

# Life Rebalanced Live 2026

## THE TRAUMA OF DIZZINESS AND VERTIGO: ADDRESSING FEAR, AVOIDANCE, AND EMOTIONAL INJURY

**0:00:04.4 Dr. Abbie Ross:** Hello to all and welcome to the third day of the Vestibular Disorders Association's sixth annual Life Rebalance Live virtual conference. I'm Dr. Abbie Ross. I'm a vestibular physical therapist, founder of Balancing Act Rehab and the Dizzy Reset, co-host of the podcast Talk Dizzy to Me, and a proud board member of VeDA. Before we dive into day three, I'd like to again thank our sponsor. The James D. And Linda B. Hainlen Discovery Fund and the University of Minnesota's Department of Otolaryngology have generously supported Life Rebalance Live since its inception in 2020. A special shout-out to Jim Hainlen, a fellow vestibular patient who inspired this event by holding his own vestibular conference in 2018 and in 2019. Jim cares so, so deeply about supporting people on their vestibular journey, and it was important to him to not only educate people about vestibular disorders, but also to provide a platform where people can connect. Now I'd like to introduce my co-host not only for this conference, but also on our Talk Dizzy to Me podcast, vestibular physical therapist Dr. Danielle Tolman.

**0:01:17.1 Dr. Danielle Tolman:** Thank you, Abbie, and hello everyone. We also want to say thank you so much to all who have contributed to this conference in some way, including VeDA's donors, staff, and volunteers. With their contributions, we're able to put the live version of this conference on at no cost to our attendees. If you wish to gain lifetime access to the presentations following the live event this week, we will have them available for purchase for \$65. Your financial support helps VeDA's continued mission to spread vestibular awareness.

**0:01:51.1 Dr. Abbie Ross:** Before we get started with today's conversation, I'd like to direct you to the poll questions for this session. If you haven't already, please complete those now. Also, feel free to talk amongst yourselves in the chat, and please put any questions you have for this topic for the speakers in the Q&A section, and we'll do our best to incorporate as many as we can.

**0:02:11.1 Dr. Danielle Tolman:** And just a little reminder, although you'll be hearing from healthcare professionals today, none of the information presented should be taken as medical advice. Please consult with your

healthcare provider before making any changes to your treatment protocol.

**0:02:25.8 Dr. Abbie Ross:** So today, day three, we're going to explore the often overlooked trauma of experiencing dizziness or vertigo. We'll discuss how repeated setbacks or invalidating medical experiences can impact mental health, as well as the role the nervous system plays in recovery. We'll also address trauma-informed approaches to care, including when and how counseling can help, what to look for in a provider, and practical strategies patients can use to regulate and recover.

**0:02:57.7 Dr. Danielle Tolman:** It's my pleasure to introduce our guest speakers, Dr. Joanna Wolfson and Jen Warner. Dr. Wolfson is a senior psychologist at the Rusk Rehabilitation at NYU Langone Health. She provides individual and group psychotherapy to patients with a wide variety of medical conditions. Jen Warner is a licensed clinical social worker and psychotherapist with advanced training and certification in trauma-informed care and integrative somatic trauma therapy, as well as holistic health and nutrition. Welcome, Jen and Dr. Wolfson.

**0:03:35.9 Dr. Joanna Wolfson:** Hello.

**0:03:37.9 Dr. Danielle Tolman:** All right, let's start with understanding the emotional impact. Dr. Wolfson, many people describe the onset of dizziness or vertigo as terrifying and disorienting. From a psychological perspective, what makes that first experience so traumatic? And we'll pass that to you, Joanna, if you don't mind.

**0:04:05.2 Dr. Joanna Wolfson:** Oh, to me?

**0:04:08.0 Dr. Danielle Tolman:** Oh, I think we actually might have Joanna frozen. All right, we'll try that again. How about Jen, we'll kick off with you. What makes that first experience so traumatic for patients? Because we see this a lot of times when somebody comes in for therapy, even they've been to the hospital at this point, they really thought at the onset of their symptoms that there was something truly wrong or they thought that they were potentially even dying in some cases. That's pretty traumatic.

**0:04:36.2 Jen Warner:** Well, Danielle, that's such a great question. And I was going through the questions that people have put into the chat, or Cynthia had put into the chat for us, and I will say I have the benefit if we

can put that in quotes of being both a trauma therapist who specializes in complex chronic illness, including vestibular disorders, and being a vestibular patient. So I will say, full disclosure, that this morning I woke up with a terrible migraine, and I, of course, am having vestibular symptoms. So I actually I hope that as we go through this, because some of the questions speak to also, what do you do about the fear and when you're having symptoms, how do you manage them? And you know what? I'm actually having symptoms right now. So it'll be the perfect time to practice some of maybe one or two of the exercises that we can do, because the trauma... Trauma has some very specific definitions, but one of the biggest is that people perceive that something is threatening their life. And as a vestibular patient, I know that we all know that when you have your first vestibular symptoms, it really does feel like your life is in danger or about to end.

**0:05:47.1 Jen Warner:** And sometimes we can have flares, and it once again feels that way. So when we talk about trauma, it's really about this sense of your life being threatened. Trauma is a sort of an overused word in a lot of contexts, but it really does apply to these conditions. And it doesn't mean that being traumatized and trauma is not an illness. PTSD is not an illness. It's a diagnosis related to circumstances. So when we are ill

or when we're having symptoms that are very, very scary, or diagnosed with something that's very scary, that can be traumatizing. It isn't always traumatizing. And I really want to make that distinction between something being like that trauma is an illness so that there's something more, even more wrong with you. There isn't. You're having a normal set of reactions to abnormal events. Feeling like the world is falling off its axis is not normal. So long answer, short question, but hopefully that's...

**0:06:55.6 Dr. Abbie Ross:** I want to dive into that a little bit more. It was a beautiful segue to my question in which, how do we distinguish then what a normal fear type response is, our body's doing its job to protect us, and the development of trauma or even post-traumatic stress?

**0:07:14.8 Jen Warner:** And that's a great question too, Abbie. And it's really about volume, right? We have a fear response sort of wired into us. We are wired for survival. So fear is... We need to have fear. It keeps us alive. The difference between a traumatic stress response and a regular stress response or fear response is about the magnitude of it. You may feel very stressed by your work or afraid you might be afraid of spiders, let's say. And it's like, that's a normal fear response. When we're experiencing a

traumatic stress reaction, it's like at 11, right? It's normal for us to be vigilant in the world. We should be aware of our surroundings. One of the symptoms or I like to say side effects, not symptoms of trauma or traumatic stress is hypervigilance. That is, right now I feel like I'm on a little bit of a boat. That's not normal per se. And it is enough to create some fear. It's like, oh, whoa, am I falling? Am I falling? If I was to continue sitting here, not paying attention to the questions and thinking, oh, my God, is everything okay?

**0:08:35.1 Jen Warner:** Is everything okay? That's hypervigilance. And then that becomes very distracting. It takes over our lives. It's really hard to navigate the world when you're feeling that way. So again, it's about volume. We should have some fear. That's normal. It actually motivates us to do things. But it's when it's kind of taking over and it's triggered regularly that we start drifting into traumatic stress.

**0:09:00.6 Dr. Danielle Tolman:** I try to put some of my patients at ease when they come in and I say, listen, I would be more concerned about you if you weren't bothered by your symptoms, if you didn't have some sort of anxiety coming into this, because it can be pretty disturbing to have such a big life change, but also symptoms that really can debilitate you. Now,

the onset of our symptoms welcome back, Joanna those onset of those symptoms, they may differ from person to person. We talk about the sudden onset maybe later on in life, and how that can really create its own trauma in that sense. But what about for those who maybe lived with dizziness since childhood? How might a long-term or developmental trauma differ from those who maybe had an acute onset later on in life?

**0:09:46.9 Jen Warner:** Joanna, do you want to? Because...

**0:09:50.3 Dr. Joanna Wolfson:** Yes. Just making sure everyone can hear me here. And I'm sorry, it just kicked me out despite the test going fine yesterday. If it happens again, I'll try and log on a different way. But I'm so sorry I missed the initial question, but I think this question seems to be about almost the trauma that can occur when people have just been living with these types of symptoms maybe since childhood or for a very long time, versus those who maybe had kind of a sudden onset of vertigo or dizziness later in life. And so I think when we think about in the work that we do here at Rusk, we see a lot of different people with a lot of different stories. And I think maybe two kinds of stories tend to emerge. So one is that when people have had any types of chronic symptoms that they've dealt with for many years, on the one hand, sometimes they feel like

they've really gotten to know their symptoms quite well. They are familiar with ways of modifying activities. They've sort of found a way to weave this part of their life the way their body works a little more seamlessly maybe into their lives, as opposed to someone who identifies as having always been extremely active, extremely capable, having no barriers to doing everything they wanted, and then has a sudden onset of dizziness or vertigo that really kind of turns their world upside down.

**0:11:10.0 Dr. Joanna Wolfson:** Sometimes people might say it would have been easier if I kind of knew what I was getting myself into earlier. They have a very far place to fall. And so those people might feel more maybe acutely shocked by what's going on. At the same time, for people that have spent a long time having symptoms, there's this other part of it where they may also have more time of accumulating instances of feeling like a burden, or feeling not believed, or feeling like enough providers don't take them seriously. And so that becomes in and of itself maybe its own form of emotional injury, of traumatic experience. And so while maybe they've gotten a while to kind of understand these symptoms and respond to them and modify things, it can be sort of this slow buildup of potentially emotional insult over time for those people.

**0:12:05.0 Dr. Abbie Ross:** And in both of those cases, I feel like sometimes the diagnostic process can be long in itself, whether you had experiences or symptoms from childhood or you had a new onset in adulthood. Can you also speak to how that can impact emotional injury? Maybe invalidating experiences, maybe even medical gaslighting? Jen, do you want to take that one?

**0:12:30.9 Jen Warner:** Sure. So people have probably heard the term CPTSD, which is complex post-traumatic stress disorder. Unfortunately, we don't necessarily use it as a standard diagnosis here. It's not in the DSM-5 yet. Hopefully it'll be in the DSM-6. But complex trauma basically presumes that one has had trauma that started early in life, and that could be there are many different things that could be considered a trauma that then is recurrent. Right? So it's chronic. And people can have either medical trauma early in their life or other types of trauma, family violence, let's say, that then as they get older... Again, trauma's not a disease. It's something that has happened to you.

**0:13:22.6 Jen Warner:** But it also, especially when it has started early in life, it primes you for how you're going to deal with other stressors throughout your life. So if you have had trauma, even if it's not medical

trauma early in your life, and then you end up being diagnosed with a vestibular condition and I've noticed a couple of questions in the chat about the onset of a vestibular condition can be absolutely terrifying but if you've already had these scary things that have happened to you over your life and then we have this event that's happened, then we can see an increase in traumatic stress reactions that may seem to providers when we talk about medical gaslighting, which we can certainly get into they may seem like, "Oh, it's just BPPV. I don't know why you're overreacting like this. You just seem so nervous. Why are you so nervous?" Often providers and I know we'll be talking about trauma-informed care in a little bit don't recognize or don't screen for earlier trauma that may have made this latest trauma even more traumatic.

**0:14:33.0 Jen Warner:** So something that's just BPPV, which is already miserable I have it a lot is an event. It's a major event. It's a catastrophic event because it's yet another thing that has piled on top of a lifetime of not knowing what's coming next. Because that's a hallmark of trauma: the sense of powerlessness, the sense of the uncertainty, and kind of always living waiting for the other shoe to drop.

**0:15:01.4 Dr. Danielle Tolman:** What I find interesting in some things that you had mentioned and referred to is the fact that our systems can kind of be primed. Right? So it's something that kind of predisposes some of our patient population to additional layers of diagnoses, whether it is vestibular migraine or PPPD, or having to live with more chronic symptoms that maybe some other people might have had resolution in much sooner versus them and their personal experience because of these priming factors. Joanna, do you see that where we kind of have that priming that system that leads to these other issues down the road?

**0:15:44.3 Dr. Joanna Wolfson:** Yeah. Well, I was so fascinated by everything Jen was saying, and I think this is so true. I think that, whenever I see someone new for the first time coming through our vestibular service for individual therapy, it's really common to get a lot of the information at first around, of course, what happened vestibularly, what led to the first event. There's a lot of focus on the medical buildup. Right? So, "I thought I had a cold. Then this happened, and there were crystals loose in my ear. Then I saw two ENTs." And I think it's really easy for me sometimes and medical doctors to kind of get locked into the, "Well, what happened in the days leading up to this diagnosis?"

**0:16:28.0 Dr. Joanna Wolfson:** At the same time, if I've seen someone long enough, there's a whole life and a whole story that precedes everything that happened before maybe day one of vestibular condition. It's not to say that every single person with a vestibular condition is primed with a trauma beforehand, but that it's not uncommon for me to learn maybe situations for people that have been these either traumatic or chronic stressors that have just kind of been playing out for a very long time or maybe playing out under the surface of the body, the skin, that can really make someone quite vulnerable. As Jen was saying, this idea that it feels horrible for anyone not to feel safe in any way. If safety has always been sort of teetering or precarious or uncertain, then once you lose control of your body which is the one thing people feel like they're in charge of then sometimes people feel like, well, there's nothing anymore to really hang on to here. And it becomes very, very frightening.

**0:17:29.7 Dr. Abbie Ross:** Your body often whispers before it screams, but sometimes you don't recognize the whispers until you're able to look back and sort of reflect. With that, I think whole person care is so, so important. Being able to look at this person for more than just otoconia or crystals being loose in the inner ear. What else is at play here? Is there a fear of lying down now that's at play that we need to address? Why is that fear

there? What led up to this? It's not to say that it's that person's fault either. It's just good to look at a person from a zoomed-out approach and see where we can intervene as healthcare providers to help them as a whole person. With that being said, Jen, can you tell us what does trauma-informed care actually look like in this context?

**0:18:20.3 Jen Warner:** Well, trauma-informed care was developed for healthcare systems, and it started being implemented more than 20 years ago, which is shocking for many of us to hear because it's like, "Oh, well, that's funny because I don't feel like any of my providers are trauma-informed." But the idea was that we were supposed to be having systems, offering systems, that recognize that trauma exists. So there are the three E's of trauma. This is part of the trauma-informed care framework. The three E's of trauma: the event itself, a person's experience of the event, and the effects of that trauma.

**0:19:01.0 Jen Warner:** Then the four R's. Okay, so we got three E's, four R's. Realization that trauma, again, exists. Recognizing the symptoms or, as I said, side effects of trauma. Responding in a trauma-informed way, that is utilizing your knowledge of trauma. And then resisting retraumatization. So if you're working with a truly trauma-informed provider and

clinic or setting, all of these things should be at play. It's supposed to not just be the providers. It should be everybody from the front desk staff on up, including the CEO, that recognizes that trauma is real and that you're not going to be able to tell by looking at somebody that they have experienced trauma.

**0:19:46.0 Jen Warner:** The trauma-informed care model is one that means, or should mean, that we are all aware of the fact that trauma is not a disease. You're not going to see it from the outside. And that we should treat people accordingly. We should be able to talk to people in a way that, again, resists retraumatization. So that means not invalidating right off the bat. That is hard to do in a healthcare system now that gives providers 15 minutes to work with patients, but it is possible. For any of us who have worked with providers who are truly trauma-informed and bringing that into the space, 15 minutes can feel like an hour because they're not causing more harm. I think all of us know what that harm would look like. So those are a couple of the basics of trauma-informed care, what it should look like. It's a bigger thing, but those are some of the basics.

**0:20:51.9 Dr. Danielle Tolman:** It definitely feels like we are hopefully moving in that direction where providers are trying to look at the whole patient and provide that care, even in a tough healthcare system that's kind of cutting down how much time a lot of those providers are allowed to spend with our patients. But we are also seeing trends where patients are doing a great job of advocating better for themselves, going in better armed with information because they have great resources from trusted places like VeDA. But also they're seeking out additional care from those who maybe have the additional time. They're investing their time or value and their money into working with people that will have the ability to listen to what they are going through and validate what they're experiencing. I think before we start to dive into some of these specific approaches to care and what that might look like, could we maybe just talk about some of the qualities or credentials that maybe people who are seeking counseling might want to look for in a therapist when they're doing their research, they're trying to figure out who to work with, and how they can continue to advocate for themselves to ensure their needs are being heard and met when receiving care?

**0:21:40.8 Dr. Danielle Tolman:** Joanna, I'm going to kick that over to you first, if you don't mind.

**0:22:08.5 Dr. Joanna Wolfson:** Yeah, sure. And I think it can be very confusing because there are many, many people out there that might provide similar types of care. Even Jen and I do similar things. We have different credentials after our names, but Jen and I would both do very similar interventions. But I think it is a little more commonplace now for especially medical centers to either have either on site, on staff, or work alongside of or know mental health providers that ideally they have relationships with that really understand a health perspective. And so I always first tell people, before you search the web which can be so overwhelming, and many people just share it is hard to find care if you don't really know or have a lead I usually say to people that of all the providers you trust, just start there. Ask them first. Is there anyone, for instance, a primary care doctor that you work with that you would recommend? Because sometimes those types of people have a whole list at the ready of people that they would already be in touch with.

**0:23:18.3 Dr. Joanna Wolfson:** And I think one of the things that can really be helpful is just that, knowing that any of the providers again, that you trust, that you feel really have your back can be in touch with any therapist that might provide support. Sometimes also it's tricky because

people don't call themselves mental health counselors or psychologists or psychotherapists. They might call themselves behavioral health providers. So I'm saying all this to say there's probably a lot of different people that could provide support and care. There is help out there is the message I think we want to portray, that you don't have to be alone in trying to find that care. We always recommend talking to your doctor. But if there's someone who either identifies as health-aligned in some way, has worked with people with any chronic symptoms it doesn't have to just be vestibular symptoms, it could be pain or other nervous system related activation difficulties usually that's a pretty good bet in terms of a place to start. And I know that VeDA has a lot of different resources too on their website about places to look and even support groups that exist. Jen, I wasn't sure if you had anything to add to that one.

**0:24:26.9 Jen Warner:** Yeah, no, thank you. I mean, Joanna, you covered it beautifully. The one thing I was going to just add was on the heels of finding providers. And it's wonderful that we as patients can advocate for ourselves, but I just want to sort of put out there too that the trauma-informed care model presumes that patients shouldn't have to do that labor. We actually shouldn't have to do all of this screening and the work to figure out a trauma-informed care model is supposed to take that burden off

of patients. So sadly, the system has not caught up with even the model that was created. So just putting that out there because I think a lot of patients then feel like, "Oh God, now I've got to advocate for myself and I have to screen this." A lot of people come to me as a provider and they say, "I'm so done with my providers not understanding what's going on for me and I can't even do it anymore." So in terms of going back to the original question, finding a provider, I really strongly recommend finding providers who are truly trauma-informed. And that means that a lot of people can put in that they work with trauma.

**0:25:51.5 Jen Warner:** And then there are a whole host of other things that they say that they work with, or that they work with chronic illness and pain, and not everybody really does or really understands what that means. Joanna and I have spoken about health psychology. It's wonderful being able to go and speak with a health psychologist who's really familiar with what and Joanna, I know you can speak more to this with what comes with health conditions. Somebody like me who's made a point I'm a clinical social worker has made a study of it, not just because I'm a patient, but because it's been a long-standing interest. So it's asking a provider please do not be afraid to any provider who is worth working with can answer your question about, "When you say you work with chronic illness or

chronic pain, what do you mean? What specific conditions do you work with? Are you a generalist in this area?" It's okay to ask that question. A lot of providers, behavioral health providers, mental health providers, are not necessarily as familiar with vestibular disorders, but they should be able to say that to you, and they should be able to work with the fear that comes with a vestibular disorder.

**0:27:18.9 Jen Warner:** So I would really be transparent. We need to be able to answer questions for you and you shouldn't waste your time. I just feel very strongly about that. I've also created a list of questions that people can ask in terms of vetting who a decent provider is for these things. And I also have some names of people. So I'm putting myself out there as a resource because it is harder to find that. And I know, of course, VeDA has that wonderful provider section on there too. So, but don't be afraid to ask. Sorry, I've taken a long answer.

**0:27:55.8 Dr. Abbie Ross:** No, that was great. We find the same thing across, I think, all vestibular providers. On their website, they might have that they treat vestibular disorders, and then we find out, well, they only know the Epley maneuver. Like, that's not going to cut it. But I think a low-

hanging fruit for people to start with and I agree with you that we shouldn't put the onus on the patient, but in today's world, it just is in some regard is making a phone call when you go to schedule yourself or to book an appointment and asking the questions right then and there.

**0:28:30.3 Dr. Abbie Ross:** Because like you said, Jen, from the front desk to the CEO, everyone should be on the same page, same culture, same type of approach. You'll know whether or not you're going to feel or you might have an indication, I should say, whether or not you're going to feel seen and understood in that first phone call, and don't waste your time or money. In fact, sometimes I encourage people, one session that's a little more money might be way better for you than 10 sessions that might not cost as much but you're getting nowhere, you're spinning your wheels. And with that, I want to lead into specific types of therapeutic approaches that you both provide or maybe are familiar with, and talking about what specific approaches are most effective for chronic dizziness or vertigo, like CBT or EMDR, etc. Joanna, why don't we start again with you?

**0:29:24.3 Dr. Joanna Wolfson:** Sure. Yes, great question. So when I think about the literature that's out there, a lot of literature has been done spe-

cifically on the condition PPPD. And even for people who may not be dealing with that specific condition, I think it's a great example of what can really help people, maybe not just even with a vestibular condition, but kind of any condition in which at this point there's been more of a chronic response to any trigger. So I kind of use PPPD, but I'm really speaking about anything we know can really just help maybe ease the pressure that has cropped up with the nervous system. We know that if we can find a way to just lower that stress response that has been superimposed upon the vestibular symptoms obviously really understandable to have a stress response to the body not feeling in control if we can lower the stress response, we take out kind of this additional insult to the vestibular system, to anxiety, and then people might find they're left with maybe a lower level of symptoms, more tolerable ways of coping. So some of the things we know are helpful is the first sounds very simple, but it's anything to relax.

**0:30:41.0 Dr. Joanna Wolfson:** So if people can find any way to kind of get into that again, kind of nervous system on fire such as really remembering to breathe. I think it sounds so simple, but I even myself am guilty of finding myself holding my breath throughout the day. Relax muscles. So for

people with migraines, having some type of way of progressively tightening and relaxing different muscle groups. No one way is the best way. Just even sometimes people are like, "I have a lavender-scented candle that I smell." It can be anything at all, but we really need to find a way to almost reverse this activated somatic sympathetic nervous system response. The second part of this, I like what you said, Abbie, about CBT. So just briefly, cognitive behavioral therapy is about identifying what thoughts are coming up, for instance, about my symptoms, and do they help me. So sometimes people have very catastrophic thoughts about symptoms, predicting something very, very bad happening if they were to try something, kind of labeling symptoms as the most awful thing all the time. And so even though that it might be partially true what the thoughts are, often if we really examine them, we find that they might further be leading to the fight-or-flight response.

**0:31:56.2 Dr. Joanna Wolfson:** And so we just want a way to just identify: what are my thoughts? Is there any other way to look at this that might be a little bit more reality-bound or realistic or even a hair softer? And that language can really impact, again, the way that the brain is interpreting symptoms, the level of threat the body's feeling. And one that I think is the most sometimes challenging for people and again, I'm sort of speaking

very health-medically here is sort of that old factor of anxiety management, which is really challenging, is to kind of do exactly what it is that feels threatening. So not throwing yourself into the fire, but kind of in very small, safe-feeling ways, just testing the limits a little bit. And the last thing I'll say here is it's very important after doing any of those things, and especially the exposure piece, to really have a language of something like a positive reinforcement language of something like, "That was really scary or challenging, or I was still dizzy doing it, but I did it anyway." And so I think that people have this idea that success means doing it with no symptoms. And actually, often that's not going to happen at first.

**0:33:00.8 Dr. Joanna Wolfson:** And so what will happen is doing it with some symptoms that understandably get activated and kind of not to be afraid of that, right? Not to completely overdo it so you can't move for a few days, but just to be able to kind of put your toe in the water even if it feels sort of silly. Right, even if you're like, "I used to run marathons and now I'm merely getting sunlight outside my front stoop." But the idea that everyone has to start somewhere, starting somewhere leads to more where, more progress. And then being able to really have the language for the brain to say, "I thought I wouldn't be able to handle that. I still didn't feel good, but here I am. I got on the other side of it." So I'm sure Jen has

a lot more to say too, so I'm going to maybe, if it's okay, Jen, I'll see if you have anything to add as well.

**0:33:52.1 Jen Warner:** Well, Danielle, that's such a great explanation of what CBT is, which I'm sure so many people have heard of. And I like to combine CBT with somatic work, right? So somatic it's the body. So CBT is your mind, essentially, and your thoughts, your feelings, and your actions. And the way that I approach so somatic work includes somatic experiencing, polyvagal theory, if you've heard of that, sensory motor psychotherapy. These are EMDR is I noticed that somebody had put EMDR in one of the questions. EMDR can be very helpful. It's not something that I practice, but and there are a couple of different reasons for that. But I would say that anything that's involving the body as well as the mind, because when we have vestibular disorders or any kind of complex chronic illness, there really becomes this sort of severing between body and mind. It's like they were a married couple who are now in a very... You know, thinking of divorcing, except they can't move out of the house. You know what I mean? Like, they still have to live together, but nobody's getting along. The mind tends to blame the body. The body is doing the best that it can.

**0:35:07.3 Jen Warner:** So as Joanna was saying, the thoughts, the catastrophic thoughts that can start to come up can be really nasty and damaging. You know, "Ugh, look at you, body. What happened to you? You used to be able to run marathons and now, oh, sunshine? Okay, dipping a toe in the water? Big deal." The body, meanwhile, does not speak in words, it speaks in sensations, right? And it is going through a lot, but it is not going to yell back at the mind using language. So in therapy, right, we work with getting the mind and the body to begin to communicate with each other in a kinder and gentler way. That is to say that the mind, as we're challenging these catastrophic thoughts, we're recognizing that the body is doing something and the mind is also helping the body to come into a more regulated state.

**0:36:05.0 Jen Warner:** So I we might not have time to do it, but we could as I said, I'm having vestibular migraine today we could practice a breath exercise, like a couple of breaths, and I can sort of show you what that might look like. But just so you know, this combination of mind and body is, I think personally, most effective because it just gets the whole being onto the same page. And we have a lot of people here today. Abbie and Danny are PTs. I love working with PTs. I love coordinating also with psychologists like Joanna because we're talking about the whole person,

right? You've got your mind, but you also have your body, and we have to kind of come back to a place of recognizing that, yeah, we can have these illnesses, we can have these conditions that are crappy and scary, and we can adapt. We're incredibly adaptable. And that's not a failure. Grief I know that we're going to be probably getting to this but we can feel like we have lost so much and we aren't recognizing at the same time what else is possible in these kind of amazing spaces.

**0:37:18.0 Jen Warner:** Because there's a lot of amazing stuff that's going on here that when we've had something traumatic happen, we can lose sight of. Because that's the nature of trauma, by the way. Before trauma, we can have this sort of large scope, and when something scary happens or when we get triggered, our scope narrows to about this much and that's all we can see. So a lot of the therapeutic work, be it in PT, be it with a psychologist or a therapist like myself, is getting the scope to open up again and be able to see things, see your own capabilities, but see the world a little bit more. Because what happens again, it is a normal reaction to an abnormal event to feel like everything has shut down to nothing.

**0:38:01.6 Dr. Danielle Tolman:** I love everything I mean, this day I think is so important for the conference because I think a lot of people, no matter

what your diagnosis is, why you're here, why you're listening, there is so much that everybody can take away from this discussion. And one of the things that I absolutely love is the discussion that you just led us into about this connection between the mind and the body and how they're at odds with one another and arguing. And we do address that in vestibular therapy very differently. We have a lot of patients, especially chronically, that become over-reliant on visual cues. The brain does a great job of divorcing itself from listening to the somatosensory cues and what the body is doing and where it is in space and being able to organize that information into productive, functional movement, which is why they're feeling so awful. So I love how this is just so beautifully wrapped up together in this multidisciplinary approach because we are working on trying to achieve the same things but with different modalities. And I also love that, Joanna, you had mentioned that starting at a base of trying to calm down that central nervous system response is the foundation, and it's going to be different for everybody.

**0:39:13.3 Dr. Danielle Tolman:** I have a lot of patients that find this comfort in prayer. They start their mornings with their devotions or prayer, and that brings them a really, really great sense of peace, more than some of the recommendations I might give them in terms of box breathing or

other types of exercises or guided meditation to help relax that. Jen, I really love the idea of maybe doing a short exercise or something that we can do with everybody watching, listening, because it's something we can literally take away with them from our discussion today that they can start implementing immediately. So if you wouldn't mind, I would love if you would lead us in a short exercise.

**0:39:55.8 Jen Warner:** Absolutely, absolutely. And notice, too, to capitalize on what Danny was just saying about prayer, because this idea of something bigger than us opens that scope that I was just talking about. So it doesn't matter what you believe in, it's something outside of here. So it gives you a broader scope, and that can actually be very, very healing in and of itself. So the exercise that I was just going to lead us in is a breathing exercise. You're going to breathe in through your nose for four counts, but don't do it yet. And then you're going to breathe out through your mouth for eight counts. And a lot of people, even when they're breathing out, tend to go as if everyone can smell their breath. We want a full exhale. So even before we start, also just feet on the floor if you can, if you're in a chair, or if you're laying down or propped up on pillows, that's fine. Just do a body scan starting at the top of your head, going down. Now, if you're like this includes me, too we get to here and it's like, "Oh my God, now I'm

really noticing that I'm rocking. I don't like this. I don't like this." And we start to do this. Okay, yes, the rocking is probably happening, but scan on down and see where you're holding.

**0:41:19.5 Jen Warner:** Okay. Is your neck tight? Well, see if you can imagine relaxing your ears and just we're going to try to soften even before we do the breathing exercise. So just do a quick scan. Imagine, too, are you holding your chest like this? See if you can find some ease in your shoulders. I like to say that we're basically made up of sticks of butter. So imagine those sticks of butter sort of melting a little bit. Neck is a stick, arms, your legs, and then softening and really see if you can soften your belly. This is where we hold a lot of our tension. And then I want you to hold your thumb. Okay, so holding your thumb, ideally we're closing our eyes, but if that doesn't feel comfortable, you can have half lids. But we really, as I believe Danny and Abbie were saying too, we over-rely on our visual system as vestibular patients. Let's give the eyes a break. Even closing your eyes halfway can be really can tamp down that sympathetic nervous system response. Eyes closed or half open, holding your thumb, breathing in very gently through the nose for four counts and then all the way out for eight counts through the mouth. We'll do it again and make the exhale sound like wind in the trees. Okay.

**0:42:54.8 Jen Warner:** In through the nose for four and out through the mouth for eight. Do it one more time. In through the nose for four and out through the mouth for eight. And again, wind in the trees. Okay, and whenever you're ready, opening your eyes very slowly, checking in. Is your body gripping again like, "Oh my gosh," or "I don't like feeling that, now I'm feeling"? You're safe. You're okay. Anxiety is the perception of fear when there is no immediate threat. So you may say like, "Okay, well, I'm " but my body, but my vestibular system. Yes, scary, but not an immediate threat. It isn't going to attack you like a tiger right now. So if you're feeling anxious and very activated, just recognizing like, "Okay, yes, I feel scared. I feel scared because there's something going on inside of my body, but it is not going to attack me right now. It is okay if I soften a little bit. It is okay if I take breaths. I can close my eyes halfway and it doesn't mean that that I'm I'm losing attention on the scary thing." It's okay to take a break. So.

**0:44:24.8 Dr. Abbie Ross:** Thank you, Jen.

**0:44:26.3 Jen Warner:** Yeah. You're welcome.

**0:44:27.1 Dr. Abbie Ross:** Off course. When you take a moment to respond to whatever you're feeling instead of reacting to it and flaring yourself more into that sympathetic state, I think an exercise like that is so key for people to hear because that's another very low-hanging fruit. It took us two, three minutes maybe, and maybe you do feel a little shift one way or another. But thank you for sharing that because I think we forget how much control we do have if we just take a moment to respond to what our body is asking for. Now, I also want to talk a little bit about caregivers because we had a question from the audience, but also we had prepared a question too about in terms of caregiving. How do you approach that? How do you take care of yourself while also providing care for another? Or if you are a caregiver for someone with a vestibular disorder, what do they have to consider? Joanna?

**0:45:30.5 Dr. Joanna Wolfson:** Yeah, so it sounds like two sides of the coin. One would be you're living with a vestibular condition and you also have to tend to someone else's needs. Very tricky when you have a lot of your own needs to tend to. And then if you are here online, a caregiver of someone dealing with a vestibular condition. I think that the first part of all of this is that sometimes the chronic stressor that anyone may have dealt with may have been almost like a forced role of always having been

the parent for anyone else, a forced role of always being in a caregiver role and sort of continuously pushing one's own needs aside to give to everyone else. And so if that's one of the themes that has played out, and even if it's not, I think for everyone, no matter what they're dealing with, there's that old adage like, "Put on your own mask before you put on a child's mask if the oxygen goes out in a plane." We're only as good as we are feeling in terms of being able to tend to anything else in our lives.

**0:46:33.9 Dr. Joanna Wolfson:** So in a caregiving role, it may just be something like I like people asking themselves maybe three times a day, "What do I need right now?" And it might be something as simple as sit down for five minutes, get a glass of water, return some phone call I've been meaning to return. But I think if we're kind of perpetually in a state of just give without being kind to ourselves first and thinking about where do I fit into the equation? And it's important for me to really take stock of this is what Jen was talking about the mind-body connection. If my body's holding tension and I'm never thinking about it, it's not really going to be releasing any tension. So that's maybe one side of the equation. The other is if you're here and you're a caregiver and you know someone in your life,

a loved one, that's dealing with vestibular symptoms, I think what's challenging is the role of caregiver or helper or family member often comes with this idea that we should be able to fix a problem. As part of it.

**0:47:37.4 Dr. Joanna Wolfson:** And sometimes doctors feel this way, too. They want you to leave feeling like something was done actively and something was fixed. And so that might look like giving suggestions, giving advice, trying to make sure that someone has heard the latest news about some revolutionary treatment. And I think sometimes what a person dealing with a vestibular condition needs is really understanding and listening and validation. And so sometimes that modality goes a much farther way. Even saying something like, "I'm sorry you're going through this. I believe you. That sounds really hard," might actually be more of what someone's looking for or feels like they need to actually bring their nervous system down. If someone's sort of living in this idea that other people think I haven't tried everything yet, people then may feel, "Well, now I'm just resentful," or "I'm angry about the care I'm giving," because if someone's trying to help, they may interpret it as, "You just don't understand what this is like. You're not inside my body. It would be great if I could have just taken this one medication and it solved the problem."

**0:48:40.3 Dr. Joanna Wolfson:** So I think as a caregiver, it's acknowledging it's a very hard place to be, especially because vestibular conditions are invisible. You can't see it in someone else, and someone dealing with it can't have it be seen visibly for the most part. So it's not an easy role to be in and it's okay to feel kind of exhausted and overwhelmed from either person's perspective. But sometimes knowing that it's okay to ask the person, "What's most helpful for me right now? Is it maybe trying to help with something practical, or is it just hearing what you have to say about how you're doing?" So I guess I'll stop there, but in terms of the two different roles, those are some recommendations.

**0:49:18.7 Dr. Danielle Tolman:** I think that you've really hit on a point where having the right language or knowing kind of what to say can be challenging and difficult for people, especially from the caregiver's perspective. I think it's really challenging for them to be able to see their loved one suffering and not knowing what they're going through or how to help because it feels like maybe nothing's helping in this moment. Jen, I'm wondering maybe if you would have any personal or professional insight or wisdom to be able to provide caregivers of maybe some language to either utilize or language to avoid when it comes to working or living or helping

their loved ones that could be maybe productive rather than something that could be perceived as harmful or resentful.

**0:50:06.2 Jen Warner:** Yeah, it's such a great question. And Joanna hit on something super important, which sometimes all we want to hear I mean, I can say this as a patient is like, "God, that sounds awful." And also remembering appointments, right? If you're a friend, not necessarily even necessarily a caregiver, remembering like, "Oh, I know you were going for that test. How did it go? How did that appointment go?" Just checking in. Those basics can be really wonderful as a patient. The other thing too for caregivers is to remember and this is true for providers as well and before working in complex chronic illness, I was a trauma therapist who worked in violent crime. And as a helper, as a provider, we want to do everything that we can to help. And this is true for caregivers. Danielle was just saying that. The thing is that if you've ever been a lifeguard I was a terrible swimmer, so I was not a lifeguard but if you see somebody in the pool, right, and they say that they're drowning, like, "Oh my God, oh my God, oh my God."

**0:51:12.8 Jen Warner:** And you are the lifeguard. You are outside of the pool. You've got all these tools and resources to throw to the person, but

they're like, "No, no, I don't want any of that. I want you to get in the pool with me." I get in the pool with you, which is the tendency of so many caregivers, so many providers, it's to get in the pool. But what's going to happen if we're both in the pool? We are both going down. I would be the first person to climb on top of you, and then we would all go down, right? That is not helping. And if you've ever read *The Giving Tree*?

**0:51:46.1 Jen Warner:** Terrible book. But she gives away everything. Everything, including her trunk. There's nothing left of her. That isn't caregiving. That's hemorrhaging. That's hemorrhaging help. And it's very tempting to do because you love the person. You see that they're struggling and they're in pain. I will say, too, my spouse has been wonderful. And one of the things that I learned as a patient is that, yeah, my terror I mean, I was definitely the person who was like, "I just want you to get in the pool with me." The thing is that they can't. All they can do is be there with you. So as patients, we also need to recognize that there is going to be a limit to how much somebody can give you in terms of help. They cannot be inside of your body. And as vestibular patients, we often want people to be like in there, knowing exactly how awful it is, and it kind of sucks. But it's like they cannot be inside of us.

**0:52:46.6 Jen Warner:** And as caregivers, we have to recognize, "I kind of almost want to be able to understand, but I can't do that." And understanding and respecting each other's boundaries. Caregivers also need to recognize what their own boundaries you're allowed to have boundaries. You are allowed to have boundaries. In fact, it's very necessary. Boundaries are not hurtful. They are actually helpful. They keep everybody safe. We need to be clear about what we can offer. What can I give? And we have to be clear about that. And as a patient, it's like, "What do I need? Do I need a hug?" Or actually, do I need something much more direct? Like, "I needed help going to the bathroom." I mean, that is true love when somebody's in there with you and you're going to the bathroom because you cannot orient yourself on the toilet. We might need that. But we have to also be clear about what we're expecting others to be able to give us. And not everybody is going to be able to give us all the things, and that also sucks. But for caregivers to recognize that and for us as patients to recognize that we can, even in this chaos, be clear.

**0:54:01.2 Jen Warner:** If we were out in a storm on the high seas, which is how it sometimes feels, we still need to know our roles, because otherwise we're all flying off the boat. So as you can tell, metaphor, I live for it. So I will leave you with all of those metaphors.

**0:54:18.1 Dr. Abbie Ross:** I was just going to compliment you on that. I also want to talk about grief. Grief comes up a lot in the questions in the chat, and also even guilt. The grief of not being able to participate in a professional realm that you once did, or as a mom or a dad or a grandparent, maybe not participating in group events as you once did. Jen, we'll start with you on this one. Can you talk to us about the grief or the guilt and how to work through those feelings?

**0:54:52.6 Jen Warner:** Well, I know I took up a lot of time. We don't have much time left, and Joanna would be also a great person to answer this. I will just quickly say that the grief is normal. Grief is a big feeling, and it's not something we have to get over, right? And we can be grieving kind of repeatedly about different things.

**0:55:14.3 Jen Warner:** So one day we may be grieving about what we feel is the loss of our previous existence, and then the next day it could be something else.

**0:55:24.7 Jen Warner:** And this is a sort of more of a therapeutic challenge, but learning to ride those waves because as with all feelings, they

ebb and they flow. They ebb and they flow. So I want to hand that back to Joanna, though, and give her a chance to answer.

**0:55:38.6 Dr. Joanna Wolfson:** Yeah, no, I love being a part of these because I just, Jen, have even learned so much from what you've had to say today. But, yeah, I think just echoing what Jen has to say, that grief is a human emotion. And grief I like thinking about emotions as what do they tell us as opposed to "I shouldn't have this," but okay, what is this telling me right now? So grief tells us that we feel we've lost something. It's not necessarily a bad thing. It tells us like we really cared about the person we were before and we've had really good things in our life and that now it feels like something's different. And so I think sometimes emotions can feel kind of all-encompassing. Like if I'm anxious, it must mean there's a threat out there, right? Like if I feel guilty, it must mean I've done something wrong here. If I feel grief, it must mean that loss is kind of like my entire life has been lost. But sometimes being very clear about what are we talking about, you know, that you can kind of grieve things differently day by day, as Jen was saying.

**0:56:36.0 Dr. Joanna Wolfson:** And sometimes when people have, let's say, a setback, they may feel a resurgence of grief that doesn't necessarily mean they're going to feel that way forever. So one thing I like I like adding the phrase "at the moment" or "right now" to a lot of phrases. So kind of like, "I've lost the ability to do this," and maybe you could add "today" or "right now." That the option that perhaps if still working on this, if there are times where things are better. It's one thing to not be able to play every day with grandkids. It's another thing if you're able to play some of the time, but not on days where it's snowing. So I think sometimes kind of allowing yourself to have emotion, not trying to fight it. It is human. It tells us something about ourselves. Knowing that it might come and go, but the emotion is not going to hurt us. It just kind of tells us something. And sometimes kind of evaluating, what is it that I'm feeling grief over? What is it that I'm feeling anxious about?

**0:57:37.8 Dr. Joanna Wolfson:** And sometimes if we have an answer to that question, it just allows things to be. We might understand it better and not feel so bad that we're on top of everything also feeling a loss or overwhelmed or traumatized.

**0:57:53.9 Dr. Danielle Tolman:** I want to kind of reiterate the fact and kind of start to wrap things up and give you guys your last chance for a good mic drop moment. But you might have seen us doing a lot of smiling about this topic during this hour. And something I want to just mention is that I know this is a very serious and heavy topic for a lot of you who are watching and listening. And one thing that brings me a lot of joy in talking to our guests today, like Jen and Joanna, is that I feel like so much of what was discussed and talked about today is so helpful and probably exactly what a lot of people needed to hear. And that excites me. It makes me happy and excited that this type of information and these resources and conversations with wonderful guests like you guys is something that is going to be helpful and put out good into the world. And I couldn't be more excited that you guys were here today to share your experience and your knowledge with everybody who's tuning in because they might feel like they need help. So I just want to say thank you to both of you for tackling such a hard topic and doing it so well and professionally.

**0:58:59.5 Dr. Danielle Tolman:** And just say that we see you guys here. We know that what you're experiencing may be invisible on the outside, but we see you and what you're experiencing, and you are in good company with those that are with us also watching alongside of you. So mic

drop moment. Joanna, I'm going to start with you. I'm going to pass you the microphone. What is your message of hope or reassurance that you would offer to somebody who's living with dizziness? What's a good take-home message for those watching today?

**0:59:27.5 Dr. Joanna Wolfson:** Maybe kind of hearkening back to a topic from earlier, but that I didn't get to say yet, is just the importance of kind of compassionate care from others who are with you in this boat. That there's a lot of information we know about how important it is to feel like let's just talk about your providers they believe you, they want to help you, they care to figure it out. And so if you are with someone where you've never, ever, ever felt that way, you don't have to stay with that person. And that a lot of good can come from just feeling like someone really sees and kind of wants to know more about what you're going through.

**1:00:05.3 Dr. Danielle Tolman:** How about you, Jen?

**1:00:08.1 Jen Warner:** Well, I wanted to just sort of also point out that as... Again as a patient and as a provider, it's so normal and I'm using this word a lot, normal, normal, normal to worry about the future, to miss the past. And that means we leave the present. It's a very common traumatic stress

response to think about the future because something scary has happened to us and it's like, well, I don't want that bad thing to happen again. So we start to project into the future and worry about what's happening next. Not only are we missing what's going on right now, but it also means that I wish we had crystal balls and could predict the future. And a side effect of trauma is that we suddenly think that we can, where it's like, oh, it's going to only get worse. We never think about the fact that it could actually get better, that it is a possibility too. So I like to say it's like a law of averages. It could get worse. But if you're going to go to the place of it getting catastrophic, you must go to the place of it being absolutely perfect and getting totally better and then average the two out.

**1:01:18.9 Jen Warner:** It's probably going to be somewhere in the middle. Back in 2021, when I thought I was having a stroke, it was the worst vestibular migraine I've ever had. I was like, that's it. I did run marathons, I did all of these things and I'm like, this is it. I'm going to be housebound. I'm losing my career. Everything is going to fall away. And I have a video of myself on Instagram climbing in Runyon Canyon just a week ago or so, Runyon Canyon in California. Granted, I got vertigo later. But you know what? It was worth it because I also knew why I did. I should have hydrated better and a number of other things. But the point is that, please, if

you're going to go to the dark place, you have to allow for the fact that the best possible scenario could also turn out and recognize that if you are going to the dark place, that that is a side effect of trauma, of a scary thing. It doesn't mean that that is a true fact that it's going to get worse.

**1:02:15.8 Jen Warner:** We can't say that that is a fact, because none of us can predict the future. So I just kind of want to leave on that note. I'm not sure I answered the question, but anyway, that's my note.

**1:02:29.8 Dr. Abbie Ross:** Both of you, so, so good. We can't thank you enough for being here. I echo Danielle's input there too. It's just so exciting to hear that people like you exist. And it's also exciting for me, and I'm sure Danielle as well, to realize that the care that we're providing is in alignment with what you two professionals also offer. So thank you for being here. If you'd like to hear more, there was just a banner that popped up. I'm sure there will be information in the chat as well from these individuals. And we'll now transition to Cynthia Ryan and Heather Davies, who will be leading our patient panel today.

**1:03:07.8 Heather Davies:** Hey, guys.

**1:03:08.8 Cynthia Ryan:** Hey, Abbie. Hey, Danielle. Wow.

**1:03:11.5 Heather Davies:** Wow.

**1:03:12.3 Cynthia Ryan:** Yeah, I got emotional a couple of times there.

Definitely a difficult topic, but also a very inspiring one.

**1:03:22.3 Dr. Abbie Ross:** I couldn't agree more. And I'm excited to hear what the patient panel has to say about this topic too. So have a great session.

**1:03:29.2 Cynthia Ryan:** Thank you. Thanks so much.

**1:03:31.3 Heather Davies:** Wow. Wow, Cynthia, I'll tell you, that was rough when they started talking about grief. Even after 10 years, I just started welling up. I'm like, woo, I've got to get it together. But I'm Heather Davies, host of the Meniere's Muse podcast, fellow Meniere's and vestibular patient.

**1:03:49.1 Cynthia Ryan:** And I'm Cynthia Ryan, VeDA's executive director. And I just want to start our patient panel by letting everyone who's listening know that we understand what you're going through. Vestibular disorders are hard. They impact you physically, mentally, and emotionally. And no part of that should ever be minimized. So we're here with you, and we're going to bring on our patient panel guests.

**1:04:18.0 Heather Davies:** Yes. Today we'd like to welcome Teena Hittie and Careen Hanouche. I hope I got that right.

**1:04:26.5 Careen Hanouche:** You did.

**1:04:28.2 Heather Davies:** Welcome, ladies.

**1:04:28.9 Careen Hanouche:** Hi. Nice to be here.

**1:04:30.5 Heather Davies:** Well, we're just going to jump right in, and let's start with you, Careen. Can you take us back to the beginning and share what was the start of your vestibular journey like? And how did those early days feel for you?

**1:04:44.4 Careen Hanouche:** Those early days were very scary ones. Still, four years later, I don't even really like revisiting that time. It was a difficult time. It came out of nowhere, as a lot of us have experienced. I woke up one morning and just felt like everything was rocking and swaying. Made it to the washroom, looked at myself in the mirror and thought, I barely see myself. Everything is just moving around me. And I know that motion is not there, but everything seems to be moving. And I had to sit down. I couldn't go to my son's sugaring off that I had volunteered for. I remember that because I just felt so bad because it was something he and I were very excited about. And it just started there. And that was four years ago, and I just felt like everything had changed. And I was just like, I need to sit down and I can't move. I can't move from this place. I don't even know how I'll get myself to see a doctor. Everything is off balance. So it was a scary time.

**1:05:47.8 Heather Davies:** I think we can relate to that. It is really scary. And what about you, Teena? Can you take us back to the beginning of your journey?

**1:05:56.9 Teena Hittie:** Yeah. Mine was what I like to describe as violent. I was a totally fine, healthy person, and after eating dinner, I just thought I

didn't feel good. And I decided to get up to go to the bathroom, and I got up and I just fell down on the floor. And I thought, well, this is like, what is this? And I get into the bathroom eventually, just praying I would throw up. And I had vertigo so violent that I didn't even know it could be that violent. And from there, I did get the help I was able to. I had an ambulance come get me and whatnot. And that just began my journey in the vestibular world.

**1:06:43.0 Cynthia Ryan:** It sounds like so often the onset of a vestibular disorder is traumatic in the literal sense that it is abrupt and acute. I guess sometimes they come on kind of slowly, but I think more often than not, it's this just rush, this traumatic experience. A lot of people describe their dizziness as life-changing. How did your symptoms affect your sense of safety and confidence and control in your life? Teena, do you want to start?

**1:07:25.9 Teena Hittie:** For me, it was totally life-changing in the sense that I was a very active person who basically tried to take care of others. And I found myself in a position where I'm in the hospital and I can't even open my eyes. I can't feed myself, I can't walk, I can't do any of these

things. I was so out of control of anything I ever knew. So it was definitely a life-changer.

**1:07:55.5 Teena Hittie:** And you wonder like, what is happening? Because at that point, way back in the beginning, you wonder like, what in the world is this? And nobody knows what it is either at the time. So you're just kind of laying there thinking... It's a very hard place to be for a while.

**1:08:13.4 Cynthia Ryan:** Absolutely. Wow. How about you, Careen? How did you feel? Did you feel out of control at any point?

**1:08:22.5 Careen Hanouche:** I did, Cynthia. I felt very out of control, and I'm someone who was always very in control of things. So it was very hard when something very out of the blue happens, something very unpredictable, something that changes your every minute of a day. It's not just something that happens and then you're back to how you were. It changes you profoundly. It changed how I parented. It changed how I had to work. I had to adapt. I couldn't work for a while. It changed who I was, essentially. And I look back and say, wow, I miss that old person. And sometimes I look and say, well, but look at the new me and look what I have done over the four years. But it affected everything. So it took complete control of me. I

became hypervigilant. I was monitoring myself for symptoms every second of the day, feeling, oh wait, now it's worse. Oh wait, I thought I could do that, but I can't do that. It was debilitating. I couldn't function. I had to have my husband help me get to the washroom. I know Jen said that in the previous chat.

**1:09:36.3 Careen Hanouche:** Really, it takes a lot to ask someone to accompany you for things that you should be able to do alone, or you were doing alone the day before. And then all of a sudden I can't shower. The shower is very triggering to me, and I can't figure out why. That's even worse when you can't figure out why you're feeling a certain way. Your symptoms are scary, your symptoms are confusing, you don't seem to be getting answers. It just completely changes everything you know about yourself.

**1:10:07.4 Cynthia Ryan:** Yeah, you said two things there. You were talking about having to ask for help to do things that you normally have to do. So it's not just a loss of control of yourself and literally your body. It's that loss of independence. And with that, what I hear so often is this sense of just a loss of your sense of self, who you were. So often we identify ourselves as a mother or with our job, and with a vestibular disorder that kind

of shifts and you start identifying yourself with your disorder. And that's like a negative thing. So later on, I hope we talk about how we can turn that around.

**1:10:56.3 Heather Davies:** Yeah. It's a big one, Cynthia. In the beginning of my journey, I found that providers were kind of dismissing, saying it was all in my head. And I know a lot of you have heard that. And it was almost to the point where I started second-guessing myself, wondering if maybe it was in my head and I'm just oversimplifying things or overexaggerating or whatever the case may be. Did you ever feel dismissed, Teena? Disbelieved or misunderstood by healthcare providers, family, or maybe even friends?

**1:11:28.7 Teena Hittie:** Absolutely. I love when you say that it's all in your head because it kind of is, no pun intended. It is in your head if it's vestibular. However, yeah, there was a lot of dismissal out of like, well, surely it'll go away and you'll be fine. And doctors blaming it on age or anxiety or whatever. You were so dismissed, no one really even tried to come up with what might be wrong. It's just like they kind of passed it off on things. And family members, how do you explain it to them to where you're doing all these things one minute and then a week later you're totally somebody else? And trying to figure out, like someone had suggested, going into the

bathroom by yourself or something like that, or trying to shower by yourself. All of a sudden you need help. That's a really that's a hard place to be because you do second-guess yourself. You do start thinking, am I crazy? Am I looking at this all wrong? Am I overexaggerating things?

**1:12:44.1 Teena Hittie:** And it really does make you look at yourself because you're trying to figure it all out and now you've got people questioning you and you're thinking, okay, you really don't need that. But ultimately that's what happens because all of a sudden you're so different and it doesn't make any sense.

**1:13:00.7 Heather Davies:** No, it's really difficult. And what about you, Carreen? Have you found that?

**1:13:06.2 Careen Hanouche:** I have definitely found that. I went through six different providers before I got answers. And I know that's a similar story to many of us. I started in the ER, went through an ENT, a neurologist, I had scans, and all the while seemed to be totally confusing all the providers I went to see and just being told, "Well, you look like you're walking fine." And I'd say, "Okay, I look like I walk " which I didn't even think I looked like I was walking fine, but I apparently look fine, but I'm not fine.

And I would say, "But I don't feel like I'm walking fine." And then they would say, "Well, maybe you're stressed at work. What do you do for a living?" And if I would say, "Lawyer," forget it. Then everyone would just typecast me and be like, "Well, it's your work that's the problem." One of them told me, "Let me prescribe you a vacation, a week away." And I was thinking, a vacation? I barely made it to this office. I can't go on vacation. So I just felt completely misunderstood, invalidated, and I started to feel the same as Teena.

**1:14:22.1 Careen Hanouche:** Am I crazy? Am I seeing things all wrong? Am I really that weak? You almost feel weak because you feel, what is this? I should be able to control this. I should be able to get down the stairs alone. You start to question everything and you just so desperately want answers because you're confused, you're scared, you don't know what's going on. And it's so difficult to explain what is happening because it's unseen. No one can see it. Everyone thinks, "Well, you look fine," or, "You look just like you did yesterday." And I would keep saying, "That's great. On the outside I look fine. I do not feel like I'm fine." And it's hard to explain that to family members. I had super supportive family members that tried to help whenever they could. But when someone doesn't go through the same thing as you, they can't possibly have the understanding you

want them to have. And that took me a long time to realize, too. That took acceptance. It took me stopping. I would tell myself, it's okay if people don't understand you.

**1:15:29.5 Careen Hanouche:** It's okay. You can't make them understand what you're going through. And that's when support groups or speaking at conferences like this and you hear people saying things and you're like, "I can really relate to that. That's me" makes such a difference because otherwise you feel very isolated. You feel very, very confused and very alone.

**1:15:53.6 Heather Davies:** I have found that I'm sorry, Cynthia. I have found that in some groups, people have told me that they've had issues with their family members understanding what they're going through when they try to explain it. But when they're redirected to Life Re-balanced Chronicles, where they see other patients that are going through exactly what they're describing, their family members, it clicks for some reason, watching someone else's story. So there are so many things out there where you can navigate your friends and family to, to try to understand those friends and family members that want to know. You know what I mean? So there's a lot of that out there, too. So I completely understand that. It's tough.

**1:16:34.1 Cynthia Ryan:** While you were talking, Careen, what was going through my head was, because I'm going through my own medical process right now, and I find that often the medical system tries to fit you into this box. And if you don't fit neatly into that box, then there's something wrong or there's not something wrong. They very often don't get that just because these tests didn't indicate something was wrong, that there's this gray area of, okay, what do we look at next? And that can be really invalidating. So I just want to recognize that. We were talking about fear. A lot of the questions that were coming up were about fear and avoidance. Did you find that early in your vestibular journey that fear influenced your choices, such as avoiding movement, avoiding driving, avoiding social situations? Teena, do you want to start?

**1:17:48.2 Teena Hittie:** Yes. D, all of the above. I didn't drive for two years, and rightfully so in the sense that I didn't feel safe and I surely didn't want to make anybody else unsafe out there. But I kind of had fear of everything. And I felt like I was relearning everything again. A lot of times, like I think a lot of us have probably felt, you feel like you're going to fall. And it's that fear like you're going to fall and your hands go out to catch yourself. I did that all the time. Everything I did, I felt like I was going to fall.

Even to walk with a walker, I wasn't sure if that walker was going to keep me or was I going to fall backwards. Driving, everything. I would crawl up the steps because I would not even think about going up them normally because I knew I couldn't. So there was definitely fear there. There came a point where it was kind of like, how long do I want to live in this?

**1:18:55.2 Cynthia Ryan:** Sounds like Teena froze up for a minute. We're going to come back to her. Careen oh, let's see. Did she come back? No. All right, Careen, why don't you share your experience about how fear affected your behaviors, your avoidance of social situations, that sort of thing?

**1:19:17.8 Careen Hanouche:** Fear dictated a lot of what I did and didn't do. So I, as I said before, had become hypervigilant. I felt like movement was counterintuitive. I felt to myself, okay, if you just don't move, you won't feel off balance and eventually this will go away. And I was told that by doctors too. "It's like a free cruise. Just ride it out." A doctor actually told me that. "It's like a free cruise. Just take a two-week cruise and ride it out and the waves will go away." And two weeks came and went and I still felt like I was on that rocking boat. And then one morning I felt like I was walking on clouds or marshmallows, and it was seemingly getting worse. And

so I thought to myself, well, I can't get in a car. Like Teena was saying, that's not safe, not safe for me, not safe for those around me. I can't possibly drive my kids. And you start to make decisions based on what you think you're capable of doing or how bad you feel one morning when you wake up and open your eyes and feel like, okay, everything's moving again.

**1:20:20.5 Careen Hanouche:** So you start to make your circle smaller. You start to close in on yourself. You start to avoid social settings because with my PPPD as well, the grocery store was the most triggering place one could go. Social settings I missed baptisms, I missed birthday parties because I told myself, I can't sit there for that long. And just sitting at a table eating with my kids was hard because who knew that sitting at a table and trying to eat while trying to focus on moving children while trying to hold your head up is there's a lot going on that people don't see. They just see sitting at a table because, yes, that is easy to do until you can't anymore. So I think that fear dictated so much. I avoided a lot. And looking back, I probably shouldn't have avoided so much. I probably should have exposed myself more. You learn as you go, and you learn what you may have done wrong, but at the time you were just coping. So you can't blame yourself. You were just trying to get through the day and trying to get answers and trying to get better.

**1:21:28.5 Careen Hanouche:** But then you realize you have to advocate for yourself. Are you going to be like this forever? Do you want to be like this forever? Or do you want to try to get answers? Do you want to take a step forward? But you start to avoid so much just because simple tasks are hard. So how will you do something bigger that's more demanding, that has more triggers, that has more sound, more lights, more movement? And you start to question yourself, well, how could I possibly do that? And then people will tell you, "Well, are you coming to this?" And you almost feel like but how? You want to almost yell it, like, "But how can I do that? How can I come to this? You don't know what I can't do daily." So you start to get it's emotional. It definitely is a mental game as well.

**1:22:15.0 Heather Davies:** What helped you begin to work through that fear and slowly rebuild that trust in yourself?

**1:22:22.1 Careen Hanouche:** It was a combination of things, Heather, and it didn't happen quickly. It was a lot of trial and error. It was a... There was a lot of puzzle pieces to put together to see what worked in my case. And some things didn't work. And I remember when I finally found a specialist that believed me, I think that's what really turned things around. And

there are providers out there that do understand. So I wish someone would have told me that. Have hope that you will find someone that believes you. And when you do, it changes so much because you start to say, "Okay, this person understands. Like, I told him I can't do this, and he gets it." And now, the provider told me, "What do you want to work on? Is it the symptoms? Is it the anxiety associated to the symptoms?" And I remember saying, "It's the anxiety. I can't the anxiety is just getting to me, and I can't rise above it." And I was really caught in that dizzy-anxious-dizzy...

**1:23:20.4 Heather Davies:** The cycle.

**1:23:24.0 Careen Hanouche:** Yes.

**1:23:24.6 Careen Hanouche:** I was just rolling in there like a hamster, and I needed someone to get me off that wheel. And so when that provider said, "Do you want to work on the anxiety?" I said, "Yes, I definitely want to work on the anxiety." I think that was my most troubling symptom with all this. And when I started working on that, there was obviously the vitamins, there was a trial and error of medication, there was VRT. I really you name it, I probably tried it. I read books on vestibular migraine. I used VeDA's resources. You would not believe how many resources of VeDA's I

used because I felt, "Oh, wow, there is actually an association that understands what I'm going through." And so I looked through resources and I found support groups, which is something I never, ever thought I would attend, to be honest. I thought to myself, "I'm not a person that goes to support groups." And it was the most life-changing decision I ever made, that day I finally got the courage to attend the first support group. So there are a lot of puzzle pieces I put into place to find a management of my symptoms. Of course, there are flare days, but even that takes finding tools to regulate how you're feeling and how nervous you're feeling about a flare.

**1:24:39.7 Careen Hanouche:** So it is a while I say it's a constant job, I always say this is like my part-time job, managing these vestibular illnesses. It's rewarding in a way to see that it is possible and there are options out there. I needed to be patient enough, and I wish that I had known that at the beginning. This is not a quick fix, and I should have been told that sooner and been told, "Move more. Expose yourself more." Had I heard those things at the beginning, I think my journey would have been way different and I wouldn't have avoided something for so long. And I think I would have easily cut off a year of I would have felt better faster, to be honest, when I look back.

**1:25:23.8 Cynthia Ryan:** Wow. Wow, thanks for sharing. I want to just let everybody know that Teena's having some internet trouble, and we're trying to work on that. We don't know if she'll come back, but in the meantime, I'm going to jump to a couple of questions from the Q&A, if we can. In between the questions that we have for you, one person was asking, "How do you keep your mind off of your symptoms?"

**1:25:49.6 Careen Hanouche:** That is a great question. It's not easy to do, but it gets easier. So it was hard at the beginning, and I would use techniques that seem so simple but that made a huge difference. So I remember my mother having given me a lavender-scented candle. And as soon as I would start to feel an onset of symptoms or an uptick of symptoms and I would start to get nervous about it, I would immediately grab that candle, smell it, and it would do something. It would distract me. Distraction was key in my keeping my mind off my symptoms. They may have been in the background, but they didn't take over at one point. So it was a lot of scented candles. It was a lot of I would open the door. I remember it was winter, too, and I would open the back door and just be like, "It doesn't matter if there's tons of snow out here in Canada. I don't care. I'm opening

the door." And that fresh burst of air on my face made a huge difference. So I would do simple things but that really had an impact.

**1:26:52.7 Careen Hanouche:** Audiobooks, because I couldn't read at the time. Scrolling on the phone was hard. Reading a book was hard. So I would put audiobooks on. I would put podcasts. If I was trying to do homework with the kids and that was triggering, I would have music low in the background, because anything that could distract my mind from focusing on my symptoms was very helpful.

**1:27:17.1 Heather Davies:** That's great. And I know we have. That's a process, too.

**1:27:20.2 Cynthia Ryan:** Oh, welcome back, Teena.

**1:27:21.6 Teena Hittie:** Hi.

**1:27:23.7 Cynthia Ryan:** Don't you love technology?

**1:27:26.0 Teena Hittie:** I know what it's like to have a drop-off.

**1:27:30.7 Cynthia Ryan:** So, Teena, we were just talking about fear and what you do to rebuild trust with your body. Do you want to talk about was there a turning point for you or a specific strategy that helped you rebuild trust with your body?

**1:28:03.1 Teena Hittie:** I don't see there's a specific strategy. I think it was just a trial and error for me to just keep trying things one way or another and figure out what's going to now work. Can it be the way I used to do it? Is it now a new way? And I think it was more so for me working through what was in my head, what was my brain telling me? That was more my issue is to that was kind of the hardest thing to overcome: what was my brain telling me versus getting over the fear in my head more than anything.

**1:28:44.6 Cynthia Ryan:** It's a mind game for sure. I think that's part of the trauma is dealing with the mind games that your brain is playing with you. That's really tough. How about you, Careen? What strategies did you use, if any, to rebuild trust in your body?

**1:29:09.1 Careen Hanouche:** I did a lot of affirmations, so I would talk to myself a lot. I would always tell people I'm my biggest coach and my biggest cheerleader because I found that I had to be, because no one could really coach me through it as well as I could because I understood what I was going through. So I began to do simple things, like while brushing my teeth, which I found very triggering standing in front of a mirror brushing my teeth, I would tell myself, "You're stable, you're strong, you're not moving." And I would start doing that and it just became something that I did automatically at one point and I would just be affirming myself constantly throughout the day. "You've got this. You've been here before. You're not going to fall. You're stable." So I found that that helped me a lot. And then I also started meditation, which is another thing I never thought I would be doing because I was a very type A go, go, go, never rest type of person, admittedly. So I started meditation and I would do just 10 minutes every morning because I found longer than that I would get very distracted and start focusing on my symptoms again.

**1:30:16.3 Careen Hanouche:** But the 10 minutes really made a difference. And it was body scans, anything that I found interesting and could calm me down. I didn't do a lot of the deep breathing because I found the deep breathing actually made the anxiety worse, believe it or not. So I would do

different kinds of meditations. I think also the third thing that I started doing was as soon as I tried to move a little more, I would start celebrating my wins. So I would start saying, "Oh, look, I made it from the bed to the hallway, down the hallway by myself." And then I would say to my husband, "Okay, today I'm going to go from the front door to the driveway." And it seems like such a small thing, but it was a huge thing to me. And he would say, "You did it!" And I would say, "But that was so big for me. I really did do it." And then we'd start to celebrate and then my kids would get in on the game and they would be my biggest cheerleaders. So it was gradually starting to do a little bit more every day.

**1:31:12.5 Careen Hanouche:** So I would tell myself, "If today you did this, tomorrow try to add two more steps." And I would start doing it that way and I found that the more I could move a little further, the more I had confidence in myself. And then my brain would be like, "Okay, well, nothing happened to you. You made it down the stairs today alone." And just gradually exposing myself that way, starting with doing it by holding someone's hand and then not holding someone's hand, then going in the store with someone, then going in the store alone with my husband waiting outside. It was a very, very progressive method I used and I think that it really helped me. I just needed the confidence and as soon as I felt that I

could get through something even very small, it made a very big difference. So the exposure definitely helped. And that's how I got back to driving, too. It was a very slow process. I just sat in the car for two minutes at the beginning. Get in the car, get over your fear, get in the car, sit there, and then get out as soon as you start to feel bad. So I think those were methods that eventually, gradually helped me.

**1:32:16.4 Heather Davies:** I love that. I think I want to backtrack a little bit to those little glimmers, those little celebrations that we have to have for ourselves. I know mine, and it sounds so strange, is wanting to help clean the house. Why in the world would I want to do that? But I really wanted to start participating again. And those are little things where just 15 minutes a day I would get up and just do a little bit and then rest for maybe 45 minutes and try another 15 minutes. But those are little wins. Those are things that we can't do right away. So anything that I hear a lot in the community about gratitude journals. Those things do add up and it just makes you slow down and really think of what okay, yeah, it's been bad, but hey, there's also some good today. So I love that you said that. I wanted to ask, did you seek any mental health counseling or therapy as part of your recovery, anything like that?

**1:33:07.3 Careen Hanouche:** I actually what I did do, I was supposed to start therapy, and then I actually went to a support group that VeDA offered. And that actually became my therapy. I actually found so much use in it, just connecting with other people who experienced the same or similar events as myself. And I'd sit there and listen. At the beginning, I never spoke. I just sat there and listened to people share their stories and what they were finding difficult or what they had succeeded in. And it helped me immensely because I felt like, "Oh, there are people out there who understand." Look at us all nodding on the screen. Someone said they managed to go to the grocery store and everyone's clapping. And it felt great because everyone just understood each other. And from there on in, I was a support group addict, I say, because I just think it's the best. And I think it provided me not only with connection, but also validation, people believing in me, me starting to believe in myself, people cheering me on. And then I felt less isolated.

**1:34:12.3 Careen Hanouche:** I would literally call it my social hour because I didn't get out as much. So I would be like, "Okay, this is my social hour. I'm going to go speak to the people I see once a month or twice a week." And we just discuss things. And it felt like I really wasn't alone anymore.

So it changed everything for me. So I think that was my therapy and I continue to do it. Four years in, I still religiously go to the support groups. I now go to the Dizzy Moms Club, which I co-founded. And that's how much support groups changed me. I took on a support group of my own and I can't miss it. I will cancel things if it falls at the same time because it's a priority. I think it's a little bit of self-care I do for myself, which I didn't tend to do before. So it's my social self-care hour. And the therapy has it's just the therapy has brought, has changed my journey. It has changed how I've dealt with the symptoms. It has changed how I dealt with the flare-ups.

**1:35:18.1 Careen Hanouche:** It has provided me with coping tips. So I think that talking about it with people who understand, or even just talking about it with someone who wants to listen and try to understand what you're going through, makes a huge difference because you do feel very lonely. You do feel like no one really gets what you're going through. And just having someone show up for you just makes such a world of difference. And I think it's something I really needed and I continue to need. I think I would feel very lost if I didn't continue doing it. It's just constant support that I need to keep me kind of at my baseline. So I found that I think you need to put your pride aside. I had a lot of pride about not

speaking about my symptoms or, "I'm not going to get on this support group and say what's going wrong in my life." I think it's just...

**1:36:15.0 Heather Davies:** I think there's a lot of reluctance about that. A lot of reluctance about people going to their first support group because they're intimidated. And you don't really have to you don't have to talk, you don't have to put the camera on. Could you speak on that for a brief moment, Careen, about if you do have that hesitancy to go?

**1:36:30.9 Careen Hanouche:** Yes, I had a lot of hesitancy. I would see it come up in the VeDA newsletter. I think months went by before I decided, "Okay, I'm going to click on this link and I'm going to join the support group. I have to do it this month." And then I found everyone was very welcoming. No one pressed me to speak at all. I spent, I think, the three first times not speaking, just listening. They were very cognizant. If you're having a symptomatic day, turn off the camera, don't look at the screen if the little boxes are moving around. And just that made me feel like, "Okay, I found my people." They even understand that staring at this screen can be triggering right now. So I just had to take that step. And I wish I had taken it sooner. I wish I had understood you don't have to go on there and

tell your whole life story. No one's expecting. And you don't have to be perfect. You don't have to show up feeling your best.

**1:37:28.0 Careen Hanouche:** You can show up feeling your worst, and that's okay, too. And you can cry, and that's okay, too. And that's hard for some people. That was hard for me. I had never gone in public and cried before. So I cried with people. We laughed together. And I'm happy I took that step. But there definitely was a hesitancy there, and I didn't realize just how much I needed the connection and validation. I thought I was handling it okay on my own and that I would come to terms with it and I could get control. But I think that part was missing, and I didn't know how much the connection piece was missing until I joined the group and started getting help from others.

**1:38:11.7 Cynthia Ryan:** Yeah, I've heard from so many people who say that when they finally joined a support group, they felt like, as you said, they found their people, their second family. And there are so many different support groups, both in person and online, and they meet at different times, they meet on different days, and they might even take a different approach or be for a specific subset of people. Like the Dizzy Moms Club is for moms who have a vestibular disorder. And that's a whole different

thing that you're dealing with as a mother, questions about how you have changed your parenting and the guilt that you feel over that and how you communicate with your kids. Yesterday during the panel, we were talking with Lara, whose vestibular journey started two months after she gave birth to her twins. So she had a lot of issues around not being able to be the mom that she wanted to be, and then talking to us about how she communicated with them as they grew up about her condition.

**1:39:29.2 Cynthia Ryan:** VeDA also has support groups for people who have had to retire because of their vestibular symptoms and then more general support groups as well. So hopefully somebody is putting a link to our support groups in the chat. Please check those out. I wanted to recognize that Teena might not be able to come back on because of her internet connection. So we'll go ahead and move on with some other questions for you, Careen. Let's talk about Heather, you had asked about mental health professionals, and Careen, you said that you started with a mental health care professional. How did you find someone that might understand what you were going through? Were you looking specifically for someone with experience with chronic illness?

**1:40:26.2 Careen Hanouche:** I started actually looking for someone who had experience with CBT because I had read that that was very helpful to other vestibular patients. So I started with that, and it was helpful because I needed to get out of my head about what was going on in my head. I found that was very helpful. I used the VeDA registry. Actually, being in Canada was a little harder because sometimes there were a little less resources for providers in Canada. But my primary care provider had actually referred me to someone who did that. I found that was helpful. I needed to be given cues or tips on what was going on and how I was reacting to certain symptoms coming on. So I needed to see it for what it was. I didn't need to project the fear into it. I didn't need to start spiraling of, "How is this going to affect what I have to do in three weeks? How will I be able to fly again?" Your mind goes there naturally. And it was helpful to hear the two experts before our panel because I felt seen as well, because I felt like, "Okay, it's normal."

**1:41:49.8 Careen Hanouche:** People worry about these things. Your mind does automatically go there. And I needed that help to be like, "Okay, hold on, slow down. Deal with what's going on right in the moment. This is how you can respond." And it was almost like talk to your symptoms. Tell yourself like, "Okay, you're here again. I don't like that you're here, but I can

function even if you are here." And give it a name. Sometimes the therapist would be like, "Give your symptoms a name. Give your dizziness a name. Call him Diego. Call him something with a D to go with dizziness." And I thought that was funny. I started thinking, "What should I call the symptoms?" and "Should I talk the symptoms away?" like just stop annoying me like a kid would do. But it comes down to the basics, and it's not something necessarily I would have thought of doing myself. I needed somebody to give me those coping tips. I needed somebody to give me those tricks. And they seem so obvious once someone gives them to you.

**1:42:47.6 Careen Hanouche:** But I never would have thought of doing that. And it did help. It did help to bring it down a few levels and be like, "Okay, this is what's happening and I'm going to be okay. I've got through this before. I don't like the sensation, but the sensation will pass. And you were able to do this yesterday, Careen, you can do this again." So it was a lot of that talking and affirmations. Like I had said before, I think that the therapy really helps because, to be honest, the physical part may have been easier than the actual emotional and mental part of this entire journey I've been on. That dizziness was not the hardest thing to deal with. That feeling came and went, and it was more what it represented, and it was more the fear associated with it and the fear of backtracking also, because

as you start to manage it, you fear going backwards again. So that's where the therapy really did help, and that's where the support groups are still helping.

**1:43:49.8 Cynthia Ryan:** Yeah. You really do need someone who is kind of detached from your situation to give you unbiased feedback on what they're seeing through what you're describing. Because so often, and full disclosure, my husband's a retired psychotherapist, but I remember him talking about sometimes he would listen to someone and then he'd really just kind of reframe what they just said so that they could hear it in a different way. And I think that you can't really get that from your friends or family or even in a support group because everybody is so invested. It really sometimes you need that separation. Heather, did you seek counseling when you were first dealing with your vestibular disorder?

**1:44:50.1 Heather Davies:** I did not. Because, unfortunately, I had to step away from my career and I lost my benefits. So I did a lot of research and reading, and that was my way of getting out of my head. And I still struggle with that. It's so crazy that you said that, Careen, because the physical symptoms, I can deal with that and pivot, but that mental game is serious. So I do lean a lot on the community and a lot of the things that you learn

as you go, like the positive affirmations and things like that. And that ugly little voice in there that's doing the what-ifs that I send to his room and lock the door. You just have little things that you do that you just have to center yourself. You can't think about those things. You just have to really recalibrate. But I wish more people had the resources for therapy because I think it's one element that I missed out on. I just had to do a lot of reading and I'm still learning every day.

**1:45:52.3 Cynthia Ryan:** Well, there are so many things that we can learn on the internet now, things that you can do for yourself. Mindfulness practices, breathing practices, other tools that you can use to regulate your nervous system and find emotional balance. How about you, Careen, with those things? Have you gone down the road of all of the wellness apps and what do you do to explore tools that can help you regulate your nervous system?

**1:46:32.8 Careen Hanouche:** I've definitely gone down that rabbit hole, Cynthia. I think that what I found worked the best was meditation in my case and just the positive self-talk. I also went down a whole I really researched a lot about somatic breathwork and healing, and I found that

that was something that resonated a bit more with me. It was easier to implement because sometimes the day gets hectic and you're trying to manage the kids as well as taking care of yourself, and it's hard to implement some of the practices in reality. So there were some things that were just easier for me. I found that a weighted blanket really helped when I needed some more grounding or I was feeling kind of dissociated or depersonalization, which I struggled with a lot. That would bring me back to myself. So I would use weighted blankets. I would also use, if I had anxiety about an oncoming symptom, I would put my hands under cold water.

**1:47:39.3 Careen Hanouche:** And just that feeling of cold water would kind of help me as well. Chewing gum. I tried a lot of things and there are a lot of things that worked, which also gave me hope because I was like, "Okay, there are some things that can really stop me in my tracks and stop this and help me get back to myself." So I think that sometimes I thought that maybe sometimes I was researching a little bit too much or sometimes community talks on Facebook would lead me down a path that would make me feel more anxious. So I had to realize when to step away from that as well, right? So you have to realize what's working for you and what's not working for you. If you're getting more anxious or you're getting less

hopeful about a situation, then I had to tell myself, "Okay, that's not working. Step back from that and go to something that makes you feel more hopeful." And that's why support groups worked for me and that's why those little tricks are easier for me to do.

**1:48:37.7 Careen Hanouche:** It doesn't involve too much effort. I can implement it easily. Even if I'm working, I can get away for two seconds and do that. So it was all things that would really help ground me, but that I could use as tools. I found that the more tools I had in my tool belt, the better I would feel about venturing out of my house or getting back to work because those things gave me confidence. And I would be like, "It's okay. I have my tools. If something happens, I have my toolkit. I have everything that can help me in a situation." And if it doesn't help, it's okay. I'll go home, I'll rest for a bit, and then tomorrow is a new day. So, yeah, I think that the more trial and error, the better. Even though it sometimes can be a little taxing, it does pay off in the end.

**1:49:32.2 Heather Davies:** Yeah, it definitely takes time to figure out what you should put in your toolbox, in your personal toolbox. Well, I know there's a lot of people out there listening today that are new on their journey. So what would you say to someone, Careen, that's newly dizzy,

scared, and a little bit overwhelmed and just kind of feels lost right now?

What would be your advice to them?

**1:49:56.6 Careen Hanouche:** I think I would tell them that and I might get emotional here but I think I would tell them that it's okay to feel how they're feeling at the moment, not to fight how they're feeling. I think I fought it too much at the beginning. I think you will get better. You will find tools that help you. There are going to be days that are better than others, but there are going to be good days, and to celebrate the good days, to celebrate the wins, to focus on what you can do rather than what you can't do. I tended to focus a lot on what it took from me, but I should have been focusing more on what I was learning and what I was able to do despite the dizzy. So I always say now, my new saying is, "Despite the dizzy, I was able to do this," or, "I'm going to do this dizzy, and I will rest after." So a lot of positive self-talk, a lot of cheering yourself on, and a lot of trying things. And if it doesn't go well, it's okay. Try it a different way the next day.

**1:51:05.8 Careen Hanouche:** Go very slow. There's a lot of tools out there you can use, but the biggest thing is just to celebrate any small win you have because that will be so helpful to you in the long run because it'll

build your confidence. And find others who understand you. There are so many people out there. You feel like your world is small at the beginning and you feel like you're the only one dealing with it, but there are so many others out there who get what you're going through and who can really connect with you.

**1:51:41.2 Heather Davies:** That's so true. It's huge. Go ahead, Cynthia.

**1:51:46.4 Cynthia Ryan:** Such a journey. And I think what I see so often I wish that I had known each of you before your vestibular disorder because I get the sense that this has changed you as a person. And obviously both of you and so many people out there have become advocates as a result of your experience, advocating for vestibular awareness, advocating for support through support groups, volunteering in other ways to make a difference for other people who are going on this journey. And I'm going to ask this question to both of you, but, Careen, I'll start with you. How do you think that this experience has changed you as a person, has changed your outlook, and changed the direction of your life?

**1:52:41.6 Careen Hanouche:** It has profoundly changed who I am, Cynthia. And I will tell anyone who's willing to listen that it was life-altering. But

when I look back, not so much in a bad way, actually, maybe in a positive way. I feel like I really wanted to get out there and try to reach people that were in the same position I was in four years ago and that I still go through daily, and try to be that person that I so desperately needed at the beginning because I was lonely and scared. And I want to help people realize that there is hope. There are a lot of people who get it and you don't have to do it alone and we're in this together. And I think it's changed who I thought I was. I used to pride myself on, "I don't rest. I go, go, go. I take care of others. I don't need anyone to take care of me." And overnight, I needed people to take care of me and I couldn't go, go, go. So it profoundly changed my character traits and my personality.

**1:53:57.0 Careen Hanouche:** And I found that I was empathetic. I didn't know I was so empathetic, but I feel like empathy was there. I feel like I am disciplined. I didn't know I was so disciplined, but I continue my VRT exercises every morning. I will not miss one morning no matter where I am. And I think I was persistent. I think I learned how to advocate for myself, another thing I never really did before or had to do. I learned to stand up for myself and to not take no for an answer, not take "it's just in your head," but know something is wrong and to trust myself. So I think it's taught me a whole lot about myself. It's taught me about who I want to

surround myself with. And it's just shown me that it's okay to ask for help and it's okay to feel like things are not okay. It's not that you're failing. It's that you're just trying to figure something out and you will get there. So it's been a huge life lesson. I think it's even changed how I've parented and the lessons I've passed on to my children. So I think there's a lot of good or purpose that came out of what happened.

**1:55:24.2 Careen Hanouche:** And I never was a believer of, "Oh, this path led me down to where I am now," but it did. And now I have a ton of mom friends who are dizzy with me and we're dizzy together. And that's okay. It's not a club you want to be part of, but if you're part of it, you might as well be surrounded by lovely people who are very resilient. So I think it teaches a lot. A whole lot.

**1:55:34.6 Cynthia Ryan:** Yeah. Yeah. Teena is behind the scenes saying that these are our besties, our vestibular besties. And I know something that my husband has always said about change, about internal change, is so often if things are comfortable, we're just going to keep going the way things are. We're not going to seek out change because change is hard. And who would want to do that hard thing if you don't have to? And so sometimes adversity is what pushes you forward to be able to make

changes that are positive changes, but you wouldn't have gone into them willingly. Heather, how about you? Did you experience that on your vestibular journey?

**1:56:27.9 Heather Davies:** I could mirror so much of what Careen said. My life has completely changed. And I really believe that as bad as Meniere's and vestibular migraine and the symptoms are, it was truly a blessing in my life because it really shook me and woke me up to what I was missing. My life right now is more intentional. It's slower. I had no white space at all looking back before the symptoms. Now, I wouldn't wish this on anybody, but it was what took me to recalibrate my life and live completely differently. And it's true, the parenting did change. I'm calmer, I'm more intentional with things. And busy is a four-letter word in my world right now. I used to be more productivity and busy, busy, busy, that was the way of life. And now that's just so foreign to me and I like it that way. And I never would have known that without being shaken by these disorders. And the friendships I've found made in this community are on a deeper level than my outside the vestibular world friends.

**1:57:40.5 Heather Davies:** Unless you're there, you just don't get that. And it's something we need. I think we all need.

**1:57:46.6 Cynthia Ryan:** Yeah. Yes, absolutely. Teena sent a comment, victim versus victory, and I love that. I want to bring that word victim out and talk about it just a little bit as we wrap up because I think a lot of people feel like a victim of their disorder. And that's totally understandable. It's like, "Why did this happen to me?" It's not anybody's fault and the world sometimes gives us random challenges. But changing your perspective on being the victim versus trying to overcome and I don't even like that word versus just, I guess, acceptance that you didn't do anything for this to happen to you, and yet here it is and you are strong enough to deal with it. You can deal with it. You don't have to deal with it alone. There are people out there to support you. We're here to support you. There are support groups. So I want everyone to know that they are not alone, that we are here, and if you need help, reach out and ask for help. And things, as you said, Careen, things can get better.

**1:59:13.3 Cynthia Ryan:** So thank you so much for sharing your experience with us today. This has been really fantastic. And I believe we might have a banner with information about the Dizzy Moms Club. So if you or someone you know can benefit from participating in the Dizzy Moms Club support group, please check that out. Thank you so much, Careen.

**1:59:34.0 Careen Hanouche:** Thank you very much to you both.

**1:59:35.9 Heather Davies:** Yes, thank you.

**1:59:36.5 Cynthia Ryan:** And Teena, thank you.

**1:59:38.5 Heather Davies:** Thanks, Teena and Careen, for sharing their personal experience. Pretty good session today, Cynthia.

**1:59:47.2 Cynthia Ryan:** Another intense one. Absolutely. Thank you to Teena and Careen. And thanks also to our sponsor, the James D. And Linda B. Halen Discovery Fund and the University of Minnesota Otolaryngology Department for sponsoring this conference.

**2:00:03.4 Heather Davies:** Yes. And as a reminder, you can purchase lifetime access to the recordings and the transcripts of this entire conference at [vestibular.org/LRL-recordings](https://vestibular.org/LRL-recordings). And you can help make sure that this valuable information that's presented today, well, this whole week, this annual event, remains free to everyone by making a donation at [vestibular.org/LRL-donate](https://vestibular.org/LRL-donate). Those links are also listed in the description box below.

**2:00:31.3 Cynthia Ryan:** Alrighty then, another great day finishing up. We will see you again tomorrow to learn about vestibular rehabilitation therapy, neuroplasticity, and exercises that connect it to everyday life. Thanks, everyone. See you tomorrow.

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