Life Rebalanced Live 2023

COPING WITH VESTIBULAR DYSFUNCTION

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[Danielle Tolman, DPT] Welcome and thank you for joining the Vestibular Disorders Association for the final day of our third annual virtual conference, Life Rebalanced Live. What an amazing week. I am Dr. Daniel Tolman and I'll be your host alongside my partner, Dr. Abbie Ross. We are vestibular physical therapists with Balancing Act Rehabilitation, members of VeDA's Board of Directors, and self-proclaimed vestibulo-holics.

[Abbie Ross, PT, DPT, NCS] I echo what you said, Dani, what a week. We have such great questions, such great audiences. Thank you for being here with us on day five, the final day. We would also like to thank staff members and volunteers for the countless hours they have put in for this event. We're so pleased to be able to bring you the live version of this event on at no cost to you, our attendees. If you do wish to access the presentations following the live event, we will have them available for purchase for $55. And the good news is every single penny of that $55 goes directly to VeDA to support their continued mission to spread vestibular resources and awareness.

[Danielle Tolman, DPT] Now before we get started, let's give a shout out to our sponsor this week, the James D and Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology. Jim Hainlen was the inspiration for this conference, having hosted his own conference for patients with vestibular dysfunction in 2015 and 2018. We very much appreciate his continued support. And on another note, if you have questions you would like to ask during the live event, use the Q&A tab.

[Abbie Ross, PT, DPT, NCS] Today's topic is Coping with Vestibular Dysfunction. Living with vestibular dysfunction means dealing with ongoing or recurring symptoms, and this can have a great impact on people's lives -- how you deal with work, relationships, your home life. Developing tools to address these challenges and getting the necessary support can make all the difference in your Vestibular journey.

We are so pleased to have two wonderful speakers with us on our final wonderful day. Dr. Lisa Farrell and Dr. Emily Kostelnik. Lisa has focused her physical therapy practice on treating adults with vestibular dysfunction for over 20 years. Part of what makes her a great speaker for this topic is she is also a certified meditation instructor. Emily brings a unique perspective as a psychologist and a vestibular warrior herself. Emily combines her personal experience as a patient with her professional experience helping people with Vestibular dysfunction from a behavioral health perspective. Thank you both for joining us. We would like you to start by telling us a little bit about yourselves. Emily, we are a little bit familiar just from that brief introduction. Why don't you tell us a little bit about your Vestibular disorder and how you ended up where you are today?

[Emily Kostelnik, PhD] Sure, I would love to. I am a clinical health psychologist. and when I was on my postdoc, I was at the kind of end of my training I was diagnosed with superior canal dehiscence syndrome. I had to leave my fellowship to undergo a middle fossa craniotomy that was unsuccessful. I went on to have a revision surgery. Fast forward to postpartum, I developed Vestibular migraine and PPPD. So, I feel like I have experienced a lot of things when it comes to the Vestibular world. I happen to have this training and health psychology, which is the interplay between illness and mental health, along with my patient experience navigating the medical system, coping with these symptoms, the work life balance aspect, handling the social support aspect, just kind of work-life balance. So, I have combined all those things together.

I really have a passion for this, and I am dedicated to this community. Just in terms of all of that, I have some online courses through Rooted Behavioral Education, and I recently launched a private practice called The Vestibular Psychologist. I am interested in working with people from a behavioral health perspective, which could mean anything related to behavior, mental health, anxiety and depression, sleep hygiene, exercise, nutrition, and how to use your social support network. I hope that gives a good overview.

[Danielle Tolman, DPT] It gives us a great overview of who you are and why you are a perfect person to be with us here at our event here today. Lisa, why don't you give us some of your background.

[Lisa Farrell PT, PhD, ATC] I'm a physical therapist, and for the last 20 years I have been solely working with adults who have Vestibular pathology. I had the good fortune of working with Dr, Susan Herdman at the University of Miami, who also had the vestibular competency based course. She retired and Rick Clendaniel from Duke took over as director. I also had the good fortune to be able to be one of the co-directors for over 13 years. That's how I got started in Vestibular rehab. I am also an athletic trainer and in the past three or four years I have been a certified mindfulness meditation instructor. It goes hand in hand with the mind body, the physical therapist who takes care of movement dysfunction helping people to get moving, but then it was a perfect marriage with mindfulness meditation.

I found more than ten years ago that my patients were no longer coming in so much for benign positional vertigo. That's what the beginning of my career really looked like; I saw a lot of that. It did transition away from the more structural problems like acoustic neuromas and Unilateral losses, Bilateral losses, and before we even had a good name for it, the more persistent symptoms of dizziness and vertigo. As well as now, since 2019, I only really see patients that have Vestibular migraine and PPPD. It's not that I'm choosing to limit it, it's just that it's a perfect reason -- they were just having so much trouble with the emotional side of it that I couldn't get my job done very well. The mind body is how I approach my patients nowadays.

[Abbie Ross, PT, DPT, NCS] Thank you both for being here. We're going to kick today off with a more general question. And Emily, I'll start with you. Emily, what are some of the psychological impacts of Vestibular dysfunction?

[Emily Kostelnik, PhD] Let's talk about the research data first. We know that those who live with Vestibular Disorders are three times more likely to experience anxiety, depression, panic disorder. There was a study that broke that down by diagnoses specifically. Looking at the diagnoses that have a more chronic course, like vestibular migraine, PPPD and Meniere’s disease, we are finding that anxiety and depression is maybe in 45 to 60% of those patients, compared to ones with a more acute course.

So we're talking about BPPV and Vestibular neuritis, where anxiety and depression tends to be around the 20% range, which is more what we see in the general population, being people without vestibular disorders. That's a general overview of what the research shows in prevalence. But it extends much beyond this. Experience in Vestibular dysfunction causes us to have a profound mistrust of our bodies. We can feel a lack of safety in our bodies. That can contribute to nervous system dysfunction. So if we think about from the autonomic nervous system we have that sympathetic, the parasympathetic autonomous nervous function. What happens is when we are perceiving a threat, we go into that fight or flight. It causes anxiety to come on board, because that sympathetic arousal is activated both by the Vestibular system itself and by anxiety.

The problem is when we get into this chronic state of dizziness, we get into a chronic state of sympathetic arousal. And this has an impact on the entire body. I know we're talking about this from a psychological perspective, but there was actually a subspecialty in medicine called psycho neuro immuno-endocrinology. It's a long word. If that doesn't tell you that all of these things are related, I don't know what will. So, we get into this state of fight or flight, the state of negative narratives, negative thoughts, this is never going to go away, this is going to be my life forever, I don't know what to do, and it has a trickle-down effect into our bodies.

So, we're talking about how we process stress, the way that our stress hormones are released like cortisol and adrenaline, and when that can become dysfunctional, that impacts our immune system. So, when our immune system is saying danger, danger, danger, I need to release inflammatory mediators. One of the ones we talked about most commonly is histamine, which I'm sure many of you have heard of, especially those in the migrant community. We have some preliminary research that links inflammatory markers to various Vestibular Disorders - vestibular migraine, Ménière's, PPPD, BPPV, vestibular neuritis, labyrinthitis, acoustic neuroma. Those are the ones we have research to show that there is some level of inflammation of. And so that's kind of like my long answer to say psychological impacts. Yes, if we're thinking of mental health diagnoses, specifically like anxiety and depression, but it's much more of a holistic picture than that. Lisa, I don't know if there's anything that you wanted to say.

[Lisa Farrell PT, PhD, ATC] You nailed it. So well said. I want to say there are physiological reasons. We know that the Vestibular system helps us orient ourselves. It specifically tells our head where we are in space -- movement, position. It also provides us with gaze stability, so when I turn my head, my eyes can stay on the target so I can look at you. It also provides balance. So, we have those three main functions. But there are also other connections in the brain, like Emily was talking about. So, for our attention and arousal, which is through our autonomic nervous system, those have connections between our Vestibular system to let us know, hey, pay attention to this threat. But also, to our limbic system.

There are connections from the Vestibular system to the limbic system that reminds us that when it's normally functioning, that sensation of rocking, that stimulation, actually can calm the nervous system. It can help us. But when it's not working, you are going to feel anxiety. Because the limbic system, especially our primitive brain, the amygdala, telling us there is a threat here. Pay attention. A lot of times that's good for us. We need to know that threat. It's just on overdrive. It's working too much. It has become too normalized. Everything is conditioned -- normal sound, normal light, normal movement, whether within yourself or the environment, it becomes conditioned.

And those that have Vestibular migraine, those that have PPPD, their bodies don't like to adapt too much. That can lead to frustrations and hopelessness and the other emotional things that Emily was talking about.

[Danielle Tolman, DPT] The interesting point that you made was that this is not in your head. That there are physical things happening. So, what patients or people living with vestibular dysfunction are experiencing is not necessarily manifested because they're too anxious or they're too nervous, or they're too stressed or they're not sleeping a lot. All of those things may affect. However, what they are feeling is validated, it is physical, it is something that is actually going on.

I think a lot of people will begin to question that in their Vestibular journey. So, I love all the education about all the systems involved and how that affects our bodies physically. Because it is so much more than a psychological issue with psychological impacts.

What are some common roadblocks for coping with Vestibular dysfunction? That is a broad question with a lot of things to touch on. Emily, is there anything you would like to touch on 1st?

[Emily Kostelnik, PhD] I think there are a lot of roadblocks. One that comes to mind right off the bat to me is access to care.

I work with people all over the country, and I get questions about what about in this state and this state, who can I see? Who was specifically trained in this? In medical school there was not a lot of training in Vestibular Disorders. Access to care and even getting the correct diagnosis to lead us on our path can be really difficult. I think the fact that a) lot of people don't know what the word Vestibular means and b) this is an invisible illness, so I think it doesn't garner the same level of support, the same level of understanding as what some other people might get if they have, say, a cancer diagnosis.

We talked a little about the mental health comorbidities. From a functional perspective, when it's difficult to get through your day, it's difficult to take care of yourself, forget trying to navigate the medical system and insurance and getting to medical appointments and all these things. Lastly, the trial-and-error nature of treatment. Unfortunately, we can't say this person with vestibular migraine is going to respond best to this thing or these constellations of things. And so, I think there can be frustration there, too. Those are some of the big picture things that come to mind for me. Lisa, please add to that.

[Lisa Farrell PT, PhD, ATC] You did mention physical roadblocks, but there is also internal to ourselves, there are also comorbidities. A patient comes to me, and I want them to walk, but they have knee pain or foot pain or back pain, they have a harder time. So that can be a roadblock. Or someone has an autoimmune disorder, MS, or POTS. Their energy is just not as good. And they must guard their energy. So, they have to be able to adapt, and even though we have these roadblocks, I'm thinking along the lines of we have solutions, not perfect solutions, but we have more ability online. We can cross states. We are getting better at that. With psychology, there are consortiums where you can have your license for many states, and that’s trying to access also with physical therapy. And there is this wonderful organization, VeDA, and our professional organizations that provide resources. So even though there are emotional roadblocks and physical roadblocks within ourselves, and even another physical roadblock is the severity of your symptoms. That can be a roadblock to getting started on a program for physical exercise and slowly trying to increase that. It can be one step forward, 2 steps back. You have to trial and error things. I do want to say, don't give up.

[Abbie Ross, PT, DPT, NCS] Agreed. And the invisibility of the illness is a major point to drive home in these roadblocks.

One that we didn’t specifically touch on is even just proper support from your family, whoever it is, just getting them to understand what you are dealing with can be problematic or at least frustrating and a process that might not happen overnight. When we think about all of these challenges and we get into more of what support options are available, what can we do to help work through these challenges?

[Lisa Farrell PT, PhD, ATC] Effective coping strategies? I'm going to take it more from the physical side, just because we have the opportunity, two sides of the coin, the mind, and the body. For the physical behaviors, I have been seeing a lot of patients who have Vestibular migraine. And I use preventative behaviors, preventative strategies that help promote healthy living. We all need to have these strategies implemented in our life. When you have symptoms due to a pathology, you need doubly commit to these things. So, the behaviors that I use is from an acronym or a pneumonic called SEED. It's basically sleep, exercise, eat, drink, and stress reduction. And that's not a mnemonic that I made up, that was actually made up by Dr. Lawrence Newman from NYU Langone Medical Center, he's a MD there. Because patient education is so important, I have developed a method to be able to help people be successful with implementing those behaviors. As a physical therapist, I am really going to push the exercise part, because movement is our friend. Maybe the body doesn't perceive it as our friend. Maybe it perceives it as a threat right now. But we need to befriend exercise.

And there are many ways of doing that. For migraines, I tried to help them raise their migraine threshold. Instead of avoiding triggers, I try to help them raise that threshold, so that when those triggers do occur, you have less of a chance of getting that migraine, and that is through those behaviors. Exercise is one of the best ones for that. We have only known that really since the 60s, with Dr. Kenneth Cooper started telling the world that physical training is good for our health. Well, it is also good for our Vestibular system.

For those that have PPPD, their ability to adapt to some trigger triggering events created the spiraling down to having persistent symptoms is the failure to adapt. And so, we have different strategies with exercise, depending on which world you come from it's basically a desensitization. You can desensitize through habituation, exposure to the thing that makes you symptomatic. But you do it in small doses, in ways that don't overwhelm you. Dosing matters, whether you have a structural problem, meaning BPPV, there's a physical problem there, or a unilateral hypofunction due to either an Acoustic neuroma, or from a neuritis -- and the dosing is different for that then for someone who has PPPD. And so, you can habituate.

But I am also a big believer in that we also need to let the brain have success. So, let's say you are avoiding even walking. Let's say you can't walk even 10 minutes without your symptoms getting worse or coming on. Instead of saying you're not going to walk at all, I am a big believer in finding that threshold and saying, let's walk 8 minutes because your body will have some success with it. So, finding that sweet spot. The last thing is, always find what feels good. Some people hate exercise, and that's a challenge for them. But if you can enjoy it, you’re reframing, you’re telling the brain, this is good for me. So those are things I do for good physical coping strategies.

[Danielle Tolman, DPT] I love that. We have a question in the Q&A to reiterate what that pneumonic was again. So, I'm going to leave that up for you guys. I love that you are really hitting home at all the same messages we've had all week with the rest of the speakers double dashed doing what you like to do. I think that's a great message.

[Emily Kostelnik, PhD] I love what Lisa said about making small, manageable behavioral goals. We want to build that behavioral momentum. The more you do, the more success you have, the more you are able to do.

A lot of what I do is attack this from the nervous system perspective and then the limbic system. Talking about the nervous system perspective, that fight flight freeze, there are a lot of exercises we can do to help bring that down to promote more of a balance between the sympathetic – fight, flight, freeze - and the parasympathetic, the rest, digest, and rebalance. That would be things like diaphragmatic breathing, box breathing, a whole bunch of breathing type exercises, progressive muscle relaxation, Biofeedback is another great one that I just started incorporating into my practice, which is awesome, which is essentially if we are talking about heart rate variability, for example, which is the most commonly used modality, you would put a sensor somewhere on your body; it measures your heart rate. You have a device that tells you if you are in an optimal range or not. You can use behavioral interventions to use to keep you in that optimal range, to promote that balance in the autonomic nervous system. That's from the nervous system perspective. Lisa, I know you are a big fan of mindfulness. But then our thoughts are so important, too. I was talking about the narrative that we tell ourselves about our symptoms, what it means to have a Vestibular disorder. The language we use around that is really important. Identity comes into that. Our relationship with our symptoms, do we fear our symptoms? Are we able to live mindfully or thinking into the future and catastrophize, looking into the past with guilt and depression?

I think we can do a thought exercise if you all are OK with that. This comes from acceptance and commitment therapy or ACT. It's called dropping anchor. It likes to use a lot of metaphors, this one may hit too close to home for those of us with Vestibular Disorders, but essentially with dropping anchor I want you to imagine you're in a boat in the water. And these sensations, these bodily uncomfortable things, Vestibular sensations, anxiety, or depression, that's the weathering patterns moving through. When you feel a strong weather pattern moving through, you want to drop anchor and give yourself a sense of stability and stick where you are rather than getting washed out to sea.

The exercise to drop anchor is ACE. Step one, acknowledge what's going on. Oh, I'm having this catastrophic thought that my symptoms are going to last forever. Or oh, I noticed that I'm feeling a little bit of Vertigo in my feet today, or just naming what it is. The C is #2, just connect with our body, that might be feeling your feet on the floor. That might be identifying somewhere in your body that feels stable or neutral. It might be the tip of your nose or one finger. I find a lot with Vestibular warriors, sometimes we want more proprioceptive input or more touch. That might mean wearing a weighted blanket or using an ice pack to get more input because that touch is part of the Vestibular system and can tell you where you are in space. So, acknowledge, connect, and E is to engage or reengage in whatever you were doing. When those thought patterns, when we drop anchor, we don't want to get washed out to sea. So we want to engage mindfully in whatever we are doing mindfully. If you were cooking, reconnect with what you were doing, smell the food. Feel your feet on the ground. Notice if you are tasting anything. This is kind of a mindfulness-based approach to bring you back into the moment.

To recap, dropping anchor – ACE - acknowledge, connect with your body, and engage. That's a small thought exercise that you could do. If you like that type of thing, one ACT book I love is called The Happiness Trap. It uses a mindfulness-based approach to try to change our relationship with our symptoms.

[Danielle Tolman, DPT] I love that technique of holding you back in to connect in a physical sense with your body, the dizzy/anxious cycle. The second we start to panic about our symptoms, our symptoms get worse, we get more anxious. So, I love this dropping anchor and using that pneumonic to bring your attention back to yourself and what you are feeling.

Lisa, you said you had a mindfulness technique you would like to share with us as well.

[Lisa Farrell PT, PhD, ATC] Well, I know about Acceptance and Commitment theory, but I hadn't heard about that thought, exercise. It's interesting. As someone who multiple years ago before I became a certified teacher, I was starting to add little things that I knew about from my own career as a ballet dancer, so I knew about feeling my body, paying attention to that body sense. A lot of times we call that up-regulating the sense of touch and the sense of where our body is in space. So I used to do grounding or body scans years ago because I wanted to not have people focus not so much on the lies in the head -hey, I'm floating or I'm rocking -- that's one perception. But we have other perceptions, and we tend to be too visually oriented. We tend to believe that vision too often. So I would have patients pay attention to their bodies by doing body scans. But I would also say, heh, everybody is in fight or flight all the time, this anxiety spiral, so I do have them do relaxation exercises, breathing exercises. And my personal life, I do have chronic pain. So I have to deal with that. So I found out about mindfulness and have been practicing it myself. For the past 7+ years I have a daily practice.

I decided I want to do this right. So I became a certified mindfulness instructor. Because there are a lot of misconceptions. I can’t stop thinking, I can't quiet my thoughts, it's too weird for me. You have probably heard all of these things. And so there was a lot of misconceptions about what mindfulness meditation is. And there was also a lot of challenges. People fall asleep while they are doing or they have roaming thoughts, and a good instructor can really help you get past those things, or a good Psychologist who was trained in that. In cognitive behavioral therapy, someone can have that. Emily incorporates it through the ACT therapy and other things. My point is, I have to, as I give someone an exercise, because we do know there are connections between our Vestibular system and our autonomic nervous system which alerts us, tells us to pay attention to something, as well as our limbic system, our emotional system, they may feel overwhelmed for physiological reasons. So it's not just about overwhelming them more with the activity that brings on their symptoms. We need to help them also before and after they do their exercises. And they need to pace themselves. Because when your inner ear has been damaged, you spend a lot more time consciously paying attention to your balance, because your orientation system is just not working as well. So, And that so takes a lot of energy. So, in reality, you do have to pace your activities because everybody only has a certain bucket of energy that they have and it's renewed every 24 hours when we sleep, if you get good sleep, but yours may be a little bit smaller of a bucket because of the vestibular system being damaged. So, you do have to not just push, push, push, overstimulate, exercise, there has to be a balance both emotionally as well as energy you have to pace to.

My pneumonic is called ABC's. We need to always be aware because we do live on autopilot. About 60% of the time, our attention is not where we want it to be. That is from research. First, become aware. B is to breathe. Breath helps us -- again, the in breath is that sympathetic response, the outbreath is that parasympathetic response. The vagus nerve is allowing you to relax a little bit. C, ask yourself if there is a change in this moment. And S is yes, there either is a positive change, so S is the “savor,” be grateful, and if there is a no positive change, then the S is for support.

You need to support yourself. Do I need to stop what I'm doing? Do I need to change what I'm doing? Do I need to ask for support? So that is the ABC's.

[Danielle Tolman, DPT] We have a question in the queue and a that I wanted to put aside because it's a great question. What advice do you give for meditation for people with chronic and very loud Tinnitus. It's very distracting to the point of not being able to focus at all. What advice do you give to somebody for meditation with this loud Tinnitus that's really disruptive?

[Lisa Farrell PT, PhD, ATC] Well, it’s also mindset. Please seek out -- there are trained psychologists, trained audiologists, that know cognitive behavioral therapy beyond mindfulness. Mindfulness meditation is training and awareness. But it's where we place our attention. Where do you want your attention, here and now, or do you want to think about the future or the past? It's being able to choose where you want your attention, and also how do you place your attention. If the Tinnitus is so overwhelming, learning acceptance is something everybody is capable of doing. But you just might need some guidance from someone so that you can have some success.

Would you agree with that, Emily?

[Emily Kostelnik, PhD] Working with a little bit of flexibility about what it means to practice mindfulness or meditation in the context of tinnitus, because mindfulness meditation does not mean you need to sit in complete silence. They could mean that you are going to engage with sound therapy that could mimic whatever Tinnitus experience you are having and can actually be quite calming for people. It might be using hearing aids as a masculine device or even leaning into the sound sometimes and being curious about it. We haven't talked too much about nerve plasticity, but where we put our attention is important, because it tells our brains like this is important, to create neural networks around this, and so our relationship with the tinnitus itself, our relationship with the sound, we are fearing the sound. Are we perceiving danger? Or the opposite? Are we telling ourselves we're safe? Are we practicing self-compassion? That can be tacked onto the tinnitus itself.

[Lisa Farrell PT, PhD, ATC] How we place our attention is important. How we place our attention is important because when we're meditating, we're accepting everything, we're welcoming is a better word. We're welcoming everything. So, if I'm sitting here in pain, and it's eight out of 10, pain, it's just there, I have to learn to be with it. And that takes training, you can't think your way into, I can't accept this pain. You have to practice. There are certain behaviors about mindfulness meditation, in particular, it's about having no expectations. So when I'm sitting there, and having the pain, I can't expect that by me paying attention to it, it's going to go away. What's nice about it is ultimately, it always does change. It's not always even in subtle ways. Even if I have it every day, it still changes. And I can notice that and like Emily saying, that starts to change your relationship,

that helps you reframe and not be so fearful of it. It's like an unwelcome guest to the party. You're not going to kick them out because you don't want to be rude to the host, but you also don't need to pay attention to them when they are talking too loud and trying to ruin things. The same thing with curiosity. You're not saying, this should be happening, or this shouldn't be happening or I like it or I don't like it, but just be curious. What is it, how big, how small, where is it in my body, is it moving, does it change? You're not thinking about it, you are experiencing it, and that makes a difference.

And the last thing is that you need to be kind and gentle with yourself. Think as if you're thinking of yourself as a young child. You would never say you must do this; you must do it this way. That never ends well. There are other ways of talking to ourselves.

[Abbie Ross, PT, DPT, NCS] What both of you have said has really hit a lot of questions about how to keep a positive mindset You gave some examples on how to do that. How do you look to the future, the mindfulness piece of it just doesn't apply to patients with vestibular disorders. But if you're a caregiver or anyone else without the actual symptoms, this is great advice across the board. And with that, I want to move a little bit into the caregiver role. I know that there are some family members that have attended this conference on behalf of their loved ones who have symptoms. So, can you talk about the role of family, friends, caregivers for those living with vestibular dysfunction?

Lisa Farrell PT, PhD, ATC] Including coworkers and teachers.

Number one is always education. There are a lot of resources. A lot of times it's hard to teach your own family or friends something. But you can give them resources. VeDA is great with that. A lot of times if they are attending physical therapy or psychology, let us do the educating, so involving them in the therapy in the sense that I teach my patients about migraine. I explained migraine, I explain PPPD, but in the same breath I'm explaining it to the person who was there to support them. And speaking about support, a lot of times people don't want to ask for support or don't feel like they can. And even in little subtle ways, I will say it out loud explicitly. Sometimes you have to ask for support. That doesn't mean you have to become reliant on them. You can tell them that they don't need to fix me, I just need help in this moment. It really is about self-care across the board. It is a chronic disorder for most people, especially with persistent symptoms. We value now physical training to keep us healthy and fit. Even people who don't exercise, they know the value of physical training to help them get fit. As a society, we are just starting to talk about the importance of training our minds to be healthy and fit and to truly learn how to pay attention to ourselves in a healthy way, in a way that it's not maladaptive by avoiding or doing things like ruminating or catastrophizing, but truly in ways that we can sit and discern, is this really healthy for me, so that we can make better choices in life.

[Emily Kostelnik, PhD] First and foremost, for any caregivers that are watching, I want to acknowledge you and thank you. I know that this impacts you, too. Thank you for being there for your loved one. It is so important to keep us afloat, I can say that myself as a vestibular warrior. And along those lines, you need support, too. And so make sure you are getting the self-care that you need. If you need therapy to process what's going on or if you need help supporting your loved one, that's important, too. The system around the Vestibular warrior is very important also. Otherwise, I think of support as more from a functional perspective of sometimes we need help driving to appointments or help with childcare, grocery shopping, or cooking.

And then emotional support, which Lisa touched on. One tip that I use myself that can optimize conversations is going into conversations when you are looking for support knowing what you are hoping for. So, if you are hoping for people to help you problem solve, name it. Say I need you to help me problem solve this; this is a fixing conversation. Or I really just want to share my feelings right now. When I'm coming in looking for emotional support, the person on the other side goes into fixing mode, and then I end up frustrated and they feel helpless. And I find that happen a lot in this community with our loved ones. So that's just kind of like a little tip as well. So, like fixing conversation versus sharing conversation is something that I like to use myself and I like to talk to other people about it as well. Like same conversation versus sharing conversation is something I like to use myself and sharing with other people.

[Danielle Tolman, DPT] I love that piece of advice, because our family and friends are not mind readers. Being able to communicate that is huge. I think we should dive into more of the Q&A's that we have coming in. We have a lot of great questions. We talk about working with psychologists or other people to help us with more of the mental health aspect of everything. Can having a psychologist on hand for counseling still benefit a person with Vestibular dysfunction even if they have a great support system at home? What other benefits can talking with a provider bring them, even if they feel confident and supported at home? What other ways do they make a difference in a person's life?

[Emily Kostelnik, PhD] Definitely. One thing I would really like to stress to people is that behavioral health is an overarching umbrella, and emotional health is a sub portion of that. I think that therapy is great and important even for people that don't have things like anxiety and depression. We all experience stressors. We could all optimize the way that we react to those stressors. The thing about Vestibular Disorders is besides the social support aspect, besides depression, anxiety, that sort of thing, we need to optimize our behavior. That means coming up with a good daily routine, incorporating exercise, figuring out how to stay hydrating, eat appropriately, schedule things, tracking our system symptoms if that is necessary. Decision making, pros and cons, like, should I travel and spend money to see this provider? Those are all things that psychologists can help you with. Because we work with behavior. So, it’s not like I think people get into this sense of, I don't need help because I don't have anxiety or depression. I just want to open the door to say that all those other things are fair game. And then I think just developing a relationship with someone. It shows even above and beyond if we're using CBT, or ACT, the relationship itself can account for change. And I think another thing that I'm big on in my private practice is accountability. We are always making behavioral goals, week to week. I am always checking in, how are you doing? Because without accountability, you are more likely to keep going. Once you've implemented something, you're seeing positive results, you build up behavioral momentum. So, I hope that kind of gives it an overall answer. But psychologists are definitely an important part of a treatment team, regardless of mental health comorbidities, or not.

[Danielle Tolman, DPT] That goes into the next question. What question should patients ask prospective providers to know if they have the right skills and training to work with someone with Vestibular dysfunction? We talked about the multidisciplinary approach, so it could be from a physical therapist point of view, a psychologist, therapist, anyone with experience in that.

[Lisa Farrell PT, PhD, ATC] How often do you treat this? That's what I always want to know when I see a physician for something. If it's not something that's in their daily practice, then they don't have a lot of experience with it, they might just be dabbling in it. There are generalists out there, especially in the physical therapy world that do dabble in all sorts of things. But especially in Vestibular physical therapy, you do need to ask about training, because there is no certification. We have tried to fight for that, tried to get that through our professional association. But right now, there are actually no governing bodies in terms of what courses they take. So sometimes it is buyer beware. So come in with the questions, do you treat Vestibular patients? I have this diagnosis or these symptoms. Can you tell me how often you are going to see me, is there something I do at home or only stuff at your clinic, and how often have you seen someone like me before. There is a handout that I sent to Abbie and Danielle with questions to ask about Vestibular physical therapy.

[Abbie Ross, PT, DPT, NCS] Yes. We can definitely get that posted, maybe through VeDA. Thank you.

[Lisa Farrell PT, PhD, ATC] I will put it on my website.

[Emily Kostelnik, PhD] I get this all the time, what mental health provider should I see? I have tried getting to make referral lists and it has not been successful, honestly. I'm going to stress; I would look for someone who specializes in chronic illness at the very least. Psychologists are not the only providers. We have awesome social workers and family counselors also. Asking, have you worked with this before, it might be difficult for someone to find someone who has worked with Vestibular Disorders because they are few and far in between right now.

But those who have worked with chronic illness, the skill set transfers very well. One parallel is chronic pain, which has gotten a lot of intention just in terms of training because it's very prevalent. And so, I think people who work with chronic pain probably can use their skill set in that way. If you are looking for a specific type of therapy, like you want to try CBT, ACT, or somatic experiencing or you're looking those for a trauma therapist, ask them, what is your theoretical orientation? How do you work with patients? How often do you see patients? How long do you work with people? Do you work with specific goals? How do I know when I'm done with therapy? I feel like it's less clear cut than PT because it seems like there are some PTs doing an internship in Vestibular Disorders. You are much less likely to find that in the mental health field.

[Danielle Tolman, DPT] We had other questions that was interesting about tips and tricks for how to deal with symptoms -- someone said, this is all great in the quiet of my home. But out and about in society, where everything is chaos around you. Should they just stay home instead? [

Lisa Farrell PT, PhD, ATC] No, no avoidance. But you also have to pace yourself. You would never tell someone like me who has never been a runner to go out and run a marathon. You have to build up to it and know your limits. One way, without specifically teaching you how to do an exercise is, as I was mentioning, and this is actually from the world of concussion, people that have exertional intolerance, they can't handle mental or physical intolerance. So instead of bringing on a headache with an exercise, they go to sub threshold. it’ a form of desensitization. If you want to go to restaurant and sound and movement bothers you, set yourself up to where you can plan ahead so that you can be in a quieter area, and ask the restaurant to maybe help you. Sometimes noise cancelling or earplugs, noise suppressing, can help with less stimulus. But I would not wear those all the time, because you could become more sensitive.

And the same with light. There are migraine glasses out there that help with tolerating the brightness or the stimulus of light. It’s not something you want to wear all the time. That can cause you to be habituated toward needing the in glasses all the time, and then limiting your time, -- letting your company know that I will be able to hang out for maybe 45 minutes. Make it a success. Make it something you look forward to instead of a chore so that you can be as successful as you can.

We overdo it all the time. And some of my patients say that it's worth overdoing a little bit. And they know the next day they will pay for it a little bit. So, if you can plan for the next day for your activities to be a little bit less active so you to recover, you don't want to pile on the activities all week long. You need some pacing with that. But you are not doing more damage to yourself, you are feeling more symptoms. You can also recover if you do the things like we talked about. It's not always about stimulation.

[Abbie Ross, PT, check DPT, NCS] Very good point. Emily, this question is for you. And we're almost out of time we have so many more questions to go over. But I wanted to make sure this person felt heard because I hear this a lot in our patient population. This person states, depression is misunderstood. It's not just a feeling of sadness all the time but perhaps more of isolation and detachment. Can you offer some words to validate this person's experience or some tidbits on how to overcome those feelings?

[Emily Kostelnik, PhD] Yes. Depression is a multi-factorial issue. There is even research that shows that it may even be an inflammatory issue. Depression and Vestibular Disorders have a lot of overlapping symptoms. So, you can have a vegetative depression where you want to sleep all the time or a more agitated depression where you feel more anxious.

If you're nauseous all the time, you don't want to eat period can impact your concentration, your memory. It's a whole constellation of things. Mood is just a piece of that. In terms of getting a handle on it would say it's important to work with a mental health provider who can help you with setting those behavioral goals getting those thoughts in check, to really optimize both the vestibular aspect but then also the mental health aspect.

[Lisa Farrell PhD, ATC] It is both multifactorial in the sense It that it has a physical impact and a mental impact.

And there are chemicals that are being released, that’s why you feel that way. But and how to talk to yourself and how active you are also impacts that too. That’s why you feel that way. So slowly getting into exercise if you're you not an exerciser and building the different types of neurochemicals that are beneficial for you.

Danielle Tolman, DPT] I can't believe how fast this this hour has passed by and how much information the two of you have provided. You can go back through the Q and A's because it looks like some of the resources have been provided in some of those questions.

Thank you both for joining us today. This was really amazing. And we're so grateful to have both of you here.

[Transition to patient panel.]

[Laura Cala] Hi everyone. My diagnosis is Vestibular migraine. Let's introduce our two panelists for day five. We've got Kristi and Sheryl. I'll pass it across to each panelist to give you a bit of background on their journeys so far, and then we'll get into some Q&A. Kristi, can I go to you first? Just tell us a little bit about yourself and your journey.

[Kristi Strong] I am a mental health counselor. I was diagnosed in fall 2018 with Vestibular migraine. I had suffered symptoms since 2017 though, so it's about a year and a half of testing. And once I figured out what exactly was happening, it was a very different route and journey of managing and coping and helped me quite a lot return the quality of life that I was lacking.

Otherwise, I write and I spend time with my dog, my family, my friends. I love reading. That's a good start, I'd say.

[Laura Cala] Sheryl, can I pass across to you?

[Sheryl Zolotorofe] In 2019, I was diagnosed with Meniere’s disease and superior canal dehiscence in both ears. I was -- I hate saying was - I was teaching for many, many years, probably over 35 years, I was teaching elementary school at the time I was diagnosed. It was pretty frightening for me. I didn't get a diagnosis right away, like many people. I had woken up in January of 2019, and I couldn't hear out of my right ear. It was very stuffy, and I had lots of Tinnitus. And I just thought, OK, it was wax. And I put off seeing my doctor because I have to work and I thought OK, I'll go on my break, and I will get an appointment and have the wax cleaned out.

So, when I did go after cleaning the wax out, I still could not hear. So that was pretty alarming, and I was sent for an Audiologist and testing. The result was that I pretty much had lost all my hearing in my right ear. They attributed it to a virus; I think it was sudden deafness. And I was OK. I was shocked, but I was OK with it. I didn't have any other symptoms at the time. I was teaching. And in March while I was teaching, I had a horrible attack of vertigo, and I had to go and lay down for about 8 1/2 hours in the teacher's lounge.

It took a lot of my body. I didn't know what was happening. I could not move. I just called my doctor after, told him -- he said OK, it's probably just an attack of Vertigo. It wasn't until months later that I finally, after seeing many ENT's and nobody really knowing a lot about Meniere’s, I hadn’t really heard about it before. Of course, I did the wrong thing. I went to Google. I was busy looking, which I probably shouldn't have. I pretty much figured out, this had to be at. I went back to my doctor and finally -- I'm very fortunate. I have a great internist who's very patient and understanding, and he will find out help and he will find colleagues to find help for me.

I was sent to a teaching university hospital here where I was put in touch with a Neurotologist who is really wonderful. And he gave me a diagnosis, and I was shocked. And just really didn't give me a lot of information, though. I was told to look at the chart in the office, and he showed me a physical part of here's your ear picture, and here's what's happening. Here's medicine. Go home and take this, and you'll just have to adjust and go to the Vestibular Rehabilitation. And so I followed everything. I did it. It's been a long journey.

I'm still doing it. I think today's guest speakers you had were fabulous because coping as such -- I think it's important to me for my symptoms -- the mental coping, the physical coping as it is getting better in my journey.

[Laura Cala] Absolutely, pure magic, and it was so validating having the doctors speak in that first session because how rare is it to get that holistic feel that it's going to be OK. It's just about really being clear about what you need. My next question -- and you sort of already got into it but I'll still ask it -- what was it like mentally and emotionally learning that you had a Vestibular disorder? I remember getting my diagnosis and being so relieved. It wasn't until much later when I sort of got a grip on the understanding and what that meant moving forward that it was almost like a grievance. It's been like a 360 journey really. You become so -- you go through that searching of looking through a diagnosis to almost feeling relieved, but then you go through that whole cycle again because you're understanding how to cope and manage with the disorder. Kristi, what were your experiences like mentally and emotionally?

[Kristi Strong] Emotionally when I first got the diagnosis it's just the initial that migraine was involved, the first Neurologist appointment that I ever had in 2017 he ruled out my migraine very quickly. I was tested for everything. Meniere’s was looked at, MS, I tested for lupus, Lyme’s, all different autoimmune disorders. Finally, he looked at everything and sent these white papers on silent migraine system symptoms. So, then I went to a migraine specialist. It was the first time I left an appointment crying for relief and happy tears. I had so many appointments with all different specialists -- cardiologists, ENTs. They kept bouncing me around. I would just start crying, and they would say, maybe this is stress, you’re young. I couldn't stand hearing that. I'm like, I'm a therapist. I know what anxiety is. I can't manage this with those skills. It's so separate and so that emotionally was a relief. Once I learned that it was Vestibular type, that it's chronic, it is mentally relieving to know that it's not degenerative over time. When symptoms were happening, I wasn't creating lesions in my brain or there were stroke like symptoms on airplanes when I was triggered. So that was mentally relieving. It was also overwhelming to know that this is a life-long management. That was daunting. I see Dr. Beh now for my Neurologist. I asked him, when does this stop? When will I just be good? He giggled and he was like, you have a chronic disorder. It's going to be management for life pretty much. It bums you out. And when I got to a place of -- like you said, the grieving happened, disappointment, just frustration that I have to always think. Even though the management and the symptoms are so much better, I still have to think more than a person would have to around trips -- what I have to prepare for. It's not just an easy thing anymore. That was tough in the beginning too. You just become used to it, I suppose. There's that acceptance of anger, frustration, sadness. Sometimes to my partner I just start crying. I deal with some type of symptom every day, and I don't talk about it, and I don't always show it, but it is there. Now those days of crying about it are over, and the acceptance that I will have some flare-ups, there still are triggers to manage, and do my best. Certain days are going to be better than others. It's not in the forefront of my mind anymore. When I realized that, that was a special moment to realize it's not taking over my life anymore in that way. I still can enjoy and reach goals and do the things that I want to do. An arc happened for sure over the past five, six years. You notice those little milestones after a week or a month, you noticed, I would have been so differently handling this prior. Now, here I am. It's important to note any level of progress.

[Laura Cala] I can relate so much to everything you've said. I know others in the chat would as well. Sheryl, how about yourself?

[Sheryl Zolotorofe] Like Kristi, I share a lot of that. I didn't have an easy time with the diagnosis. For a year I was in denial. I kept waking up and thinking, this is going to go away. I'm going to be different. It's not really happening to me. I think being a teacher and I had written curriculum for many years for my school. I was in a private school, so I was able to do that. My whole life revolved around planning. I planned years in advance. I think I planned my life like that. I live by myself, and I have three children are still in their 20s. One is still in college. And everybody is in in a different state, so I'm by myself. And I thought wow, I've handled everything my whole life. I don't know how I'm going to do this because I've been vegan since I'm eleven. I worked out. I was very active, and I thought OK, what am I going to do? Do I have to go live in a special place? All these thoughts were coming to me because I was hearing from the doctor's and reading -- probably which I shouldn't have been on. There were no support groups. I live in southern Florida on the east coast. I looked all over. There were no support groups for this. I've had to go to work, I had to teach, and every day it was getting harder. I couldn't hear the kids. I taught 3rd grade, so you're bending. At any moment, there's so much movement in the class. I found myself working 100 times as hard just to manage a day and get through it I really pushed myself to do it, and I think while I was working, I wasn't really thinking about what I had. It really helped take my mind off it but then I got to a point after COVID when we had gone virtual -- I just really couldn't do it anymore. I was very depressed. I got depression. I have a lot of anxiety from Meniere's because I felt like in 1 minute, I had lost everything -- my balance, my hearing, I was just overwhelming feelings. I really didn't have a lot of support. my friends were a -- because of our age, we were teachers. A lot of my friends were going out at this time, retiring. And really, I couldn't do it financially, nor did I want to. It was my passion. I went through everything -- the crying, the grieving, the loss. I was so angry and frustrated about, how could this be? I took such good care of myself. What did I do? I was going down that path of reliving. Should I have done this? Maybe I should have eaten this. I kept thinking this was my fault. I had a lot of guilt. Had a lot of guilt with my kids that I didn't tell them in the beginning because I didn't want to worry them. They were on their own journey for school and all. And when I told them, I probably told them too much. They were worried. But my friends were supportive. my doctor was supportive I got into mental health therapy right away, and my doctor was very kind. I would call him at night sometimes and he would walk me through -- don't worry, we are going to get help. He explained that -- steady is winning. He helped me understand that I wasn't going to be how I was before, but that -- I don't want to say that I've accepted it, but I've adapted well. And some days are definitely -- every minute is different with the way I feel -- some days are a lot better. I think as time has gone on -- and I'm only four years in. For me, the time has helped because I don't really -- the more time that passes, I don't remember how I used to be. I don't remember what it's like to walk and not bobble and have very frightening acts where I end up in the hospital. And with even the time that passes, I'm getting used to how my life is now. My normal.

[Laura Cala] thank you so much for sharing that. It's so validating, and I can see people in the chat talking to. Thank you both for sharing what you have. Can we go into the next question where let's talk about strategies for coping with some of the things that we've discussed -- coping with anxiety, lack of understanding and support from loved ones, gaps in the healthcare system, personal pressures. How do you navigate -- you're so frustrated, and you go through the grief, and you go through the acceptance. And that's just emotionally. You're dealing with so many other factors. I think Kristi might have mentioned before. It's not going to go away, it’s something that’s forever needs to be managed. What are some of your strategies Kristi for coping with some of those?

[Kristi Strong] For the physical symptoms -- it's a black and white bag. It's like a pharmacy for migraines and stomach issues because sometimes it affects my stomach or that's also something that I deal with so that comes with me everywhere. And having the prep kit really helped ease my mind because I knew it was there -- bottled water too in case I needed to take any of the pills. I do a lot of natural supplements too. I have sea bands for when there's Dizziness for the -- there's motion sickness patches and I keep my migraines stick right here for when I'm working. So, I think having things easily accessible just gives me peace of mind that if something does arise, I can turn to that. That's something that that I use for any type of symptom -- everything's in there. It's like the care kit. I have that. I read books that helped too, like Heal your Headache. Managing food intake does help. I really miss aged cheese and wine. The blue light glasses, which I think we're all wearing. I don't know if you guys have them to. That's a big one. For the emotional symptoms for coping -- I'm a big reader, so I like getting the more knowledge I can the better. Like Sheryl mentioned, support, so whether I find it on reddit groups or Facebook groups, reaching out to the Dizzy Cook blogger. We became good friends. Any reading piece I could to inform myself really helped so then I could inform my loved ones and friends and even my clients. Basically, all my clients know that I can have migraine attacks or symptoms. Especially in the beginning when it was more prevalent and it would knock me out for a whole day and I would have to reschedule, they were super understanding. I was fortunate -- I'm fortunate enough to have very understanding, caring family members. I never felt like I was being attention-seeking or misunderstood if I had to miss something they would just offer sympathy.

I felt really bad or guilty if I had to cancel last minute on things in the beginning especially and would feel very hesitant to plan or RSVP yes to something. I think friends -- there was a point where I felt a little misunderstood there if I did have to cancel a few in a row, and I didn't want to be seen as just using it as an excuse. There was a lot of battle with that I had to get over -- the people pleasing and making sure that other people are comfortable versus my own comfort. If I had to do this, if I had to leave early, I just know that that option is there, if I look weird or whatever, if I just start out, I just need to go. Sometimes I would get nausea when it was really bad. One session, I had to flee this session. I ran to the bathroom and threw up. I just do what I have to do for my health, and it's OK. If they can't deal with that they fade away and you have the people that totally understand and it's fine, and it really forced me into and challenged my putting others comfort first. I just can't push myself to the extreme for other people and to look better than I am kind of thing. Coping with that -- pulling back, I wouldn't plan more than one big thing on the weekend, a party or something. Vestibular therapy really helped. And support, reaching out -- I would know when to pull back on those (online) forums. Sometimes they were a little too heavy and discouraging, and sometimes it was hopeful and there were good stories. It was sometimes just checking into myself and listening to what I need in this day and this moment, what's going to help me. Mindfulness, meditation, things like that do help me cope mentally, as well as physically. [

[Laura Cala] Sheryl, what are some of your strategies for coping?

[Sheryl Zolotorofe] I share some of the same. I have triples of my medicine and I have a bag in my purse, which is now probably 50 pounds, it just keeps getting bigger. Rescue medicines, and I carry double of things. Some things -- I had to set up or reset up my house to suit my needs. I've had to put things at eye level. I used to buy huge ladders for setting up my classroom. Those days are gone. Standing on chairs is gone. I can't really look up and down and up and down. Everything within the kitchen is pretty much at eye-level. I've rearranged my closet so I'm not reaching up for things. Again, because my situation is different, I live alone. So when I need help, I really have to take care of myself. I do keep a little bag with clothes and overnight things by the door because I have left the house when I have an attack I do need to get to the hospital. I've had the ambulance come. The EMTs have to come. I keep that by the door, so I just have what I need -- medicine, glasses, clothes. I do have a lock box on my front door in case somebody needs to get in -- a friend or somebody else -- and I'm having an attack. I've had some violent attacks where I've fallen and knocked myself unconscious. I have to feel prepared. And I think feeling that really empowers me to feel whether it's psychological or it does work. But I feel secure. And I feel a lot I have a lot of my bases covered in case.

I didn't have any -- I was never on social media. Because I was so busy, I really worked around the clock. And when I wasn't working, I was out with friends. But when my kids had come down to visit one time, they set me up and they said you need to go find a support group. And like Kristi was saying, you pick and choose what is going to work for you and stay away from the ones that are too much of one thing. I connected, and I found really good communities. I learned something important from other people with Meniere's and superior canal dehiscence. I didn't know, my doctor hadn't informed me that everybody Meniere's it's different. Everybody's severity is different. No one told me. I learned -- I was looking at people's posts and I thought, wow, how does this woman go on vacation. How is she horseback riding? I'm not able to do those things. I became OK with; I do what I can.

I do a lot of writing. I do a lot of -- I have some very small -- I can't go into large stores yet. I'm working on it -- small museums that I can go to that are quiet. Sound is really a trigger for me, as well. When I was teaching, I realized, when superior canal dehiscence was discovered, I almost passed out when the kids were sharpening pencils in the room. Somebody is always falling off a chair. A book is always falling. The noise is just a din, and it just became too much. But I find small -- one or two people I can have over or meet outside. I can't hear when I'm inside a restaurant and there's other things going on. It's really difficult. And a lot of times I was embarrassed -- to tell people after asking people to repeat things. I was getting the gist of the conversation by the context of what I was hearing. I miss a lot of words. And at first, I was told, maybe try a hearing aid. It might help. Honestly, having the chronic progressive disease really affected me financially. All the appointments, and all the medicines. It's really hard to deal with not having an income, and you have to prioritize, what do I really need?

And readjusting your life -- I wasn't used to this. I was used to having an income. The therapies are expensive. I found, again, a great physical therapy place. Things weren't found for me the first bit around. I had to go to other places. One of the physical therapy places -- I was shocked that they wouldn't be a little more mindful. It was crowded, noisy. They had music on. There was so much going on, I had an attack my first time going. I found a better, bigger place that was affiliated with a hospital. I found hours to go where -- I think in Florida there's an older population, so people are not working. The mornings are very busy. I go later. I readjusted my life. I found going to doctor's appointments, I will go first thing in the morning when my medicine is, I'm at a better place. I can find a parking space. Everything with Meniere's for me, it has to be very well planned out. I have to go to my son's college graduation next year and I'm already -- I'm thinking, it's outside. It's on a field. I'm not really good at navigating soft grass and the beach anymore. I'm planning a bit and I'm making phone calls. I think that's the big coping strategy that I have found where I can take control of a lot of things that -- of course, you really have no control of anything but, as much as I can, doing things where I'm more in control. I feel much more secure about going out and dealing with my life.

[Laura Cala] I love that. And it's so relatable. It also leads it to one of the questions asked by Joe. Joe asks, how do you respond to the questions asked by well-intended friends and acquaintances on how you're doing?

For me, I sometimes just say I'm fine because I can't be bothered going into the rigamarole of explaining myself. Like we've said before, we are managing it. We are moving forward. And sometimes, it is incredibly frustrating to explain it to someone who is like -- and I think I said this the other morning -- well, you've still got that, have you tried this? Have you tried that? Kristi, how would you respond?

[Kristi Strong] It's an interesting question to think about. At this point, if I told somebody that I had a flare in symptoms -- Monday morning I felt really dizzy and I couldn't drive to the office, so I opted to just do a telehealth that day. Monday and Thursday are the only days I go into the office now, otherwise, I do virtual appointments. My mom kept checking in, how are you feeling? It was nice to be checked in on and, I think it's my battle of not wanting to be fussed over. I got it, and I'll let you know if it worsens, and I need something or just to vent. When it is the ones that ask and then offer, did you try this test or that. I just try to field it as politely as possible. Well, it is diagnosed., it’s vestibular migraine. It’s not something else and I'm OK where I'm at. I'm managing it. Thank you, though. I'll think on that. Sometimes I'll say that. And overall, thanks for checking in -- that that kind of thing. You kind of just take it for their caring -- some people offer solutions because they don't know what else to say, sometimes. Or maybe they experience something similar, so they relate. And that way, they're trying to relate. If it's said in a criticized way, I've never really experienced that. Again, I think you would just say thank you for that opinion or I did think about that, or I didn't think about that. Whatever it is. Try to maybe go to another topic. How are you doing?

[Laura Cala] I love that. How about yourself Sheryl, how would you respond?

[Sheryl Zolotorofe] It’s like what we’ve been saying all week, it's been so interesting seeing what people say and what you said, Laura. I think having the Meniere's gave me permission to let a lot of people go out of my life. It's just too much. And there's a lot of -- I can't go into a large space. I'm not going to go to restaurants anymore. I can eat outside. All these lines that I had to draw for myself because I don't want to accommodate other people and let my own health be at risk.

But everybody has an answer. Maybe you should eat meat. Maybe you're not drinking enough. Did you try this medicine? Or I've had people tell me, you just need to relax. I have heard everything. Maybe you need to go to work. Maybe that will help you. None of my friends have ever heard of this -- what I have . I didn't hear of it. I have sent them -- the people that I do care in my circle, my tiny little circle now -- I sent them the Life Rebalanced (Live conference). I sent them the information. If you do care, please look up what I have so that you will have a better understanding.

People do ask, how are you? And I say, I'm OK, and it's because people don't know what to say, this is a life-long disease, it does get worse, it's progressive. A few people have said, I'll talk about anything, but I don't want to dwell on my health. I'm still the same person. I don't want to be the sick person. I don't want people to treat me -- yes, have empathy and compassion and maybe come to my house if you want to spend time with me just so I can have company. I'm not a very dependable friend. And people get mad. Other people are doing and meeting -- I'm home a lot. Not everybody can change their life to suit your needs. People are working around it, and we just don't really talk about it unless I'm really having a horrible day and I'm afraid, or I need somebody to help me through. It's one of my rules. Don't ask because I don't ask you. How are you feeling every day. I want to be the person I was prior, in terms of relationships and all of that.

I have a lot of guilt because of course -- it's sort of ironic, but one of my sons is a professional musician, so guitars and he tours. And I have not been able to go to these arenas. I have not been able to get to 1 performance. I will never be able to go. That's a big part of my grief that I'm currently working through. I'm hoping that getting live streams and somebody will video. But having other people really understand -- you want to, but sometimes you protect your health.

[Laura Cala] I love that. And arenas -- I can relate to being in one back in 2017 from when my symptoms onset, and it was one of the worst experiences of my life because the sound and the light and -- no, setting boundaries, and a lot of people on the chat are right there with you. It's so validating to hear other people talk about it, so thank you. Let's talk around experience with mental health counseling. For me, that was one of the best things when I got my diagnosis. I went to a psychologist here, and the Psychologist was able to help me with so many techniques -- just managing -- at the beginning, prior to my diagnosis, I think I got the anxiety label so many times. There was one time that they thought I had generalized anxiety disorder. I was like, I fully appreciate that I am anxious, but I am anxious because I don't know what's going on with me. I am not anxious for the sake of being anxious. For me, my experience with mental health counseling has been fantastic. To this day, I know that I can go back and see that Psychologist at any time. It was an absolute lifesaver.

Just mapping some of those initial feelings out and talking through -- even within that grieving and acceptance phase, it was so helpful. What are your experiences, Kristi?

[Kristi Strong] I think it helps you become mindful of your thoughts that can increase suffering on top of the sensation. A lot of those fear-based thoughts I was able to catch more and reel in and stay present. Especially for dizzy moments where you feel that, oh, and you get disoriented. And I would get afraid, am I going to fall over? I have Vertigo. Now I'm not really paying attention to other people or what's happening. There was a shift when I realized that's not helping. That's going to add into the physical symptom part. That's going to add into the emotional and mental suffering, in addition. That, I can manage when symptoms aren't as easily manageable. I would say, OK, this is the symptom of dizziness. Can I take a moment and use something for my black and white bag? Will it let me ride it out? Sometimes it just passes more easily that way and come back to something that I can engage in and ground myself with. So, I found therapy was comforting for that piece and skill wise and encouraging the check in that I needed -- the self-care, the boundary setting. It's OK to disappoint other people and not always accommodate them and their events and being OK with not being as dependable as your past self could be. Just being able to vent the emotions really helped as well -- just have that space that I could say whatever I wanted and be, even if it wasn't completely understood in the terms that they didn't have vestibular migraine, but they understood the emotionality of an identity change.

[Laura Cala] Absolutely. Sheryl, how about yourself?

[Sheryl Zolotorofe] I went through probably 8 or 9 therapists. Some were not knowledgeable. Some did not do the research. It makes a difference. I have two people now that I go back and forth for different areas when I need it, but I do see somebody quite regularly. And it's probably going to be -- I can go, and I can leave and I can come back in a month if I need it. I have a lot of strategies that I didn't have. I do a lot of -- I'm one of those people that talks to myself as I'm doing things. I coach myself. You can do this.

A shower is a real fear. Like I said, I have anxiety from the Meniere's, which I'd never experienced before. I was very confident, and Meniere’s took all my confidence away. Being here today is the first thing I've done back in public speaking. I used to speak in school, to parents, hundreds of parents. I lost myself in my confidence. If I'm in front of people, will I have an attack? All these things are in my head. Can I hear above the Tinnitus? There's so much chatter in my head. I talk myself through activities. Yeah, keep walking. Yeah, you went to the car. It’s almost like every little accomplishment is a big deal for me. Yes, you went in the store. Yes, you're almost out. I have to do that inner dialogue with myself and be my own cheerleader all the time. And when I finished, I do reward myself with something on Amazon perhaps. I have to have some gratification. I work hard, and there's nobody in my house to tell me, good job. Therapy is though -- I can't even stress how important. If you don't feel important, I've always advocated for my students. I was a person who never asked for help, ever. I have learned if you don't feel right, get somebody else.

I had a therapist fall asleep on virtual while I'm talking. I mean -- I felt bad about myself for a long time. But if you keep looking and never give up, the mental health aspect of being chronically ill is paramount. I can't say enough because it's just so necessary and things I didn't know, strategies and coping strategies -- I had no idea what I could do. I thought, that's a good idea. What works, you keep. What doesn't work, it's OK to not be applicable to everybody. In my community online, I found wonderful people that I've exchanged phone numbers with that have good ideas -- I've never come in contact with a live person who had what I have. I depend on other people to help. It was good for me to release that asking for help, which is a new concept here.

[Laura Cala] It’s a common theme. That fear of being a failure. You become so organized and prepared so you can minimize the uncontrollable.

From the Q&A: Have you gone on disability? How did you navigate this process, and was it hard? I don't have any experience in this side. I did go from full time work to part time work, to not working for a little bit. and then back to full-time My symptoms first onset in 2016 to 2023, and now I am back to full-time work, effectively. Kristi, do you?

[Kristi Strong] No, so similar when symptoms were a minute to minute -- I did have to cut back on client caseload and cut back my schedule -- I cut back on a lot of things I was doing in general -- workshops, extra hours. At this point, I'm not -- and I didn't want to be back to where I was anyway because it was just way too much. I'm kind of -- I don't want to say, in between. It's more manageable. I can tell when it’s too late or burnout is coming. I put up boundaries more now if people want to be seen late or if they communicate outside of session too much. Where I used to respond at any time on the weekend -- things like that. It's shifted in that sense, but I didn't have to go through disability. My last practice, the owner did suggest disability at some point. I was upset because I didn't need it yet. I was still able to work, I just couldn’t work as much as she would have liked. I was like, let me have my autonomy here, pretty much. If I need it, I will. It was a weird moment that she suggested. Unfortunately, I know people who have done that, and it's necessary. I can't speak fully on that whole application process or the mental, emotional piece that comes with it, as well.

[Laura Cala] Again, so relatable to so many people -- that journey. How about yourself, Sheryl?

[Sheryl Zolotorofe] I did have this experience. My attitude was two things -- and finding myself after I stopped working, leaving my profession when it was really the thing, I truly loved every aspect. My attitude was, I'm going to work as long as I can. I don't not want to work. I don't know what I'll do with myself if I don't work. I tried it -- I worked a year after I was diagnosed, and I have noticed I probably had a major attack and ended up in the hospital twice a month.

I did work. And then in 2020 we went virtual when COVID hit, and I thought, wow, this could be so much better for me. I can be home and do virtual because I didn't really use the computer only for work. I wasn't on it. When I did Zoom, I had that experience. I call it zoo, when you’re teaching. I didn't realize I was going to have 4 pages of students in tiny boxes. Again, it was the first time we've all experienced Zoom. I had kids with rabbits on their head, dogs, parents. There was so much going on visually for me that it made my symptoms worse, and I was working 24/7.

We were available all day and night. That summer, I made the decision that, for my health, I couldn't do it. It was really the hardest thing I've ever done because it became who I was, which is not a good thing either. But I did attempt -- I had to get attorney, and I did go through the process. It took me 3 years. I was denied three times or four times. And you're living with absolutely no income. And it was very hard. I can knock wood. I was just approved last week.

[Laura Cala] Congratulations.

[Sheryl Zolotorofe] It's part of that process. I'm not happy. I'm not sad. It helps financially. But it leaves me a big space in my life that has to be filled. Still working on it. It's a very difficult process and my doctors were on board. If they were very good about submitting paperwork. My state -- again comment every state is different. I'm in a state, Florida, notorious for turning people down. I'm also at the point where it's only good for one more year -- I think until you hit 65. I'll be there in in a few months. It was either -- I get it, but again, the time I will have it is very short. I think they did that on purpose. Because I was meeting people here that were on disability with back problems, and they are out playing golf. And I thought, wow. And I think because I have two rare diseases, and their research -- it's not a popular disease. There's not enough research. It's a difficult process, but you need to stay in there because if you really are at that point, and you can't because your health dictates it -- just be patient because it will happen.

[Laura Cala] That's terrific advice, and congratulations again. You've got a lot of people saying that in the chat there, people are happy for you. I think that's one big thing that's been spoken about this week and that's been showed with all the patients -- that message to keep going. If you don't keep fighting, nothing is going to happen. Our hearts are all with you there. I'm mindful we've only got 10 minutes left, and we could talk for so much longer. Let's talk about -- and we have talked about in some circumstances -- how has living with a Vestibular disorder changed your life? For me, it's been a few years now. I can, hand on heart, say that there were parts of my life I was crazy busy. I am edging up there again now but more on my terms. And it's funny -- it's the boundaries that go with that. I used to be available 24/7. I'm not available 24/7 now because I need that time to wind down, to exercise, to be mindful. For me, I don't know if I could do that all again. I, for me, it changed my life for the better because, yes, I lost a lot of friends, but maybe they were never the quality friends that I was meant to have.

Similar with the job -- before, I went from full time work to part time work, and now I work from home. I don't know how I'd coped with working in an office. But life, for me, changed for the better. How about you Kristi?

[Kristi Strong] the biggest change was grappling with that; I couldn't be the above and beyond type worker anymore. That was really difficult was that I had to step back from things. I don't know if it was a prideful thing or if it was just weird. It felt frustrating to not be able to do as much in a short period of time, and I do have to pace myself.

Like you said though, it's forcing you to take care of yourself and to be mindful of that and to have more fun. I think I prioritized fun, and relaxation more than I did the work and goal mentality and achievements and showing product versus overall quality of life in between the goals met and whatnot. That was strange and then, eventually, it just changed for the better in that way that it really put me on other aspects of my personality and identity.

And just the thinking -- like I mentioned before, you just have to prepare a little differently or do the things that you love and didn't want to forsake differently. I love traveling and flying to other countries and such, so that was something that I really wanted -- that was a big goal. I need to work toward being able to fly and travel still staying determined. It really showed my resiliency and determination, for sure, to get to those places, to not have to sacrifice something completely, to just modify it.

[Laura Cala] Sheryl, Amy has asked if you underwent surgery for your SSCD?

[Sheryl Zolotorofe] I check into it. I have not. My Neurotologist said at this point because of my age and other things -- I'm waiting on it. Have not ruled it out, it might happen. I do need it on both sides. Having someone be my caretaker -- I don't really have that option. My kids are, like I said, they are in school and out of the country, but right now it's not off the table come up but it's not happening tomorrow. I can't say Meniere's it's a gift I wouldn't like to return, but I have learned a lot about myself. I have never ever stopped in my life working and managing my kids to do anything that I really enjoyed. I didn't make the time. I’m doing everything I always wanted to do that I'm able. I'm painting. I'm writing a children's book; I'm just breathing and not being schedule. That’s a big thing. I was very active in community theater that I had a passion for. I'm still able to do a lot of that, and I worked my whole life in Florida to -- the part that I did live here originally. I grew up in Manhattan, New York. And greyhound racing -- I'm a big animal person. So, things that I have a passion for, I've been able to be of help, and I have time now.

So, I think it's being selfish about myself, and I am putting myself first for the first time and taking care of me -- and selfless at the same time where part of my personal therapy is – when I do things and give time to other volunteer organizations that I enjoy. I feel good about myself when I'm helping someone else. It's part of my healing, also, that combination of both. I would have never been the person -- I would have been multitasking for the rest of my life, wearing myself to a frazzle. It's something I'm grateful for, if I can say that. I've really gotten to know myself. I certainly have a lot of time by myself to do this. I'm glad. I don't want to cry, but I brought my tissues. It's the first time I can say I'm actually -- not thankful, but I'm grateful for this that happened at this time.

[Laura Cala] I love that, and it's such a perfect way to close. Quickly, before we log off is what would your advice be for someone currently trying to find ways to cope with living with chronic Vestibular condition? For me, I can remember how frustrated and scary it was. But now, coming out of a few years, just look at women like Kristi and Sheryl who are so incredibly strong, who are here today telling us their story.

Vestibular warriors are some of the strongest people I have ever met. We will get through it. Yes, it is something that you will have to deal with for the rest of your life, but you manage it, and it becomes your new normal. Give yourself the time and the space that you need, and I truly believe it will get better. Kristi, can I pass across to you?

[Kristi Strong] Hope is something that is always as a driving force -- hope that there will be better days, hope that there is another side was my biggest help overall. And to detach from idea of how you expected life would work.

I had a goal of publishing a book at 30. It didn't happen until a few months ago at 34. Just different things like that -- you've got to detach and know that it's different now, and that's OK and release of that control. So I would say, release control and let hope guide you. Let determination and hope keep you going.

[Sheryl Zolotorofe] Hope is such an important word because you are hoping -- you are hoping for everything. You are hoping for more research. You are hoping for advancement in medicines. I think patience -- giving yourself a lot of patience in that, look, there are days that I'm not so brave. I cry a lot. I have days where I’m frustrated, and I can't stand this. But I think, for me, I don't think I will ever accept, but I've adapted pretty damn well I think, for me. You adapt, and you sort of feel free where you live your life, you make the changes you need to, you are not afraid of -- you can still walk down the street with your head up, and it's not a shameful thing to have this. I think trying to stay connected to people and not isolated and reach out and get help, just ask for help. There are so many people that are there, especially with this site and VeDA and the support available. The big thing is helping yourself because nobody is really knowing inside your head. And hope -- I think that's a good word.

[Laura Cala] Thank you so much to both of you for sharing your stories with us today. Thank you both so much.

Thank you so much to VeDA and Cynthia for getting all the links up as people have been talking. Day 5 -- is over thank you to the James D. and Linda B. Hainlen Discovery Fund and the University of Minnesota Department of Otolaryngology for sponsoring this conference.

As a reminder you can purchase lifetime access to this entire conference. You can help make sure the valuable information that is presented at this annual event remains free to everyone by donating. These links will also be posted in this description box below. Thank you, Kristi and Sheryl for sharing with us. Hope you enjoy the rest of your day.