Life Rebalanced Live 2026

YOU ARE NOT YOUR DIAGNOSIS:
LIVING WELL WITH CHRONIC VESTIBULAR CONDITIONS

0:00:00.6 Abbie Ross: Hello everyone and welcome to the second day of the Vestibular Disorders Association's sixth annual Life Rebalanced 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. Is that...? Is anyone hearing an echo...?

0:00:37.2 Danielle Tolman: Just stick with us for a second while we work on our technical end.

0:00:44.2 Abbie Ross: There's... Support here, because I'm not sure what's happening.

0:00:52.1 Danielle Tolman: Let's see here. Let's keep going. So as you heard, we're here with Dr. Abbie Ross and not only is she the founder of Balancing Act Rehab and the co-host of podcast Talk Dizzy to Me, but also the Dizzy Reset and she is a proud board member of VeDA. My name is Dr.

Danielle Tolman and I want to thank you all for joining us today. Before we dive into day two, we'd like to thank our sponsor who has made this event possible year after year. The James D. And Linda B. Hainlen Discovery Fund and the University of Minnesota's Department of Otolaryngology have generously supported Life Rebalanced Live since its inception in 2020. A special shout-out to Jim Hainlen, who inspired this event by holding his own vestibular conference in 2018 and 2019. Having experienced vestibular symptoms firsthand, Jim cares so deeply about supporting people on their vestibular journey and it was important to him to not only educate other people about vestibular disorders, but to also provide a platform where we can connect.

0:01:59.3 Danielle Tolman: Now again, I am Dr. Abbie Ross's podcast co-host on Talk Dizzy to Me and I'm also a vestibular physical therapist and I want to welcome you guys as well. We 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 awareness for vestibular dysfunction.

0:02:42.9 Danielle Tolman: Before we get started with today's discussion, I'd like to direct you to the poll questions for this session. If you haven't already, please complete these now. Also, feel free to talk amongst yourselves in the chat and please put any questions you have for the speakers in the Q&A section and we'll do our best to incorporate them as we go along. And just a little reminder that 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. Today we're going to explore what is truly meant to... What it truly means to live well with dizziness.

0:03:21.5 Danielle Tolman: We'll discuss how people can maintain their self-identity despite a diagnosis by integrating sustainable self-care strategies, building resilience, and adopting lifestyle choices in ways that foster confidence and improved quality of life. It's my pleasure to introduce our guest speakers, Dr. Kathleen Stross and Dr. Megan Daly, who are both physical therapists and certified health coaches. Dr. Stross has decades of clinical experience guiding patients through evidence-based rehabilitation while addressing the emotional and physical challenges that often accompany vestibular conditions. Dr. Daly, who owned and operated her own practice dedicated to treating vestibular dysfunction as well as working as a health coach for those living with dizziness, is currently taking the time to advance her knowledge and career by studying public health in Ireland. Welcome Dr. Stross and Dr. Daly.

0:04:16.5 Kathleen Stross: Hi. Thanks for having me.

0:04:17.1 Danielle Tolman: We're so happy you guys are here. All right, so Dr. Stross, could you kick us off today by describing what living well might look like for someone living with vestibular dysfunction?

0:04:29.8 Kathleen Stross: Yeah, that's a great question. I love that. With vestibular dysfunction, one of the most interesting things I got out of yesterday's talk was that the more we zero in on how to help people with chronic vestibular symptoms, the more we step back and look at the whole self. If you watched yesterday, you heard the words life experience or living... Life experiences. Yeah, the life experience that people have. It's really a step back into looking at the whole person. And so I'm happy that the vestibular community scientifically now is saying, what is it like to live well? That's what we are focusing on.

0:05:08.1 Kathleen Stross: So for me in my practice, what that means is giving people authorship or agency over their own life despite their dizziness. Not necessarily by eliminating every symptom, but restore confidence, capacity, and connection. It's the opposite of a fear-based diagnosis-seeking anxiety and rush towards diagnosis and finding a pill or a magic solution. It's grounded, it's empowered, and most importantly, it's self-directed. And I have details on each of those steps. We go from putting function over fear, from clarity from chaos, autonomy over dependence, integration over fragmentation, and identity beyond illness. So I mean, this is a talk that could go on for a long time, but for living well, it really just means you have authorship over your story. Make it a good one. And all the best stories have challenges. Don't forget that.

0:06:13.0 Abbie Ross: Yeah, I couldn't agree more. And I also just want to give a round of applause to Danielle for holding down that intro while I had some tech difficulties. And thank you audience for bearing with us. I couldn't agree more. The lived experience and then also taking self-agency over your well-being and what that looks like for each individual, which leads us into another question. Megan, I'll throw this one to you. When people experience this self-identity crisis because they feel so consumed by their symptoms, how do you help them?

0:06:46.3 Megan Daly: Yeah, that's a great question. It's really easy to get caught up in the symptoms and the diagnosis, and most people are navigating the health system in a way they've never had to before. And so it can just really knock you off your foundation. So I think one of the things that I help people is to really find that steady ground again and go back to the basics. Right? Your identity can be wrapped up in work or your role in your family or whatever it is that's been taken out by this vestibular disorder. And so suddenly you again feel off-axis. And so it's like find that foundation again, get back to your root, and really tune in to what you need, right? And try to just get rid of all the extra things that can be circulating around you, like, oh, I should be doing this, I should be doing that. But let's bring it back to the basics and root. And, you know, everyone's gonna have a different root or foundation, so really working with each person individually to figure out what that means for them so that they can get more clarity with what they're doing.

0:08:02.5 Danielle Tolman: I like what you mentioned in terms of kind of getting caught up in all the stuff that's happening, especially with these changes and just that kind of panic of, I can't do this, and, who am I? And, what am I doing? It's really easy to get lost in how quickly everything changes, especially when your world is moving around you maybe, or you don't have that steady foundation under your feet. Kathleen, are there any specific strategies that you utilize with patients that help people find that foundation and kind of get them back to their core?

0:08:33.9 Kathleen Stross: That's a great question. In the beginning, it's normal to be focused on symptoms and description of those symptoms. Anybody who is hit with sudden onset of vestibular symptoms knows this, and then we go to seek anxiously and rapidly a diagnosis and a treatment. Shifting people into the symptom management and curiosity about their experience is one of the first things to do, and that helps us regulate our nervous system. The first thing we have to do is move from fight, flight, freeze, flee, panic, anxiety, find all that's wrong, to being calm and creating a new relationship with your symptoms. Developing a curiosity, I always say, hands up and open and consider what your body's telling you.

0:09:28.9 Kathleen Stross: Thank it for what it's telling you. Listen to it. It's communicating with you and it needs your gratitude, your support, and your attention. So let it speak to you and curiously consider what it's telling you. So the first thing I do is teach people to suspend judgment. That means suspend judgment when your body speaks. Go, hmm, that's interesting. I feel that right now. Thanks for letting me know. I promise to take that into consideration. So we don't automatically jump to conclusions about good, bad, panic, freak, leave, whatever, but we consider. And we understand then in the process what our value is. Our value is to stay present in the moment that we're in, to be effective, and to be content or even enjoy ourselves ultimately, right? And so when we do that by developing a curiosity about our symptoms, suspending judgment, that is one of the first steps that we do. Thank you for telling me. Thank you for my body to communicate with me, and having that self-loving relationship.

0:10:41.5 Abbie Ross: Yeah, I agree. That's a message that I echo a lot is your symptoms are communicators. You almost want to be thankful that your body is telling you that something is off. You mentioned having compassion and such. How do you teach someone to have that self-compassion when they feel like their world has just turned upside down, Megan?

0:11:05.5 Megan Daly: Yeah, that's a great question, right? Because that's the first thing I think people do is they start to beat themselves up, like, I did too much, or, I did something wrong. So I think it's a lot of what Kathleen said is getting you in that good nervous system state so that you can recognize that it's not something that you did. It's not your fault. And to be able to self-regulate and say, what is this trying to tell me? And what can I do? Right? Like, what's one coping strategy that I could have? I really like giving that to people too because it's like have a coping strategy so that you have an outlet for this. Because if you start to beat yourself up, it's like, okay, let's channel that into something else. Right?

0:11:52.1 Megan Daly: You may not be able to turn it around right away and be like, I'm the most amazing person even though my whole world is spinning upside down right now, but you could take a step in that direction and say, you know, this isn't my fault, and, I'm gonna channel this into a hobby, or take the dog for a walk, or just do something to shift it away from the self. Again, taking the dog for a walk could be more challenging, right? So it could be something as simple as just sitting and regulating your breathing, things like that too. So, it's very specific to each person depending on where you are. I always like to start with that one step. How can we shift this away from just beating yourself up?

0:12:39.3 Danielle Tolman: I think, too...

0:12:40.6 Kathleen Stross: I want to add to that.

0:12:41.7 Danielle Tolman: Please, please. Yes.

0:12:44.2 Kathleen Stross: I was gonna add to that that certainly before we can get our mind to buy into a mindset shift or a new way of thinking, our body, which has been in control for all this time with these symptoms, we have to demonstrate to the patient that they can get to a place where their symptoms are reduced. And so the first exercise is helping them prove to themselves that they can calm their symptoms. And I call it finding zero, using a zero to five scale of symptoms. Zero is none, five is the worst. Getting them to find zero, find a moment where there are no symptoms. Once they do that, they sort of feel like, okay, I can do something, and developing that unique strategy, like Megan said, to be their answer to when their body talks.

0:13:37.6 Danielle Tolman: I think a part of the compassion that we also need to consider and allowing yourself some grace is being okay that you aren't able to function at the level that you were at prior to the onset of your symptoms. Being okay that you can't do all of the same things and keep up with the housework and the family life and everything that was on your shoulders prior to that. I think that especially I see this with a lot of young moms or people with families that they feel like they can't keep up and they feel very guilty about what that means for their family dynamic or having to ask people for help, or... Again, just even asking for help and asking to allow others to come in and provide support when needed. So, Kathleen, is there anything that you encourage with your patients in terms of looking for support or anything that you coach them on when it comes to not being able to jump right back in and go back to life as normal?

0:14:36.4 Kathleen Stross: Right. Well, that self-compassion is important and different personalities have different sort of buttons that need to be pushed to help them shift that. But perfectionism with ourselves and with our experience in life is one of the biggest roadblocks to recovery. Understanding that we are human, and that is being honest with ourselves, being unashamed of weakness, being mindful of the situation we're in right now, and then accepting where we are right now and then never giving up. That's my H-U-M-A-N. And that perfectionist of I've got to show up for everybody so that they will like me, or, so I'll be enough. This goes back to root and often developmental needs that people have to be accepted and loved and to not be alone. So, depending on that person's base fear... We talked about this last year, I can't believe it seems like yesterday that we were talking about this topic in the conference last year, about a cycle. You find the cycle that perpetuates in someone's mind and figure out where to break it. And that's one of the early steps in doing that, to find what cycle are they stuck in.

0:16:02.6 Kathleen Stross: I'm not enough, or I don't want to be alone, or I'm not loved, or whatever that deepest worry or concern is. Breaking that cycle allows you to sort of exhale and settle into this is who I am, this is my human experience, this is my story. If I lost a leg yesterday, I wouldn't be beating myself up that I couldn't walk up the stairs tomorrow. Why is it that this invisible illness is treated differently? So sometimes we use metaphors and examples of if it was this, how would you feel? Or another idea is if it was your loved one suffering, how would you show compassion to them? And so often we know how to treat others better than we know how to treat ourselves. So with experiences and discussion about how we would love someone else helps us see that we're not really holding ourselves to a fair level of performance.

0:17:01.6 Abbie Ross: This reminds me of teaching people to take an inventory on their thoughts, on their behaviors, on their habits, and identifying, okay, what's helping me in this healing process versus what might be holding me back? And again, it's not that it's your fault. It's just getting real with yourself and identifying what you can do more of versus what you can do less of. And Megan, you talked about taking that first step. I think that's so important. One step even. You don't have to take all the steps. So let's talk a little bit about pacing. And it could be physically, it could be emotionally, it could be socially. How do we determine what that first step might be in those different realms?

0:17:45.9 Megan Daly: Yeah, I think pacing is really important when you're dealing with this, because we've all had that experience where you do too much and then it feels terrible and you have to take extra time to recover. But on the other end of that, we also have to look at not doing enough. And this can also happen with vestibular issues, is that you are afraid of any of those symptoms or what could happen, and so you do less and less and less. So, that is not helpful either. So finding that middle ground can be very challenging, but that's something that I would always talk to my patients about because you're kind of on this roller coaster, right? You're going up to these huge peaks, and then you're crashing all the way down and just going up and down. How can we level that out so you're not riding this roller coaster? And one of the techniques that I really like to use is the traffic light because it's so relatable.

0:18:44.0 Megan Daly: And I think everyone here has used this before where you get a sense of which activities are the red light. Like, okay, if I take a step, but my step is to jump across this canyon, that might be a red light. Like, that's gonna be too much. I need to stop that activity and then just take that tiny step to the edge instead of jumping, right? And then if we're gonna underdo it, it may be like, I'm just not gonna get out of bed. But that might not be enough. Like, you've got a green light. You can keep going, you can keep moving, you can keep doing more. And then that yellow light is that in-between where your body is kind of like, okay, this activity is great, but we might want to think about slowing down and stopping soon. So that's one technique that I really like working with my patients on to visualize it, get a sense of, okay, what is the step? What is not enough, what's too much?

0:19:43.8 Kathleen Stross: I like mnemonics, so I have a STOP mnemonic. When you see that red light, S-T-O-P, I teach people to stop and think and organize and proceed. So stop doesn't necessarily mean stay stopped, because you're gonna need to do something either to resign to rest or alter your plan or continue forward after a few deep breaths. So, that's another thing. I like that traffic light a lot. Really good. And once people have or learn from a good therapist their strategies, they know what to deploy on a green light to continue, and they know how to deploy on a yellow light or on the red light, and so they know what that means. I think one of the biggest answers to decreasing anxiety and fear is to decrease what they call rumination. And if we're ruminating on what do I do now? Then that holds itself in its own nervous system level of panic and process. So when we come through with I know what to do, I'm gonna do this on red, this on green, this on yellow, and then you have power there in those decision-making.

0:21:05.5 Danielle Tolman: I'd like to break that down just a little bit to maybe give our viewers, our listeners, an idea of what that looks like to categorize your reds, your greens. What type of symptoms or signs do you let your patients or the people that are working with you think about, feel, or identify as things that are telling you that this is good, this is green to keep going, or what are these signs look like if they are kind of leaning into that red zone? Like, what should they be looking for when they're trying to figure out each of those colors for themselves? Kathleen, let's start with you.

0:21:44.0 Kathleen Stross: Well, like I said, I use that zero to five symptom scale. So first I teach people what is zero, and I do try in session one or two to reset the nervous system to zero, teaching them through breathwork, somatosensory orientation, or the feeling of gravity using a technique which I call the BARK technique: breathing, relaxing, feeling. Feeling gravity pulling you straight down into the chair, tell yourself you're steady and not moving, and a hand on the head. So when they practice their breathing, relaxing, and feeling, and you can do this at home while you're watching, breathing, relaxing, and feeling, sitting in a full supported chair, feeling gravity and telling yourself you're steady. The hand on the head also helps the neck stabilize the head so that the head feels clearer.

0:22:31.1 Kathleen Stross: So once you know how to get yourself to baseline, we practice this. I've done a lot of driving retraining with people, so I mean, that's a big thing of how do you develop a routine to get yourself at the baseline ready to do an activity? They learn what that is because they need to be under a three on the zero to five symptom scale to be able to proceed. Once they get to a three, it's a yellow light and they have to employ a strategy, whether it's water, cold washcloth, stopping, breathing, relaxing, and feeling again, or sometimes eating protein or carbs, depends on what their situation is like. So we educate with self-discovery. I think self-discovery for a person in rehabilitation is the most important part of it, rather than brochures and information handed out. People still hand out brochures and information, but if I experience something to calm me and ready me for activity, and then a coach goes with me, a therapist goes with me to show me how to use it and return to that yellow light, I can turn reds into yellow and back to green again with practice.

0:23:42.5 Danielle Tolman: That is amazing advice. I think that's really, really helpful. And I think it's worth mentioning that I like that you use the word symptoms. Right? So, when we're kind of navigating between the red, the yellow, the green, we're looking not only for dizziness, but anything else that might accompany or elevate when you're in those different situations. Right? So, whether it's dizziness or nausea or that foggy or the heavy-headedness. Megan, are there any other symptoms that patients could look out for that kind of move between those colors?

0:24:13.8 Megan Daly: Yeah, I always try to teach patients to try to learn what those warning signs, I call them warning signs. Like, what are your warning signs that are happening? And that could just be that they notice things get a little blurry just for a second, or they just feel a little bit of shifting, or they start to get that funny feeling where they get kind of hungry, which could be that precursor to the motion sickness, nausea feeling. So they're not quite there yet, but they're just like, oh, I'm feeling really hungry, but I just had lunch. That can be a really telling sign that you're starting to come out of the green and go into the yellow. And sometimes people just feel a little bit weak or they'll start to just trip. Like they've been walking fine and they're walking down a straight hallway, but like, oh, they just caught the toe. And that can be a warning sign. So just those little things I like to teach patients to look out for.

0:25:06.4 Abbie Ross: Also... Oh, go ahead, Kathleen.

0:25:08.5 Kathleen Stross: You know, words that we tell ourselves really matter. And so when we're trying to establish a trust with our body and a mindset that's resilient and not perfectionistic, we might change our words. So I teach people to exchange the word symptoms to signals, which goes along with sort of the traffic light. I don't use the traffic light, but I love it because it fits perfectly here, what you're saying, and we're just expanding that metaphor. But signals. So what is your body telling you? What is the signal? And I try to eliminate the word symptoms because, again, it's a signal. And then that develops a trust that your body is communicating with you rather than breaking down. And that's a different chemistry in your brain. I always say, what are your words? What kind of chemicals are your words and your self-talk telling your brain? And you want it to be positive, loving, supportive, and compassionate.

0:26:01.9 Abbie Ross: Yeah, so true. And something I like to use in conjunction with the traffic light system is a movement or activity ladder. So if at the top of the ladder is the ultimate goal, driving to the store and back, there are so many different steps or rungs of the ladder to get there. And if you start at your base or, in your terms, Kathleen, your zero, what does that activity look like versus what is the next step? Maybe it's driving to the... Maybe it's backing out of the garage and that's it. Maybe it's getting to the end of the street and back. Maybe it's going through the grocery store doors and that's it.

0:26:36.2 Abbie Ross: So building up that ladder and really breaking down tasks and then using the traffic light strategy to learn when to go up a rung or maybe when to go down a rung. And I also like to tell people that if you have the experience where you went into the red and maybe you feel like you overdid it a little bit, you're still learning in that process and your brain is still learning too. So it's not a failure. It's actually a very important part of your healing. I also want to talk about examples of maybe some complementary therapies that may make a meaningful difference for people living with dizziness. And I'm thinking maybe practices like specific yoga or sometimes people ask about massage or chiropractic treatments or psychological services. Kathleen, do you want to start us with that one?

0:27:33.7 Kathleen Stross: Sure. I mean, I think that... Again, this is a very individualistic question. Do I think people can piece together a team? Absolutely, yes. A holistic approach doesn't mean one holistic person. Most of my clients have a team that they find is helpful. Some people prefer massage and bodywork. Other people prefer breathwork. Yoga, I love. Obviously, for those, certain positions are less accessible than others. Tai Chi, breathwork. I'm seeing all kinds of beautiful app or organized programs that people have access to now on their phone or on the computer. Some people like to swim, even though I think that that makes it sometimes more difficult to feel the surface and to feel gravity. But whatever you bring together... An important adjunct is to make sure that if your nervous system is stuck in an unhealthy state of anxiety and symptom hyper-focus, hypervigilance, and maybe there's a recovery from trauma that needs to be explored.

0:28:55.6 Kathleen Stross: If that's true, I will always recommend someone get additional help and psych support for recovering a developmental trauma or an experiential trauma because that wires their vestibular system differently. The gut is involved, the mind is involved, the neurochemistry is involved. So medication might be appropriate from a neurologist or psychiatrist or even regular doctor that... Or even ENT that suggests those drugs that are helpful in vestibular disorders that have an impact on the nervous system: SNRIs, SSRIs, things like that. So I think... That's not alternative. Sorry. But whether it be whatever works for the patient, if it doesn't hurt, it might help. And the chance that it might help, and again, it's worth trying. So I let people, rather than tell them not to do something, I kind of let them explore and say, let's try it. But we just need to not try everything at one time because I want to know what works and get them back to that healthy state.

0:30:00.8 Abbie Ross: Megan, did you have something to add to that?

0:30:02.8 Megan Daly: Yeah, I was gonna say that's exactly what I was... I want to agree with Kathleen. Right, you want to bring the pacing into this too. The alternatives can be fantastic. Just don't do it all at the same time. And what works for one person may not work for someone else, so it can be a bit of trial and error. But I fully support anything that's gonna help regulate your nervous system. I love yoga. People try restorative yoga, some people like hot yoga, some people like flow yoga. I really like to suggest Pilates for people that feel like it could be helpful too because that movement can be great for balance training and support, as well as massage and any kind of bodywork can be really calming. And then getting into, if you have any past issues, if you have any developmental traumas, if things have happened, not everyone does well with talk therapy.

0:30:57.5 Megan Daly: Talk therapy can be great, right? We talk about cognitive behavioral therapy, talk therapy, but sometimes things like EMDR could be more helpful for some people. So kind of exploring those avenues as well, going into somatic work and all of that entire realm. If you do okay with needles, acupuncture can be really helpful, or as an alternative, acupressure if you're not as comfortable with the needles, I mean, all of the holistic treatments that go with traditional Chinese medicine. So there's quite a list of things out there. And I find that I learn as much from my patients as I help them. They'll come to me with a modality that I may not have heard before that they have tried and found really helpful, so then I add that to the list of things that I can recommend.

0:31:44.7 Abbie Ross: Yeah, I love it. And I think also to add, it's a combination approach. There's not one thing that's gonna be a quick fix and the next day after you have acupuncture the night before, you're dizzy-free forever. No. It's a combination, and you have to find what helps you specifically. And I also want to add that regulation doesn't always mean calming. Sometimes regulation means you need to actually move the very thing that may trigger symptoms or that you're fearful of. That might be part of the picture for you from the standpoint of bringing everything, from the nervous system perspective, bringing everything back into that reset that Kathleen was talking about.

0:32:28.0 Abbie Ross: We actually have a question that I think in the chat we have it from the audience, but also we have a question already in that there's an importance to social connection and community in the vestibular world. And I want to talk about what that means for someone's overall wellness. And then specifically to bring in the question from the audience, this person is talking about social in-person connection, and they have issues when they have word-finding difficulties and they have limited communication bandwidth. So maybe their social battery drains quickly. So first, social connection and community, what does that mean in healing? And then what are tips for improving that? Kathleen?

0:33:13.2 Kathleen Stross: I do feel like sometimes when you're spending time focused on you, you have to recognize there's a cost, and the cost is a little bit in community. I think of our community as concentric circles. So we can't be everyone's best friend and be out there active necessarily in the whole community doing all of our projects when we're spending time focused on us. So recognizing that there may need to be a constriction of these concentric circles of what your bandwidth is, that's a given. You're gonna spend time focused on you for this certain amount of time, a year, two years, whatever it is, and that's not the time for you to be the head of the PTA and HOA committee and all of these things. So I ask people to be reasonable and pull in and choose the most important things that are healthy for them. We sometimes are over-giving of our time, our energies, and our efforts, and there's a time to be selfish.

0:34:12.8 Kathleen Stross: So what community brings you the best feeling and the best outcome and aligns with your values? So one of the ways to measure... We don't have to make decisions on every single thing. What we have to do is know our value. If my value is that anything I choose to do right now has to be for me and promote my plan to restore and recover and refuel and revitalize over this next year, if it doesn't match that, then the answer's simple. So you don't want to have to ruminate on every answer. You want to set your value and then make the choices that are aligned with those values. I mean, and that's value-based behavior, and so that's important. So for some, it's a little more, for some, it's less. But the quality of it and the fact that it aligns with your value and your plan to work on yourself and your recovery is key.

0:35:17.0 Danielle Tolman: I like the idea of aligning things to what you find value in or what makes you feel good. And when it comes to working in that in-person connection and trying to integrate, I have a lot of patients who find the things that they can do that bring them joy and bring them happiness and try to find a way to incorporate their friends into that. Right? So like, whether it's having a family game night and doing something that doesn't require a ton of head movement or being in big, busy, and visual environments, finding a way that they can still take the things that bring them joy and value but also invite in those social circles, the people who are close to you. I think they understand, especially if they care about you and your journey and everything that's going on, they'll be more than happy to forego the crazy new trendy restaurant that's loud and busy and has all these foods that maybe you can't eat because they trigger symptoms, and be happy to have a night in and do something a little bit more that's friendly to your symptoms. Megan, do you have anything to add to that?

0:36:14.9 Megan Daly: Yeah, I was gonna say I think those are all really great points and I would add, it's about stating your needs and what your limitations are and really finding that support group that's going to meet you where you're at. So that could look like, like you said, that busy restaurant for book club might not be ideal, but maybe the book club can come to you and they don't mind that you're gonna lay on the couch the entire time. And you might not talk about the book. You might just listen to them talk about the book and they bring food so you don't have to prepare it. Right? So it's meeting you at whatever level you're at.

0:36:50.4 Megan Daly: Maybe you're comfortable preparing the food for the book club to come over. Maybe you're not, and they can show up and help you with that, or you join a group or you're already part of a group and you go to that session and they understand that you might not be able to think of the word or they just let you do your thing and then you just talk when you can, but you're there in your community and they're supporting you. So you're still participating in it even if you don't feel like you're fully participating by being in the trendy restaurant, carrying the conversation the whole time. You're still spending time with people, which is so important. That sense of community is so important when you're going through this.

0:37:36.3 Abbie Ross: And something I've heard over and over again from people, too, is actually discovering new hobbies or things that they enjoy that they may not have considered before, which I always think is just the coolest thing. Like you're learning more about yourself even in this time of a challenging experience. Now, of course, we want to prioritize the people who understand and are conducive to our healing and supportive, but we have a couple questions about maybe the opposite. So, Kathleen, how would you say you should best explain it to others so they can try to understand what you're going through? And how do you continue to show up as yourself in work, relationships, different environments where you don't feel seen?

0:38:22.7 Kathleen Stross: That's a great question. Environments where you don't feel seen. I think that the sense of... The relationship with yourself is how you show up to a place, and so identifying what your needs are and setting expectations. That's going to be the most important thing is setting an expectation for what you need. So let's go back to values. If my values are that I want to show up to a place and be able to contribute and that's what's important to me, then I'm going to set reasonable expectations with that. So I'm going to show up and I'm going to be able to visit with people for five minutes and then I'm going to be happy with that. And my boundary is... This boundary has to do with me, is that I'm going to leave if my symptoms get past a three on a zero to five scale. So my values are that it's important for me to do something I enjoy, to get community, or to create something I can sell, like someone is doing furniture in the group and I love that, hearing what people are finding their passion. Or my value is that I entertain my family on Sundays.

0:39:33.5 Kathleen Stross: My value is this. My expectation is that I'm going to function within a zero to three on my zero to five symptoms and I'm going to set boundaries to not push it past that yellow light. So that's just a lather, rinse, repeat on what are my values, what are my expectations for myself, and how do I set my boundaries so that I don't push myself over the edge? And we can't control other things and other people. But, so living with these values, expectations, and boundaries might mean that we ask more questions, we pre-plan, we sort of plan for the worst and expect whatever happens. Don't get where you're expecting the worst, but you have a plan if something happens. You know what your needs are in every one of those stages that you're in, and so you have to be decisive and pre-plan and then act on it. So I think that gives people power.

0:40:30.1 Danielle Tolman: I like the idea of boundaries and knowing what you need and giving yourself the power to make those decisions for you. And I can probably imagine what a lot of people who are watching are like, but this is my job. I don't have control over that. And they just don't believe me and they think I'm faking it because I don't look sick, which is really, really tough. And what I've seen, especially with a lot of my experience with some of my chronic patients, is that sometimes a really hard decision has to be made to change a job or to change that situation, whether it's to ask for accommodations or sometimes just to find a whole new job, which, you know, where I will give my patients a lot of props.

0:41:12.4 Danielle Tolman: Recently, I've had a couple of instances that are actually popping into my brain just in the last couple of weeks where I've had patients actually take control and completely change their whole job situation and sometimes even the work that they're doing, which takes a lot of bravery and it takes a lot of steps and planning, but for the most part, it improved quality of life for them. Megan, have you had to help coach people through life changes like that or having to accept a new normal? What does that look like for you?

0:41:42.3 Megan Daly: Yeah, I've had to help a number of people through major life changes like that where they were leaving careers and they might have had to change where they were living and move and get into a better situation and deal with some really difficult conversations around what was going on. And so in that role, I become their coach to help them through and just let them guide what they need and encourage any kind of counseling or other additional support that would help with the process too. But really take a look at back to that foundational, like, what do they need? Are they doing this to please someone else or can we really focus on what they need? And again, what's that first step? What does that look like? What is that boundary?

0:42:35.3 Megan Daly: And, I would always love to have a counselor coach working with me in my office to work through some of those situations because you can get into all kinds of sticky situations if you're changing jobs and people are really giving you a hard time about not recognizing your illness, even though there's legislation to protect people. So it can get quite uncomfortable. So it's really just being next to them, coaching them, helping them, encouraging them, empowering them to keep going, take that first step and keep identifying their needs while also managing whatever they're dealing with symptom-wise and family-wise, because this stress can increase symptoms. And so it's like, let's... It's just like the alternative therapy. Let's try it. Let's change things, but let's not change everything all at once. So can we map this out to make it more manageable to fit into what you need and your treatment plan?

0:43:35.4 Abbie Ross: And part of that again goes back to recognizing what are all the things influencing my symptoms? Is it a certain relationship? Is it my work environment? What do I have self-agency over that I can change to make myself and my well-being improve? I want to also talk about flare-ups because I think flare-ups are a topic that people struggle with in terms of feeling like maybe they're back to square one or the progress that they've made was all for nothing. And then maybe also there was a question from an audience member, not getting stuck in that self-pity on those more difficult days. So Kathleen, how do you teach people to build resilience and then also have confidence in their ability to work through the exacerbations?

0:44:26.7 Kathleen Stross: Yes, I want to answer that and then I want to go back and make sure that I answer the question about when people are asking, what do I say to people? Because I realize I didn't answer that and I want to. When we talk about recovery, we have to understand that recovery may be remission of symptoms, but it also may mean learning to improve your quality of life and feel good in the midst of symptoms. But for everyone, whether you're a vestibular patient who gets to a place where your symptoms are actually in remission, you need to understand that relapse, another R, is a part of recovery. So we have an expectation that relapse will come and we equip ourselves with a toolbox for when it comes. We study triggers, things that set us off so that we can control as much as we control, but understanding again your locus of control being small living in this big world. We have to be understanding and compassionate with ourselves about it's going to happen. Something will happen that I can't control. I eat the wrong thing. I take the wrong pill. My doctor told me to take this medicine for this symptom I have and it threw me back.

0:45:48.2 Kathleen Stross: Just know that that's part of it and that you don't go it alone. Have a coach, a therapist, a loved one, a support group, VeDA, whatever it is that you can go to, but with an expectation that a relapse is likely to occur. I'm not going to spiral, or I'm going to control and recognize that this is going to happen. So I think again that's an expectation, an expectation that relapse follows remission, even recovery, as an expectation that I have power and agency. The second thing I wanted to make sure I go back and tell people is what to say to others. I think the word vestibular is a tongue twister even for me, as much as I say it. So I think that if you're having problems with word finding or brain fog or stumbling or whatever to say, you know, I have a neurological condition that trips me up sometimes, that causes me to not find the words.

0:46:45.8 Kathleen Stross: I have these word finding problems. You don't even have to say, I have a certain condition. You can say, I have this balance issue. I have this thing. So if you make sort of light of it, but you put it out there and acknowledge it, I think less is more in that situation because what you want to have others experience in you when they're with you is a trusted relationship with your body. And maybe that trusted relationship is, I can't predict what my balance is going to do. So you can trust that your body is a little bit unpredictable. I trust that. I value that, and I'm going to be comfortable with that. Sometimes I can't find my words. Sometimes I stumble and lose balance out of nowhere. So I have this thing where I lose my balance if I turn around quickly, or I need to face the wall. Is that okay? Can I sit here?

0:47:42.5 Kathleen Stross: I just don't want to look out at all the busy things. I have this thing that just makes me enjoy it more if I sit facing the wall at the restaurant. Or I need to put this cotton in my ears because I'm a little bit sensitive to sounds. Or do you mind if I wear these headphones? I'm sitting next to you on the plane or whatever, but I really want to control the noise. I can still hear you, but I'm going to put these earbuds or these headphones in. Whatever it is, you declare. So, declarative. In a declarative way, this is who I am. This is why I am. This is what I do for me. Because no one's going to love you as much as you do, and no one can care for you as much as you can. So being okay with that and declaring it to the world, whatever it is.

0:48:27.8 Danielle Tolman: There's so much to be said for taking control and giving yourself grace and having compassion for yourself and navigating social situations and navigating and understanding your support system are huge aspects of recovery. But so are the consistent little habits and lifestyle modifications that we build along the way, which can be difficult if change has to be made or to integrate these new approaches to care. It can be challenging to be consistent. And as you guys know, consistency is key when it comes to working with this patient population. So, Megan, what are some effective ways that you have helped coach people when it comes to integrating different types of habits or new habits and being consistent with them, whether it's diet or meditation or exercise, without having that person become overwhelmed? How do you coach these individuals to work this into their daily routines and be successful with it?

0:49:26.9 Megan Daly: Yeah, that's a great question. And I'm going to try to tie it back into one of the comments I was going to make before, too. So remind me to talk about relapse if I don't get there. But as far as making these, I think it's great for the patient to identify what they think is the area they want to focus on. Right? It's setting your own goals. What are we going to start with? Instead of me directing, like, okay, we're going to do this. It's like, what's the most important thing for you to start with? And then what does that look like in your day-to-day? So we may talk through their daily schedule and say, okay, that's really going to fit well after lunch. Or maybe that's not going to fit in every day to your schedule because of what you have to do and what you're managing. So what's ideal? Okay, well, ideal is maybe we get to it twice a week. Great. Let's start with that. Right?

0:50:17.1 Megan Daly: Because I'd rather have a consistent twice a week than trying to fit it in five to seven days a week and then getting frustrated and stopping it because it's not working and then letting it go and not trying it for a couple weeks until you become capable of trying again. So it's finding that frequency. Like, how often is this realistically? Realistic is one of my favorite words in this, too. How often is that realistically going to fit into your day, into your week, into your month? You know, it's totally... I've had patients that are in such a difficult place with what they're managing that once a month is absolutely fine.

0:50:56.1 Megan Daly: If you are starting once a month, if you're starting once every other month, it may seem, you might want to say, oh, society says this is not enough. But if that's what works for you and that's what stays consistent for you, that is a great place to start. And then you keep setting those goals to work up to more frequently, like once a week, twice a week. So I really like to sit down and look at the schedule and look at what's realistic. And then to tie that back into reality and relapse, no one can stay in the green and the yellow zone or be perfectly consistent all of the time. We know relapse is going to happen, and I will often give my patients permission to do it on purpose and guide them... Give yourself permission to do it on purpose. Right?

0:51:40.4 Megan Daly: You have a really fun event scheduled this weekend and you really want to go, and you know it's going to put you in the red zone. You know that you're going to have to recover from it, but you are going to have so much fun. And it's, you're safe. It's not like you're going to go to the amusement park for four days in a row, but you're going to go do something fun with people that you care about. And you go into it knowing that you're going to do too much and you're going to have to recover. But the coping that you get from it, the love that you get from it, is absolutely worth doing that activity. Plus, it gives you a sense of how much you can handle. And usually by pushing yourself like that every so often, it helps you continue to go forward in your recovery.

0:52:27.7 Abbie Ross: And also you're getting that social connection and community feel, which can be helpful to your whole recovery process.

There's a hot topic amongst a group that I run, and it's about grief and guilt and shame around your symptoms. Those are maybe three different things, but Kathleen, why don't we start with you, and how do you help people work through those types of feelings?

0:52:55.0 Kathleen Stross: I love that. I think that I'm glad you do that. Whatever you're working on with grief, it's such a pervasive problem for us, especially guilt. Guilt and grief. Guilt is appropriate when we're doing something wrong. Identifying a feeling appropriately is one of the first steps. What am I feeling? Is it really guilt? Am I doing something wrong? I always say, put your feelings on trial. Is there evidence for that? Are you doing something wrong, like not doing your exercises, or your husband or your spouse reminds you to walk every day like you said you're gonna do and you're not doing that, or you're being dishonest? So those are reasons to feel guilty, if you're being non-compliant or if you're lying, cheating, stealing, things like that, guilty. But grief is a natural process of learning who you are now, in the now. The, I am not my diagnosis, means I am something else. And learning what that I am is, is a part of the program that I work through with people. For me, my I am, I can share, it's not a secret.

0:54:18.1 Kathleen Stross: It's my contract with myself. I am whole and free. That's mine. I'm whole and free. And when we talk about what are our values, this is who I am. I'm whole and free, and no one's gonna allow me to not be that. And I bring that. And again, I have triggers, I have symptoms, I have things and patterns, but I am this. So I help people decide who they are and what they want to be. Maybe it's, I'm loving and creative. Maybe it's, I'm caring and a pet owner. Maybe I love dogs and I'm compassionate to animals or something like that. Whatever you are, you be that. And when you know what that is, you don't have to feel guilty for not being that. Because I'm not saying I'm a physical therapist who works full-time and that's 60 hours a week, every week. That's not who I am and who the Creator made me to be. So what we are is not what we do. It's who we really are and who we were created before the world happened to us and before our vestibular system happened to us.

0:55:33.5 Kathleen Stross: So knowing your I am helps you focus on what you really are and not be guilted or have grief of losing that. Because there's no guarantee. As a physical therapist in neurological care in my early career, I always thought for some reason, I would have these dreams that my legs don't work. I actually still have those dreams. And I thought, am I gonna be okay if my legs don't work? And I got to the place where I was like, yeah, I actually would, because that doesn't define me. If my legs don't work, what's the I am? And there's still a whole and free woman there. So I think kind of breaking that into what is the I am without the not what I do, but what's my purpose?

0:56:17.3 Abbie Ross: And diving in a little deeper to one of our questions from the audience, what about guilt and how you're showing up for your family? Maybe in your role as a parent, or maybe you have an elder parent that you're a caregiver for. Megan, how do you help people work through that?

0:56:33.4 Megan Daly: Yeah, I think that's one that comes up very often. And again, it's being honest with yourself and recognizing that, but also getting comfortable for asking for help. So if you're trying to take care of someone and you're also trying to take care of yourself, you can try to give 200% and take care of both people, or you can take a look at what options are there to make things easier for you. And since the pandemic, we've seen a lot of shifts that have helped with that. You can now get grocery delivery or grocery pickup, things like that, where you may not necessarily have to go to the grocery store if you don't have time this week or at all. Right?

0:57:14.6 Megan Daly: You could have it delivered to your house. You could have it just curbside so you could pick it up. So making little changes like that can really help you, especially if you're really holding on to like, I need to do everything. But so many people find that it's so helpful once they've hired the cleaning service to come in and just deep clean their house for them. You know, there's a lot of resistance at first because you're like, I want to be able to do everything. But once that happens, you realize how much space and time it opens up for you to be present as a caregiver for those other people and for yourself. So any kind of easy thing like that. And, go ahead.

0:57:56.8 Danielle Tolman: I was gonna say that's huge. I mean, that's everything. It's time that you didn't realize that you could be spending putting that energy and effort into something that brings you value rather than having to have that feeling of needing to be able to do everything yourself. I know we're getting close to our hour, and we do want to ask one more final question of you guys. Megan, we'll start with you. What message do you want patients to take away about their capacity to live fully and meaningfully even with a vestibular condition? What is your mic drop moment take home from today?

0:58:28.4 Megan Daly: Yeah, my mic drop moment is that it may seem challenging, and there are days where you just have so many emotions, but there is hope and there are options. Right? You may seem like there's nothing left to do. Some people may say, there's nothing we can do for you. There's always options. There's always someone or something that is out there to help you. It may be a challenge to find it at first, to get there. It can be quite a journey. But there's always hope and there's always options.

0:59:00.2 Danielle Tolman: The mic is passed to you, Kathleen. Go ahead and drop it.

0:59:04.5 Kathleen Stross: Well, I see in all of you vesties out there a person who cares deeply about themselves, their role in their family and their community, and a person who wants to give, give back and be productive. I see that. And you're seen and you're heard and you can find your way and you can identify yourself and knowing who you are, even with your symptoms, because it's part of your story. And you can turn your story into something positive to help others when you continue to ground yourself in who you are and why you're here, regardless of where you find yourself feeling today. So, just want to empower you all to stick with it. Never give up. Never give up.

0:59:53.5 Abbie Ross: Dr. Daly, Dr. Stross, thank you so much for joining us today. Audience, if you want to find them, I think we have a banner about to drop and also feel free to chat and enter the information there on where the audience can find you. We are about to pass the baton to Cynthia Ryan and Heather Davies, who will be facilitating our patient panel.

1:00:17.6 Cynthia Ryan: Hey, Abbie and Danielle. That was such a supportive session. I loved it. What do you think, Heather? Oh, hold on. You're muted. We were all muted in the background there.

1:00:32.2 Heather Davies: If that's my only technological problem today, that's good. I know. Stoplights and ladders. I can't wait to go back to the replay and take notes. This is so good.

1:00:42.1 Cynthia Ryan: Yeah, definitely. And there were so many great questions in the Q&A. I know they didn't get to all of them and I'm sorry. We will be having people go back and check on those. So check back on the Q&A later. And we'll also have a transcript of all of those Q&A questions that's part of the recordings package. So if you haven't purchased the recordings package, go ahead and do that so that you can get all those great answers to the Q&A. So, let's go and bring on our patient panelists.

1:01:18.7 Heather Davies: Alrighty. Well, we have Adam Lindo and Lara Bishop. Welcome.

1:01:24.1 Lara Bishop: Thank you.

1:01:25.5 Adam Lindo: Hello. Glad to be here.

1:01:26.4 Cynthia Ryan: Hi, Adam and Lara.

1:01:27.4 Lara Bishop: Yeah, and [inaudible].

1:01:30.3 Heather Davies: Fantastic. Well, we're just gonna jump right in and I'm gonna ask Lara, when you were first received your diagnosis, how did it change the way you saw yourself in your daily life?

1:01:42.8 Lara Bishop: Oh, that's a question. Let me think back 14 years ago. I've had this 16 years, but it took two years to get my first diagnosis of vestibular migraine. I think when I got the diagnosis, it was a relief to know what it was, but then suddenly it was very overwhelming because I then had this name that I was like, oh my God, I now got to research this name and cue endless hours and evenings of trying to find out about this neurological condition that I had no idea about. The only source I had was the Vestibular Disorders Association website because 14 years ago, there wasn't really any support groups. There wasn't any kind of... You know, there was a few forums, but they're a bit scaremongering, to be quite honest, and I dipped in and out of those. I was like, oh, I don't think I want to go on those. It's much, much better now, obviously.

1:02:49.4 Lara Bishop: I think also what happened was I kind of slumped into a bit of depression, to be quite honest, because I'd had two years of searching for the answers and it was exhausting. I was being bounced from GP to consultant to back. It was like a pinball machine and it was absolutely exhausting. You get this diagnosis and then you look into it and you're going, oh my goodness, what on earth has triggered this? Is there something that I've done in my past? The guilt comes in and you're like, did I drink too much when I was younger? Did I go out too much? Did I spend too much doing Pilates? I don't know what. You think of what you've done. Obviously that eased when I found out that it was hormone triggered, so that kind of eased that. I felt for quite a while self-blaming. I felt broken, to be honest. I'm sure you guys probably resonate with that because I was kind of underground with it for a long time.

1:04:00.2 Heather Davies: I think a lot of people can resonate with that, Lara. Yeah, just a sense of loss. Well, before we go any further into that, Adam, what about you? When you first received your diagnosis, how did it change the way you saw yourself and the way you lived your daily life?

1:04:17.1 Adam Lindo: So at first, I don't think it affected me at all because my prior experience was I had a problem, I'd go to a doctor or a specialist, and within a few days, weeks, or months, the problem was gone. And so even though my diagnostic process took months, after I got the diagnosis, I was like, okay, I'm still doing vestibular therapy, but it wasn't until the weeks and the months that began to pass that I understood the gravity of my situation. And that's when I began to realize how much this was impacting every facet of my life: my relationships, my career, my social life. Like, every single aspect of my life was impacted. And it also impacted how I viewed myself very much on, like Lara said, I began to be so self-critical because I was hyper-aware of these inadequacies that was not coming out. I wasn't speaking correctly and I felt like I was in a spotlight, literally in a spotlight on stage, and now I had a room full of people noticing something that I was dealing with also in the shadows. So it definitely caused me to mentally and emotionally tank at that period in time.

1:05:31.5 Cynthia Ryan: Yeah, we heard some people in the chat and the Q&A talking about shame and embarrassment and guilt for not being able to do the things that they used to do, and I think that those are all really common, especially in the beginning of your vestibular illness. What do you think and... I'll start with you, Lara, what helped you to begin to shift from focusing on what you had lost to finding ways to live well with your condition?

1:06:05.8 Lara Bishop: I think I spent two years researching for everything under the sun to try and make me feel better, whether that's alternative sort of treatments or supplements or whatever it was. I got to the point where it was actually my vestibular rehabilitation therapist said to me, I think you could benefit from some CBT therapy, which I pushed back on a lot. I was like, no, no, I don't need that. I was in denial with my anxiety and my depression. All I could think of was I've got this diagnosis. That's it. I wasn't sort of thinking about all the mindset stuff, and that's really king in this. I know that now. So, I went on a bit of a journey. I did, in the end, get referred to a CBT therapist, cognitive behavioral therapist, if people don't know what that is. So it's talking therapy, and that really helped me to really map out a plan, figure out what I was feeling. And then she got me into something called EFT tapping, which is emotional freedom technique. You feel a bit mad tapping on the meridian points, but I'm doing it now because obviously I'm a bit nervous. But it calms you down.

1:07:20.1 Lara Bishop: And, she taught me that, and she taught me to actually... One thing that she was really helpful with was actually if someone said to me at the time, how are you feeling? Because there was a few sort of rumbles in the jungle, Lara's not well, family or friends started to hear. She actually said, well, people were asking me how I was, and I was going, I'm fine. I'm fine, absolutely fine, when I actually wasn't. And she said, tell them how you're feeling. Actually be honest and say, actually, I'm not having a great day today, or I'm not having a great week, or I'm not having a great month. And that really kind of released the pressure in a way. I didn't obviously announce it to everybody, but it just took the pressure off. I then was a little bit more open. So definitely mindfulness and meditation.

1:08:11.5 Lara Bishop: I got into a tool called, the first one was called Headspace, and it was like a iPhone app which you pay a subscription for. Then I went on to Insight Timer, which some people probably would be familiar with, and that's really good because it's got categories and topics and stuff. I think it's still free. And now I do quite a lot of hypnotherapy audios that my hypnotherapist has given me for different types of scenarios. So it could be taking a flight or train or different situations. But definitely the mindset, the mindfulness and meditation, and thinking, believing that... Obviously I was grieving my old self, so actually embracing the fact that this could be a new chapter.

1:08:58.1 Lara Bishop: In a weird way, it was a bit of a let's change it on its head type thing and think, how can I spin this to be more positive? And I'm gonna have a new chapter and it's gonna be my new thing 14 years later. But I think it's also about, and I know this now more than anything, is actually choosing hope more than fear. So it's actually not fearing all the time. Yes, I have the vertigo attack, straight away I'm really scared about it. [inaudible] 14, 16 years, it's just kind of live in the moment, don't think about what-ifs, and trying to just choose hope more than... You know, hopefully tomorrow's better. [inaudible]. So I think definitely mindset's king in this. I think people often forget that.

1:09:58.4 Cynthia Ryan: That was huge. There was so much in there. Both the recognition...

1:10:02.8 Lara Bishop: There's even more. I...

1:10:04.0 Cynthia Ryan: I know. It's a huge topic. I mean, it really is. This is about life. But recognizing the connection with the mental and emotional part and dealing with that in whatever way works for you. For you, it was counseling, mindfulness, and other techniques. Adam, what is it for you? What was that point for you when you decided that you went from being lost to finding ways to live with your condition? And I know that mindfulness must be a big part of it because you have a health coaching business called Mind Living Well, Mind...

1:10:45.9 Adam Lindo: MindWave. MindWave Wellness.

1:10:47.0 Cynthia Ryan: MindWave Wellness.

1:10:48.7 Adam Lindo: Yes. A little bit of a tongue twister there for you. But yeah, to share with you that that shift began, if I just rewind briefly, I spoke of how I was really struggling emotionally. And my life basically looked like this: it was me doing the bare minimum to get by. So going to work, getting my groceries, trying to keep a tidy home, and going straight to bed so I could do it all over again. And that was my rhythm, and it wasn't much of a life. And it wasn't until there was a moment I was in bed and I just visualized this crossroad. And I realized I'm at a crossroad. I can either continue this path. I had been in vestibular therapy for over a year. I've tried medications. I've pretty much been told, all right, we're done with you. This is it.

1:11:37.9 Adam Lindo: Or I could ask myself this question: what if? What if there is something that can actually help? What if I can actually do something to impact my health and this condition in a positive way? And so I began to shift my mind into curiosity and see if there were ways that I could impact my health positively. And even though I was an advocate for myself during the diagnostic process, it was taking ownership in a different way and being my own advocate of research and seeing what's out there, because I was very desperate. And that shift and asking that simple question is what led me eventually here and to the tools that I have that not only help me, but also help other people as well.

1:12:27.2 Heather Davies: That's awesome. I think we all have different things that shift us. For me, it was remembering my dreams. I was in such a dark place that I had to remember the dreams that we had built together. And not only for myself, but for my family, I wanted to get there. And how can I live this life with these symptoms the best way? And that took me on a journey as well, just like both of you. So it's huge, and it is different for everybody. And that little click is gonna be different for everyone, but you've gotta find that. You gotta strive for that. Can you share, Adam, some of your specific routines or lifestyle changes that helped you stay stable and maintain the quality of life that you have today?

1:13:12.2 Adam Lindo: Yeah, yeah, I'm happy to. And I want to clarify what I do now is not what I did then, and what I do now I could not do then. And so the things that I'm about to share have shifted through every season and every moment of progress that I made. So right now, specifically, my focus is on my quality of sleep and extending my physical activity from three days to four to five days. Now, I say that because when I first began with my diagnosis, I could barely do a push-up or two without being sick for weeks on end. So I... Even though physical activity is very helpful, it was not helpful for me at that time. So those two specific things... But what was even more impactful for me when I first began was my diet.

1:14:02.4 Adam Lindo: In that season of life, I was in a home where we were focused about gut health and I was the chef of the family. So, I was focusing on foods that were fermented and eating kimchi and having foods that were very high in histamine. Well, little did I know that I do not methylate histamine very well. And my body was dealing with vasodilation and vasoconstriction, all things that can significantly impact your vestibular system. And so when I was able to identify what those things in my diet were and remove them temporarily so my nervous system could calm down, goodness, I felt so great. So diet, physical activity, and then quality of sleep are some big significant ones, but there are sure many others as well.

1:14:51.2 Heather Davies: Sure. And what about you, Lara? I know you share openly about your daily routines and lifestyle changes. What has helped most maintain your quality of life?

1:15:03.0 Lara Bishop: Yeah, this is the biggest topic. This is the biggest question because I could go on and on about this forever, but obviously we have got unlimited time. So, obviously the mindfulness we've touched upon, very good meditation, mindfulness routine. Okay, it doesn't happen every day. Life gets in the way. But I do try and do at least 10 minutes, half an hour every day of that. Regular exercise. So I do a lot of weight training, but it's gotta be regular. I think with my vestibular migraine, I don't know if everybody's like this, but I know it likes routine. So Monday, Wednesday, Friday I'm doing that. Monday, Wednesday, Friday I'm also on the bike [inaudible].

1:15:45.2 Lara Bishop: Tuesday I'm on Pilates. So I have to keep it as similar as possible because my vestibular migraine seems to like routine. Adam picked up on the sleep. I have to have this... I wear my watch. I have to charge it at the end of the day because the battery is rubbish, but I wear my watch every night just to make sure that I'm getting enough sleep and what the quality of sleep is. I'm quite fascinated recently. My husband got me into it recently. And it's the same bedtime routine, same sleep, same wake up.

1:16:16.3 Lara Bishop: And if I don't have that, it kind of just shifts me a little bit. It's not major, but it's trying to stay to routine. Adam's touched upon the diet. I'm massive on the diet. I mean, a big journey of gluten-free because it helped my inflammation because I have some inflammatory conditions. So that was good and anti-inflammatory. I'm lactose-free because I discovered that lactose gave me headaches quite a lot. So I went lactose-free in 2015. I'm [inaudible] spikes in adrenaline that caffeine caused and the downturn on it was not great for me. I'm [inaudible] after a panic attack after having a heavy night. I decided that was that. I can't [inaudible] hangovers and that kind of thing. I wanted to strip everything simplistically back. I am a huge [inaudible]...

1:17:26.0 Cynthia Ryan: Lara, I think it might be your earbuds are giving us some feedback.

1:17:30.5 Lara Bishop: Oh. Is that better?

1:17:31.5 Cynthia Ryan: That's better.

1:17:33.2 Lara Bishop: Oh, how strange. Sorry about that. So the gut is the second brain, as they call it. So that is definitely something that I'm really into. And so I try and keep my foods one-ingredient foods. I try not to have processed stuff. So looking at the diet, like Adam said, is really important. As I said, I could go on and on about it.

1:18:01.1 Cynthia Ryan: Well, one of the things that I find really interesting is you both mentioned similar things. Diet, exercise, sleep. Sleep is a big one for sure. But also that it's just different for everybody. Not only within the vestibular community. What works for you, Lara, might not be what works for you, Adam. But also that your typical quote, healthy diet, what you were talking about, Adam, you were healthy, you were eating a healthy diet before, but it wasn't working for you. So you really have to listen to your body and figure out, and it's sometimes a slow process. And I think they were talking about this in the speaker session. If you're gonna make a change, try one thing at a time. Don't make a whole bunch of changes 'cause then you don't know what's working and what's not working. Try one thing at a time. So here's a kind of a related question. How.... We're talking about connecting with your body. How do you decide when to push yourself versus when to rest and honor your body limits? How do you know what those limits are? And when do you push yourself versus resting? Lara, do you want to go ahead and start?

1:19:12.2 Lara Bishop: Yeah. It's very personal, this, because everybody knows their limit and everybody has certain, you know, you might be stronger than the next person or something. But I'm quite a doer, so I like being busy all the time, which is to my detriment sometimes that I need to just calm down and listen to my body probably a little bit more. And, I... Definitely, if I've had a relapse or an attack, the worst thing I can do is go to bed for days. And it is... I've tried it in previous years. It's just not gone very well. My body just needs to sort of move around like in a sloth-like fashion for a little while, because if I don't move, my brain's not gonna compensate. It's like having a wing out. I need to get compensated and balanced again.

1:20:07.3 Lara Bishop: I think with me, not doing too little and not doing too much. Yes, I will go and sit on the sofa or lie down on the bed and do my meditation if I'm having a real vertigo spin or having a really bad day. And I will rest in different intervals. I just make sure that my limit seems to be about 20 minutes. As soon as I reach 20 minutes, I'm starting to really get bad. So it's about quickly for me getting back into things and getting the equilibrium [inaudible]. I think it's also about sort of grounding things [inaudible]. So yeah, I think it's a very personal thing. I suppose I've just over time got used to kind of how to deal with it. And it's very different. So many people contact me going, oh, well, I couldn't do that. I need to rest in bed for a day or two. It's just the way that my body works, really.

1:21:11.6 Cynthia Ryan: Yeah. How about you, Adam? How do you decide when to push your body and when to rest?

1:21:18.4 Adam Lindo: Yeah. So similar to Lara, this was something that was a struggle for me in the very beginning, really understanding my body and what it was telling me. I thought I understood my body, but not to that level. And unfortunately, I put myself in some situations that made myself worse because I was ignoring those. So now I find myself consistently checking in with my body. So, before I find myself going to do any type of activity or engage in something, I am checking in with myself. And I believe what I'm about to say will also validate the conversation that we just finished having previously today. And so I check in where I'm at, establish, did I sleep well today? Have I eaten well? Have I taken care of myself? And where am I at threshold-wise? Am I close to that? And that already will inform how much I do, what I do, if I need to change the day, if I need to cancel plans. And then when I am engaging in the activity, I am consistently listening to my body and seeing what that input is giving to me.

1:22:21.8 Adam Lindo: Sometimes it's a shout and sometimes it's a whisper. And because I've learned to listen to my body, I am aware of those whispers, whether it be this tightness in my neck or that slight dizziness.

And from there, I have then a decision to make. Am I going to push the envelope, which I've been able to do so because I've raised my threshold and I understand my body at a greater length, or it's time for me to call it quits and I can resume this at another time or ask for assistance. And so it's that constant check-in with myself prior and during those activities.

1:22:54.9 Heather Davies: Absolutely.

1:22:56.4 Lara Bishop: One quick thing I just wanted to say, I just think Adam's hit the nail there is the migraine threshold. [inaudible] a migraine with aura I had [inaudible] I had to call an ambulance because of it. Since then, for the next four months, my migraine threshold was very low and I couldn't do as much as I normally could do. So I think that's a really good point about migraine threshold and continuously checking in, and especially if you've had an attack, to just take it really slowly and easy after for a little while, which I could be better practiced at that.

1:23:37.3 Adam Lindo: I agree...

1:23:38.3 Heather Davies: Yeah. And this doesn't happen overnight. Go ahead, Adam.

1:23:42.1 Adam Lindo: Yeah, I was just gonna add that I know for me personally, my threshold is one way in the prodrome phase versus the postdrome phase of a migraine. And so it's a little bit of a moving target, but I find it to be so much easier when I'm constantly checking in because my body is communicating with me. So it just takes me the moment to pause and to listen, and then I find myself having a far more positive experience at the end of the day.

1:24:10.1 Heather Davies: Right. And this does take time. It takes time to learn all these techniques in our body because we push aside so much. You know, I'm just, oh, it's just stress. I'm just gonna keep plugging along. So it just really takes time. And many people fear that their symptoms will prevent them from doing things. I mean, we all do, like traveling, exercise. Sounds like both of you do have an exercise regime, and going out and socializing. What have you found that makes those activities possible for you again? I know the checking in, but, I mean, there's a lot of people that are listening that are just at the beginning of their journey, and I'm curious what advice you can give them on that today. Oh, we'll start with you. Yes, Lara. Sorry.

1:24:53.5 Lara Bishop: Okay, sorry. This is one... Traveling has been a huge topic for me because we love traveling as a family. For years, I avoided as much traveling as possible at the early stages of my conditions. My husband kept saying to me, I want to go long haul. I want to go explore further than just Europe or England. And I kept pushing back on it, saying, I'm not ready yet. I don't feel I can do a long-haul flight. So I very steadily exposed myself gradually to plane journeys again because we used to travel a lot pre-vestibular stuff and pre-kids. And I wanted to hopefully get back... I never thought I would be able to get back to that. And it feels emotional now getting back to that. But 2022 was a turning point to me and I said suddenly to my husband, I'm ready. I think I'm ready. And we took a flight because I'd done one-hour flights, two-hour flights, one-hour flights, four-hour flights, and I'd built it up in increments over so many years. And then I suddenly got to 11 hours. I was so excited. But I think with everything, it's not just flights.

1:26:09.6 Lara Bishop: I think with everything, I've had an approach of gradual exposure to triggers, gradual exposure to vestibular challenges. And I think if you stop doing the stuff you want to do, obviously within reason, I still can't go on a boat, but if you stop doing the things you dream of like, [inaudible] you would not do anything. And I think if you can just try to build up your tolerance to build it up. In walking, I started doing just going to the gate, back, and then going to the field the next week, back. I would have sort of limitations for a little while and then I'd build [inaudible]. I've reached that tree, so next month I'm going to reach the end of that field. [inaudible] miles. And so it's that gradual [inaudible].

1:27:11.3 Cynthia Ryan: Lara, you're going in and out. Sorry, I can only hear a couple words here and there.

1:27:16.0 Lara Bishop: Oh, okay.

1:27:17.3 Cynthia Ryan: Trying to... Oops. Are you still using your earbuds?

1:27:25.3 Lara Bishop: Yeah.

1:27:26.0 Cynthia Ryan: Can we try without your earbuds and see how that works?

1:27:29.1 Lara Bishop: We can.

1:27:30.6 Cynthia Ryan: Let's try that. Okay, sorry about that. Just wanted to make sure we were getting all of it. You might have to... Okay, try one more time. Go ahead. Go ahead and test your audio.

1:27:46.2 Lara Bishop: Is that better?

1:27:47.7 Cynthia Ryan: That is better. Let's give that a try.

1:27:49.6 Lara Bishop: Okay, right. That's fine. Sorry about that. So I have also a toolkit that I take everywhere as well, especially if I'm traveling. So I've got it here. I won't go through it, but it's got lots of little bits in it that help me get through the traveling or wherever I'm going or a big event like I had on Saturday. I have isolating earplugs for the noise because otherwise my tinnitus would go wild. So I think it's just adapting and trying things out. And I think the more you do things, the more your brain knows it's safe to do. And I think it's just that repeat, repeat, repeat thing. I don't know if Adam, be interesting to hear what he thinks about that.

1:28:33.4 Adam Lindo: Yeah, I would echo a lot of what you say, Lara. I think two things that come to mind, I'm shooting from the hip a little bit here, but that was important for me and I think for others is building that sense of safety. A lot of fear and anxiety can come from the thought of, oh my goodness, getting in a car, traveling, going on a plane. These were things that I too thought, man, how this is going to completely impact me. I grew up on a boat... I love boating. I love travel. I am terrified of roller coasters, but I also love it at the same time. Am I going to be able to do this again? And so, I have gotten to the point now where I've been able to accomplish those things, but it was through building safety and confidence that I can and realizing some days are going to be harder than others, but having that sense of safety and then also giving yourself time to be able to do that. Lara, you mentioned about building up your tolerance. That I find to be so pivotal in anything.

1:29:30.5 Adam Lindo: You may not be able to vacuum or go work out, but you may be able to clean the countertop. And that can be a form of physical activity for you that builds you up to get to the gym maybe one day. And so I think those are two key things. But, it's actually very simple, and this is what I believe helped me get to where I'm at today. It is utilizing the tools that we've been discussing. So the simple things of learning how to listen to your body, engaging in that physical activity, making sure that you're hydrated and you're aware of your hormone levels and making those little shifts. They may seem so simple. It's also, what do they say?

It's stupid easy, I think is what they... Or you know keep it simple. And so, but when you harness it in the right way and according to how your body needs it, it can do some pretty amazing things. And it did take time. I gave myself patience. But by having that with repetition and engaging in that and trusting the process is, I believe, partially what led me to where I'm at and why I'm able to do some of those things.

1:30:36.4 Lara Bishop: I think also just to pick up on these things is that this is why people wonder why I share about I'm taking this flight abroad or I'm taking this train or I'm going to that big event. Because it's so important that people see a patient like myself with three vestibular disorders doing these things. And then it kind of gives... I then get messages saying, oh, I hope one day. How do you do that? What tools do you use? And it's a lot of EFT tapping and a lot of isolating earplugs. But it's possible, and I think it's to give people hope and inspiration that one day they can be in that position as well.

1:31:18.2 Heather Davies: Absolutely. I think that's a gift.

1:31:18.5 Cynthia Ryan: So is not...

1:31:21.5 Lara Bishop: Huh?

1:31:21.8 Cynthia Ryan: It's not not having fear. It's facing your fear and not pushing yourself through it. But, or I loved what you said, Lara, gradual exposure and what you were saying...

1:31:36.8 Lara Bishop: Slowly, slowly.

1:31:38.0 Cynthia Ryan: With yourself, little by little, and developing those tools. And you can develop those tools based on what works for you and also learn from others. Participate in support groups, get on some online forums and see what other people are doing. There are a lot of, as you said, Adam, little things that you can incorporate and just build up your own toolkit.

1:32:02.9 Lara Bishop: And I think it's about also... Oh, I've lost my train of thought now. That's the menopause for you.

1:32:13.3 Cynthia Ryan: On that same note, we were talking about... We've talked about lots of different complementary therapies. We're talking about tools, complementary therapies. You've talked about mindfulness, meditation. Are there other complementary or what people would consider alternative therapies that you've tried? Maybe yoga, tai chi, other creative sort of endeavors that just help you cope with your vestibular symptoms? Adam, do you want to start?

1:32:48.3 Adam Lindo: Sure, sure. Could this expand beyond therapies? Just little tools in my toolkit?

1:32:51.5 Cynthia Ryan: Yeah.

1:32:52.5 Adam Lindo: Sure. So one thing I have with me here, you saw Alicia wearing it, I have my migraine glasses. I also use the Truvaga and not a Cefaly device, but a trigeminal nerve stimulator, ahead of term. And I have also found breathwork to be so helpful for me. At first I thought, that's woo-woo. How is breathing going to help? I'm breathing all the time. But I've learned that when utilizing breathwork at specific times when I feel the onset of stress, that it can in a way be as effective as an abortive for me where I won't have a full-on flare-up or I won't feel nearly as dizzy when I engage in certain breathwork exercises.

1:33:34.6 Adam Lindo: And another thing that I found to be helpful for me, I was at first very apprehensive about anyone touching my back or neck because in the beginning of my story I actually went to a chiropractor and it made things worse. But now that I have made my progress, I have found massage therapy to be quite helpful for me, especially when I have a lot of shoulder and neck tightness when I'm in the middle of a flare-up or having a vestibular migraine. And having that relaxation of a massage therapist after a day or two of being sore, but that has definitely helped me manage this in a way. All these things are part of my toolkit.

1:34:16.3 Cynthia Ryan: Awesome. Yeah, great suggestions. How about you, Lara?

1:34:21.4 Lara Bishop: I absolutely love hobbies. So I love creative stuff. I like to learn something new each year, if not two or three. So I love crafting things. I like learning new stuff. So I think actually getting busy with hobbies and stuff is a really good thing. I also used to go to a chiropractor, and I actually now go to an osteopath, which is much more gentle and it's like a massage, actually, which is much more attuned to me. I tried acupuncture for a while. It helped with the stiffness of my neck because I did VRT for vestibular rehabilitation therapy for 18 months, which makes your neck get pretty stiff and sore. That did help, but it in the end sort of gave me a few migraines. I think it's just something that's just very personal that I don't often do that now. So yeah, I think it's just finding bits that make you sort of zone out, I suppose, which the crafts and creative stuff does for me. That's what I love doing, and music as well, and cooking and all sorts of things.

1:35:42.4 Cynthia Ryan: Yeah, we actually have had some. VeDA has a social hour and we sometimes do crafting. One of the things that we do, which I found really surprisingly fun and relaxing, is creative doodling. Has anyone ever tried creative doodling where you're just... And you can be making a purposeful design or just not? But there's just something mindful and getting out of your head. You know what I mean?

1:36:10.1 Lara Bishop: Yeah.

1:36:11.0 Cynthia Ryan: Because I think we overthink things, and sometimes we just need to get out of our head in order to let it go and relax.

1:36:21.2 Lara Bishop: That's what by going through CBT I learned. I was in it for three or four years, and I saw her every week, and I got a very good rapport with her. And what we used was art therapy because I'm an illustrator by trade, and she wanted me to use something that relaxed me, that I could connect with. And at the beginning of the CBT therapy, on day one, I drew, or I painted a black swirly hurricane, and there was a chink of light in the middle, which was me. By the time I finished the four years with her, I did another painting. We did a few bits all the way through, but at the end, the painting was a rainbow. And it signified that I was free and it was colorful and it was really amazing, actually. So I think art, poetry, all sorts of different creative stuff can really help you.

1:37:15.1 Cynthia Ryan: Absolutely.

1:37:17.4 Heather Davies: Agreed. Well, what role... And Adam, what role has the community played in your journey? I know Lara has a private Facebook group called Mummy Seeing Double, and that was pivotal for my journey, but I can tell you about that later. But Adam, what role did it play for you, community in your journey and connecting with other vestibular people?

1:37:42.4 Adam Lindo: So my journey may be unique, but I'm sure there's some that can relate to this. I don't think I really had community in the beginning for quite some time. In fact, it felt very isolating because whenever I would go to a doctor's office, I felt like I was the only person in the room that looked like me. And, those... Whenever I would go to online forums and just read other people, I didn't feel like I could really connect with those people other than it being very, very negative and terrifying to me. And so that community from those who understood what I went through was very, very small. The very first person that I recognized that had something that seemed similar to me was Alicia. And then it also came from my own social media, deciding to take the leap of being vulnerable and sharing my journey because I thought, man, there is someone that's like... If I feel like I'm the only one out there, there's gotta be people that feel the same way. And so being able to share that vulnerable side of me and then connect with people who understood, it made me feel great.

1:38:53.1 Adam Lindo: It made me feel great, one, that I was having an impact on others, but realizing how there are people out there that understand that even though I look completely fine on the outside, that sometimes on the inside I feel like I've lost my marbles. And there are other people that can laugh with me and they understand. And so that just enhanced and took that level of safety up even more because I didn't feel like I was this zebra out in the world that no one else understood this. So, for those that had similar conditions as me, very pivotal. And then I'd also add my faith community also played a large role in that, those that maybe didn't understand what I was going through, but they cared about me. And so having that opportunity to be vulnerable meant a lot because I did many times feel alone, that no one understood. And just a simple hug or presence was enough for me at that point.

1:39:53.9 Cynthia Ryan: Adam, I have a question. You were saying that you didn't see a lot of people that looked like you in your doctor's office. And we, at least in the online vestibular communities, they tend to be more women than men. Was that an issue for you, that you couldn't feel like you could connect with the community because there weren't as many men that were part of the community?

1:40:22.5 Adam Lindo: I don't think so. I don't think so. I grew up mainly around women, so that I don't think would have been a barrier for me at all. It was that everyone around me, it could be also that I live in Florida, was much older than I was and they were dealing with balance issues, but not similar to me. And so I just felt like, do I really belong here? I'm I...? First I was feeling invalidated by my care team and then also just observing what I had around me and like, is this real? What is going on here? And so it did feel very isolating when I was trying to describe what I was going through. There was no one else that I knew around me that had gone through a similar thing at that point. So I just felt very out of place.

1:41:07.7 Heather Davies: Yeah. Thanks for explaining that. Yes. And Lara, with your I know your community support is huge. Could you share a little bit of why you started that group and how has that changed your outlook and confidence dealing with vestibular disorders?

1:41:26.1 Lara Bishop: Well, it was a brave decision to go public because I was so worried about being judged and having any negativity. I think with nowaday... It's 2017 I started the public blog on Instagram and Facebook. And then I felt... In fact it was one of my vesty friends that I'd met and said, what about doing a private group that everybody can... Because not everybody wants their family or friends or work colleagues or whoever to know. And I do understand that. The original idea I wanted to do was to share my experiences. I was ready to share what I'd been through and to help others navigate it. I don't have a magic wand, unfortunately. I wish I did.

1:42:15.5 Lara Bishop: But I'm there to support and show hope and inspiration, and that was the idea for the blog. And then the private group's been amazing. And it's like Heather knows, it's like a little family and we all get it. And I think that's the thing. You don't often, if your support network publicly is not great, then it's a community that you can go to which is a safe zone. You can get tips and advice and just rant one day if you want to. We're always there to help. And I think I've met some amazing people through this. It's been quite an incredible journey in respect of I've made some really good friendships. I've learned from so many people. I've learned from lots of tips and things that have helped me on my journey.

1:43:11.5 Heather Davies: Yeah. I've found that in that group alone, there are so many different support groups out there online, in person, and even on private Facebook groups. Just finding that group that is a perfect fit for you. And this one may not be for everybody, but it was the first place that I ever felt seen and found my people. And could find... And it's the place that actually gave me, trying to find the word, to find my own voice to say, to say, okay to live like this, and that other people are doing it. And if I have a bad day, it's those people I can lean on and say, it's just one day. It's just a few minutes.

1:43:55.1 Lara Bishop: Yeah. And we're there. Yeah. Sorry.

1:43:55.5 Heather Davies: Yeah. You might feel the same way, Lara, that when I'm having a bad day, pouring into others kind of lifts you up. You might find that too, Adam, that it really reminds you that we're here for each other and how important community really is for our healing and our day-to-day life.

1:44:20.5 Lara Bishop: And I think we understand that you don't have to be in there forever. If you want to dip in and out, if you want to be there whilst you're having a bad time and you want to go away. And then I've had some people come back and tell me how they're doing and it's been amazing. I've seen posts about their success and it's wonderful. But it's whatever people want to use it for. There's no obligation to stay in or whatever. So it's just a nice community. Yeah, it's been a real interesting journey.

1:44:54.7 Cynthia Ryan: Yeah. As you said, Heather, there are so many different groups. It's helpful on VeDA's website, and I'm hoping somebody's going to post that in the chat. We have lots of online and in-person support groups, and you can participate in one or several. As you said, Lara, you can drop in or attend them every month or every week, finding the one that fits for you. And people really do develop, I can't tell you how many people I've talked to who have developed friendships that they say are deeper than the friendships that they have outside of this online community. And these are only people that they, for the most part, only meet online.

1:45:36.2 Cynthia Ryan: Although we do have so many people who form such close friendships that they then make an effort to travel to meet each other in person. I just love seeing the community come together like that. And so it feels like in some ways that we develop this vestibular community. But then how do we communicate with the people in our personal lives who might not understand what we're going through or what our limitations are? Our friends, family, coworkers. What advice would you give to people to communicate, how to communicate with others about what you're dealing with and what you need? Adam, do you want to start?

1:46:29.1 Adam Lindo: Sure. So I don't think there is necessarily a script that can be given on what to say, how to say, and there's also not a timeline of when you have to say something. You decide when you would like to or if you would like to share about what you're going through. I know for me personally, what I said and how much I said was dependent on how close I was or how close I am to that person and that relationship that I have. And so those that were closer to me, they got more explanation and understood why, and they asked questions because they cared about me. But the moments that I found that I would share about my diagnosis, especially for those that I worked alongside, it was typically on days when I found myself struggling or it was impacting my work.

1:47:26.3 Adam Lindo: And rather than make an excuse or just not say anything, I used it as an educational opportunity to share what is happening. Why am I acting this way? And what I found is that they responded with care, and they actually supported me in that time where I was struggling. And I know that I was able to share that because I felt with those people that I would be seen, heard, and understood. And so my encouragement would be, again, in your own time, you decide when the right time is and what depth that you would like to say. And I'm losing, I lost my train of thought of what the last thing was going to be. And maybe we'll come back after Lara and I can share with that.

1:48:12.8 Cynthia Ryan: Yeah, feel free to pitch in if you have more to share. Lara, do you want to talk about...

1:48:18.1 Lara Bishop: I remembered what I'd forgotten about half an hour ago.

1:48:23.0 Adam Lindo: Perfect.

1:48:26.4 Lara Bishop: So yeah, I remember when I got first diagnosed, I sent a load of my family and friends a load of links from VeDA's website. Whether they read them or not, I know certain people did, I know certain people didn't. But I think it's a really challenging thing. A lot of friends and family don't get it because they haven't got it. But it doesn't mean they can't support you. I mean, I don't understand my dad's Parkinson's, I don't understand my friend's cancer, I don't understand certain people's because I haven't got it, but I can still be there, I can still support them, and I can still show an interest. I think I've distanced myself from the people that just will not support. I think that's been very cathartic for me, and I've had to draw the line there.

1:49:21.7 Lara Bishop: But I'm very lucky that I have a support network of amazing friends, this community, family that do support me amazingly. I think it's very difficult for the partners in this to understand, and it's very frustrating. I can't go on that walk, I can't go on that plane journey, I can't... It's just constant, and it feels like you're just being quite annoying, but they do eventually understand. But I think it's... Yeah, I think I've just got... People do get really upset if people don't support back, but I just think I've got quite hardened to that. And I say to people, just leave that. That's them, that's not you. You just go on your own journey and you work with the people that do support you. So I think that's quite a learning curve. Otherwise, you get a bit bogged down, a bit upset if people don't give back.

1:50:23.1 Cynthia Ryan: One of the things we've known each other for a number of years now, and one of the things I've loved to see is your daughters grow up. So how old were your daughters when... Lara has twin daughters. How old were they when you first started having vestibular problems, and how did you communicate with them about what you were going through?

1:50:42.6 Lara Bishop: They were two months old.

1:50:44.6 Cynthia Ryan: Oh my goodness.

1:50:45.8 Lara Bishop: Yeah. So as soon as my menstrual cycles came back after the C-section and birth of the girls, I started getting symptoms. Wasn't for two years until obviously I knew what I was dealing with. But I think the early days when they could communicate and I could communicate with them, it was really hard because I couldn't look after them in the way that I wanted to look after them. I felt like I missed three years of them growing up. But they were very sweet. They used to bring me my walking stick, bring me my porridge in the morning if I was in bed.

1:51:23.1 Lara Bishop: I think it's taught them empathy and more respect of people that are not very well. So it's been good for them. I try and hide as much as I can, but obviously if you fall from a vertigo attack, it's really difficult. What's happened to Mummy? Because a lot of that was going on. So yeah, communicating with them on a serious note about it wasn't until they were into their teens because they couldn't really grasp it. And now they're teenagers, it's sort of, whatever. But then that's teenagers. I know they do love me deep down, but it's a tough age, 16. But they're lovely. They're really lovely.

1:52:13.0 Cynthia Ryan: I get that. Number one, first, you're making me cry talking about your kids.

1:52:17.8 Lara Bishop: Stop.

1:52:18.4 Cynthia Ryan: Talking about your kids. And as someone who's... I mean, I was a teenager when my mother first had her first vertigo attack. So I can totally get that. On the one hand, it's scary. On the other hand, that's just my mom. It is difficult to relate.

1:52:34.9 Lara Bishop: It's upsetting to see anybody, especially your mum. It's hard for kids in this.

1:52:42.9 Adam Lindo: I did remember what I was going to say now. So I'll add this, and this is something that is a pretty consistent thing that I see in the comment section of my community, is apprehension of sharing what they're going through, feeling like they are a burden or that those around them won't allow them to feel seen, heard, and understood. And, it's a real thing. It's a reality that many of us experience. However, I also like to point to the opportunity that lies. If there is someone that you can share, if you choose to, what could become of that? It may result in you having an added support from someone. They can be a supportive figure when times are hard or be a person of presence for you when you are having a hard time. Again, it goes down to your decision, but also realize there is opportunity for you, but also for them to step up and be a supportive figure for you too.

1:53:40.9 Cynthia Ryan: People like to help.

1:53:42.9 Lara Bishop: Yeah.

1:53:43.7 Adam Lindo: Exactly. Exactly. We just need to give them the opportunity.

1:53:48.7 Heather Davies: It's true. And that does take time and trust.

1:53:52.8 Adam Lindo: Exactly.

1:53:53.8 Heather Davies: I'm curious, Adam, looking back, what you have learned about yourself through this experience that you may not have discovered without vestibular issues.

1:54:04.4 Abbie Ross: Yeah. This one made me think quite a bit. And I think looking back, I have come to realize how persistent and tenacious I am. I've been told that I am very stubborn, but I did not realize to what depth. And it also makes sense because of how life-changing this condition is. It literally flipped my world upside down. It was literally spinning. And I did not know what my life was going to look like, but I knew I had to do something. And so had I not gone through this, I would not have realized this. And now I find myself so much more stable when I do encounter rockier times because I understand what I've gone through, but also I have these extra tools in my toolkit that I have built and learned how to hone and utilize in other situations. So I feel more grounded. I feel the healthiest that I have ever been in my life. And I've been really able to refocus the lens of my life in a more positive fashion and be grateful for the aspects that I've learned through having a vestibular disorder.

1:55:15.6 Cynthia Ryan: It's interesting that you use the terms tenacious and stubborn almost in equal because stubborn seems to have a negative connotation and tenacious is more of a positive connotation. So it's like turning this negative thing into a positive.

1:55:32.8 Adam Lindo: Exactly. Exactly.

1:55:34.5 Heather Davies: For sure. And what about you, Lara?

1:55:37.9 Lara Bishop: I've learned that I'm stronger than I thought I was. Because anyone that's had to deal with some of the attacks that I've had in my head, I mean, how I've got through them, quite frankly, makes me emotional thinking about it. But I've had hundreds and hundreds, and each and every one has been ridiculous and floored me. I've learned empathy as well. Like I said about my daughters, I've learned respect. I've learned to listen more, I suppose. And weirdly, in a weird way, and my mum thinks I'm mad to say this, but I feel that I've been given these as a gift. And I feel that the gift is to help people. And that was my ultimate mission, that I'm here to help. I'm on this earth to help. It's a kind of a positive way to put on the conditions that feel negative. But it's my life's work, I feel. I want to leave this earth with a legacy that I've actually been able to do something and help others.

1:56:42.5 Cynthia Ryan: And we thank you for that because as you said in the beginning, it was hard at first to go public with this very personal journey where you're struggling. So we've got just a few minutes left. As we wrap up, I want to kind of bring it all together and ask you both, what does living a full and meaningful life mean to you today? And what would you tell someone who's still struggling to believe that it's possible to live a full life with a vestibular disorder? Lara, do you want to go ahead and start?

1:57:20.8 Lara Bishop: Yeah. This is a wide topic, but I think look at who's around you, look how much love you have around you, how much you're supported and loved. Love yourself, learn to love yourself. I think it's really important. For a long time, I hated myself and I wondered what the hell I'd done to deserve this. So spend time with family. In fact, it's proven now research that socializing is really good for our brains and everything. I live within my limits, my limitations, but I try not to be defined by what I've got. I try and live as full a life as possible within my limitations. I think to say to someone that's in the depths of it, there is hope, there is inspiration. It's easy to say that, but there is. And I think you have to think yourself well. I think you have to think... I like to think how I want to feel. So this year I want to feel better. You just keep saying it to myself, whether it's EFT, affirmations, tapping, or whatever you use.

1:58:34.4 Cynthia Ryan: How about you, Adam?

1:58:36.3 Adam Lindo: Yeah. So for me personally, the question was what brings meaning to my life today?

1:58:44.4 Cynthia Ryan: What is living a meaningful life to you and what would you suggest to someone who just can't see that there can be meaning to their life anymore?

1:58:53.4 Adam Lindo: Right. Right. So for me, that's not allowing myself to be hindered by self-limiting beliefs about what I can do and who I am. A lot of this echoes what Lara said is that I was very self-critical, but then I learned my body and I am more capable than I realize. And once I let go of that limitation and allow myself to take that leap, that step of faith, even though there may be some fear and apprehension, I have found myself to be delightfully surprised and I have seen others be able to experience that same thing because your body is very wonderful and complex and it's trying to do the best that it can and we just sometimes need to support it.

1:59:33.6 Adam Lindo: And so rather than echo what Lara has said about... And others have said about there is hope, I'd encourage you to ask that same question that I asked myself. What if? What if there is something that you can do? What if there's something that you could do right now? Or it could even be a mindset shift that can take place that can stir hope within you, a little seed of hope that can hopefully grow into something more in the coming days or weeks. And I hope that by listening to our stories and even as this conference continues, that what-if continues to permeate into other aspects of your life and it can help you progress forward in whatever way that looks like to you.

2:00:18.9 Cynthia Ryan: Thank you both so much. You are both such an inspiration. This has been a really meaningful and emotional discussion for me and I hope for everyone who's listening as well. Thank you for sharing your experience in living a life with a vestibular disorder.

2:00:35.4 Lara Bishop: You're welcome. Thank you.

2:00:36.5 Adam Lindo: Yes, thank you for having us.

2:00:38.2 Cynthia Ryan: So we're gonna put on the screen here where you can go to learn more about Adam. This is Adam's website, Mind Wave Well, and we've got Lara's Mummy Seeing Double blog as well, so you can connect with Adam and Lara there.

2:00:54.6 Heather Davies: I know. I had to grab my tissues, which I knocked off. It was so good. But thank you, Adam and Lara, for sharing your personal experiences and living life as a vestibular patient.

2:01:07.8 Cynthia Ryan: And I want to take a moment to thank again the James D. And Linda B. Haylen Discovery Fund and the University of Minnesota's Department of Otolaryngology for sponsoring this conference.

2:01:18.8 Heather Davies: Yes. And as a reminder, you can purchase lifetime access to the recordings and transcripts of this entire conference at vestibular.org/lrl-recordings. And you can help make sure this valuable information that's presented at this annual event remains free to everyone by making a donation at vestibular.org/lrl-donate. Now, those links are also listed below. So yeah.

2:01:46.1 Cynthia Ryan: All right, everybody, we're at the end of today's session. I will see you tomorrow for our session on the trauma of being dizzy.

2:01:54.3 Heather Davies: Yes. Bye-bye.

2:01:55.6 Cynthia Ryan: Okay.