well because it starts counting the base of my skull like wraps around the head and yeah, Neck. Neck issues are a rough.

Yeah. I'm starting to notice more and I will go back years ago before all of this started happening I remember – it was a DO, just our family provider, he happened to be that chiropractor – that's how he started and then he went back to school. He was looking at the cervical curve in my neck and how flat my thoracic spine is typically we are supposed to curve. He said that's going to bother you when you get older and he had me turn my head and press against his hands this way and there's a real weakness, especially going in

this direction and he said that's going to bother you later in life. Well here we are. I really think everything is connected in some degree or another.

[Laura Cala]. Absolutely as you understand more I always find when listening to the conference when you hear the doctors explain more, you take it on a different level. When you go at the initial onset it's very hard to take it, what is VRT, such foreign words and as you start to ride through it you're able to absorb more of that information. It is all connected.

But Dizziness is the tip of it but it comes into all of it. I'm going to switch across to a question that's come into the Q&A from Pamela, how do you handle anger? Anger is driving me in my relationships and it's unfair to my loved ones. I'm so mad at this disorder I blame myself for getting it and I'm angry I'm no longer perfect. I was never perfect by the way she said. Can I switch that over to you Lisa? Are you able to provide some insight?

[Lisa Thompson] Yeah I get the less than feeling for sure. Sorry (tearing up). That was a struggle for me too, Pamela. Because I tend to be a very social, outgoing person. I was probably out more than I was home. All of a sudden I felt, Casey touched on this, this feeling of justice being isolated and broken and afraid to go anywhere then people going well are you going to come or not and then trying to put on a good face because you don't want that question, you don't need to feel less than, you don't want to miss out, don't want people to think less.

I just really found my spiritual side, really kind of reconnected through this. That felt like that's pretty much all I had left in regard to my own attitude toward myself, toward my world, to be able to find peace with that. Don't know what kind of condition we will be in a year from now, five years from now, tomorrow. The anxiety, the fear, although, the insecurities, all those things, I really started spending a lot of time journaling, praying, crying,

praying some more I'm finding support with people you really learn who your real friends are.

I realized I actually had somebody tell me you're making this more of a thing than it really is to us you're more worried about what we're thinking kind of that's not what we're thinking, you are being harder on yourself. It's just what it is so Lisa you need to just chill and relax I would say, rip into a journal. You can really scream, cry, get it all out and a lot of times you are not sharing those feelings, they're not manifesting with loved ones and friends either they're not feeling that way anyway or you're not, you are working through your own stuff on your own. That is my approach to it anyway. God gives you a lot of peace when you ask for it.

[Laura Cala] I actually think that makes you stronger that's something that took me a long time to realize, I was right there, the same feelings as you Lisa, and Pamela .

I think taking a step back and as we have talked about, people have got no idea what it means to survive for us and all of the different things we do on a regular basis to make sure we're OK. That feeling of feeling less than, we are actually so much more than I think we could ever be. That is where my love for everyone in the Vestibular community is because our struggles make us strong but unfortunately we don't see it half the time because we were just in that survival mode and to me that is the definition of being more than.

You are an amazing individual Lisa, as are you, Casey. Not to say that we don't have, I don't have those days now, but it is an emotional roller coaster and a lot of people are commenting on the chat as well so we are right there with you. Casey, do you have anything to add to that?

[Casey Dill] I have struggled immensely with anger and sadness over just feeling everything that Pamela said, Lisa said, you feel inadequate, less than, and like "why me" kind of thing.

I've done a lot of therapy and I think what's been most helpful for me now is finding the right kind of therapy and I do internal family systems therapy now as opposed to cognitive behavioral. Internal family systems is more helpful for me in terms of dealing with my own inner critic and the different parts of yourself that make up who you are. X self, child self, the trauma from your younger life.

I think it's also really healthy to express your anger to get really angry and express it in a healthy way. Don't take it out on your family but sometimes punching a pillow feels really good. You just have to find ways to let yourself feel that. I think that's a really good way to kind of work through your emotions is to actually feel your feelings and express your feelings whether that's through a journal or a therapist or somebody you trust, it's still something I work on all the time.

I still have days and I'm just like so upset that this is my life and how unfair it is and how no one sees it. My family might understand me now but other people just don't really get it. And oftentimes you get unsolicited advice like have you tried such and such, drinking water, --

[Lisa Thompson] Or the people that go ohh I get dizzy when I sit down and stand up. Not the same.

[Casey Dill] People just don't get it and they want to offer advice, which is great... that's the only thing that people know how to do like, what do you say, you know? So people often just offer they're like, Oh, well, have you tried cutting out sugar from your diet? Yeah, I have. Have you tried, you know, whatever it is. And it's like, trust me, I have tried it.

[Laura Cala] If it was going to work I would be doing it. 100%.

[Casey Dill] I wouldn't be complaining about a symptom if I found the magic cure I will let you know when I find it.

[Lisa Thompson] I found that connecting with the Vestibular community and a positive way, I will say when I first started finding different groups and chats and so forth, some of them were horrifying, then somehow I started stumbling on more and more helpful information, positive, more caring and embracing type conversations and environments. That was really uplifting.

So I would encourage Pamela to keep engaging with things like this. Connecting with people maybe in your own community that are Vestibular warriors, whether they have the same diagnosis that you do or not there's a lot of similarities. I also found that this experience, I became and I've shared conversations with other people that I felt the same way, became more open-minded, more compassionate, and more patient with people that have difficulties regardless of what those are. Do I still get impatient yes do I still get those days where I've missed something and I'm home and I'm going I hate this, I hate this? What is it going to be like when I'm 65, or 70?

And gratitude journal – a lot of people say that it's really cliché, but on days where you just feel like just dizzyland and life is sucky just try to think of three to five things that are good that you are thankful for. Sometimes it's my cat crawled up next to me she's right there I just keep adding her I don't know she's not moving but just finding those positives. That is exactly what changed me for the better. Did it suck? Has it been hard? Absolutely but it's made me a better human being.

[Casey Dill] In the realm of support groups or online I also went down that rabbit hole about the forums that are not so positive. That was really challenging because I would read story after story, feeling very hopeless. That was really damaging for me and brought on a lot more anxiety and doom and gloom. Luckily I was able to unfollow the group and remove myself from it.

I have found a group by doctor Yonit Arthur, she has a YouTube channel that I found. Her YouTube videos were hugely positive and helpful for me. I think it is the steady coach on YouTube. She has a community of dizzy people that you can be apart of and that has been so life-changing for me in the past couple of months that I've been in her group. Everybody has different Vestibular issues but we all relate to each other in some way and a lot of our stories overlap and we find similarities and we celebrate our wins and we boost each other up when we are at our dark moments. It's been a really positive community to be a part of as opposed to the scary Facebook groups.

[Lisa Thompson] I personally, I'm single so I have to support myself. I remember coming home that day and sitting in the chair and just bawling. The big and dramatic, embarrassing wailing, bowling, what is going to happen to me my life is over. I have a slate coffee table with iron trim and I'm sure one of these days I'm going to fall on that and that will be the end of it.

I got that all out of my system and all of a sudden it dawned on me, I'm not any different than I was a week ago really. I just have a name for it. It might get worse, it might not so what can I do?

I know this is the life rebalance live so this will be a shameless plug. This would have been almost two years ago, a year and a half ago, I found the Life Rebalance Chronicles series so I would tell Pamela if you've not watched that I would really encourage anybody who has not watched that on YouTube, watch that. Because I sat there and laughed and cried and listened to those folks and thought, look what they're doing and we're all in this name boat and I found a couple of books early on that -- one was called overcoming Ménière's which was all about low sodium, written by a gentleman, can never remember his name, Ph.D. going through working on his doctorate and started – he was debilitated by Menieres and his symptoms started and he was like, no sodium. You're nodding your head,

Laura you know the one I'm talking about. The other one was on the Vertigo it made me laugh then I went back and as I read a chapter I would watch the Instagram video that went with it. I felt very empowered by it, finding those things where you do control one little aspect of your symptoms or your day or your routine. Where you feel like you're doing something, you are helping yourself you're going to feel more empowered and less out of control.

[Laura Cala] I see another question for you. Charlene has asked do you still have to take antidepressants?

[Casey Dill] Yes I do take antidepressants as well as benzodiazepine. Hopefully, I will get to a place where I can just take the Benzo as needed but right now it's a very low dose daily medication for me. Anxiety meds have been a huge blessing and managing my PPPD because a lot of my PPPD comes from anxiety it's very much like a dizzy anxious dizzy cycle I need to take a whole-body approach to it. I do still take antidepressants and I don't see myself stopping that anytime soon.

[Laura Cala] Another question on the Q&A says I'm interested in flying and driving again after years of ear pressure function so I've had a bit of conversation around travel in the last few days what have your experience has been with travel and not driving?

[Lisa Thompson] My experiences with flying have been the time I'm supposed to fly again on April 5th. That may be a different experience that I've had in the past I've heard a lot about them read a lot about them, I found them very uncomfortable I did not care for them.

I felt like I had more pressure. I had that heavy head feeling where your head started to feel like it's going this way so I was like, no. On the trip home I did not use them and I felt better. Oddly, my ears feel more normal in my experience so far on a plane than they do on the ground day-to-day. Ideally I should live on a jet 24/7 and I feel better. Driving, I have more anxiety around

driving. I used to drive much further distances than I do now. I have anxiety around that. I'm a salesperson so I do drive a lot but I used to drive to Chicago a lot which was about a 3 hour drive from where I lived.

I drove to north Carolina once. I have anxiety I had a Ménière's attack on the way to a concert in Indianapolis after driving about an hour and a half, looked down at my console, looked back up, bang. Spent a couple of hours sitting in a parking lot at a truck stop which was awesome. I cracked my windows oddly. Sometimes it can feel like there's pressure inside your car kind of so I will crack my windows sometimes regardless of temperature. Sometimes that will help.

[Laura Cala] I've had so many experiences where I guess like you I'm so used to driving whereas now the anxiety of being on a highway with so many other cars and the unpredictability now I'm obviously better but I would stop at a truck stop and bawl my eyes out. It would be taking that time and I think maybe that's the message, start somewhere and you do a little bit more and a little bit more. That's for me how I found I got better I think I stopped driving for eight to nine months and when I was confident to start again it was that little bit more and a little bit more. Casey, how about you?

[Casey Dill] As far as driving I definitely pretty cautious and anxious about driving. I prefer to just be the passenger although that is not really a pleasant experience for me either. I stopped driving for many many months in my most recent setback.

I probably did not drive or maybe next month except her one little test drive like 5 minutes around the neighborhood kind of thing. I still don't really like driving too much if I'm having a bad migraine day I won't drive if I'm having a dizzy day. I can do it and I like to prove to myself that I can do it because it's good for your sense of independence. For flying, I have always been an anxious flyer. I have very bad anxiety in general so flying is, takes a lot out of

me remember I've survived all my life and it's usually once I'm in the air I'm good and I can chill a lot of times I can go to sleep. We're getting up in the air it's anxiety inducing for me. It does make me more dizzy weather going up and just the movement of the plane as me more dizzy but I think that's more of an anxiety thing thing than anything. I always bring a bunch of tools with me whether that's, I take dramamine beforehand or something similar I always take my anxiety medication. I'll do essential oils that are calming. I have my noise cancelling headphones and I will listen to really upbeat fun music or something that's really calming to get me in the zone.

I don't ever fly alone which I know is not possible for some people. I've flown alone one time and it went great but I prefer to not fly alone because I want to know that someone is with me that knows me. Knows all of my worries because that brings me comfort. I also love the window seat. I want to look out the window especially during takeoff. That helps me, some people would prefer the aisle because they don't want to see.

[Laura Cala] That is fantastic that is really helpful. I'm mindful that we are in our last 10 minutes question is, regular day, what does a day in the life of your life commonly look like now? That can include things like the diet supplements, medication. What is typical for you and managing your condition.

[Casey Dill] Everyday is different but also every day is the same. I have a morning medication and a nighttime medication kind of bookends my day. I recently went back to work so I'm starting to get into more of a routine. The longest time I've been out of work so my days were very much like getting from one moment to the next. I do try to follow a migraine diet. I do spend a lot of time at home. I tried to get out and go for a walk. Go out and run errands. I have a hard time at the grocery store but when I'm having a good day I try and go so I get that real-life VRT experience. Now with going back to work, I'm kind of taking baby steps with that. I try and do a lot of self-care.

Self-care has been huge for me whatever that looks like for you, personally, I like my alone time. I like taking a bath and reading a funny book.

I do also read a lot of books about anxiety or emotions. Self help type books because I find that to be comforting to me. My days are pretty boring honestly. I don't do a lot. I like to sew so that's a form of self care but also something fun for me to do or playing computer games. All those sometimes that can be too hard to visually which is a bummer because I would spend a lot more time on the computer if it didn't bother my eyes so much. Maybe that's a good thing to keep me off the computer.

[Laura Cala] That's really great. Switch across the building visa -- nice switch across to you Lisa?

[Lisa Thompson] I had to laugh at Casey. Alone time. I'm the same way. I have a morning routine, I get up take my morning meds and then I spent time reading a little bit more personable meditation and also different spiritual art self help oriented type books then journaling. And then I typically kind of have a hybrid model with work right now. So working and I tried to get some exercise in when I can. We are coming out of winter so it will be a better temperature and more sunlight at the ends of the day so I will be able to get more exercise in as the weather continues to get warmer.

I like to cook. I can kind of keep my diet under control. I tried to spend maybe one or two nights a week I try to spend some time with friends, try to at least have one fun thing going on in the weekend. Sometimes with me and the cat and Netflix so I do have my phone go on do not disturb at about 8:30 trying to get off the screens I think that helped my sleep quality. Do I always do that? No. I read before I go to bed usually it is normal and just to kind of relax and unwind I really tried to get a good night's sleep. I'm kind of a nut about, kind of obsessed about my sleep quality on fitbit and watching that and I'm always like why did my heart rate go down and I'm trying to figure that out.

I'm kind of, I'm a little bit boring.

[Laura Cala] The good type of boring. I ask you two perhaps give a piece of advice or some words of the whole person someone at the beginning of with their treatment journey? My message is to keep going. I think Casey highlighted and Lisa highlighted you've got to give everything a go some things aren't going to work unless you try them you're not working out.

[Casey Dill] That pretty much sums it up. Just keep trying. You will probably find a lot of things that don't work for you but that's all part of the process.

You'll eventually find the right people, the right doctor whatever it may be. Things will eventually click into place and you'll have a direction to go. And it took a really long time for me but grateful for the path that I'm on right now. I encourage looking at your symptoms from a whole body perspective, don't just get fixated on one particular thing especially when you do have a specific diagnosis. I was definitely one to read endless things about my specific diagnosis as opposed to looking at it from a whole body perspective and trying anything that might help.

Keep going, it's hard but you can do it.

[Laura Cala] Over to you, Lisa.

[Lisa Thompson] We were going through this and we touched on it with Pamela's question, feeling out of control of your whole body and everything but you are the boss of your body. Once I got that in my head whoever you are working with Casey touched on this, find the doctor and the therapist that feel right for you. If you're feeling gunky when you're with them and you don't feel good about that relationship or they kind of make you feel less than, you don't need that doctor. There's somebody else out there that can help not only your body but also kind of make you feel better about the journey you're on and you're the boss of you so if you're not comfortable

with something -- if we're throwing a lot of meds at you or telling you to stay off the internet, stuff like that, that's probably not where you should be. You want to feel confident in that relationship and you want to feel like it is productive and that you are respected in that space as well and keep trying.

Find what works and throw the other stuff away and maybe what's working today might not be working six months from now and be open to trying things. Just listen to your body. Listen to it. That whole body connection thing I completely agree with Casey. I really believe that is true it is not just here as a pill go feel better. Yes, medication has a place, absolutely but there are also things we can do outside pharmaceuticals that can help us as well.

[Laura Cala] Ladies that we could listen to you for so many more hours than what we had today. Thank you both so much for sharing with us. Thank you to everyone that has joined us to Cynthia and the other moderators that have provided links and resources on the chat. Thank you again to the James D. And Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology for sponsoring this conference. As a reminder, you can purchase lifetime access to the recordings and transcripts of this entire conference vestibular.org/LRL-recordings. And you can help make sure that the valuable information that is presented at this annual event remains free to everyone by making a donation at vestibular.org/lrl-donate. Those links will be listed for you in the description box below as well. So thank you, everyone again for for joining us. And thank you, Casey and Lisa, for sharing your experience with us. We're both following your journey.