

Life Rebalanced Live 2025

ADDRESSING ROOT CAUSES FOR IMPROVED VESTIBULAR HEALTH AND WELLNESS

ABBIE ROSS: Hi everyone. Welcome back for day four of the fifth annual Life Rebalance Live. We're over halfway through the week. What a week it's been. I'm Dr. Abbie Ross. I'm a vestibular physical therapist, neuro-clinical specialist, founder of Balancing Act Rehab, co-host of the podcast Talk Dizzy to Me, and a proud board member here at VeDA. I'd like to begin by thanking our sponsor who has made this event possible year after year. The James D. And Linda B. Hainlen Discovery Fund in the University of Minnesota Department of Otolaryngology have generously supported Life Rebalance 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, so deeply about supporting others in their vestibular journeys. And it was important to him to not only spread education about vestibular disorders, but also to provide a platform for us all to connect. And now I'd like to introduce my co-host, Dr. Liz Fuemmeler, vestibular audiologist, acoustics and co-host of the podcast A Dose of Dizzy.

LIZ FUEMMELER: Thank you so much, Abbie. It's great to be back with everyone for another day and we want to say a huge thank you to everyone that's contributed to this conference in some way that includes VeDA's donors, staff, volunteers, and with their contributions, we are able to put on a live version of this conference at no cost to the attendees. If after this week you want to gain lifetime access to these presentations, we will have them available for \$60. And your financial support really helps. Continued mission of VeDA to spread vestibular awareness.

ABBIE ROSS: And before we get started, I want to direct you once again to

the poll questions. They should be live now. Go ahead and answer those if you haven't already. And also don't forget to check out the exhibitors booth. There's a lot of great information there. Feel free to continue talking amongst yourselves in the chat, but make sure any questions that you have make it to the Q&A section for today's speakers. We'll do our best to get to as many questions as we can.

LIZ FUEMMELER: And as a reminder, although you're going to be hearing from incredible healthcare professionals today, none of the information should be taken as medical advice. So please make sure to consult with a health care provider around you before making any changes to your treatment protocol.

ABBIE ROSS: Today, day four, we're going to talk about the root causes of vestibular dysfunction and why Treatment often requires a multidisciplinary approach. Whether there's dietary consideration, metabolic considerations, hormonal considerations, mental health, environmental. The list goes on and on. We'll debunk the myth that vertigo is a diagnosis. It is not. And we'll talk about what factors may impact a person's ability to respond to treatment.

LIZ FUEMMELER: This is going to be a great topic. I'm super excited to learn myself today. And it is my pleasure to introduce our guest speakers for the day. Dr. Kathleen Stross and Maria Machala. Dr. Stross is a physical therapist who has specialized in treating vestibular conditions for over 35 years. Maria Machala is a certified nurse practitioner specializing in otology and neuro-otology. Welcome, Maria and Dr. Stross. Thank you so much for joining us today.

MARIA MACHALA: Thank you for having me.

LIZ FUEMMELER: So we're going to get started here with Maria. And as a nurse practitioner with this ENT focused specialty, very curious on how you approach your patients who come in, who are looking for the root

cause of their symptoms. Can you touch on this for us?

MARIA MACHALA: Yeah, definitely. I think one of the most important things is when I start out, I just let the patient talk, even just a few minutes of listening to their story. You learn so much. It's really more of a holistic view of the patient. What's important to them, what their activities are, what their support system is like, just in hearing them describe their vertigo or dizziness. So I always give them a few minutes, even though I have my set of questions that I like to ask so I can kind of narrow down maybe what the causes are. But I try not to do that right off the bat.

ABBIE ROSS: And what about you, Kathleen? What is your approach to determining root causes?

Well, I like what Maria said, and I agree with that, that listening, especially on the first interaction, is important. I take a look at medical records and get all of the diagnostic test results up front because really, that's not most interesting to me because most of my clients come and they've already sort of been through the regular track of things, and then they get to me after, when the natural pathway that they followed hasn't worked. So the diagnostic and lab tests are rarely the most important thing. I begin with the questions of tell me the top three worries and concerns that you have. And that's a really broad question, but it often includes I'm worried or concerned that I'll never get better. That worry, if that's stewing all the time in the person, changes their body, it changes their mind, it changes their chemistry from the neurotransmitters in their body, it changes their gut. And so these are the things I want to know, or I'm worried that my spouse will find out that I'm sick and I'll not be able to care for them with their cancer diagnosis or something.

KATHLEEN STROSS: There's so many things people are worried and concerned about that have an interaction in their overall medical response, response to rehab.

ABBIE ROSS: Yeah. I love what you both have said there. Everyone is so individualized, and if you learn where they're coming from, what their perspective is on their current experience, it can really help guide your treatment and give them the specialty care that they deserve. Now, I'm sure both of you have heard this in your offices. A patient comes in and says I went to the emergency department, or I went to so and so, and they told me I have vertigo. What are you responding with when they say, I was diagnosed with vertigo? Maria, why don't we start with you?

MARIA MACHALA: Yeah. So I explained that vertigo is not a diagnosis. It's a symptom. And there can be many different causes. And I also think it's really important to clarify what they mean when they say vertigo. Vertigo is, I would say, a specific type of dizziness. It's a sensation of movement. And so I want to make sure we're on the same page when we're using those words. So I'll ask a lot of questions about what exactly they're feeling, ask them to go into a lot of detail to determine, whether it's vertigo, lightheadedness, imbalance, because there are so many different causes of each of those.

ABBIE ROSS: And I always tell patients no matter what you're feeling, it's not crazy. It's not weird. Sometimes people hold back in what they're experiencing because they're afraid of how it sounds. But that actually really helps us determine root cause. Kathleen, did you have more to add?

KATHLEEN STROSS: Yeah. What I was going to add was I used. The example of vertigo is like saying stomachache. You could have too much acid or not enough acid in your stomach. You could need one thing or the opposite thing. The same goes with treating the symptom of vertigo. You could need more of something or less of something, and it really depends. I agree. That's usually the first and most important piece of education we give them is to help them understand what it is and what it's not or that we don't know, and that even given the best effort of

whatever medical practitioners they've seen, there's often a unclarity or an ambiguity about the diagnosis and probably could be some disagreement. If you took five different specialists to look at them, you might get five different answers. And I think that's the unique frustration among our population of patients that we see.

ABBIE ROSS: I really like what you said of you may need more of something or less of something, because I think when you're experiencing vertigo, adding something or hearing that it needs more of something sounds very overwhelming. But if that's the key to treatment, I think that's a really great perspective. So thanks for explaining that. Let's talk in general. So obviously we're looking at a very holistic approach to vertigo, to dizziness. How do each of you approach the treatment of vestibular symptoms from your specialties? And how is this maybe different than typical providers or typical treatment? We can start with Maria.

MARIA MACHALA: So when talking about treatment again, I think it's important to understand, like Kathleen said, where the patient is coming from and what their concerns actually are. And so when we talk about it and we finally got into what the possible causes are, because oftentimes there, there are many. I talk about the treatment options of all of them and what we know. You know, I do, I really value evidence based practice. But then I do explain that there's a lot that we don't know. And just because something hasn't been studied doesn't mean that it's not going to work. But it gets trickier with recommendations. So I explain what we know through the scientific process, I explain what I've seen through my experience, and I explain what I've seen patients respond to just learning from patient experience over the years. We talk about the pros and cons of each one and then we come up with the treatment plan together. So some people want to try everything all at once and others want to do a very conservative approach. And I think it truly depends on the patient. It is not one size fits all.

ABBIE ROSS: I really like how you're pointing out that it's sometimes a

science and an art and experience and processes. That is such a wonderful way to put it. Kathleen, what about you? What does your approach look like?

KATHLEEN STROSS: Well, it really looks like sort of peeling an onion. When I start with what are the biggest worries and concerns, that shows you what's utmost important to the client. And then so I begin sometimes just during that first session, trying to get to what is most on their mind. You know, you've probably been in a doctor's office, as I have, where you feel like they're running the show the way they want to know the practitioner is. And so you could leave the office without ever having shared what's really on your mind and what your biggest worry is, why you're really there. So as I listen, I dive into what really, I think is bothering the patient the most and is their biggest concern. You can see that on their body when a patient feels like you're on the right track for them because they relax into that and they... You can tell on their face when they feel heard and seen. And that's what I try to get to that point where you're like, okay, wait right there. Or I'm listening to their words and sometimes I'm listening to the story and if they glaze over something, because now we're all trained to go so fast in reporting to our practitioner because we know they only have five minutes, and so we have to go really, really, really, really fast.

KATHLEEN STROSS: But sometimes I'll say, stop right there, right there. Go into that some more. Because you. I'm listening to again, their story and making sure that they don't go over the parts too fast that may really be telling. Maybe they're telling you more about when their symptoms are happening. Maybe they're telling you or skipping over something that we know as vestibular rehab specialists and practitioners that is important. They'll give you clues in their story. So I sort of follow that through. And then, of course, looking at evidence and looking at all of the diagnostics that I have, and then I'll test what I think if I think they have a visual complaint, a postural complaint, or a holistic complaint, like having to do with stress management, sleep, or diet.

ABBIE ROSS: Another important point. Maria, did you have something to add?

MARIA MACHALA: I was just going to say we come up with the treatment plan, but I always encourage the patient to come back. If it doesn't feel right, it's not working. And we will start over and we'll look. So just being flexible with what I'm doing and encouraging them to follow up closely until we have it figured out.

ABBIE ROSS: Right. Thank you for adding that. It's interesting. When you listen to a patient talk, sometimes they don't realize how important a seemingly small detail might be. For example, there's some more recent research about the timing of symptoms. So if someone says to you, well, it only lasts under 30 seconds and then I'm okay. Or if they say to you, I feel it all the time, you're already thinking diagnostically differently in those two scenarios and how you're going to approach treatment. Other than thinking about the vestibular diagnosis, there are other facets to our health that we're also considering when we're speaking to patients and some overall topics like dietary, nutritional, metabolic, health considerations, environmental considerations, like is it allergy season? Is there an inflammatory process happening hormonally? Where are they at in menstrual cycle? Or is it menopause, post menopause mental health? Do they have anxiety, depression, any history there, migraine history? So with all that being said, let's take one topic of your choice. We'll start with you, Maria, and then we can go back and forth between you two providers and give your take on each topic.

MARIA MACHALA: I think one thing I always bring up is sleep. I think that is so important to our overall health and how we cope with anything, stress, pain, dizziness. And so I like to dive into sleep, what their sleep patterns are like. If they have any evidence of sleep apnea, I'll get a sleep study. If they really do struggle with insomnia, I will usually refer to a sleep specialist. So that is definitely something that I prioritize in our visit.

LIZ FUEMMELER: We've been learning a lot about sleep this week, and I think it's been, it's been so interesting for all of us to hear how much of a cornerstone that is for successful treatment. Kathleen, what are your thoughts on that.

KATHLEEN STROSS: Or what do you do leveraging off of that sleep? I mean, the constant fatigue that people feel can feel with vestibular problems can be multifactorial. So sure, it can be that your brain is so focused on finding equilibrium that you feel tired. It's exhausting to stay stable and to see and move the way you need to with a vestibular disorder. But at the same time, they could have multiple things going on. So I agree with that, that we have to really look at what other causes can be contributing to fatigue. And when you were talking about symptoms, timing, and the importance of that, I was thinking about what that does in my brain when I hear someone say it's all the time. If a person says it's all the time, I often dig into that to see if there's anything or any time they can bring forth where they're not having symptoms. That gives me an idea about the patterning of their mind and their brain. I say, what fires together, wires together. So sometimes when we think about the words we use, we know that that's where our brain can sort of get stuck. So I look at people's awareness of the moments in their day and the moments in their life and can they find a moment? And I challenge everyone today to do that.

KATHLEEN STROSS: Listening. Is there a moment in your day where you feel good? And sometimes helping them initially find their way back to just a moment of feeling good is important. It's easy to see the natural reaction of a hypervigilance or a hyper awareness that comes with vestibular symptoms when people say, tell me how you feel. So of course you turn up the awareness train of let me think about it. She's asking me, is it my head or my body? Is it my feet or my trunk? What it is my ears or my eyes? So we encourage that hypervigilance or that hyper awareness sometimes. And then a lot of times I have to dial that back to show

people how they can find just a moment each day or even during my session of wellness.

ABBIE ROSS: I love that. Yes. All these moments and hopefully the moments become more frequent.

KATHLEEN STROSS: Well, they do, yes.

ABBIE ROSS: Now, Maria, I had a follow up question on sleep. So we heard from a speaker earlier this week about sleep apnea being more prevalent in 3 PD cases. So when do you refer patients for a sleep study or to a sleep specialist? Because sometimes people may be sleeping or in bed the appropriate number of hours of night and don't even understand if their sleep quality is good. So what are some of the things you hear from patients that make you think, yes, I need to send for sleep analysis.

MARIA MACHALA: So I always ask everybody about snoring and sometimes people don't know they're sleeping alone. But it's always nice if they bring somebody in, like a partner who can confirm that they do in fact snore. If they just don't have good sleep quality, if they're waking up frequently and then how they're feeling throughout the day, are they tired all day? Which again can be related to dizziness. But sometimes it's multifactorial and then is it easy for them to just take a nap in the middle of the day? Those are all warning signs and I would certainly order a sleep study for that. And then some patients, they don't have snoring or issues like that, but if they have trouble falling asleep or staying asleep, I will certainly refer to a sleep specialist. Fortunately, some of the medications that we do use in dizziness, like if we're treating migraine, Meniere's disease, we can use those and it can actually help the patient sleep. So that's good. But I'll typically just order the sleep study myself and then follow up if they do have sleep apnea, we'll get it started and then send them back to primary care or a sleep specialist to manage it.

MARIA MACHALA: And obviously we know there's more. I'm sorry,

there's more and more evidence that sleep apnea, it affects the inner ear directly and then also indirectly. Like I said, if you're tired, it's really hard to cope with any symptoms.

ABBIE ROSS: Absolutely. I think that's super helpful because sometimes you've been dealing with a vestibular disorder for a while and maybe haven't had sleep analyzed. So it sounds like that would be a recommendation to ask your provider about if you should have that looked at. So thank you. Is that typically, I know we're talking about many facets and we're going to get to some other ones very soon, but is sleep something you look at first or does it matter? As we're looking at these root causes like diet, nutrition, hormonal, is there one that needs to be looked at first?

MARIA MACHALA: Not necessarily, I don't think I just make sure I touch on all of them at some point during the visit. And it depends on what their symptoms are too. Like if they have brief episodes of dizziness throughout the day and no real other inner ear symptoms or migraine symptoms, that can be a sign of sleep apnea on its own. And so then I will focus on that. But if they have Meniere's disease, migraine, we'll talk about all these things and we'll eventually get to sleep.

LIZ FUEMMELER: I have a quick follow up on this as well. Lately, many of my patients with BPPV are on CPAP machines. Are you aware of any correlation there?

MARIA MACHALA: I am not. I wonder if there is a higher incidence of sleep apnea and BPPV. I know there's, in patients who do have sleep apnea, there's a higher risk of dizziness, but I don't know about specific types. But that's an interesting point.

KATHLEEN STROSS: I was going to add to that to help direct our testing and our further inquiry. Sometimes I use a chart that are a questionnaire called a multi system questionnaire and you can show it there. I have a

picture of it and it's just a quiz or a questionnaire that the patient can fill out and it asks questions about symptoms, about how often they have them, never or almost never, all the way to frequently. And it covers many different areas, all the areas of the body. And I just took a little zoom shot here of showing how it asks about the head, the eyes, the ears, the digestive tract, joints and muscles, weight, and then it goes into all of them. This is a holistic multi symptom questionnaire that looks at where we might... Helps me, helps guide me to where we might need to go to look at root causes. Because you can see in the head that there are dizziness. What does that mean? Of course, this is not written by a vestibular specialist, but we can go in into that a little bit more. But watery or itchy eyes, eyes swollen and red, dark bags under the eyes, bloated, belching gas there, this questionnaire.

KATHLEEN STROSS: And you can, you can take it off now. But it helps direct me into what systemically or yeah, systemically. Which system of the body might need help. And it directs us to sleep or toxins or metabolic or inflammation or dehydration. So sometimes you can use a holistic questionnaire in your practice to help guide you to what area needs to be addressed further and then follow up with a sleep questionnaire or a dietary questionnaire, nutrition or an exercise or activity questionnaire. But most of the things are pretty simple. We just have to back up and look at the whole picture. When you say someone has a CPAP machine. Well, there's a whole lot there. There's a whole lot there besides just sleep apnea for many people. And that looks at their whole overall health from inflammation and metabolic and energy production and why they're having trouble sleeping. So I think sometimes the more we specialize in medicine, the farther we get from seeing some of these root causes. So taking a backup look at the whole person visually with your eyes how do they look? Do they look like a picture of health? If they're walking in looking like a picture of health, chances are you're going to find their vestibular diagnosis and be able to give them a treatment plan that's going to work.

KATHLEEN STROSS: But if you start learning that they're having to be treated by many specialists looking at many interventions in many different areas, then there's a holistic, a potential for a holistic problem that may be related to lifestyle or some of the simple systemic.

LIZ FUEMMELER: Yeah, I love that we've been echoing the whole person, looking at the whole person throughout this week. And one thing I like to do too, which I forgot to bring up in another talk this week, is asking patients to imagine a pie graph. Maybe you're familiar, maybe it's bringing you back to fourth grade math or whatever subject that is, but either giving them a pie graph that they then complete and note how much of a part of their life is impacting them? Whether they think it's related to their symptoms or not. But is it sleep? How much does that impact their life? Is it work? Is it their boss? Is it their relationship? Is it the food they're ingesting? Are they staying hydrated? Whatever it is? And I like to look at that pie graph in the beginning and then see how it changes over the course of care. And that, I think, not only gets you as a practitioner looking at the whole person, but also gets the patient to start thinking about, okay, wait a second. Like you just said, we're not zoomed in on this one thing, but we're going to zoom out and take into consideration everything.

LIZ FUEMMELER: So if we move to another facet of potential impacts from a root cause, or maybe not the root cause, but part of the overall picture, can we talk a little bit about that metabolic health piece? Kathleen?

KATHLEEN STROSS: Yeah, I mean, I think. I think how our body works as a machine is really looking at metabolism. It is the foundational work of how our body works and metabolic dysfunction. Actually, 93% of adults have suboptimal metabolic function. This has to do with how we change food to energy and how we convert that efficiently and how it leads to our function. What it means is if you have an underpowered metabolic function, it leads to underpower or suboptimal functioning of your cells.

Now, to not get too overly scientific, our cells do all the work for us everywhere, from repairing things to activating things, to communicating.

KATHLEEN STROSS: I mean, everything is about cellular function. And each cell has a powerhouse or a battery inside of it. And how well that works is the basis for everything and the efficacy of every intervention. So I think about my cordless vacuum cleaner with a lithium battery. It's great, it's efficient, it works great. But if the battery starts to get old, it's just not going to do what it needs to do. And it's really about changing our batteries and looking at metabolic dysfunction and how we power our cells and the different cell types which the body has more than 200 different cell types.

KATHLEEN STROSS: Different cell types, when not powered properly, create different kinds of symptoms. So when I looked at this holistic questionnaire we're looking at different cell types and different systems in the body and how they are powered. And this is looking at the root cause, really, of how our body responds to any intervention. If you have liver disease, you're not going to metabolize medications as well as someone else does. If you have gut issues, you won't be responding again as well as you should. Or your own diet can be causing inflammation. So inflammation doesn't always mean outside infection. Like, I have a cold, so I can tell I'm inflamed because I have a foreign agent, a virus or a bacteria. Inflammation can be our own body responding to our own body environment. And the environment we create for it is not only what we put in it, but where we live, what surrounds us, the relationships we have, our sense of self and identity and purpose and our thoughts and our moods and air, water. I go back to food again. I can circle back to that again. And the word oxidative stress is how we age, how it's...

KATHLEEN STROSS: I always thought about oxidative stress like being rust. Rust in our body. Is our body rusting and aging? What's happening to our cells? Are they living as long as they can, as healthy as they can? There's a lot of talk about DNA now and how effectively and accurately is my DNA

replicating. Because this is the engine behind everything, every symptom and every response to every treatment. So those are the things. There's some basic blood tests that can be helpful. There are some basic questionnaires. There are things in our modern society that have greatly impacted our metabolic function that I think we are beginning to talk about more widely as people tune into this light and temperature and food and emotions and movement, all these things have an impact on our metabolic function. And sitting in front of a screen has a negative effect, unfortunately. And I think after Covid, we started to really talk about what does a sedentary lifestyle do to our body as a whole? Why are people sicker?

LIZ FUEMMELER: That's great. Yeah. So many things to think about. Taking a step back, Maria, are there when you hear some of these complaints like Kathleen is discussing, or maybe some of these factors that are affecting patients overall energy and healing. Are there specific tests? I know Kathleen alluded to it as well, but any specific tests that you may recommend for patients to try to get to the root cause of maybe a metabolic issue or another issue that you feel like may be the cause or contributing?

MARIA MACHALA: Yeah, I agree. This is also important. And I always tell patients what's good for your inner ear and your balance system? It's the same stuff that's good for your heart, your brain. So we know these things like diet, exercise, sleep. And so I think that can give them some control and power something that they can do to optimize. But I also, I think it can be a source of stress sometimes. You know, we know the foods that are good for us, but we also know that food can be very expensive and some of that food is not easily accessible for people. And then same thing with your environment. You know, like if you live in a place that has crazy weather changes and you have migraine, it's not like you can just pick up and move your life elsewhere. So being aware of these things but also explaining that this just a part of it and we optimize what we can, we change what we can. So when it comes to certain lab

work and stuff like that, again, it really depends on the symptoms. I work in ent and so a lot of times patients have already seen their primary care and had that basic workup.

MARIA MACHALA: But if they haven't or if they don't have a primary care provider, I'll recommend things like looking at iron and ferritin, B12, TSH, thyroid function. We know that abnormalities here can cause dizziness. So again, it really depends on the patient and what their healthcare team is like, how much they have access to. But a lot of times I will refer those patients to primary care.

KATHLEEN STROSS: That's a great idea. I was thinking about that. Because people have access to tertiary care providers or specialists sometimes and they bypass their primary care practitioner. And at VeDA, we often talk about get the diagnosis from the balance center or go to the specialist. But you'd be surprised how many people skip that primary care evaluation. That would include blood tests like fasting glucose, fasting triglycerides, A1C, total cholesterol, waist circumference. You know, these are the basic things. HDL cholesterol, blood pressure management. So these are the things, these root cause things, these are those best seven tests that the primary care doctor should do to make sure. But if you go straight to the neuro-otologist who is really focused in on the vestibular system and the brain, they might miss that. And hopefully they say they also the nurse sends you back to the primary care to say you need to go do some basic things and then let's really dig into the vestibular system. But unfortunately we don't, we go right into vestibular testing and then when you get a negative test, you're like, hmm, I don't know what's wrong. Well, sometimes we have to go back, take a step back and look upstream rather than downstream.

LIZ FUEMMELER: I was going to now shift gears a little bit into more hormonal health and how this can impact especially in the, the female population. How can hormone changes impact vestibular health? Maria, do you want to start that one?

MARIA MACHALA: Sure. Yeah. We know hormones, they can directly affect our balance system or inner ear, but also an indirect cause. And we know things like migraine and Meniere's disease can be very hormone dependent. And so with the menstrual cycle, pregnancy, menopause, those are some key points in life. And we'll see patients who will get much worse during those times, and then we'll see other patients who get much better during those times. Hormones are very complex, and so I think it's something to be aware of and meeting with a hormone specialist, if that is playing a part.

LIZ FUEMMELER: Kathleen, any suggestions or tips from your side that you like to ask about or send patients out for?

KATHLEEN STROSS: Well, I heard you say especially the female population and female hormones, but hormones to me, go way beyond just the sex hormones or the female and male hormones. But the hormone balance in the body is so complicated from hormones that are released. So I look at it a real broad term of hormones that are released in the body under stress versus under rest. And restoring, balancing oxytocin versus cortisol is key. We talk about hormone impact on our ability to recover. And I think as practitioners, we are more aware that we need to get patients into this sort of parasympathetic or rest, restore, relax, regenerate, rejuvenate, all those great R words for the parasympathetic system versus the fight, flight, or freeze. So when people talk about hormones, I often, I mean, I'm not an expert in female medicine, or so I would refer out for that. But the hormone question to me is a broader one looking at all of the body chemistry, and that's how I approach it. And then if it is specific to gender, I refer out, because that's just not my area of expertise.

ABBIE ROSS: Kathleen, following up on that, what do you hear from patients? What are patients saying to you that make you think this could be a hormone issue, whether that's related to those sex hormones or

not? What are patients reporting that make you think that could be a root cause?

KATHLEEN STROSS: Yeah, anytime someone says things about all the time something like a general steady state of unwellness that is not provoked and not in a time pattern that we think it's traditionally a vestibular motion provoked or activity provoked. So when it's a general sense of illness or unwellness, and certainly we look at age factors, and this is the MSQ that I showed you before also directs you when you analyze those answers to if it's body chemistry, that kind of thing. Because things like sweating a lot or not enough, things like bowel patterns, regularity, urination, headaches, brain fog, I mean, these overall systemic kinds of symptoms, we call them vegetative or neuro vegetative symptoms, just about your constitution, how's your body feeling, are more. This is the whole being. And so all the time, all of me, people who have trouble pinpointing where. Because the hormones affect multiple systems, you can see it in their skin, their nails, their eyes. And so it's a more general, general feel, I think.

LIZ FUEMMELER: Yeah, very good point. If we also consider environmental factors. So perhaps allergies or pollen or mold exposure. Can you talk about what you see in your clinic, Maria, regarding environmental factors that impact vestibular function?

MARIA MACHALA: Yeah, I hear a lot that allergies can trigger symptoms. So I think that's an important thing to touch on. And some people might not be aware of it, but when I hear they always get worse in spring or fall than you know, I recommend looking into that a little bit more, seeing an allergy specialist, maybe other environmental things. You know, you got to look at their work environment. So are they having to be on computers all the time? Are there fluorescent lights that can be very triggering? Are they in really busy environments or is a lot of physical activity and then their home environment too. And like I was saying before, weather changes, stuff that we can't really control. So you got to look into all of it.

And like I said, even if you can't control it, sometimes, just knowing that it can be a trigger. I think knowledge is power.

LIZ FUEMMELER: Kathleen, any tips or again, things that you hear from patients that make you think this could be environmental, or does it depend on the patient's report?

KATHLEEN STROSS: Well, it does and the treatment that they've tried thus far. So if they've gone to vestibular rehab elsewhere or gone through and had good medical management with regards to their vestibular symptoms, and they're still systematic, usually in general, you're going to hear them be unwell. So a general sense of unwellness without cause. We look at toxins and the environment as being possible. I'll have patients say I just feel like I need to go to the mountains. Every time I go away on vacation, I feel better. Okay. So we think, well, you have stress issues, but you could also look at, well, let me think about where they live and tell me about the home. And then you can inquire further to see, well, what if you leave your home and go to a park? Is that better too? So it's not the altitude or the mountains or the amount of humidity, but it is the air quality, certainly. I live in Texas, where we have, in the Gulf coast hurricanes. Mold is a huge issue for people. People are, I mean, I can't count the number of people who've been to 10, 20 doctors without resolution understanding that an environmental inspection of their home would reveal mold that they never smelled and never saw and that that was the root cause and it leads to early death.

KATHLEEN STROSS: It's insane. So these people who find something in their home environment are immediately asked to leave. And it's like, well, why is that so down the list? It's far down the list on our questioning of people. But depending on where you live and with all the water damages and floods, I mean, sadly this is not, I shouldn't even say not specific at all to the Gulf coast because the floods are flooding is everywhere now. And just being aware of mold remediation and the importance of that and the impact of the chemicals used to remediate

the flood. So not to mention our cleaning products and things like that. And I'm not neurotic about any of that. I live in a, I shop at the grocery store. And when we talk about cost, it doesn't have to be complicated and it doesn't have to be expensive. You know, vinegar being your cleaner of choice, for example. Cheap, super cheap, super cheap. Add some essential oils in there, whatever you have your, your thing. So there's lots of little ways to get back to simple. Get back to the way the farmers thought and did and the way they cleaned and the way they, they did things. Oh, that's what I have to say about that.

ABBIE ROSS: I love it. There's so, so, so much to consider. And I often think about, like my great grandmother and my great grandfather, for example, and how did they live? It was so much simpler and they were quite healthy. Maybe there's some things I can replicate and take away from their life to positively impact my own. That leads us into another facet of health care that certainly impacts vestibular function and that is mental health. Are there certain diagnoses that one may be predisposed to due to anxiety or certain personality types? And we do have a question in our chat about some recommendations for managing stress and anxiety. Maria, why don't you start that one as well?

MARIA MACHALA: Yeah. Mental health is such an important Part of thinking about the vestibular system. And I think it's something we have to be really careful with how we approach it. So I think it's important to address it. And I'll get to that. But I hear so many patients come in telling me that they've been told their symptoms are due to anxiety or something like that. And unfortunately, that can feel very invalidating to the patient. And it can contribute and it can be a cause, but not always. And so it just tends to make people feel like it's all in their head, or maybe they're already trying to do everything they can to manage their anxiety and they're still dizzy, and that can feel really defeating. And so I do think it's important to bring up. It is not the first thing that I bring up. I really focus on the dizziness and a lot of other things, and then I do get to that. And whether they have a history of anxiety or depression in their chart, I

don't even really touch on that. I just say this can be a problem for some people, it can be a contributing factor.

MARIA MACHALA: So it's something to look into. It's not my job to diagnose their anxiety. That is not my specialty. But I encourage them to really look into that. And some of the things that I do probably do treat anxiety and depression, like, I will refer to cognitive behavioral therapy a lot. And that's beneficial for any kind of symptom that you have. When you have something all day, every day it's hard not to think about it and focus on it. And it helps to just kind of reframe the mindset, maybe take away that negative aspect of it. And then some of the medications that I do use, if I need to use medication, they can also treat anxiety and depression. But when I prescribe those, I make it very clear that's not my goal of treatment. I'm treating your dizziness. If you get that secondary benefit, great. And then if that's still an issue, I definitely will refer them to mental health provider.

MARIA MACHALA: So we know some of the causes of dizziness, migraine, 3 PD. We know that there's a much higher incidence of anxiety and depression in these patients. And it's not... I don't think it's necessarily cause and effect. And I think vertigo and vestibular issues can actually trigger anxiety in somebody who never had it before. So if you just focus on treating anxiety, you're still not getting to the cause of it. So Very important. But it has to be approached in the right way.

ABBIE ROSS: Yeah, certainly has to be approached in the right way. And one of the things that I love to tell people when they're, when they're talking to me about it is of course you feel anxious about the world spinning or being dizzy or feeling like you're walking on clouds. I would be concerned if your, your alarm system wasn't going off. That's actually a sign that you have a healthy system, that your body's telling you, hey, look out for this. Let's look into this. Kathleen, do you have tips, strategies, techniques that you guide your patients in to help in this realm?

KATHLEEN STROSS: Yeah. You started it by saying, Abbie, that this is a normal way to feel. This is a normal response. Your brain and your body's job is to alert you of when things aren't right. So sometimes, and I say you can't fix normal and we don't want to. So a normal fight or flight response to danger, that's normal. And anxiety and worry and concern, normal. We address it when it begins to impact their ability to do the things that will help them get out of a cycle. So I think about. You can picture the graphic you said pie chart earlier. I'm going to say now the circle of arrows or a cycle. Every. Most chronic patients are in a cycle of some sort. Most things that make us in a state of dis ease or unwellness is a cycle of sorts. So I try to see if there's a cycle that they're in. It could be a dizzy, anxiety, dizzy cycle. It could be a dizzy inactivity, dizzy cycle. It could be a anxiety eating cycle. There's all kinds of cycles and you look at which one is... Seems to be perpetuating. This person's keeping them in a rut or a state of unwellness and then go there.

KATHLEEN STROSS: But certainly it's only when it becomes a cycle or a merry go round. They can't get off of that. We have to intervene. And just, just for the audience to know it's true, true that so many of the medicines that are demonstrating good effect in vestibular patients with chronic symptoms are used off label, they're used for the vestibular symptoms, but they are engaging the nervous system and the body chemistry that has to do with mood. And when we look at things like triple PD or vestibular migraine, I mean, that's all what we're talking about is sort of root cause or upstream things. Diet, stress, exercise Salt, sugar, caffeine, nicotine, alcohol, those used to be the things we said all the time when we were looking at Meniere's patients and fluid imbalance. Salt, sugar, caffeine, nicotine, alcohol, those were the basic things 35 years ago. And now it's even more looking at food as triggering migraine in a vestibular system which may not have a headache at all. So we know and recognize by looking at the medicines we're choosing and the remedies we're recommending for things like triple PD and migraine that this is a holistic conversation and handling the emotional journey of

the patient is important to recognize and to refer out for it.

KATHLEEN STROSS: I do in my holistic coaching a lot of work to check in on patients self efficacy, their sense of self, how they feel about themselves and if they're ready to make a change. I use motivational interviewing skills, which is a technique to ask open ended questions to guide a person to be able to think through the power they have or the agency they have in their own health and wellness. I mean, I think key our role as healers or as providers is to give the patient agency over their own life, their own body, give them knowledge and then give them actionable tools. So sometimes just giving a person their agency and power and giving them things to start doing, like I just want you to go outside and stand on the threshold of your home every day is a first step and then it turns into walking two or three thousand steps a day, let's say whatever it is, but it's little things and giving them power and that does a lot to address that feeling of helplessness, hopelessness and emotional fear. That's normal in the situation.

ABBIE ROSS: Yeah, and I love what all three of you have said, that anxiety is a normal part of any creature chronic health condition. And we know that patients are seeing five to seven or more providers before finding out the root cause. So of course you're going to feel some of that. So thank you for validating that. We talked about nutrition and diet on Monday of this week and really got into foods we know we should be eating in the gut. But there were some interesting questions in the chat. Maria, I'm going to ask the first one to you. Does intermittent fasting play a role in either helping or hurting vestibular symptoms and disorders?

MARIA MACHALA: So you know, there's probably not a ton of evidence on that and how it directly affects the vestibular system, but we know things like hypoglycemia can contribute to Migraine and a feeling of dizziness and stuff like that. And so again, this is very patient specific. If they're doing these things and they're not getting any better, then maybe try going off of that specific diet and seeing if things improve. So a lot of

this is trial and error. So, yes, I think it may contribute, but not for everybody.

ABBIE ROSS: Yeah. Wonderful. And, Kathleen, what about dehydration? There was a question in the chat about dehydration and vertigo or dehydration and dizziness. Can you talk to us a little bit about that?

KATHLEEN STROSS: I like a question about hydration when I'm asked before about what are your top three health tips that you would give anybody or what do you think is most important in general for overall health? I think hydration is the top of my list, followed by flexibility and core control. As a movement specialist, I think hydration, flexibility, core control for movement and engaging in the world. It's that important. It's important for everything. I mean, how our cells function. We're made up of more than 70% water, so it is critical. However, it's part of balance. Balance is not just standing straight up, but balance in fluids. I can't tell every client to go and drink a lot of water. It depends on sodium levels and their diet and their ability to rid their body of excess water.

KATHLEEN STROSS: So this is the conversation about their lymphatic system, their sweating, their urinating, and all the systems that balance water and their diet with sodium. And if they're having blood pressure issues and on blood pressure medicine, then it takes a holistic approach to look at, how do I. What do I say about dehydration. And that is a conversation to have with knowledge of what their primary care doctor has suggested for them, because you don't want to go against what they've said.

KATHLEEN STROSS: I have a client I can think of who, who's like, no, we're not. We're trying to manage blood pressure. So we have to reduce fluid intake. Okay. Or if we up fluid intake with water and salt, then they're going to be taking and a diuretic so they can pee more to lower their blood volume. Blood volume has a lot to do with blood pressure. And it is a whole cycle of looking at kidney function, diet, lymphatics. But if I mean,

I think, I think hydration is a... Certainly a conversation for each individual to think of as essential and then whether they need more or less unique to them. But most practitioners can have a conversation about that.

LIZ FUEMMELER: Absolutely. There was something you alluded to earlier in the talk about posture. And there's actually a question about posture from our audience. And I also want to include some other questions from a more zoomed out perspective. Can you talk about posture but also any cervical spine involvement and how that might impact someone's symptoms?

KATHLEEN STROSS: Yeah, I definitely can. I mean, that's part of your original. My first 10 milliseconds of observation of someone is how their body holds itself and how it presents itself. And we require adequate blood flow to the brain and our inner ear in order for those things to function. And our blood travels through the neck to our brain and to our inner ear specifically. And not only blood flow, but the sensation that our body has from muscles and soft tissues. And these things can be impacted by posture. So a forward head, rounded shoulder, forward posture, which I turn sideways and show in this sort of thing, or even just being this way has an impact directly on the vestibular system as a whole. Because the neck sends information to the brain about head position, just like the inner ear sends information to the brain about head position. Those things tell your body what to do, whether it's to tilt one way or the other or to be straight. The problem is over time, the migration of the head forward and the migration of posture, it happens so slowly that the brain doesn't consider it abnormal anymore.

KATHLEEN STROSS: Anything that happens slowly over time just the brain doesn't, doesn't necessarily see it as a problem. So awareness of posture is one of the early and really fast impacting ways you can have an impact on someone's sensation and their feeling of wellness. Getting the head up, I always say string pulls you up and then gravity pulls you down. So with grounding and feeling steady in your seat or firm in your feet, it's not

as effective as it could be if you were to first get... String pulls you up and then gravity pulls you down. Ears over shoulders, over hips over feet. So it's the alignment to allow not only nice blood flow to the brain and the inner ear, but alignment of tissues to hold the head stable. Because when we talk about fatigue in the vestibular system, the fatigue also comes from the extra load placed on musculoskeletal system to hold a person in a biomechanically incorrect position. Like, if you're leaning a little bit, you're biomechanically off center, and then you're having to use a lot of muscles to hold you there. It's like a Jenga tower. You know, we talk about the game with stacking blocks, if we have head over shoulders over hips, and things are balanced, that's a good place to rest.

KATHLEEN STROSS: It takes less energy. And so posture is really important and a quick, easy fix. I think that doesn't require medication, blood tests, lab tests. It's about awareness, habits, and it's the first place I start when I see that it's needed.

ABBIE ROSS: I love these tips. I feel like they, especially in the screen culture, many of us are leaning over things. So Thank you. Similar to that, we have got a few questions. Maria, maybe you could take this one about TMJ. And patients are asking, is this the root cause for vestibular migraine? Is there any tips or things to help with this?

MARIA MACHALA: So we don't know the root cause of vestibular migraine. We, we're learning more and more about migraine. We know that it's a genetic disorder, but we don't understand it fully. We know there is a strong association with TMJ disorder. So I do think it's an important thing to treat for many different reasons. It can cause pain and other issues. So I think it's important to treat. And if you, if your dizziness improves with that or your migraines improve with that, then that's great. It's not something I typically focus on unless I see there's a trigger if they're having a lot of pain or. But it's not typically something I correlate with vertigo.

ABBIE ROSS: And then... Sorry, go ahead, Kathleen.

KATHLEEN STROSS: I was just going to add to that. When we talked about the neck, for example, and the sensitivity of the tissues there, the jaw, the head, the face, the base of the skull, the neck, all of these things are really prone to what we call trigger points or pain, referred pain. They cause referred pain, that cause headache. And those are, in my experience, different than the migraine type event that I think is inside the skull, inside your head, rather than the outside of your head. But the outside of your head can certainly trigger symptoms, and that includes the soft tissues of the shoulders, the neck, the front, the back, the base of the skull, the head all the way. And that's a myofascial or what I call neurofascial kind of conversation to have. And it often does involve the jaw. So it's one of those things that we kind of rule out pretty easily. If we can look at popping, clicking, pain sensitivity, things like that. I mean, to have a client open their mouth and see how their jaw tracks or to stick their tongue out. And those are quick, easy screening tools usually. So we can kind of see if that's part of it.

KATHLEEN STROSS: It's not a root cause, but it's and remember, this is an and conversation with these people. It's this and this, this and this. And so we look at it that way rather than being a single cause effect.

ABBIE ROSS: The whole person. Now, before we wrap up today, I want to touch on one more topic that's come up a few times, and it's relating to viruses and how they impact one's symptoms, whether it's preceded symptoms or exacerbated symptoms. Viruses like Epstein Barr, herpes simplex, Covid. Maria, can you talk to us about that?

MARIA MACHALA: Yeah. So we know that viruses can affect the vestibular system. You can have vestibular neuritis that is typically attributed to a virus, not necessarily one specific one or one that we can treat with antivirals. And then as far as preventing things like this, I would, as a mother of two young children, I would love to have a way to prevent viral

illnesses. I think it's just general health. You know, eating a good diet and sleeping well and exercise, all these things that help us to prevent infection. And so in the virus can affect the inner ears in really specific ways, too. So if somebody comes in with bilateral sudden hearing loss or a bilateral sudden drop in balance system so both ears are affected, then I do look at specific viruses and then other infectious causes. So not just viruses, but I think of things like Lyme disease, syphilis, things like that. So, yes, viruses are important to understand when it comes to vestibular health. So it really depends on how the patient is presenting.

ABBIE ROSS: Thank you so much and thank you, Kathleen and Maria, for your contributions today. Such a good talk. It gets you thinking about all facets of life and how you can really improve your health, not just through the standard care, but by zooming out. So thank you both for being here. If you'd like to learn more about either presenter talk today, check out the banners at the bottom of the screen. Check out today's agenda. More information will be there. And we will pass the baton for this fourth day of life rebalance. Live off to the patient panel led by Hollie Smith and Heather Davies.

HEATHER DAVIES: Hello.

HOLLIE SMITH: Hi, ladies.

ABBIE ROSS: Another great session.

HOLLIE SMITH: It totally was.

HEATHER DAVIES: I found myself straightening up and changing my posture immediately. It's me pulling the string.

LIZ FUEMMELER: It's been really amazing to learn even some of these simple tips. I think vestibular gets so complicated and we know there's so many complex causes. And I think I have learned a lot about some of the

simple tips that can make day to day life even better.

HEATHER DAVIES: Absolutely. Well, you ladies did a wonderful job in the first hour and what fabulous guests that you had. And thank you so much for getting us started today.

ABBIE ROSS: Yes, thank you.

HOLLIE SMITH: Oh, Heather, I am very focused on sitting up straight.

HEATHER DAVIES: Oh, my goodness, me too, Hollie. Hello, I am Heather Davies. I have been diagnosed with vestibular migraine and Meniere's disease. And I'm host of the Meniere's Views podcast.

HOLLIE SMITH: And I'm Hollie Smith and I co-host the VeDA retired support group. I have superior semicircular canal dehiscence, vestibular migraines, and Meniere's disease. And we are so excited to get started today.

HEATHER DAVIES: We are welcoming our patient panelists, Marissa Aldrete and Julia Savoie. Hi, ladies.

MARISSA ALDRETE: Hello.

JULIA SAVOIE: Good to see you.

HOLLIE SMITH: Oh, my goodness. We're so excited for this second hour and a great talk. So we're going to start off with Marissa. And Marissa, I was wondering if you could briefly describe your vestibular journey.

MARISSA ALDRETE: Yeah, yeah. So my journey began back in 2011. I was in a place in my life where I was working full time. I was really stressed. I had a two year old, so life was just busy and I was having more regular bad headaches or migraines with pain. And all of a sudden, like one day, it

was almost like a light switch and I had a sudden onset while I was driving where everything just changed. Like there was no more pain. It turned to like a feeling of unbalance, disorientation, just not knowing what was happening with my body at that moment. As we all know, it can be very scary, especially when you you have that first onset and then driving. So that kind of, that was my first onset. And then dealing with that over the course of a few years, trying to figure out exactly what it was, it was a little while back, so we didn't have all the resources we have today. So it it did take me a while to get a diagnosis, but it was it was a long haul with that.

MARISSA ALDRETE: I did lots of different techniques and things, disciplines to try to manage it, you know, as the lovely ladies before we're talking about with looking at diet, doing vestibular rehab therapy. Mine was so affecting of my vision, so I did vision therapy. I had a wonderful doctor that helped me with all that. So in finding, I wasn't able to take some of the traditional medicines that they recommend to treat vestibular migraine, I had to resort to some other techniques, then incorporate that in. So that's kind of how things started for me. You know, it was a long, of course, like all of us, it's a long journey. Had some good times, some good years in between where I wasn't very symptomatic at all. And then things kind of came back for me a few years back again. And so just still focusing back on okay, it's a bunch of different things. It's not just one thing we're going to do, it's a whole bunch of different things. So what helped me really was the diet and doing my therapies and just incorporating all those different things into my healing.

MARISSA ALDRETE: And medication actually was a part of my journey this time. I needed that to help me. I was in a very tough place, and that, along with the other therapies, has gotten me into a very good place now. So that's kind of how my journey has gone. I was trying to make it short. So that's...

HOLLIE SMITH: I'm happy to hear you're in a good place now.

MARISSA ALDRETE: Yeah.

HOLLIE SMITH: It certainly sounds like you have a multidisciplinary approach, and there's certainly no shame in medication. And I'm so glad that you brought up that that is a piece of your puzzle for sure.

MARISSA ALDRETE: Yes.

HOLLIE SMITH: Well, thank you for getting us started today.

MARISSA ALDRETE: Yeah, of course.

HEATHER DAVIES: And, Julia, how about you? Can you briefly share about your experience living with vestibular disorder?

JULIA SAVOIE: I was diagnosed with Meniere's disease at 20, but my symptoms started even earlier. I was 18 when I first experienced that vertigo attack, and it was very violent and very sudden. And other symptoms included tinnitus and hearing loss that was fluctuating between the episodes, as well as nausea and vomiting. And at the time, I was dismissed by the doctors, I was only 18. I was told I was too young. I was probably fine. I would grow out of it. So it went on like that for a while, until when I was 20, I was already in college. I found a doctor that specialized in dizziness and hearing, and he ordered the right tests to finally diagnose me with Meniere's disease. However, at the time, I wasn't given a lot of direction. We tried two medications, but they didn't help. So I was, they told me that we should just wait and see. So that was the whole approach. And I remember getting home and Googling Meniere's Disease and all it said online that it had no cure. And that was also 13 years ago, so we had way less resources. So I thought, okay, there's nothing I can do, so I'm just going to continue living my life.

JULIA SAVOIE: And not only did I not do the right things to improve my

situation, but everything in college pretty much worked against me. My diet, my stress levels, my sleep patterns. And after moving to the US after graduating from college in my mid-20s, I started experiencing drop attacks. And those are different than vertigo attacks. It feels like being violently pulled or shoved towards the ground. And one of those attacks left me pretty badly injured. I broke my nose, I fractured my cheekbone and got 14 stitches on my forehead. And that was a big wake up call. That was the moment when I knew that something needed to change. And I started doing my own research and implementing those dietary and lifestyle changes and saw a big improvement in my symptoms, which inspired me to become a holistic nutritionist. And I remember reading that quote online that said that you should strive to be a person that gets out of a burning building, but comes back with water for the people who are still stuck inside. And I thought, I so badly want to be that person.

JULIA SAVOIE: Until a year ago, I unexpectedly found myself back in the birthing building, again, dizziness. But this time it felt different. It felt more like being imbalanced, nausea and a lot of visual symptoms. And I was diagnosed with vestibular migraine this time, which shouldn't surprise me because I knew that a lot of Meniere's disease warriors also have vestibular migraine. But similarly to Marissa's story, I before experienced migraine with headaches like regular migraine that came with light and noise sensitivity and a pounding headache, and then it would go away. So I was surprised that this was also a migraine, but it felt, the symptoms were very different. So it's definitely very humbling to having to go back and revisit all the approaches I took back then and do physical therapy exercises again and having to worry about going out and symptoms. But I'm happy that I have so many more resources already than I did back then.

HEATHER DAVIES: Absolutely. Julia, do you feel that you got a diagnosis for the root cause for your dizziness early on? I mean, how long did that take?

JULIA SAVOIE: I don't think I did with Meniere's. It took two years. As I mentioned, I was dismissed a lot. I was told it was hormonal imbalances, it was stress. It was... And while all those things can of course contribute to Meniere's disease symptoms or trigger them, that wasn't the root cause. So it took two years. When I finally found the right doctor that validated me and listened to my symptoms, he ordered the hearing test, which showed 40% hearing loss on the left side, and ordered all the balance testing, VNG, VMP, ECoG, rotary chair test, which checked how.

HOLLIE SMITH: All that fun testing.

JULIA SAVOIE: All the fun testing, yes, that checked how my inner ear and brain communicated as well as checked eye movement. So to assess the inner ear function and those, yeah, that was enough to diagnose me with Meniere's disease. With vestibular migraine, it took about 10 months, which probably is average, I would guess, reading other people's stories online. And again, we started with blood work ruling out other conditions, and then I had an MRI, which was normal. And based on my symptoms, my neurologist was able to diagnose me with vestibular migraine.

HEATHER DAVIES: It's a long, long journey, I know. Marissa, how about you? Do you feel that you got diagnosed, figured out the root cause pretty early on, or was it a delay also?

MARISSA ALDRETE: Yeah, no, it was a process. Yeah. Like Julia said it definitely takes a while. And especially back then, we didn't have all the information that we have now. So it was the same thing. I was told, oh, it's just anxiety, stress and like Julia said, yeah, that stuff can affect us. But I knew there was so much more to it and just to keep looking. And so, no, it was probably closer to, like, three years when I for sure got that exact diagnosis. And, yeah, as you were saying it's so hard to believe that it stems from migraine because you always think of pain, and it's like, we don't have pain. We have the dizziness, the nausea, all that. So, yeah, just that whole journey to get the diagnosis.

HOLLIE SMITH: It can definitely be a complicated situation, for sure. And, Julia, I can so empathize with your being a teenager. I was 19 when I got my Meniere's diagnosis and was also given that you're a stressed out college student excuse. And just like Marissa was saying that's not the root cause of it. It certainly can play a role, and it's very stressful when you're going through it. So a shout out to those that are on the young side of things that are going through it and that have been given that while you're a young person and you're just stressed out and that it is a stressful period for sure. But you're not alone in this and keep pushing forward until you get that root cause, that final diagnosis where it totally makes sense and you have a more complete picture for sure. Marissa, you mentioned taking medication. And so there's a question that's popped up in the chat as far as would you mind sharing what kind of medication you're on and for what purpose and what was the most helpful for you as far as medication side of things?

MARISSA ALDRETE: Yeah, well, and just to say quick back when I was first diagnosed and they gave me a medication again, they didn't know exact like dosing and things. And that's what really turned me off. I couldn't handle it. They had given me like a really high dose, like 50 milligrams of nortriptyline, like right out the gates. And I was like, I would never took a medication. And that just wiped me out. Like, I literally had to sleep it off for like two days and I was like, oh my gosh, if this is the medicine, I cannot go this route. I'm not going to be able to do this. So yeah, and that time it seemed like the other therapies worked. But later on, as I mentioned, yeah, now that I do take medication, yeah, I don't mind sharing. I've taken Aimovig for the last, well since 2018 when it was like almost brand new. I started it in December of 20, 2018. That's a monthly injectable that I do. And I take the 70 milligrams, the lower amount. So I still do that every month to this day.

MARISSA ALDRETE: I also, what I feel was a turning point for me was adding in the Effexor. I take that, I've done that since, it's probably '21,

2021, when I had been seeing Dr. Bae. And again, it goes to show I'm on a higher dose than I ever thought I would be on. So it doesn't, but that's what I needed to get me to the point I needed to get to. So don't be afraid. I know I was very afraid to try a new medicine when I met Dr. Bae, just after everything I had gone through, I was like, I don't want to try anything else. But sometimes just having, if you could have that trust in your doctor and just, I really had no other choice. So I was like, I'm going to try this, and it made a huge difference. So, yes, yes, that's what I've been taking and has helped.

HOLLIE SMITH: When you find a doctor you can trust, it's easier to trust trying the new medications, knowing it might work for you, it might not work for you, but the courage to continue going forward, the right providers make all the difference in the world. You're totally right. I'm so glad you brought that up, Marissa, on being able to trust your doctor in order to be brave enough to try those new things. Were you able to get your medications covered by your insurance then?

MARISSA ALDRETE: I was. Thankfully when Aimovig first came out, they had some coupons and I was able to sign up for a program. So, yeah, I pay, I think it's like \$5 for each one, maybe 10 now. But yeah, it's a monthly program that I'm able to do. I'm so thankful for that because, yeah, otherwise it would be like probably \$1200 or something a month. So I know everyone it depends on kind of your insurance and things, but I'm very thankful that I've been approved and I have to reapply every year. But I'm thankful that I'm able to continue with that for now and that it's affordable for me. Yeah.

HOLLIE SMITH: Thank you for sharing that part of your story, Marissa. I know that helps a lot of people understand what's out there and that everyone's different. And as far as you go, Julia, have you found any medications? And then I know you mentioned diet and supplements. How does that intertwine with the medication portion? Do you take medications and supplements together? How does that work for you?

JULIA SAVOIE: Sure. Should they talk about vestibular migraine or Meniere's or both?

HOLLIE SMITH: Both, because you have both and it's the intertwined... There's a lot of people in the audience that have both. Heather and I both have both.

JULIA SAVOIE: Definitely. So I started addressing different areas of health that could impact Meniere's disease when I first started. I knew, for example, I had hormonal imbalances. So I started working on that and changing my diet and changing my lifestyle and trying to move more. And that was a very helpful change. There weren't any medications that helped me specifically for Meniere's. I did try betaserc, and I know it can be life changing for so many people. I know so many people with Meniere's that say that was, that was the most impactful thing they did on their journey. I know it is not FDA approved in the US and it can be difficult to get unfortunately. For me, it didn't change any symptoms, it didn't affect me in any way. So I stopped taking it. I did try the diuretic medication, but that kind of left me feeling lightheaded a little bit all the time and also didn't affect my symptoms. So I stopped taking that. So there wasn't any medication I was on for Meniere's. It was just the diet, it was focusing more. I used to be a very restrictive dieter and I would find new diets online and try them for two weeks only to just binge on the weekends.

JULIA SAVOIE: And it wasn't a healthy situation. So I definitely, instead of restricting, I started focusing on adding more whole foods and building a balanced, nutritious meals, and cooking from scratch in general was a huge thing for me. Not even focusing on specific ingredients, just making my own food at home. And as far as migraine goes, I did try to heal your headache elimination diet, but because of my history of restrictive dieting, it was very tricky for me to stick with it. I did it for a while and funny story, when I went to see my neurologist, I had to first meet with

the nurse practitioner at that clinic. And she said, listen, we don't have the test yet, but I can tell you have vestibular migraine. I've seen it so many times. And she said, the thing you have to do is follow the heal your headache diet. She's like, that's the one thing you have to do. And I was like, okay. She was really serious about it. She emphasized it like three times. So I got home, I already have both Alicia Wolf's cookbooks. So I was like, I know what I'm doing.

JULIA SAVOIE: And then when I met with the neurologist, I asked about it and he said, you don't need to do that. He said, all you have to do is eat a Mediterranean diet. So it's very tricky to know what to do exactly. But again, I focus now more on implementing more brain healthy foods in my diet and anti inflammatory foods. As far as medication goes, I'm not on any preventative medication, but I do have Nurtec, which is also maybe very tricky to get. My doctor had to fight my insurance very hard in order to approve it. And I only got eight pills a month. So I have to, if I do feel symptoms, I have to kind of gauge how bad they are and whether I should wait or use one of my eight monthly pills. And I also take a supplement. I'm trying to remember what it's called. I think it's called MigreLief. Am I pronouncing it right? It has, and I found that helpful as well. So I take that daily.

HOLLIE SMITH: Yes. That's one of the combination supplements. They touched a little bit on that yesterday at yesterday's talk. But that's very helpful information. Yeah, go ahead.

HEATHER DAVIES: I have a question. Can we backtrack a little bit? I am very curious in finding the root causes of and triggers of these things. I followed ace. I wrote a symptom journal. Did either of you do anything like that or keep a diary of stress or foods or anything that might be triggering? Julia?

JULIA SAVOIE: Yes, I love journaling. I tell everybody with dizziness to journal their symptoms, their triggers. It is so helpful for you to start

noticing patterns, but it is also very helpful data for your health care team. I bring my journals with me to the doctors and I know I get flustered, I forget things. And if they ask how severe were the symptoms and how often do they happen, I have everything there in one spot. I think it is a very valuable tool.

HEATHER DAVIES: And what about you, Marissa? Have you used a diary of any sort?

MARISSA ALDRETE: Yes. Yes. Like Julia, I'm a big person that loves to journal. That was a good outlet going through this whole experience to get your feelings out as well. So not only, I did keep like a symptom journal of what I was feeling exactly. And yes, what I ate and things, because it is such a valuable tool when you do go to see your doctor and things. But yes, then I also just it was a great way to get all my feelings out about how I was handling things with going through this. So, yeah, I'm a big believer in journaling. I think it's a great tool.

JULIA SAVOIE: I love that. I also write down three things I'm grateful for, and it's such a simple mindset shift. But especially on those high symptoms days when it feels like everything's going wrong and it's so easy to focus on the negative. Just finding three little things that you're grateful for.

HEATHER DAVIES: Three little things. Yeah.

MARISSA ALDRETE: Couldn't agree more. It's so important to find those little glimmers every single day, regardless.

HOLLIE SMITH: It makes all the difference in the world for sure. Julia, you mentioned being able to focus on the holistic diet and the nutrition and all of that. And you said that you have focused on adding more, bring healthy foods into your diet. I was wondering if you can give us like five or so of the most helpful foods you have found to add to your diet instead

of, we talk all the time about subtracting and eliminating and all of that. What have you found to add to your diet that's been really helpful?

JULIA SAVOIE: So one of the healthiest foods for brain health are healthy fats, which is something I definitely didn't eat enough of. So walnuts, fatty fish, salmon, for example. I love to add as many anti inflammatory foods in my diet. I find that very helpful. So those can include dark leafy greens, berries, for example.

HOLLIE SMITH: Right. And do you adhere to the low sodium diet or do you more listen to your body? How does that work for you?

JULIA SAVOIE: Oh, that's tricky. I don't track sodium anymore. I don't specifically, I mean, because I mostly eat whole foods, because I cook a lot at home, those foods are naturally going to be lower in sodium, which allows me to add a pinch of salt to my cooked meal and still be okay and have that not trigger symptoms.

HEATHER DAVIES: Absolutely. That makes sense. Oh, I'm sorry.

JULIA SAVOIE: When I go out, I do notice that I'm so used to eating less salty foods that not only is everything at restaurants super salty tasting, but it also can trigger symptoms sometimes.

HEATHER DAVIES: Absolutely. And Marissa, I believe you are in the healthcare coaching business as well. And in addition to that, you host a support group which meets tonight. Correct?

JULIA SAVOIE: Yes.

HEATHER DAVIES: I was wondering if you wanted to share anything about those two things as long as we're on the health topic and your group meets tonight. So I thought that might be helpful for people in the audience and hopefully Kyler can put information in the chat as well.

MARISSA ALDRETE: Sure. Yeah. So I was a former preschool teacher, that was my occupation. And then of course, after going through all this, I realized being in the classroom was not an appropriate place for me. It was way too triggering and just, it was just way too much going on and it just wasn't going to work for me anymore. So I kind of really had to look at things like what do I want to do that's really gonna help people. And I was at that time and still I'm focused on, as Julia mentioned, like I had Alicia Wolf's and Dr. Bae's cookbook too. I had both of those and was doing a lot of the recipes all the time. And so was focusing on the whole person, the whole picture there. And then actually one of our members and our support Support group was becoming a health and wellness coach. And I had approached her and just wanted some more information because that sounded like something I'd really be interested in. And yeah, so back in '23, I went back to school and took some courses on becoming a health and wellness coach.

MARISSA ALDRETE: And last March I became certified, to be board certified to be a health and wellness coach. So very excited. And yeah, actually now I work for a platform where we help people prepare for surgery. So we are focusing on, and it's all virtual, so I'm able to work from home. We focus on their nutrition, specifically their protein intake before and after surgery we talk about their physical movement, how that looks for them and what they'd like to be doing and also kind of their mental overall well being through the surgery process and things. So I'm very happy and grateful to be doing that. You can see I have some screens behind me. I want everyone to not lose hope because when I was in my worst, I could not look at my phone, I could not look at any screens. Could hardly look out my window if things were moving. And through therapy and through medications, I now use three screens dreams to work on. And I'm on them several hours a day. I'm not gonna say it's easy. I do definitely have my days that are harder. But I'm doing it.

MARISSA ALDRETE: And so I hope that gives some people hope. So that's

that. And then as far as our support group, those of you have maybe seen some of our videos, my good friend Joy Holton, she's another VeDA ambassador, a good friend of mind, vestibular migraine patient. We have our Thursday night support group that Holly mentioned. Finding joy in your vestibular journey. We have that every Thursday night. And Joy, she has been doing this consistently for two years now. I've taken a little break recently, just was starting work in the fall, but getting back into it now. But it's a wonderful group for anyone with any vestibular disorders to come and just know that you're not alone and hear other people's stories and get that support, which is so important for all of us to have that outlet to talk about our symptoms and hear from others. So yes, we have that Thursday nights. We're very proud of that. And we do have a YouTube channel that we have not done in a while. We need to get back to it. But we have some great videos on there that's finding joy in your vestibular journey.

MARISSA ALDRETE: So you can check that out as well. So, yeah, lots of good things.

HEATHER DAVIES: I have to mention that whenever you go to these groups, because I didn't know about that until I met with you a couple years ago, Marissa, if you aren't comfortable speaking, you don't have to speak. You can sit and listen until you're comfortable and find your rhythm in the right group.

MARISSA ALDRETE: Yeah. Joy's always so good about bringing that up and reminding people. She's like when we have a new person, you don't have to keep your camera on. You know, you can just listen, whatever makes you comfortable, we want everyone to feel comfortable and welcome. So, yeah.

HEATHER DAVIES: Yeah. Thank you so much for sharing all that because I'm sure the support groups have been such a big help for so many people. And your commitment to, both you and Holly and Joy is just

amazing. I wanted to ask both of you, how do you talk to your medical providers and advocate for yourself? It's very hard at the beginning, I know, for personal experience, but I'm curious how you do that today. Julia, can you take that on first?

JULIA SAVOIE: Of course, I would say there are three things I would suggest, be clear, be prepared, and be persistent. By be clear, I mean, be clear how you explain your symptoms. And because a lot of us have been dismissed in the past, we want to use the right phrase. And doctors really want to know what we're experiencing. Dizziness, for example, is an umbrella term. It can mean anything. It can mean feeling faint, it can mean vertigo. It can mean feeling imbalanced. So it's really important to explain exactly what you're going through, even even though it may sound silly, and be clear... I found that I am more likely to get an answer from the doctor if I ask a direct question, rather than what could cause dizziness and there are 500 causes, and the doctor is less likely to go into it. But if I ask, what do you think of this treatment for me, or do you think my hormones impact my symptoms? The second thing I said was prepared. I come prepared, like we mentioned earlier with a journal. So I have all the data there for the doctor to review.

JULIA SAVOIE: And I like to bring a friend or a husband in my case.

HEATHER DAVIES: A support system. Yeah.

JULIA SAVOIE: Who can ask the questions and help advocate for me. That's been very helpful. And being persistent, the last thing is very hard for me. I'm a little bit of a people pleaser. And I think, especially at the beginning of my journey when I was younger, it felt like the doctor is the specialist. They know what's wrong. So I should just listen and I should just be quiet and go with it. And...

HOLLIE SMITH: I think a lot of us do that.

JULIA SAVOIE: Yeah. And I think now I understand that while the doctor may be the specialist in their field, that may be amazing, but I'm the specialist on my body and I'm the expert on my body and I know when something feels off. I know my baseline. So being persistent and if the doctor doesn't want to investigate any further than considering seeking a second or a third opinion and finding a doctor that specializes in the condition we're dealing with, I found that not every ENT has an extensive knowledge on Meniere's, for example, and not every neurologist treats a lot of people with vestibular migraines. So finding the right practitioner is very important.

HEATHER DAVIES: Absolutely. And just to mention that vestibular.org if you go on there, they do have a healthcare provider list. And also ask in the groups, ask people and I will, I've recommended someone to someone and they didn't have the same response I did. So if you don't have that, keep moving, keep moving. If you don't have that rapport, keep moving, you'll find it. You've got to have someone that's on your team. It's so important, so important. Thank you, Julia. I love those three. I'm gonna have to go back and write those down. Be clear, persistent. And what was the other one?

JULIA SAVOIE: Prepared.

HEATHER DAVIES: Prepared. There you go. And what about you, Marissa?

MARISSA ALDRETE: Yeah, I couldn't agree more with what Julia said. I feel the same way. I also would always go and bring my notes and have someone with me, a support person. And I think as Julia also mentioned we were younger back then when we were first seeing doctors, and yeah, I was the same way. I was a little more soft spoken and just kind of wanting to listen to what the doctors were saying because they're the experts. But I have learned to advocate for myself now that you don't have to settle for that doctor that's going to tell you one thing. And you know, like Julia said, you are the expert of your body. So I really want to

emphasize that, that you don't have to settle, if a doctor isn't working, move on. There are other ones you can find that will suit you. Don't give up, keep, keep looking and don't settle because it's so easy to just be like, yeah, it's okay and just kind of follow along. But if that's not helping you and you're not getting the answers you need, like, you need to have a good partnership with your doctor.

MARISSA ALDRETE: And trust, as we mentioned, and it is very hard to come by. I know that I've seen so many providers. I'm even still in the process of, I'm sure a lot of out there that saw Dr. Bae being out of state, that I'm where I am, I'm not able to see him anymore or virtually meet with him anymore. So I've had to do the same thing. I'm kind of back out there trying to find a neurologist to keep up my treatment. And it's hard. I'm still kind of on the search. I have someone, but I'm not 100% sure. So kind of just, yeah, but don't settle. And yes, so important to just be prepared and listen to your body and your gut and your feelings about who you want to be working with and who's going to be helping you.

HEATHER DAVIES: Trust your intuition for sure.

MARISSA ALDRETE: Yeah, definitely.

HOLLIE SMITH: You ladies have great advice. And to go along with what Heather was saying, VeDA does have a great help directory. I'm sure Tyler will put that in the chat, the link directly to the healthcare directory. And then there's also a link to the support groups, which a lot of times people are more than willing to share experiences with doctors. But one thing I want to encourage people, even if you're not a support group leader, you've never been to a support group, this is your first time, if you are brave enough to just make a topic of discussion here on the conference platform and just say let's say you live in South Carolina, just write South Carolina doctors, maybe someone will respond to you just in the chat. So don't be afraid to reach out to people while we have this beautiful conference platform where we have 4,000 people, someone hopefully

can respond and have some sort of direction. If you are feeling completely lost, reach out. This is a great week to do it to interact with people who truly get it and have tried... Yes, exactly. So if you're brave enough to say something, someone else is probably also thinking it.

HOLLIE SMITH: And the same thing there are meetups, if you haven't had a chance on the conference platform. Not just the support group meetings, which last all throughout the year, there's meetups that happen just during the conference. And if you haven't had a chance, I know someone has one set up for Central Florida. So you can create, yeah, you can create your own meetup and see if someone else would just be willing to meet with you in your area. So just a couple of thoughts to kind of play off of what these ladies were saying. But you have such amazing things. And as we kind of switch directions, I was wondering, Julia, if you have had any like tests to kind of, that are kind of marketed to help you discover more of the root causes of things like mold testing, allergene testing. Were they worth it? Were they not worth it? Sometimes these tests aren't covered by insurance. And so I know that's been a question for a lot of people. Are these things worth it? Have you tried them? What are your thoughts?

JULIA SAVOIE: Sure. I'm smiling when you're talking about it because I am so into wellness and I'm so interested in those things, I tend to just click on everything and then I'm bombarded with ads and for different tests and the supplement and everything. The phrasing, the wording they're using in those ads, it makes you. Makes it sound like that's the one thing you need. If only you have that one test, everything will turn around for you. So it's definitely very tricky. And especially us in the vestibular community, we may be a little bit more vulnerable to that because we're suffering so much we want that relief. I personally would recommend going through your doctor first, especially if you don't know what's causing your dizziness. And even if you do, those tests may be better regulated. And as far as those tests that you can do at home, I would consider doing a little cost benefit analysis. What will you really get out of

it? Will you be able to, will it affect your treatment plan? And will you be able to address it yourself? Or will you have to schedule another doctor's appointment? And the doctor, it may take a couple months and the doctor will have you do that test again anyway.

JULIA SAVOIE: I have ordered this test. It checks for like over 100 different biomarkers. But the great value in it is that a medical doctor reviews the test and then can recommend supplements and dietary changes based on that. So I found that to be worth it. And my doctors, or my neurologist also ordered a sleep study, which is something that the experts were just talking about to rule out sleep apnea because it is a common contributor to, or a trigger to Meniere's and migraine. But that came back normal. So I would definitely be cautious of those tests, especially the food sensitivity tests tend to be not very accurate, the ones you order to do at home. If I would definitely recommend going, asking the doctor to refer you to a specialist to order those tests. And that way maybe your insurance will be able to cover at least a part of those costs because they can be expensive as well.

HOLLIE SMITH: For sure. For sure. Well, thank you for sharing your experience on that, Julia. And I love how you circled back around to the sleep apnea test that they did talk about earlier today. And what about you, Marissa? What about like testing for mold allergens? Like all of these things that not necessarily your mainstream doctors will be on the lookout for? Have you tried any of them and what have your experiences been?

MARISSA ALDRETE: Yeah, so I haven't done much of that kind of testing. I did do on a couple different occasions just some regular, I went to an allergist and just did like some basic allergy tests. So more testing for like outside irritants and things like that and a few food allergy things, but nothing like too invasive or anything like that. And so, I mean, I didn't get that much out of it, I would say, for what I did. But I didn't do anything more in depth. So that's the kind of testing, that's the only testing I did as

far as like allergies go. Other testing, different testing I did do with Dr. Hayne in Chicago here on a couple occasions. He did a lot of inner ear testing like the VNGs and the rotating chair, those kinds of things. And what that did was rule out that it wasn't an inner ear issue, that it was more of the vestibular migraine that was causing it. So yeah, those are really the only types of testing that I've done.

HOLLIE SMITH: So the traditional battery of testing for those that haven't had that, like Marissa was saying, Dr. Hayne in Chicago is one of the more well known doctors and he does have a great website that VeDA does have a lot of his stuff linked on their page. But a bigger medical testing center runs the traditional vestibular testing, like Marissa was saying. So that's an important thing to have if your doctors recommend it as part of your journey. But more of like the things you see advertised on social media, you have steered clear from that, it sounds like.

MARISSA ALDRETE: Yeah, yeah.

HEATHER DAVIES: I have a question, Marissa, for the testing, the typical testing that we do for vestibular disorders, to rule them out and to find them, did you find that when you went to a different doctor that they wanted to run the same series of tests that you'd already had done? Did you have that experience at all? So I had, each doctor that I went to, I found that they wanted to have their providers do their particular testing and to have to go through the caloric testing three times just to find the accurate, it's just ridiculous. So I'm just trying to find out, is this something that you had to do on a repeated basis before you were diagnosed?

MARISSA ALDRETE: Yes, well, I have heard that and I was asked, yes. But I actually just stayed with Dr. Hayne and did like two sets of testing with him like years apart because I just, yeah, I wasn't gonna go go through. Like you said, when you've done an Ernie, like multiple times, yeah. So no, I mean, thankfully I only did it a couple times, but it was with the same

doctor.

HEATHER DAVIES: Oh, good. And what about you, Julia?

JULIA SAVOIE: Yes, it happened to me. I had all the testing done back in Poland, all the VNG and all the vestibular testing and hearing test. So when I moved here, I had everything translated and I thought, I'm going to go to the doctor and they're just going to review it. And they were like, no, you have to do it all again in our hospital. And yeah, that was not fun.

HOLLIE SMITH: That was tough. Yeah, I was curious about that, if I was the only one that had to go through all that.

HEATHER DAVIES: I've been through multiple testing too, and sometimes it makes sense. Like when I had the SSCD surgery. Of course they're going to want to run the CT scan on the same machine that they're going to use to, like at UCLA, they have technology where they show your particular scan on top of your head as they're doing the surgery so that they're doing it in a more precise way. That type of thing makes sense. But sometimes when you go through the huge whole battery of testing, and that's tough on your system, that can feel excessive. And I know in the comments someone made a comment about how sometimes there's quantity quotas and so make sure that you're advocating for yourself. So it sounds like sometimes there's great reason when the same doctor's saying we need a post and pretest, that kind of sometimes can make sense. And then when you go for surgery, sometimes that makes sense. But so there's times when it feels like enough's enough. So the next question that's come up in the chat is how do you explain your condition to others? Because sometimes the term vestibular is not always easily understood, especially if you're explaining it to someone that doesn't see you every day.

HEATHER DAVIES: So how do you help them to understand that? By people that are just not familiar with vestibular migraine or Meniere's or

any of the other vestibular symptoms and disorders. How do you help them understand that? So Marissa first, and then we'll go to Julia.

MARISSA ALDRETE: Yeah, that's such a great question, Hollie. And I think for, like, a lot of people, I avoided that for so long, like, having to explain what it was. I just isolated myself, which wasn't good either, but I just didn't want to explain everything 'cause I knew they wouldn't understand and I didn't really understand. So it was, I did a lot of avoidance in the beginning, but I'm still trying to figure that out, actually, like a really good way to explain it. I think I say different things depending maybe on the person. But I think a lot of times, if someone, if I do say vestibular, I try to explain it as it's a balance issue and with that. But more so I think just kind of saying it's a disorder that stems from migraine and it affects my balance and can make me dizzy and I'll have these attacks and that kind of thing. So I think to answer your question, I think I'm still trying to figure that out, like, the best way to explain it.

MARISSA ALDRETE: I think you just, you'll say different things to different people and, yeah, I would love to hear, like, what Julia says and some other people. That is a hard one.

HEATHER DAVIES: Yeah. There is very little awareness. And I find that it's not only, it's also in the healthcare community sometimes, or just, you would think more doctors would be aware of vestibular issues.

MARISSA ALDRETE: No.

JULIA SAVOIE: I have a story for you guys. When I was first diagnosed, it's not funny. It's more defining. It's just my dark humor. I went to the dentist and they, and I was very nervous about it because that was back when my symptoms were very active, my Meniere's, and dentist office says can be very triggering for a lot of us. Everything about it is awful. The neck position, the bright light, the noises, the smells. So I was very nervous and I shared with the dentist that I have Meniere's disease. And

he was very skeptical of that. And he said, I don't really think there's such a thing as Meniere's disease. He said, I think you have loose crystals in your inner ear, and if you shake your head really hard, it'll just pop back into place. And that's one of those conversations that just keeps rattling in my brain. And, like, I keep coming up with responses, but unfortunately, I didn't say anything. I was just shocked. And he was almost offended that I didn't, like, try to shake my head, like he told me.

HOLLIE SMITH: Are you gonna drive me home?

JULIA SAVOIE: Right. So there is very... Yeah, there's a great need for that awareness. And this is very important work that you guys are doing here at VeDA to spread that awareness. And to answer your question, it is very tricky. And like Marissa said, I also consider who I'm talking to and how much I want to share. And I'm more likely to share the difficulties and the struggles with my friends. It's important that they understand what it really means. And especially vestibular migraine, whenever I say it's migraine, people tend to really dismiss it and be like, I have migraine too. But what they really, and not to invalidate their experience, because those migraine, those headache migraines can be also very troubling. But this is a very complex disorder that really affects you on so many levels. So when I'm talking to my friends, I will explain what I'm going through, what it feels like, how scary it is. But when I'm talking to other people, like Marissa said, I tend to just talk about the general, give them general info and tell them that it affects my balance.

HEATHER DAVIES: I'm the same way. How about you, Holly? How do you respond to people?

HOLLIE SMITH: Oh goodness. How first of all, I have... Thank you. First of all, I have to address the Julia's saying, the doctors as Jen is saying, just shake your head, please, no one listening at home. Please do not, don't do that. But secondly, like Julie was saying it depends who you're talking to. And like Marissa said it's a complex situation that's not always easy to

have that elevator speech. But the more you practice your elevator speech, the easier it is. At first, it was super emotional for me, especially when I had to leave my career teaching. You have this awkward moment of when are you going back to the classroom? Are you teaching yet? Are you in a different district? And you're having these multitude of questions just as you're trying to step foot into the real world again. And for people that are not super close, or even for people that are close, that you're just not having a good day, but you just don't want to go into it, my favorite phrase is I'm hanging in there. So that kind of gets you out of that situation where you're not being untruthful, saying, oh, I'm good, when you really aren't good, because your body knows you aren't good.

HOLLIE SMITH: And then you kind of go into this, like, fight or flight, like, I'm not being truthful. So I'm hanging in there. On a tough day, that is something that kind of gets you out of those awkward moments. If somebody's calling you and saying, hey, how are you doing? I'm hanging in there. Yesterday, when the weather was so bad and Heather and I were talking about how systematic that is for so many of us, it was a really hard day for me. I was hanging in there. I was holding my own. And for that, that was good enough. But for other people, you give them more and more information, depending on how close they are. And sometimes you'll hear me when we're introducing, sometimes I'll just say that I have SSCD. Sometimes I'll say I have SSCD, and vestibular migraines and Meniere's. Really, the truth is I have SSCD, which is the superior semicircular canal dehiscence, which is holes in your inner ear, if you aren't aware of that. It's one of the super rare ones. Vestibular migraine, which is one of the most common. Meniere's, which is a little more rare, but not as rare as SSCD. And then I also have pots, which can competes with Meniere's disease as far as high sodium versus low sodium. So there's this balance you have to find. So it just depends on the situation. But it can be really tricky, for sure. There's no easy answer. Heather, how do you answer that question?

HEATHER DAVIES: I really mirror all of that. It just really depends on how

deep of a relationship I have with the person I'm speaking to. And If I can go deep with them, and if not, then it's very superficial. And I love what you said of just hanging in there, because I just tend to avoid it, just, I usually don't see people when I'm not feeling well.

HOLLIE SMITH: The worst days for sure.

HEATHER DAVIES: Yes. For sure.

HOLLIE SMITH: Absolutely. And Heather, your podcast is amazing. For anyone that doesn't know, Heather hosts the Meniere's Muse podcast, and it's very amazing, and she has some very real conversations with people, just like we are today. And we're so impressed. And I can't even believe that we are about to wrap up day four. And, Heather, I think we should give our guests a chance to say anything that we just haven't gotten the chance to talk to. Yeah. So, Julia, would you like to start, anything that we haven't gotten a chance to talk to, whether it's the root cause or something else in the vestibular world that you want to make sure our audience knows about.

JULIA SAVOIE: Absolutely. I think maybe one thing we didn't talk about is mindset, how important mindset is on your healing journey. And it's not only that you're gonna think you're healed and you're suddenly gonna be symptom free. It's not that. But believing that you'll never get better can truly become an obstacle in your healing journey. And sometimes when I'm having symptoms, I think of my body as a toddler throwing a tantrum, and I'm the parent, and sounds weird when I'm saying it out loud, but bear with me. So I'm the parent, and my body's that the toddler is throwing a tantrum. And it's so natural to get so angry and be like, stop it. Just get so tense and so angry. And instead, I'm trying to be the kind of parent that squats down, gets to the kid's eye level and says, what is it that you need? What is happening? And learning to forgive my body for not being perfect and learning to, instead of judging it and being angry with it, to lovingly listen to the cues it's sending me and trying to do what

I can to help it, and that's it.

JULIA SAVOIE: And trying to, I would also suggest just being patient. A lot of us have become better, and a lot of us with vestibular disorders are living full lives. But like you guys said, it takes a lot of trial and error and trying that multidisciplinary approach, not just focusing on the diet or not just focusing on one thing, but thinking of stress management and trying medications and trying vestibular physical therapy and eating healthier, and all of those things together really do make a difference. And I would also say, I read somewhere that people underestimate what they can do in one day or overestimate what they can do in one day and underestimate what they can do in a year. And it may feel like one day doesn't make a big difference in your symptoms, but if you really stick with those habits, you will notice a big difference in a while. So just being patient and trusting yourself and forgiving your body.

HEATHER DAVIES: That's beautiful. I love loving and listening to your body. What a beautiful thought. Oh, Julia, how wonderful. And Marissa, what haven't we gotten to that you really want to make sure that people understand or tips and tricks that would be helpful for those in their journey?

MARISSA ALDRETE: Yeah. And I just want to say what Julia said is so important, and I went through that as well, just really to learning to give myself that grace and to have that patience and so, so important, Julia. So, yeah, I just want to say for me, a big thing in my journey was just feeling alone and so isolated in this, and just wanting people to know out there that we have, VeDA has so many wonderful support groups. There's so many more resources now. You know, VeDA is a wealth of information that you can find with your vestibular condition and just not to isolate yourself. I know sometimes we need that space, but you need that communication with others, and it can just be so helpful to talk with others and to not feel alone. So I just, I really want people to just know that there are people out here that can help them and just feel supported

and to not feel that isolation and aloneness. You're not alone and so many people reach out.

HOLLIE SMITH: Yeah. And would you say you recommend... Yeah. Would you recommend reaching out to a support group and getting involved that way, too?

JULIA SAVOIE: Yes, definitely.

HOLLIE SMITH: I know we had in the comments that someone said they weren't sure if they were well enough to go to a support group. What would you just say to that, Marissa?

MARISSA ALDRETE: Oh, my gosh. You know, as we talked about, like, you do not even have to have your camera on. You can just listen. I mean, we've had people that have been on the couch or in bed, like, it does not matter. We all have been there. You do not need to feel uncomfortable about that. We are there to support you and just wanting you to help you and not feel alone. So, yeah, you do not have to be, feel well enough to come. We've had people and that's really when you need it the most. And we oftentimes think like, no, because we're so bad we shouldn't go. But that's really when you need the most support. So, yeah.

HOLLIE SMITH: And you can show up in your pajamas. Just please don't show up with no clothes. Pajamas are totally fine, bathrobe is totally fine

HEATHER DAVIES: Well, thank you, ladies, Marissa and Julia, for being here. It's been such a pleasure and I have learned so much and it's so great seeing your faces and I'll see you in the community. If you'd like to learn more about Marissa and Julia or follow their journeys, please check out the banners below and they can also be found in today's agenda. Alrighty. Thank you both so much for joining us.

MARISSA ALDRETE: Thank you so much.

HOLLIE SMITH: Oh, my gosh, Heather, that was amazing. How is tomorrow our last day?

HEATHER DAVIES: I know. It's flown by, hasn't it? It's just gone way too fast.

HOLLIE SMITH: It totally has. And those ladies were just fantastic. And the speakers this morning were just wonderful. And what a great week. A big shout out to Cynthia and the whole VeDA team who makes this conference go on so smoothly. The people behind the scenes, the volunteers in the chat and just amazing.

HEATHER DAVIES: Yeah.

HOLLIE SMITH: As we're wrapping up, we wanna say thank you again to the James D. And Linda B. Hainlen Discovery Fund and to the University of Minnesota Department of Otolaryngology for sponsoring this conference.

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 that valuable information that's presented at this annual event remains free to everyone by making a donation at vestibular.org/lrl-donate. Those links are also listed in the description box below.

HOLLIE SMITH: Tomorrow is the final day of the conference. I hope that you will join us to learn about the advancements in telehealth and the technology that are making vestibular care more accessible. We are so excited to see you for Friday. And Heather, what a great week.

HEATHER DAVIES: It has been great.

HOLLIE SMITH: Well, we'll see you guys tomorrow.

HEATHER DAVIES: Bye, everyone.