

# Life Rebalanced Live 2026

## VESTIBULAR REHABILITATION THERAPY (VRT): NEUROPLASTICITY & EXERCISES THAT CONNECT IT TO EVERYDAY LIFE

**0:00:01.8 Abbie Ross:** Hello to you all and welcome to the fourth day of the Vestibular Disorders Association sixth annual Life Rebalanced Live virtual conference. I'm Dr. Abbie Ross. I'm a vestibular physical therapist, founder of Balancing Act Rehab and the Dizzy Reset, co-host of the podcast Talk Dizzy to Me and a proud board member of VeDA. Before we dive into day four, I'd like to again thank our sponsor who has made this event possible. The James D. And Linda B. Hainlin Discovery Fund and the University of Minnesota's Department of Otolaryngology have generously supported Life Rebalanced Live since its inception in 2020. A special shout out to Jim Hainlin, a fellow vestibular patient who inspired this event by holding his own vestibular conference in 2018 and in 2019. Jim cares so deeply about supporting people on their vestibular journey, and it was important to him to not only educate people about vestibular disorders, but also but provide a platform where people can connect. Now I'd like to introduce my co-host not only for this conference, but also on our Talk Dizzy to Me podcast, vestibular physical therapist Dr. Dani Tolman.

**0:01:11.5 Dani Tolman:** Thanks, Abbie, and hello everybody. Welcome to day four. We also want to say thank you so much to all who have contributed to this conference in some way, including VeDA's donors, staff and volunteers. With their contributions,

we're able to put the live version of this conference on at no cost to our attendees. If you wish to gain lifetime access to the presentations following the live event this week, we will have them available for purchase for \$65. Your financial support helps VeDA with its continued mission to spread vestibular awareness.

**0:01:46.6 Abbie Ross:** And before we get started with today's discussion, I'd like to direct you to the poll questions for this session. If you haven't already, please complete these now. Also, feel free to talk amongst yourselves in the chat. The chats have been popping off during these sessions. It's been fun to catch up on all the banter going back and forth later on. So please also put any questions you have for the speakers in the Q&A section, and we'll do our best to incorporate as many of those as we can.

**0:02:13.5 Dani Tolman:** And just a little reminder, although, you'll be hearing from healthcare professionals today, none of the information presented should be taken as medical advice. Please consult with your healthcare provider before making any changes to your treatment protocol.

**0:02:27.7 Abbie Ross:** Today we're going to talk about vestibular rehab, something near and dear to my heart, of course, which includes the principles of neuroplasticity, which is the brain's ability to adapt, reorganize, and learn through repeated, meaningful experiences. We'll also discuss why progress is rarely linear, why there's no silver bullet, although we wish there were, and how working with a qualified provider can help you tailor therapy to real life challenges and obtain sustainable progress.

**0:02:58.0 Dani Tolman:** It's my pleasure to introduce to you our guests, Dr. Kellianne Arnella and Dr. Mike Studer. Kellianne is an occupational therapist with nearly 15 years of experiencing and specializing in adult neurological rehabilitation. Mike is a physical therapist, an author, and an accomplished public speaker specializing in neuroplasticity. Welcome, Kellianne and Mike. It's fun to have you here. All right, so first, let's dive into what neuroplasticity is. Kellianne, how do you explain the concept of neuroplasticity to your patients in a way that helps them understand its role in rehab?

**0:03:35.1 Kellianne Arnella:** I think that's a really great question and without sounding like the typical healthcare provider, but it really does depend. I like to make a unique definition with the same base for each person. This way they understand it in a way that's meaningful and appropriate for them. Of course, I start with neuroplasticity is the brain's ability to change itself with specific prompts and practice. However, I often take it a step further and create a definition that's specific and meaningful to them, like using activities in a way that help drive change, that help... That have the best demand, to help encourage not only movement, but progress and return to their activities and tests.

**0:04:31.0 Abbie Ross:** I love it. Now, there are some key principles of neuroplasticity that apply to vestibular rehab. Mike, can you tell us what some of those principles are?

**0:04:40.8 Mike Studer:** Absolutely. And first, let me just say thank you, Kellianne, for your answer. Always starting with patient and person first. I want to just tag one quick thing onto that and say that I go back to a person's profession or things that they have

of interest, and then I create an analogy of neuroplasticity that fits with their knowledge base. One of the things that I like to do is say it's like an open field full of weeds with no connections. You start creating a pathway, you start tromping down some weeds, and before you know it, after you've traversed that pathway a number of times, you start to create an information superhighway where you can travel faster and on a wider range. So that's a little bit there. So again, now, Abbie, to your question very quickly. Kleim and Jones in 2008 talked to us about intensity matters, salience matters, repetitions matter. They have a great article for those of you that are interested in looking at that. It's widely available. We know and operate through those principles. But what we're now understanding is that there were a few things missing based on developments in neuroplasticity that include sleep matters, engagement with the activity matters, belief matters, which Dr. Whitney talked about on Monday, context matters, and dosage matters. And I'm writing a paper with Beth Fisher about adding to the principles of neuroplasticity now.

**0:06:14.3 Dani Tolman:** I love that you kind of tie in a little bit of what we had kind of just touched on with Kellianne, kind of bringing this into everyday activities in life. So in order to make those changes happen and to reinforce that, how do you connect those therapy exercises to real life activities? Do you have a couple of examples? And Mike, maybe I'll throw this over to you first. How do you connect some of those exercises to make that matter to the person that's doing them, rather than having them just look at something and move their head? There's a little bit more to that, right?

**0:06:47.0 Mike Studer:** Yes. Thank you for the question, Dani. It's very soft skill based motivational interviewing. Gives us a lot of opportunities. Because I learned this about you, I realize this is important. And so I've structured this activity to enable you to walk to the mailbox, get into and out of the bed with being symptom free. And so there's two parts very quickly to your question. I demonstrate that I'm building an individualized program, and then I create exercise snacks in an individual's life so that they can easily and regularly and frequently access the VRT, as I mentioned, walk to the mailbox, hallway head turns into and out of bed with repetitions loading and unloading dishes, and the list goes on.

**0:07:42.1 Dani Tolman:** I love that. Exercise snacks. If I can just give my patients a snack all day long, I feel like it's much more easier to convince them to do those exercises. We're not exercising, we're snacking. That's perfectly acceptable. Kellianne, do you have anything to add to that?

**0:07:55.9 Kellianne Arnella:** Yeah. So as occupational therapists we base... Our profession is based on meaningful activity. And one thing that I like to do is really start the first sentence of any evaluation for me is really like, what makes you you? What is this limiting you from being able to do? We use the Canadian Occupational Performance Measure as a way to really tap in and utilize those qualitative ingredients and make them more objective so that we can then not only develop activities and treatments that reflect those, just like what Mike just said, but use them as a way to also measure progress and bring the client back to where they're... What was meaningful to them,

what's difficult to them, and how each exercise, each intervention is really building them back to those tasks.

**0:08:55.3 Abbie Ross:** And, Kellianne, you have some really good examples of this on your social media, because sometimes we get stuck in a box of what vestibular rehab looks like. But you show us very well how you can incorporate rehab exercises into everyday life. Can you just share some of those specific examples? I have a cannoli in my mind right now.

**0:09:19.0 Kellianne Arnella:** We could talk about the cannoli. So I think all of us are this way. I mean, I know I am, and I hope I'm not alone, but I cannot turn off my OT brain. My neural brain doesn't turn off. I see things everywhere, and I'm like, this is it. Find the... I think I just work top down, bottom up all the time. But I was filling a cannoli the other day, and I was like, oh, here's the convergence. I'm working on... It reminds me of piercing a straw or bringing your fingers together, and you're scanning back and forth. You are integrating saccades, you're integrating eye teaming. But it's something that then you get the reward after. And oftentimes, it works both as a treatment, but also to get that buy in, get that belief that we're talking about that the clients see like, okay, it's not just that I'm getting dizzy or that this is triggering this, but I'm using this skill in every day.

**0:10:20.7 Kellianne Arnella:** I have also people come into my house and I'm making videos. I have letter charts all over the place, rainbow letter charts on my calendar. But really, it shows how often we actually use these skills and how under... I don't want to

say underappreciated they are, but they are sort of like... They sometimes we don't realize how much we use them for throughout the day, or the clients don't realize how much that dysfunction can impair them. Just looking at a calendar or filling a cannoli, for example. And I think when we kind of as clinicians can kind of bridge that gap and build those activities into their sessions and into their interventions, it's like magic.

**0:11:04.9 Abbie Ross:** And all of a sudden, you're not spending 20 minutes on these specific exercises. You're building the exercises into your everyday routine. You're improving your participation. You're actually maybe doing, dare I say, enjoying yourself when you're exercising. So, Mike, I've got a question for you next. Let's talk about lifestyle factors and how they can impact our ability to heal and be productive in our rehab. Maybe sleep, stress management.

**0:11:36.4 Mike Studer:** Yeah. If I thought about sleep first, I would tell you that sleep prepares us to be our healthiest selves. So it prepares us to have the greatest amount of alertness, to have the most well framed mindset, to reduce appropriately at times our cortisol levels, provides a capacity to encode information, learn new information, which ultimately is the underpinning of neuroplasticity. And finally, sleep allows us to consolidate and put together the meaningful events, movements and facts of our day. So sleep is huge. And that's why we're adding it to one of the principles of neuroplasticity. Also, let's please understand that when we are in a deprivation of sleep, that our sense of alarm, fear and rumination will all increase and it'll be harder for us to be able to function without those creating a barrier. When we look at stress management, we understand a couple of different things. One thing, according to a paper that I just

wrote in research that I did for that paper, there can be some intentional stress, especially in rehabilitation, that we can put ourselves through so that we become more tolerant of uncomfortable situations.

**0:13:05.2 Mike Studer:** People hear about thermal stressors, exercise stressors and uncomfortable situations. So we get a small dosage of feeling uncomfortable and we become more resilient. We all know that stress management is a high recommendation, but it appears as though there's a lot more science to be built to improving our tolerance, rather than just saying you got to get that stress out of your lives, which sometimes can feel impossible. The last thing is physical activity. And we know that... I could go on a one hour diatribe. I'll keep it to less than 12 seconds by just telling you that movement matters for blood flow, for dopamine, for positivity, for body health, and for capacity to truly do the things that you need to.

**0:13:53.1 Dani Tolman:** You bring up a lot of really great points. First of all, those lifestyle factors are laying a foundation for success going through rehab and allowing you to set yourself up for great neuroplasticity to take place. Now also, we're talking to a patient population where some of those things are really, really hard to rein in, especially if we're really stressed or anxious or fearful of our symptoms which is leading to maybe disrupted sleep and other issues like reduced physical activity. It's kind of hard to tease those apart sometimes. So fear and anxiety, they often accompany our vestibular symptoms. What's the difference between the two of them, both fear and anxiety? And how do they impact somebody's outcomes as they go through rehab? Kellianne, I'm going to throw that over to you first.

**0:14:45.6 Kellianne Arnella:** So I think we talk about this a lot. You see it in the literature a lot about the cycle that it can create. Where you have these symptoms and you might be fearful of participating in certain activities which can exacerbate your anxiety around a situation. I think that a lot of the clients that I see experience that. And when they unfortunately can get maybe vestibular therapy, that's not necessarily focusing on other components. The emotional components, the physiological components, the return to life when it's not as holistic of care, it can kind of create a worse situation or create... Make that cycle worse. They can't get out of that. My process is really kind of validating those concerns, making sure that we have a comprehensive team available to us and addressing one component at a time to start before we put it all back together.

**0:15:58.9 Dani Tolman:** Now, Kellianne, I'm going to have you pause for one second because we need our comprehensive team who's working behind the scenes to actually restart our stream because something isn't going through properly for our conference here. So all of you, those who are watching who are able to see us, hang tight. We will be right back. We're going to get this all reset.

**0:16:18.8 Abbie Ross:** Hi, everyone. So sorry about our technical difficulties. We love technology. We love technology. We love technology. But we're going to do a little recap for anyone who missed some of the conversation so far because there was some really good stuff from both Mike and Kellianne. So we're going to have them join us back. We'll start with Mike. Kellianne is joining us momentarily. And again, we're just

going to recap a little bit of the highlight that we've talked about so far before we continue on in the program. Perfect. Hi, Mike.

**0:16:52.1 Mike Studer:** Hey.

**0:16:53.0 Abbie Ross:** And there's Kellianne. Perfect. So, guys, let's back up a little bit because I think the feedback was that our audience wasn't quite getting the messaging. There was some buffering happening, technological issues. So let's go back to first what neuroplasticity is. And Kellianne, why don't you start us off with that.

**0:17:13.2 Kellianne Arnella:** So I am... Sorry. I'm just re turning everything off after re-connecting. So neuroplasticity, the brain's ability to change itself with a lot of very specific ingredients. That is my in a box definition. But often, not often. Every single time I meet a new person, I recreate a definition that is very specific to them. A way that helps them understand the specific ingredient that they might be using within that session, but also that they understand the why and how of their overall program and why we do what we do and why they should do what they do in order to drive the biggest change.

**0:17:59.1 Abbie Ross:** And Mike, did you have anything to add to that?

**0:18:01.7 Mike Studer:** Very quickly, think of a story. You're walking on your way home from school. It's an open, weed filled pathway. When you make that first pathway

through there, you're connecting neurons. The more frequently you traverse that pathway, the faster you can travel. That's neuroplasticity.

**0:18:19.3 Dani Tolman:** Man, we talked about some things that set good foundation for neuroplasticity to take place. One of those things being some lifestyle factors that help improve that. Mike, could you kind of list those off for us and talk a little bit about how those lifestyle factors might give us a better foundation to build neuroplasticity?

**0:18:38.8 Mike Studer:** I can. Thank you, Dani. So sleep actually prepares us to be most attentive, to be of a positive mindset, to have cortisol levels low and dopamine ready to be primed high, and gives us a growth mindset so that we can see possibilities. Additionally, sleep gives us the opportunity to consolidate important memories, facts, and experiences throughout the day. Stress management helps to be able to regulate our symptoms so that they're not magnified. And in fact, physical activity helps body's fitness capacities, blood flow to the brain, dopamine viability as a fertilizer, and neuromodulator, if you will. So those three: sleep, stress management, and physical activity are among the top lifestyle behaviors.

**0:19:32.0 Abbie Ross:** And then, Kellianne, when we consider how to connect our rehab exercises to someone's life challenges, we're talking about a principle called salience, something that means something to someone. Can you also identify some of the other key principles that we consider when we're creating therapeutic programs?

**0:19:53.1 Kellianne Arnella:** Absolutely. So I think what just jumped in my head as we were talking about salience is generalization. And being able to take the components that you're working on, the progress that you've made in the clinic, the progress that you work on in your home programs, and actually apply them to the things that you do every day. Before Mike was talking a little bit about context. And that is something that is really, really beneficial, but can be a challenge in taking what we do in the clinic, not only physically, the exercises, but also in the application of the context to the activity. And so I really love to do that. I mean, as an OT, I feel like it's in our DNA. But it is really, really necessary for neuroplasticity to maximize the benefit of what drives change.

**0:20:50.0 Dani Tolman:** One thing that we had touched on a little bit ago earlier on is this idea of snacking on some of these exercises and kind of spreading them out throughout the day. And I think that I love the visualization of snacking on these exercises. It's not something you have to take on this big lump. It's not like you have to set a big chunk of time out of your day to do these exercises. You literally just snack. You work them in. You kind of make them part of your routine. An individualized approach, which I think should be very much stressed for everybody. Not only should be individualized based on what you're experiencing and whatever dysfunction that you're experiencing from your diagnosis, but also to have that buy in, to feel like you're doing something that's meaningful to you and your goals and creating that personalized approach to care. Mike, do you have something to add to that?

**0:21:43.0 Mike Studer:** Sure. Exercise snacks gives us the opportunity to make it enjoyable, make it salient, as Kellianne mentioned, but also make it accessible. Frequency is one of the keys to vestibular rehabilitation therapy working. You get all of those, plus you get a transition into real life. And the final thing is you save time, because it's known as habit stacking. I'm working on my balance as I'm brushing my teeth, I'm getting into and out of bed and habituating my capacity to tolerate that plane of motion. The list goes on and on.

**0:22:18.8 Abbie Ross:** So essentially, we're snacking and we're stacking. I think we might need to make a T shirt. I like that. Now, I also want to address fear and anxiety, and maybe if there's a difference between those and how they can impact someone's ability to show up in this way. Because we know that if movement creates symptoms, then fear and anxiety may exist around that very movement. Mike, can you start that one?

**0:22:45.8 Mike Studer:** Certainly. You know what? Kellianne did a great job of talking about top down and bottom up, and we need to be very respectful, and I want to give her the stage to breathe into that, literally and figuratively, a little bit more after I'm done. First, let's answer the question. Anxiety is the unproductive rumination on a thought or an action that is very unlikely to occur. It's unrealistic, it's likely going to be responsive to medication. Fear is the rumination that maybe isn't quite as dysfunctional and maybe even more likely to occur based on my recent lived experiences. Less responsive to medication, more responsive to exposure based therapy. Surprising oneself that they were able to overcome something because it changes the predictive

brains likelihood of thinking that's going to negatively happen to me because of my recent successes. Kellianne.

**0:23:50.0 Kellianne Arnella:** So I really like to think of this to, neuroplasticity can work both for you and against you. And this is one of those areas that it is, you have to think of it from both ways. If you are fearful of a movement, you're going to avoid the movement. Your brain's going to kind of follow that path through the meadow instead of the one that's going to address and adapt to the challenges. And so we have to think of things from the top down, the bottom up and sort of like really create not only just this backwards linear model, but it's really comprehensive and really taking into account not only the physiological components and things that are occurring that are creating those symptoms, but also the emotional and the psychological components that are impacting how people are able to participate and perform their exercises. Which is one reason... This is like the explanation I use when I'm talking with clients about creating those snacks. Not doing everything all at once where they're going to get dizzy and be done for the rest of the day. But they can do a small component throughout the day that's going to drive that change in multiple ways under multiple conditions and hopefully reduce that response of fear and that that anxiety surrounding situations.

**0:25:09.3 Dani Tolman:** I think you make a good point in the way that what we do seems very counterproductive in theory. Somebody said, well, if it makes me feel bad, why would I do it? And if it makes me feel scared and it's all like, why would I do that? And this is why we have job security, because we need people like us to help work with

our patients, to encourage them how to do them in a therapeutic approach, in a way that's individual to them and what they need without overdoing it. So there's that first thought, well, I shouldn't move because it makes me feel awful. And that's a misconception. What are some other common misconceptions that patients might have about rehab. Mike, let's start over to you first.

**0:25:47.5 Mike Studer:** Well, I think the most common misconception is that vestibular rehabilitation is straightforward, and it's the same exercises for every person that has the same this condition. That is the worst misconception we can possibly have. Kellianne has been very eloquent today, as of both of you, noting that person first has to be not only a moniker, but it actually has to be a lived experience. The other thing is that vestibular rehabilitation has to be structured and within a setting with intent, because we also understand that just like Kellianne was talking about and Abbie mentioned this as well, vestibular rehabilitation and opportunities are everywhere. So you see that walking out into, let's say, a forest gives you different visual opportunities that can be rehabilitative in nature. And so I really think that the misconception is that I have to do it seated. I have to do them all at once. And it's that the same that everybody else gets. Nothing could be farther from the truth than those three misconceptions.

**0:26:54.6 Abbie Ross:** Yeah, I couldn't agree more. And it leads me to a couple questions that we got from the audience that I think I can tie together here. How do you know when you're continuing to make progress? The slow progress, let's call it, versus

plateauing? And then the second part is, is there an age limit to neuroplasticity being able to take place? Kellianne?

**0:27:18.8 Kellianne Arnella:** All right, two questions there. So I always, as... I think there's a balance that we have to make between a person's lived experience and then being able to appreciate their progress. But it also puts the value on us as clinicians and the way we use our objective measures to see how they are actually improving. I often tell people you're with yourself 24 hours a day. It is difficult to see the change from day one to day two. But when you start to look a few weeks down the road and go back and kind of appreciate where for us, I value my documentation. And I look back and I say look, this is where we were. We combine the subjective information with the objective information to say you were here and now you're here. And oftentimes we have an issue where sometimes people say, but I don't feel better, and I say, look, there's value in the objective components that we looked at. Help yourself, come up with a... Not a mantra, but validate it for yourself. This has improved. I should be feeling better in a way that helps them appreciate their progress. Regarding being older with neuroplasticity. Now, neuroplasticity doesn't expire. There are components that physiologically change how quickly neuroplasticity can occur. And Mike, you can fill in on this one. But there are certain things that change as we get older. Our vision changes. Our... Just we age. Some things are different. But I believe that neuroplasticity does not expire and we can continue to make changes even as we age.

**0:29:21.3 Mike Studer:** I'll have to support you 100% on that and I will support your belief with facts. We know that people can have images of their brain seven years after

stroke, then go through aggressive rehabilitation, and we have reimagining of their brain and their brain has changed. This has occurred throughout many different diagnoses. Neuroplasticity in vestibular rehabilitation is the underpinning. It is the foundation for how we even learned about neuroplasticity. The age related factors are actually just blood flow, which can be mitigated through movement and the expression of a brain fertilizer known as brain derived neurotrophic factor. There are no other factors that are age based and even those two are mitigatable, controllable through lifestyle.

**0:30:18.7 Dani Tolman:** I love, Kellianne, that you mentioned celebrating... Kind of celebrating those small wins. So although the patient may not be able to see a stark difference, maybe in a couple of visits, we might be able to say, but you weren't able to do this the first time without having to stop within five seconds or now have you noticed that you've been able to go do this, that and the other thing where we couldn't even think about doing that before, which might seem really small and slight, but something, again, it's progress. It's forward movement. Doesn't matter if it's within the first week or it's a couple of years down the road. Which kind of leads me into another question about, is it common for patients to have to go through rehab or vestibular therapy or anything along those lines? Maybe more than once? Can they get different results? Can they recognize different benefits from different episodes of care? So, Kellianne, I'm going to kick that over to you first. What do you think?

**0:31:10.7 Kellianne Arnella:** So I think this actually is a good... I might like kind of re-wind a little bit where we were saying the misconceptions of rehab, especially with VRT. So I often have clients come in and they're like, well, the doctor told me that I

couldn't get better. That this was it. That I would have to just take this medication to feel better. And I think that that kind of plays into this a little bit, where not only do we have people that see one person who specializes in... Specializing in one area before they get to another person, which, yes, then they would have to have multiple episodes of care, but it's also sometimes finding the right clinician that is effectively delivering neuroplasticity as a principle, but in their exercises and activities that will make it specific to them and allow them to really have that change.

**0:32:13.5 Kellianne Arnella:** But I think that you might have to go through a few rounds. There might be... I'm often explaining that we can get you to a certain point. It's not a plateau, but it is a natural kind of like, we are here, let's work, let's reinforce the growth and the change that we have created here. And then we go on to not be a patient for a little bit. And then they might come back and say, okay, I've... We're able to do this. We're going to continue from here. I think it is a healthy component of a therapist and patient relationship to have that where they're not dependent on us so much. And that might look like slower progress, it might look like repeating a program, but really it's developing that autonomy and that accountability on the patient's end to be able to work independently and then come back when they do need to kind of upgrade their exercises and activities from there.

**0:33:14.8 Abbie Ross:** And because the level of intensity or the dosage matters, I think as your level of participation improves, your goals change. And then maybe you need a little tune up, maybe the programming has to be more intensified, the dosage has to go up in order for you to continue the neuroplastic changes. Mike, generally

speaking, what can one expect in a vestibular rehab experience? And maybe even touch on how do they know that their provider is a good provider? What should they look for?

**0:33:46.6 Mike Studer:** Oh, that's excellent question. So first and foremost, a good provision or care needs to be started with listening. Is this provider giving you an opportunity to tell your story, your personal lived experience, and then do they seem to integrate, not just act like they're hearing. Are they listening? Are they integrating what you've told them further into that session and with the provision of the home exercise program? So there's one, starts with listening. Number two, expect just like Kellianne said, they're doing some measurement. We can only manage what we measure. So they need to be doing some conducting some objective measures that you could have found on the internet that they're likely to do. Okay, balance tests and otherwise. The third thing is, when they come to make a prescription, are they including you? So are you part of the team? So there's three things. Are they listening, are they testing you, and are they including you?

**0:34:54.4 Dani Tolman:** I feel like listening is a huge, huge part of all of that. So many people say they feel so much better just having somebody validate what they're feeling, what they're going through, but not only that, also listening to what their goals are and incorporating these exercises into everyday little snacks that they can work on. I think that's really, really important. So looking for those qualities in healthcare professional, when going to seek out care is great. And don't hesitate to interview somebody.

You can call and ask them, have you heard of these terms? Do you work with these diagnoses? What kind of equipment do you have to work with patients with dizziness or balance? I feel like that can give you a lot of insight as to who you're working with. Kellianne, do you have anything to add to that in terms of maybe on the occupational side of things?

**0:35:42.1 Kellianne Arnella:** Yeah, I think also a lot of this is a team approach. And I think that knowing that when a clinician refers you externally to themselves, it's not a failure on them, but it's a more comprehensive picture. So this is really easy to do in these large medical centers where we're all kind of integrated in one space. So at Rust, we were able to refer from a neuro ophthalmologist to a neuro-otolaryngologist to a physical therapist, an OT, a neuropsychologist. When you're in the community, it's really sometimes a little bit challenging to do that. But I think, there is so much value in having the the insight of the different disciplines and how if something can't be addressed by one, it can be kind of not modified, but more just by my skill set versus somebody else's skill set. And I think this is a call to any clinicians who are listening, but it's okay to also create those networks outside of the larger systems, create those referral webs that you can integrate a more comprehensive level of care or type of care for people with these conditions.

**0:37:02.7 Abbie Ross:** I couldn't agree more. That multidisciplinary approach and also social media has been so powerful in this regard. Just connecting different clinicians and then connecting patients to clinicians. Connecting patients to patients. Such a cool experience in a lot of ways that social media has provided for this specialty type

of care. Question for you, Mike. Is vestibular rehab appropriate for absolutely everyone with dizziness? Why or why not? Can you explain that?

**0:37:33.0 Mike Studer:** I would actually say yes, because in the hands of an expert that knows vestibular rehabilitation, one can easily find out if their dizziness is in fact vestibular in origin. And so it's a great place to go to understand. Oh, I've ruled this out. It's actually orthostatic hypotension, a drop in blood pressure when I stand up. But it's through the hands, eyes, and brain of an expert that they know whether they can truly help you or not. But in fact, just having them give that full and objective scientifically based assessment can be powerful, even if they're not going to treat you.

**0:38:20.6 Dani Tolman:** I think you're absolutely... We have to rely on our healthcare professionals to know what's appropriate and when it's appropriate and kind of lean into that. Sometimes we need a lot of feedback from our patients as well. They might give something a go. They might seem like they're responding well to that, but it turns out they come back in the day later. Maybe it was too much with those delayed effects, but again, having... With the right people to work with, they're going to know what's appropriate, what to refer to and how to progress that to really make you successful. It's going back to finding that right person. Kellianne, do you have anything to add to that?

**0:38:56.7 Kellianne Arnella:** No, I think that you really... I think you really nailed that one. I think that there's, again, it's just... There's value in knowing that stuff and knowing when... Just really that personalized approach, too. I would kind of use this as a

way for anyone who's a... Someone who's experiencing symptoms on this, again, I don't know Abbie or Dani, who said it. You can interview your clinicians. You can interview who you're working with and then ask them if you aren't feeling better, what else can I do? Where else... Is there another type of clinician that might be able to help me through the barriers that I'm experiencing? If this is not... If this is where this is? I've had people that have come that were told, well, I can get you to this point. And that's it. And didn't really give them a referral outside of that. And I think that it's knowing sort of our limitations as clinicians and being able to rely on our scientific evaluation, but being able to also know when we can refer back or refer out and go from there.

**0:40:15.8 Dani Tolman:** I think it kind of comes down to, again, listening to that patient and having that patient be able to communicate what's going on with them. We might be progressing the patient along thinking that things are going great, but internally, maybe things are continuing to compound or make them feel more symptomatic, where that's where they kind of reach this point of like, I don't think anything's working, nothing's going on. And I think that there's this idea that treatment or improvement is always linear. A lot of people think that once you start, it's just going to get better and better and better and that we don't have these natural normal fluctuations. So while a lot of times vestibular therapy is not a no pain, no gain situation, there's times where we have to expect that symptoms might increase and understanding what that level looks like. So, Mike, could you maybe talk about that a little bit of what that looks like in terms of working in this therapeutic range without pushing it too hard? Like, how do we know what's too hard and how do we gauge that maybe from the patient's perspective? How do you coach your patients on learning those boundaries?

**0:41:18.9 Mike Studer:** Dani, thanks for the question and the way you framed it so eloquently. We would never want to use guilt or fear mongering. And if you're experiencing that as a patient, you may want to at least verbalize that back to the therapist. And if that's not received, you may need to look elsewhere. We need to understand now, as vestibular rehabilitation and healthcare in general has evolved, that the patient is always the expert. And if this is a day that I can or cannot tolerate this, we need to not lean into them or lean on them. We need to also understand that consistency beats intensity. And a little bit every day is very healthy within the boundaries of what you can tolerate. We also have to understand that there's health to be procured in what's known as gamification. And you've had a streak of doing your vestibular rehabilitation exercises for seven days in a row. Let me give you a mulligan today, which, if you're not in golf or other forms of sport, gives you an opportunity to take a pass today and keep your streak uninterrupted. So we do know that there are days and times that you don't feel up to it. We give people the opportunity to continue the streak, know that even at a low intensity, it's still very healthy to try to consistently deliver a dosage. But again, patient is the expert, and none of this would have worked if we didn't start off our relationship with the patient to know that vestibular rehabilitation is not linear, it's curvilinear. We have to start with that so it doesn't feel like a failure when we have a day that is not as successful.

**0:43:06.9 Abbie Ross:** I couldn't agree more. And I also like to tell people you're actually learning so much, even on those days that don't feel as successful to you. These are just as important as those days where you feel like you're on top of the world. In

fact, I think they might even be more beneficial to your healing with all the information you're getting from that kind of response from your body. Kellianne, we have a question from the chat that I want to address. Does it make a difference where in the timeline of the onset of your symptoms you start something like vestibular rehab?

**0:43:44.1 Kellianne Arnella:** I think that's a great question, and I'm going to answer it in the frame of neuroplasticity. So while, yes, it might be really uncomfortable to be living with these symptoms for a very long time, based on the science that Mike so eloquently explained for us in terms of how neuroplasticity is not... It doesn't expire. We can tap into those same principles in order to drive change well after you've had the symptoms for quite some time. Just like I said earlier that neuroplastic can work both for us and against us. There might be different challenges or different barriers to creating change, but it doesn't mean that you can't make progress even after having symptoms for a year or two or hopefully not that long. But I do know that that does occur.

**0:44:41.5 Dani Tolman:** Now, questions about barriers to progress. This is also from the chat. We're getting some really good questions today, Abbie. Can medications affect or impact neuroplasticity? And I'll leave that up to either one of you guys, if anybody has an opinion on that.

**0:44:58.3 Kellianne Arnella:** I saw this pop up in the chat, and I was... I can't talk about the pharmacological parts of this and the physiological responses. Mike might

have a better answer there. I might do the research on that because now I'm interested. But especially with anti anxiety medications or beta blockers, something that's going to calm your nervous system down as a way to help you be more mindful and more present in your sessions and to be able to have more control over your response, your psychological, emotional, your physical response to these exercises and the symptoms. I think that that is a reasonable adjunct therapy to working on your vestibular rehab there. This is a bigger conversation, I think when we start to treat these with medications but avoid the active ingredients. However, we need both sometimes. And I think that there's an emphasis on, yes, that can help you be more mindful and participate more, do more exercise, snacks and have more drive, more change. But we really do have to emphasize that active part as well.

**0:46:14.6 Dani Tolman:** I couldn't agree more. I feel like there are some times where all of the lifestyle modifications and all of the attempts to do everything to kind of calm down, like a really just chaotic situation aren't enough. And that's where medications do sometimes have a really great role for facilitating that care and that improvement. Mike, did you have something to add?

**0:46:35.8 Mike Studer:** It's a massive topic. I'll keep it short. Medications are a tool and we can't rely just on that tool all the time. Kellianne and I, neither one of us can prescribe it. If we think about all the options that your brain can use to influence your symptoms. Cognitive behavioral therapy, growth mindset, successful experiences, near misses, gamification. Then we think about all the things that your body could do to influence your symptoms. Exercise, breathing, meditation, mindfulness, awe. And some

of those cross both directions. Music, fun, play, sleep, rest, nap. Medication is just another tool that can help the body influence the brain's expression of the symptoms. We don't want to become reliant on it and we don't want to use medications to mask it, then we won't have the factual response of how the individual is truly benefiting.

**0:47:40.1 Abbie Ross:** And what you didn't hear either of them say is that medication is the silver bullet because it is not. You have to do the work too. Although it can help, as they both stated. I want to talk about specific participation type things in life like driving, going shopping. Can we break down some tips for some common environments or activities that tend to cause symptoms for people? And maybe we start with driving. Kellianne.

**0:48:13.1 Kellianne Arnella:** So driving. I was just having this conversation actually not with a patient at all. I think I was with my kids and I was explaining, they were wondering why they can't drive. I'm like, you don't understand how much driving actually entails. And a few years ago I did have my CBRS, which is your Certified Driving Rehab Specialist certification. But that also really focuses on the physical components of like manipulating a car. But when you think of it from a vestibular perspective or a visual perspective, there is so much going on that we have to attend to and respond to. And there is so much. So there is our gaze stabilization, what we're looking at on the road, how we are converging and diverging in order to see something up close on the dashboard, look at the wheel, look at what's in front of us, adjust to this mirror, to that mirror, to the mirror on the other side. We're auditorily responding to whoever's in the car, the cars around us, if there's an ambulance in range. And then you also have this... A

lot of this visual motion that's coming at you that really kind of can set off your vestibular system.

**0:49:37.3 Kellianne Arnella:** And when you are in sort of... When you're having these visual or vestibular symptoms that can impact your ability to drive your car. And so I think that some people... Your body also is very... Our brains are incredible. They go into fight or flight. They can recruit every possible function to help us through a situation like driving when we are having symptoms. But then you might have that crash afterwards where you have used so much cognitive, visual, vestibular energy to do that one task. And then everything else is really challenging. And I've had people kind of report both where they have a very difficult time driving because of their symptoms and whatever is causing their vestibular crisis versus someone who's able to drive, but then they can do nothing else. And I think it's again going back to this person centered intervention and listening to the specific story that is the lived experience of that person and where they're having the challenges and how something like driving... As clinicians, we can explain that. We should explain. It's not something that should be taken for granted. It's actually not that easy to drive. We use a lot of systems and we've we've learned over time how to be really good at it. And then when a system is challenged, it can really fall apart.

**0:51:03.6 Dani Tolman:** I think that's a great explanation of just really how complex of a task it is and how draining it can be for somebody who's recovering from vestibular dysfunction or other symptoms. Mike, do you have any go to tips or things that you

find yourself working on frequently with your patients when it comes to getting them back to driving?

**0:51:21.6 Mike Studer:** 100%, I'll keep it very short. The brain is predictive, and we're just starting to become aware of this. Neurons that fire together, wire together. I'm going to get in the car. I've experienced dizziness in the car. Doesn't matter, passenger or driver. And so when we understand the predictive brain thinks you're going to have nausea, dizziness, or vertigo in any situation, driving or otherwise, the brain is likely in a confirmation bias, believing and looking for that symptom. And so what we want to do is give the brain small bits of opportunities that are unexpectedly successful. And we call this reward prediction error. I predicted I was going to have nausea, but we did a short drive in a very predictable pathway and I didn't experience nausea. Brain has to change its predictive model. So, Dani, my question... My answer back to you is we give people real life situations that had been triggering small dosages that are tolerable and unexpectedly successful.

**0:52:31.7 Abbie Ross:** And I think that extrapolates to any activity like shopping, like going out with your girlfriends on a Friday night, whatever it is, a family gathering on a Sunday evening. Thank you both for those answers. Mike, I believe we talked about this in our first segment, but I want to touch on this again based on a question we got from the audience. What does the latest research show about neuroplasticity? And maybe you can talk about your upcoming paper. And then I want to add to this. There was a question on using visualization or perhaps maybe guided imagery. And we talk a little

bit about belief and how that can support or inhibit neuroplastic changes. So can you handle that question?

**0:53:15.2 Mike Studer:** I can. As a matter of fact. And I'll tell you, the first thing I'll start with is the last part of your question. Belief matters is one of the new eight principles that we're adding to the Kleim and Jones paper. Belief includes autonomy. What I believe is actually going to be included. That means you get some autonomy, you get some agency in the therapist to patient team. Choice is inherent in belief. Well, I don't really like to be on the treadmill. Sorry. This is our best way to do vestibular rehabilitation. You need to do it on a treadmill. But why can't we do this outdoors? Choice matters because it actually creates that predictive brain. This isn't going to work for me. This is my favorite way of doing this. And it will actually elicit a dopaminergic pathway that's known as the placebo effect. When dopamine is present and I believe this is going to work. It increases the effectiveness of any pill, intervention procedure, therapist, or hospital system. I believe in it that increases neuroplasticity because of this predictive brain nature. Now, without going on too much longer of a diatribe, I think that starts to address both the first and second point of your question. Because that patient actually has elevated capacities for neuroplasticity because you gave them the opportunity to be an agent in the team.

**0:54:52.1 Dani Tolman:** Love that. I mean, that team approach is a big thing. And all aspects of all of this. I kind of... I'm looking at some of these good questions that are popping up in the chat. We've got a lot of that are kind of specific to vestibular rehab, being helpful with different diagnoses like TBI and Canvas. I think that we can kind of

say if we have symptoms that are related to vestibular dysfunction with those diagnoses, there's likely a role for that to help out. Somebody had also asked about the use of cognitive behavioral therapy, or CBT, and is there a role for CBT in the scope of OT practice? So, Kellianne, do you see the use of CBT when working with patients?

**0:55:39.4 Kellianne Arnella:** Sure. So I don't... I can't say that I... I'm not technically certified in CBT, but the principles of CBT, very similar to what Mike was just saying, and applying it to how one anticipates the response that they're expecting versus what they actually experience. And so we use those principles in the reverse sense as well. So how can I take you doing, let's say, like heart charts or letter charts, for example, and then how do you think that this applies to shopping in the grocery store, scanning the aisles, looking for different items, and then kind of recreating... What I do is really talk to them about it, include them in the decision making, include them in what they expect the experience to be like. And then I also take the intervention and apply it in that way. So now we take the letter charts and we're putting them on the background of a grocery video on the computer screen before I actually take them into a grocery store, if I am lucky enough to do such a thing. So I do think that there is value in the concept and the principles of CBT to be applied in vestibular rehabilitation, but not without the physical components also. So I think really actually bringing them through physically, those active ingredients, bringing them through that way. That was the only question that you asked, right? [laughter]

**0:57:13.8 Abbie Ross:** I tend to be doing the double whammies over here, but I have one question for both of you. Take your time answering it because I feel like this will be

what people walk away with. For anyone who feels stuck right now, speak to them directly. What message do you want them to hear? Mike.

**0:57:33.2 Mike Studer:** For people that feel stuck and for individuals that are taking a break in therapy, there are always body systems that you can improve that will make your brain more responsive and body more responsive for a next round of change, next round of therapy or otherwise. So if I feel stuck and I'm not progressing, I could work on my body strength, my flexibility, my cardiac, my cardiovascular fitness. And indirectly, you'll be actually helping your brain be more ready for a next round new exercise or may make a breakthrough with the very exercises that are currently feeling a blockade or barrier.

**0:58:27.8 Abbie Ross:** Your turn, Kellianne.

**0:58:30.7 Kellianne Arnella:** I really love that answer, but I mean, I agree with what Mike said. I'll add a little bit to it that if you're feeling stuck, if you're feeling blocked, it's the idea what I would want you to take away. It's the idea of finding that other path way. So if there is a bridge out and where you're trying to go, your brain might take longer to reroute itself and figure out how to get there. But with guided help and with specific ingredients in your task and finding the right group of people around you, we can navigate that new route and get you where you are trying to go. I think thinking of our brains as a GPS, sometimes it might be silly, but it is a way to really help that buy in and help you understand that this is how it works and this is what we're navigating.

And it is possible. There's research that supports it and there is... We are seeing the brain change and it is possible. And that's all.

**0:59:35.9 Dani Tolman:** I love it. Abbie, I don't know about you, but I am super excited to go dive back into the clinic this afternoon. Feeling very refreshed and revitalized and excited to go work with everybody and get them moving. Thank you so much to Kellianne and Mike for joining us today. If you'd like to learn more about them, make sure you check out their information on our app. And in today's agenda. And at this point, we'll say goodbye to our guests and say hello to our next set of moderators that are going to carry us over into the patient panel. Hey, Cynthia. Hey, Heather.

**1:00:10.6 Cynthia Ryan:** Hey, Abbie. Hey, Dani. Wow, that was quite the morning.

**1:00:16.7 Dani Tolman:** Nothing like to keep everybody on their toes. Very excited about that.

**1:00:21.1 Cynthia Ryan:** I wanna just shout out to everybody who hung with us through our technical issues, which are unfortunately they happen. And thank you all for starting us out with a great, great topic. People in the comments were saying this is the most important topic for them and I have to agree. So thanks for leading us through a great conversation.

**1:00:45.9 Dani Tolman:** Well, we look forward to seeing you guys tomorrow. Have a great meal.

**1:00:50.7 Cynthia Ryan:** All right. Bye-bye.

**1:00:52.0 Dani Tolman:** Bye.

**1:00:53.3 Heather Davies:** Wow, Cynthia, after listening, I realized that, like Abbie said, I think it's time that I have a tune up for some of the areas I'm still struggling with. So that's interesting. What a great topic.

**1:01:04.4 Cynthia Ryan:** It's always good to reconnect and I loved the message that they both had at the end. There's always hope, there's always a pathway. And something that I'm constantly reminded of is that it's so important to find the right provider. Not every physical therapist is a vestibular specialist. So finding the right provider, both in terms of qualifications and in terms of fit. Someone that you feel like you can communicate with and who's listening to you. So let's bring on our patient panelists and we'll get into a conversation about their experiences with vestibular rehab. Hi, Sarah. Hi, Jeannette.

**1:01:47.7 Sarah Page:** Hi.

**1:01:48.7 Jeannette Tousignant:** Hello, everybody.

**1:01:50.0 Cynthia Ryan:** So today we're welcoming our patient panelists, Jeannette Tousignant and Sarah Page.

**1:01:56.5 Sarah Page:** Hello.

**1:01:57.9 Cynthia Ryan:** And we're going to talk about their experiences with VRT, which I know are going to mirror what so many of you are experiencing. So, Heather, do you want to get us started?

**1:02:07.2 Heather Davies:** Sure, sure, sure. Jeannette, welcome. First off, and how did you...

**1:02:12.2 Jeannette Tousignant:** Thank you.

**1:02:12.3 Heather Davies:** You're welcome. How did you first learn about VRT and when. What were your expectations going in, if you had any?

**1:02:21.3 Jeannette Tousignant:** Well, very interestingly, I first learned about VRT as a physical therapist. So that was my job for 35 years, until about 30 years into it when I learned I had a vestibular disorder. So part of my practice was working with persons who have neurological conditions, and I ended up specializing in working with people with concussion and vestibular disorders well before I even realized I was one of them. So I knew of VRT most intricately as a clinician to start out. And then, gosh, the surprise when I realized that my vestibular reflexes were all wonky. And I fortunately found out fairly early on that I had a vestibular disorder called superior canal dehiscence. So my introduction to VRT was first professionally, and then when I became a

patient, it was very much shock. And fortunately, gosh, I think just knowing what I knew from the educational background made it a little easier for me to understand what was going on and kept my panic levels low. So I'm grateful for that. There was very little panic for me just because of my knowledge base, but some shock to realize that was me, if that makes sense.

**1:03:47.4 Heather Davies:** I can only imagine.

**1:03:49.1 Cynthia Ryan:** Yeah, yeah, yeah.

**1:03:50.2 Heather Davies:** Absolutely. And what about you, Sarah? How did you first learn about VRT, vestibular rehab and what were your expectations going in?

**1:03:59.0 Sarah Page:** I first learned about it through my providers, through UNC and the local... My general practitioner, I guess you could say, and the neurologist that I started to see first. So that was about two and a half years ago. And the first thing that they kind of had me do was just regular vestibular therapy in town locally. And I did that for a little while, but I was unable to get myself there by myself. I always needed someone to drive me, which made it very difficult. My husband works and my son was still in high school at the time, so my parents kind of helped me with that. But it was... The management part of it was very difficult and I was so dizzy after it. It was just exasperated, all of those symptoms. So they were kind enough to create a plan for me that I was able to do at home. They had an app that they used and that was helpful

for a while and then kind of did some more research and started seeing other doctors and they kind of pushed me into some other types of therapies.

**1:05:20.6 Cynthia Ryan:** That's great. I love that they adapted it for you right away. First of all, I wanted to say, Janette, people are calling out your flamingo in your background. So, [inaudible] Fiona

**1:05:34.3 Jeannette Tousignant:** Fiona has present. Yeah, this is my favorite little Fiona. She's a wind up toy and I take her on vacation with me and I let her walk around wherever I'm at and I take pictures and... Yeah.

**1:05:45.0 Cynthia Ryan:** I love it. I love it.

**1:05:47.9 Jeannette Tousignant:** Call me a vestibular nerd

**1:05:52.4 Cynthia Ryan:** Or as Dani and Abbie say, vestibulaholics.

**1:05:56.0 Jeannette Tousignant:** Very much so, yes.

**1:05:57.5 Cynthia Ryan:** Did either of you see multiple VRT care providers? Did you have to try one that didn't work and, and try another one.

**1:06:12.5 Jeannette Tousignant:** Not so much for me as far as trying different VRT professionals. I think the frustration for me really was that I didn't get diagnosed until

2021, and prior to that I was seeking physical therapy, massage therapy, some chiropractic care to deal with my chronic headache and neck pain. So I really was very largely unaware that I had slow VOR reflexes. And I really think that for those of you who maybe are unaware of what superior canal dehiscence is, essentially there's an anatomical anomaly in the floor of the cranial vault in your skull, and there are small holes in the bony surface where your brain rests. And when those holes are present, or even if that bone is just anatomically too thin, it can impact how your balance organs function. It can essentially create what's called a third mobile window. And that's fancy terms for the balance organ isn't going to work like it's supposed to when that's the case. So I think for my entire life, it's very likely. I think back to as a child and just being very anxious and nervous on carnival rides and not tolerating going through a tunnel.

**1:07:34.4 Jeannette Tousignant:** If you're driving through a tunnel and there's little lights that flickers funny. Oh, I just would panic and just close my eyes and shudder. So even as a child, I was having trouble with vestibular reflexes. And then as I aged and had a couple of concussions, my brain didn't really do so well with that inefficient function of my vestibular system. And that's when I started to recognize things. Like I was practicing karate at the time, and during karate class, I would get very startle reaction and disoriented as to where I was in space. And that was very odd and anxiety provoking. And gosh, I couldn't stand being on a computer or a phone for very long. I get such neck pain. So I was having symptoms that I just kept equating to age or I needed new glasses or neck pain. My family has history of migraine, so I just thought I was a migraine ear. And really none of that was true because once I got diagnosed and started

treating it, a lot of those symptoms started to fade. So multiple VRT, no, multiple practitioners to try to address all the symptoms associated with my disorder, yes.

**1:08:50.9 Jeannette Tousignant:** And the relief. I remember being in the doctor's office when they said, well, Jeannette, your scans and your testing shows you've got bilateral SCD. And I went, oh, yay. Because I had a diagnosis. And then afterwards I'm like, oh, well this is huge. So no, I haven't done a lot of different VRT clinicians. I understand it. I do a little bit of on my own. But I have a wonderful practitioner in my hometown who I used to work with alongside years ago and he's my resource now for how to address my vision, my VRT needs overall directly. And I feel very fortunate, very fortunate that I haven't had a lot of medical gaslighting or had to seek multiple different practitioners. But I agree with everything our first panel said today. As a client, as a patient, it is essential for you to have that buy in and that therapeutic alliance with your practitioner. If they are listening, if they're willing to really put weight on your symptom patterns, if they're willing to look under that rock and say, you know what, this doesn't quite make sense to me, but let me check. That's huge. As opposed to, it'll get better with time. I mean, that kind of placating is just really hard on the journey. So I have to say I've been very fortunate that I haven't run into too much of that myself, to be honest.

**1:10:16.4 Cynthia Ryan:** I love your perspective as both a patient and a health care professional. It's a really unique perspective and I also find it just really interesting. And I think that there are a lot of people out there who like you have had symptoms throughout their life, but always said, well, it's just this thing, it's just not that never

thought or had a healthcare professional help them dive deep into what the real cause of it is. And even as a healthcare professional you, it wasn't obvious to you as well. So I mean, I think one of the messages here is, this is really hard. It's really difficult. It's easy to become frustrated as a patient, but it's not... I mean, and there are gaps in the medical system. I want to acknowledge that but it's just really hard too. It's not necessarily anybody's fault. It's just really a very difficult... These are very difficult conditions to triage and diagnose.

**1:11:21.5 Jeannette Tousignant:** Definitely.

**1:11:23.5 Cynthia Ryan:** Sarah, I know you said that your healthcare, your VRT healthcare professionals, they helped you get onto a Virtual program right away. What was your relationship with them? Was it just one provider? Did you have multiple providers? Do you feel like you had a good relationship with them?

**1:11:46.4 Sarah Page:** So that would have been my regular physician to begin with. And then the neurologist, they... There's a clinic in the town nearest me, and it has every facet. I guess I'm not sure how to say that exactly, but each type of medicine, like internal medicine, neurology, all that. So he just sent me upstairs to see that doctor up there. And so they sent me to the physical therapy in town that did vestibular therapy. And so I think I went maybe four or five times in person. And it was very difficult for the reasons mentioned earlier. And so they actually had that app. So that worked out pretty well for me. And then I started to see different doctors, different neurologists at UNC and at Duke and even at Boston, Mass Eye and Ear. My husband and I went up

there. I was able to get an appointment up there with a specialist. We were getting answers, and all the doctors were saying the same things, but all of the recommendations for how to fix it or there is no fix, but how to help it and how for me to get back to daily life. And I was unable to work. And those were all different. And so the different types of therapies, I guess, we just started to look into. And that's how I actually found out about VeDA through them. And then from there I found out about Mass Eye and Ear. So I'm kind of going back a little bit in the timeline, but that's okay. And then through VeDA, I also found the GyroStim, which I do believe helped me quite a bit. We spent a week in Asheville in August, and I did the GyroStim therapy for a week. So it was two sessions per day for five days. And it was intense. It was a lot.

**1:14:00.9 Heather Davies:** Sarah, I'm not familiar with that. What is it? What is it you're saying? GyroStim.

**1:14:05.6 Sarah Page:** GyroStim.

**1:14:07.8 Heather Davies:** GyroStim.

**1:14:09.9 Sarah Page:** Mm-hmm. G-Y-R-O-S-T-I-M, GyroStim. There are only... So I think there are five of the machines in the United States. There aren't very many, and it's a giant machine. It's a little overwhelming to look at. I did send some pictures, if that's something that's available to put up on the screen. I don't know if you wanted me to talk about this right now, Cynthia, or not.

**1:14:37.1 Cynthia Ryan:** Let's see. If Elizabeth is listening in. And we have.. We do have two of those pictures. Let me see. I'm gonna decide which of these pictures. There we go. There's a picture of the GyroStim.

**1:14:52.5 Sarah Page:** This one is... Actually, this is a photo of the neurocom. And this is a balance testing machine that they harness you into. So the way... Evora clinic in Asheville, the way that they do it is you meet with the doctor who you see right there and then he does an initial evaluation, they go through your health history and everything just like they normally would. And then he puts you into this machine, harnesses you in. And he stood right behind me the whole time. So basically it measures how your body responds to the balance, whether it's hip related or in your ankles. And that can determine how you perceive, like how you walk. When I'm walking down the hallway and it's dark, it feels like I'm on a boat or that I'm rocking. And that's coming from my hips, which I didn't know before for this. But so this is part of the evaluation. So the floor on this moves, the wall panels move, that back wall that I'm looking at moves, but all without your knowledge. So he tells you this is what's going to happen, but you don't know when or how it's actually going to. So it's a little dangerous actually. But it does provide some insight. So they do this on the first day and then they do it again on the last day. And then the other photo, there should be one more.

**1:16:30.1 Heather Davies:** Sarah, you're harnessed in there, right?

**1:16:32.2 Sarah Page:** Yes, completely harnessed.

**1:16:32.9 Heather Davies:** If I remember correctly, you are like all buckled in. You're not going to fall or anything because you are...

**1:16:36.7 Sarah Page:** Absolutely, absolutely. And he did tell me that if you, if you grab the wall or touch the wall, it counts as a fall. So you have to really... It knocks points off. You have to be very careful. It was very difficult and we had to stop a few times because I got so dizzy and weak and shaky and it's kind of an intense thing.

**1:17:01.2 Cynthia Ryan:** I don't think we have the other photos, but maybe you can just describe what the... What the GyroStim is like... It's like a big chair. It looks like you're in like something that is training you to go to space.

**1:17:16.3 Sarah Page:** Absolutely.

**1:17:16.9 Cynthia Ryan:** There's this frame, circular frame around you and you're harnessed into that chair and then the whole thing moves. So it's basically moving you in different planes, if you remember, or if you know about the... How the inner ear, the anatomy of the inner ear. You have three semicircular canals in there in three different planes. Like, one is this way, one is this way, and one is this way. And if you move this way, it triggers one. If you move this way, it triggers another. So that's what the movement of the chair is kind of simulating moving you into different planes. And you know that when you're part of vestibular rehabilitation therapy, it's called gaze stabilization. It's to retrain the brain to put together the signals that are coming from your eyes and

your body as your body moves. So as the GyroStim. And I'm not doing a very good job of explaining this. I'm not a health care professional.

**1:18:22.9 Sarah Page:** You are.

**1:18:23.6 Cynthia Ryan:** As the GyroStim moves your body, you're using your eyes to track a laser. Is one of the exercises, it's a laser pinpoint in different planes so that you'll have a laser pointing over here, and then you have to look over there, and then you'll have a laser pointing over here, and you have to look over there. So it's trying to recalibrate where the eyes are pointing and where the body is moving in space. These are showing that there are therapies that you can get in an office using equipment that are very sophisticated. This doesn't mean that that's the only kind of therapy that's going to work. There's a lot of therapy that just takes a tool that you can use at home. But there are... I think it's a great example that there are different kinds of therapies with both simple tools and with very complicated devices. Let's see. So what... Let's move on and talk about what was most challenging for you guys with vestibular rehabilitation therapy. What were your... What was the hardest part of it? Jeannette, do you want to start? Hold on. You're muted. Thank you for muting yourself when you're not talking, that does help us. But sometimes it's hard to remember.

**1:20:00.6 Jeannette Tousignant:** Yeah, no, I think to answer the question about what's hardest is really, I needed to keep reminding myself that the balance organs, each of them for me were functioning inefficiently to a different tune. Essentially, they were each their own drummer. And the way the vestibular system works well and its job is,

of course, is to tell us where we are in space. And it does that by sending signals from our balance and hearing organs to the base of our brain. And that brainstem area starts to digest that information and figure out where we are and what's going on. And then it sends that data to many other places in our central nervous system in our brain, which is used in many different functions. And if that incoming information is inefficient, the brainstem has a little bit of trouble figuring all that out. And then the messages going up to the brain can be wonky in many different areas of our output. Balance is what's going on in the environment, and then what do we need to do to respond? So we keep our balance.

**1:21:09.3 Jeannette Tousignant:** And in my circumstance, each balance organ was doing their own thing. And it gives the... It makes it very difficult for the brainstem to then recalibrate. Vestibular rehab therapy is designed to tax your balance organs, tax your brainstem, so that the brain can adapt and recalibrate to this different set of circumstances. And that's all that neuroplasticity that was being mentioned in the first part of today's session. The input we get directly impacts what we can rebuild and then produce as an output. And when you've got a balance system that isn't static, giving consistent information, it's really hard to make measurable progress. So with the dehiscence circumstance like mine. Essentially, what's happening is weather, pressure changes me blowing my nose. Sound, my goodness, noise itself, because of the third mobile window, because that hole I had in the base of my skull, noise wave... Sound wave frequencies would make my balance organ misfire, misinterpret where I was in space and created a very difficult circumstance for my vision. So our balance organs, those semicircular canals and the utricle and the saccule, the other part of it, it all

drives what our vision reflexes do. And the information that my balance organs was giving to my brain was constantly changing. So my brain was constantly trying to figure out what up.

**1:22:46.1 Jeannette Tousignant:** So the things that would change how my balance system functioned were out of my control. I couldn't control sound. I definitely struggled with profound hyperacusis, if anybody is unaware of that term. Essentially, it's just the brain really hearing noises too loud. And for me, it was... Hyperacusis is a little bit like if you go into a restaurant and you're sitting and having a meal. If you were to actually smell. And if your brain registered every fragrance coming off of every plate that walked out of that kitchen and past your table and you had all that smell all the time, it would be really kind of disorienting. And for those with hyperacusis, what happens is you can't delineate what sound to pay attention to. So every single sound in my environment was weighted the same by my brain. And it made it very difficult and energy consuming to pay attention to the conversation. I was really focused on, A. B, that vibration was screwing up how my eye muscles worked. So the hardest part for VRT is when your system is constantly changing. That brainstem adaptation that we're trying to get our brain to recalibrate by doing our exercises can't catch up.

**1:24:07.8 Jeannette Tousignant:** That consistency of doing drill that is important for your particular deficit, it's duration of doing, its consistency, it's targeted focus. If those things aren't met, if it's constantly changing, the brain can't quite figure that out. So that was my challenge. And fortunately for me, I've recently had surgery to repair both of the holes, and my most recent surgery on this right side was three months

ago about. And it's been a journey, but I can tell that the things I'm doing are sticking now. So finally what I do is working. So the frustration of doing something and having it not work or hold, I get that. I've lived it. And that is the hardest thing. I think the hardest thing for VRT is when it's just not sticking for whatever reason.

**1:25:02.1 Cynthia Ryan:** That makes a lot of sense. And that was a great explanation, a great analogy of hyperacusis. That really helped me to feel it, to taste it, so to speak. I go in on the analogy.

**1:25:15.4 Jeannette Tousignant:** Yeah. I mean, if you... One thing, if you think about how much brain energy it would take to actively not hear something or actively not smell something, that's what folks with hyperacusis experience. They're using their brain energy to disattend, which is exhausting. It's hard.

**1:25:35.0 Cynthia Ryan:** Right. Yeah. I'm sure a lot of people can relate to that frustration of things not working. And I think again, it comes back to finding the right provider to help you to get to the root cause. This is why it's so important to get to the root cause of your dizziness and not just treat the symptoms. Sarah, how about you? I mean, we saw on the device that you were on how challenging something like that would be. But besides actually just balancing on that device. What was the most challenging part of VRT for you?

**1:26:13.4 Sarah Page:** I guess the... It was a little intimidating to begin with, especially to get into that giant machine that you described and had really no idea what to expect in there. And getting out, getting in, you're dizzy because you have to go up some steps. And then just having the therapist strap you in is a little bit much too. You're in like this giant seat. You have straps here and across your belly and then another one at your stomach and then your knees and your ankles. There's no way you're going anywhere, but it still feels like you may, especially as you progress through the machine and through the treatment process. So they start you out real easy and you have the laser pointer in your hand, which you mentioned before, and the chair moves and then you have to move just your head and try to hit that target with that laser. And they... It's usually about 45 seconds, maybe a minute. And the quicker it goes and the more you have to turn, the faster, like I can't really do it right now. I'll fall out of my chair. But it's very difficult. But I feel like it was a good experience for me and I think I would do it again if I had that opportunity.

**1:27:41.0 Sarah Page:** One thing to mention, I don't know if this is true for everyone or all insurance companies, but the actual GyroStim machine is not covered by insurance. Most of them, you do pay for that one out of pocket. It's \$100 per session. So for that week of 10 sessions, that's \$1,000, which is a lot. They offer a one week and a two week plan, I guess that people have done. I only did one, but I did want to mention that just because for anyone who may want to give that a try, it may take some planning to get ready for that to be able to afford it. But the actual evaluations by the doctors are covered under insurance.

**1:28:31.4 Heather Davies:** Sarah, I'm glad you mentioned that about the finances. I found also during the assessment process that when you went to one provider and another provider was ordering the similar test, often the tests aren't transferable from one to another. So we'd have to have the test redone. And I found that doing that I'd have to come out of pocket a lot. So a lot of companies do like a forgiveness thing too, or you can ask if they have some kind of grant that you can apply for. I was very lucky that I went to a particular multidisciplinary clinic and had those fees waived. So it's worth the shot. If it's something that you can't afford to just ask. I mean, worst case scenario, you're going to be where you are originally. But learning how adaptable the brain is, Sarah, and it can be real powerful. And how did understanding neuroplasticity change your mindset toward recovery? That's a big question. [laughter]

**1:29:40.1 Sarah Page:** It is. I'm not sure how much it really changed my mindset, to be honest with you, because it's not something that I could sustain, obviously. Here at home. I've tried some different things at home. They gave me some good therapies to try here, which my son has to stay on me up to make sure I keep doing because they're difficult and they make you feel unstable. But that's the point. That's what they want us to have to do. And to try to tell your brain that is like reasoning with the wall. It's very hard to do. So I do feel like I did gain from that, but the sustainability is a little bit more difficult. And I am kind of stuck at home. I'm at the mercy of my parents or someone else to take me to these therapies. And that gets very difficult. So I guess making myself more accountable, I have to work on that but help... Yeah.

**1:30:51.7 Heather Davies:** Sometimes the physical. Everyone thinks it's the physical that is the issue. Sometimes it is that the headspace, the mental game and staying motivated. Yeah. Jeannette, what about you? What has helped with your mindset toward recovery? You sound like you've got a pretty straightforward and you're doing really well. Can you share with us?

[overlapping conversation]

**1:31:17.5 Jeannette Tousignant:** Thank you for thinking I'm doing real well. Yesterday afternoon was a tough story for me. I really had... I have my low moments, and I fortunately now have some go-to buddies that are excellent at listening. When we're in our low spot, it's really helpful to be able to just let that come out and recognize that that's one of the highs and lows. I think it was Dr. Studer that was saying, rehab is not a straight line. It's curvilinear, and I have my lows. I think the whole part... What was powerful for me in my understanding of the vestibular system, and then now living through trying to retrain mine. That neuroplasticity, it really comes from finding ways to integrate what I know I need to be working on within my daily tasks because it's just true what Sarah is saying, like to make yourself consistently do your drills every day. That's tough. Especially because this... The progress can be so minute that it's hard to stay engaged. So, one of the things I know I need to work on is my head position in space and how that changes my posture in my lumbar, spine, and my lower back.

**1:32:31.7 Jeannette Tousignant:** So, I'm finding it really helpful to have... I am the queen of sticky notes. I should own stock in 3M because they are everywhere in my

house. And there's one by my kitchen sink that just reminds me every time I bend down to get soap underneath the kitchen sink to double-check my posture while I'm doing that task. If I bend down to pick up my dog's water dish, that's a postural cue. If I'm getting on and off the toilet, and it's a day that I know I'm lagging behind or I'm sore, I do it four times just in that one visit to the bathroom. Because it's that dosing, it's doing more of something in small bites that really has made the difference for me. I was a swimmer. I did karate. I know what it's like to commit myself to a physical exercise regimen. But this is brain exercise. It's different. It's not exactly the same. And if I know I need to work on my posture, and if I know that when I bend over to pick up the dog bowl, that's a chance for me to work on it, that's helpful for me.

**1:33:43.5 Jeannette Tousignant:** But if I have a sheet of paper that says, did you do your squats today? No, that doesn't fly with my brain. But if I'm doing something that I know is helpful in the middle of a task that's meaningful to me, that's my golden ticket. I really need to allow myself the opportunity to do it during a task. And I've gone to my physical therapist and say, I know this is a problem for me. I know I'm bending down wrong. Can you watch how I bend over to pick up this dog bowl? And just cue me on what I need to do different, because I'm missing an opportunity here. That works for me. I need to do it during a task because a regular exercise session is something that I'm not very good at doing, and I think it's paying off. I think practicing during the task is better.

**1:34:28.7 Heather Davies:** I love that you say that because I do hear in the social media, someone will talk about their loading the dishwasher, the simple movement, just

loading the dishwasher and putting the dishes away. Just little things like that. But if we think of it as a way of our therapy, it just reframes it and yeah, stay motivated...

[overlapping conversation]

**1:34:46.9 Jeannette Tousignant:** And if I can add one more thing that, what has really unlocked it for me is taking the opportunity to do some therapy with my counselor and trauma-based paradigm. That trauma-based counseling is really helpful for my mindset and meeting up with the people that I met through the medically retired support group that Vita sponsors. Huge. I have a lot of experiential knowledge as a clinician that has helped me. But it's the people and it's the real-life circumstances, and it's the getting tips from that wonderful community that has saved my behind. I can't be in my head about this. I have to have support. Huge. I just can't stress enough what that trauma-based therapy and my community support group does for me. I don't care how much knowledge I had as a clinician. It's those people and that effort that has made the biggest difference for me, period. Hands down.

**1:35:53.7 Cynthia Ryan:** I love that peer support as both support and accountability in some ways, I mean that's... I want to kind of go back to what some of the speakers were saying. Mike Studer was saying consistency over intensity is one ingredient to success. To just be consistent in what you're doing and finding, which I think comes back to the accountability. Finding ways to hold yourself accountable for doing your therapy. And part of that is finding what works for you and what you're going to enjoy doing. For you, it's integrating it into daily life, for someone else it might, it might be

the routine of knowing this is the... These are the exercises that I need to do. Everybody is going to be different, and VR virtual reality. I just want to kind of throw that in there, is another way that you can make therapy fun and it's not for everyone necessarily, but it is a way to make therapy fun. There's also, I think they talked about it a little bit in the speaker session. There are software that some physical therapists have.

**1:37:13.7 Cynthia Ryan:** One of the software platforms is called Vertigenius, where they can prescribe your exercises through the software. And then when you do the exercises at home, you record what you're doing and when, and there even is some software where they can, using your phone or a pair of goggles. Track your eye movements while you're doing the exercises to make sure you're doing them correctly. Because I think that that's really challenging also when you're doing therapy at home. And I know I'm... I'm going through to a physical therapist right now for a shoulder problem. And when I go back, he gives me exercises, and then I go back and I do them, and he's like, you're not doing it right. So it's not going to be helpful if you're not doing them right. So getting that immediate feedback that you're doing them correctly can be really helpful. I'm wondering, kind of on that note, how do you integrate... How do you adapt your homework and daily routines to support your. Your VRT progress? How do you integrate that into your daily life? Sarah, do you want to start that?

**1:38:43.1 Sarah Page:** Sure. I tried to move around as much as I can at home. It can be very difficult, especially when I am feeling particularly bad that day. You want to just kind of not have to do anything. And my husband and my son tried to keep me kind of stable, stationary just to, I guess, keep me safer because I fall quite a bit. Bu like, I tell

them I have to get up. I can't keep sitting here. Like, I just can't. I have to at least do something. I have to empty the dishwasher like you said, or go out and play with the dogs or I have to do something. Just sitting there is just not conducive for me. It feels like I'm giving into it. Even though I'm not feeling well. I don't want to base my whole day on that one episode or that hour that I'm not feeling well or that. So I do try to keep that mindset for myself that even when they say that, well, just rest, you don't have to do it. Yeah, I do. I have to get up, I have to go to the farthest bathroom just because I have to go a little further to get there like. And it can be very hard for them because they know that in an instant I can... That wave hits you and you just fall over. And unfortunately, that's just part of the deal. But if I am feeling particularly bad, I use the walker in the house, and I still try to do what I can with the walker which can be kind of defeating in its own right. I'm 45 years old and I'm using a walker in my house. Like you have to kind of try to push past that part of it and not see it as something bad, but see it as something that's going to help me not get hurt today.

**1:40:47.3 Sarah Page:** So I guess those are the things I try to do. My son likes to take me to town. We live like 30 minutes from any town. So we go to a bookstore, we go have lunch, we go sometimes to Target. Depends on how I'm feeling. It's a big store. But he's really good about getting me out of the house and if he knows that I can handle it that day. So things like that, just the support really. But it does help. So I guess without realizing it, as Jeannette said, maybe I am doing little bits of therapy that I'm not even realizing that I'm doing. And I love the Post it idea. I have them everywhere too. But I never thought about doing it that way. So I think I will do that.

**1:41:32.8 Cynthia Ryan:** Safety first. I just want to say there's nothing wrong with using a mobility device. Whatever works for you don't push yourself past your limits. Jeannette, how about you were talking about the things that you use your post it notes to remind you in your house pay attention to posture, other things that you do in your home or daily routines to support your VTR progress.

**1:42:04.4 Jeannette Tousignant:** Actually, yeah, definitely I'm relying on my community of support. I reached out to my neighbors when I was having surgery and explained things like gosh, when I get back from my procedure, if you're going to the grocery store, give me a shout. I wouldn't mind driving along. And maybe I don't even go in the store that day. I just sit in your car or maybe I just walk along with you and I can push the cart while you shop, but that will help me. So I've reached out like that. I definitely ascribe to the use of tools. So kudos to you, Sarah, for using your walker. I think of tools as something that helps me get to my goals faster. If I want to make a pie and I want to do a homemade crust, I'm not going to try to do that with a hammer. It's the wrong tool and if I don't grab my rolling pin, it's going to be a really wonky looking crust. So my canes, my walking sticks, are my thing for when I go for walks outdoors. And I live in the Upper peninsula of Michigan.

**1:43:10.1 Jeannette Tousignant:** There's a lot of snow and ice here, so my walking boots have ice cleats, metal cleats on them, so I don't slip. When I go to the grocery store, I use a cart, and I force myself not to lean on it, but just to kind of push it. So I'm using my tools, I'm using my friends and my neighbors. I have a dog and a nice neighborhood area where I can walk him. And I challenge myself to turn my head and my

eyes and track where he's going because he's erratic. So that's some good visual tracking drills. And all of that stuff makes me feel good when I've had days that I just don't get off the couch and I have sad texting conversations with my friends because I just feel so crummy. And if I've overdone it one day and my brain is completely exhausted and the battery just hasn't recharged overnight, that's really defeating. I've had a lot of those days recently, and that's a tough pill to swallow, but kind of reminding myself of that curvilinear path and just relying on the people that are more than I could cry. The number of people who just came out of the woodwork for me this past year, two brain surgeries in one year, is a lot. And I needed many people to help me pull that off and get me through the recovery phase. So it's not pretty. It's hard. And when your family can stand by you by just listening, or if you find that one bestie friend that can do that for you, it's a game-changer. Yeah. Community. Community and accepting tools has kind of been my thing.

**1:44:52.8 Cynthia Ryan:** I love that. And people, when you ask for help, people are willing to. People want to help. They just want... They need to know how. And so I love that you made these very specific asks. Can I go to the grocery store with you? People are definitely...

**1:45:11.2 Jeannette Tousignant:** They are. And. And I've had many people say to me now, Jeannette, we ask you for help, and you're there. If you don't ask me for help, quite frankly, I'm going to be kind of mad at you. I'm like, oh, well. And then I don't want to disappoint anybody. So they do want to help. And you just have to remember that you're not a burden and you have people who want to be there for. For you. And

it's hard to talk yourself out of that pit. Not gonna lie. Been there many times, but it's a truth. It's a truth.

**1:45:39.0 Cynthia Ryan:** And I also love your comments about. About tools and equipment. I mean, I, as someone who does a lot of... I do a lot of outdoor activities, and I know that if I go out there and I'm not dressed appropriately or I don't have the right tools like walking sticks, it's going to be a different experience. It's not going to be an enjoyable experience, but if I have the right tools. You were talking about cleats on your boots when it's icy out there. Perfect example. Cleats on your boots and walking poles. And you can get out there and you can walk, but don't do it without those tools and those safety precautions.

**1:46:26.4 Jeannette Tousignant:** And every time you use a tool in the community, you are a steward to what we're all going through. We can, in every moment that we choose to use a tool and to honor our vestibular selves and be authentic about it and say, oh, pardon me. You're at the grocery store, you've got a cart. Say, I really need to sit down for a moment. I just have to pause and then I get my little ginger chew out of my bag and I sit for a minute, and then I can continue. And anybody who sees that I just did the rest of us a favor. I mean, do all of us a favor and use your tools and be a steward. That feels good to me. And I'm a little less shamed. I'm less apt to shame myself if I have that perspective, if that kind of makes any sense.

**1:47:16.7 Heather Davies:** No, it totally does. It totally does. It also, there's other... You notice other people out there struggling, and you wonder, do they have a vestibular

disorder? And so I love that. That perspective is great. And, Sarah, I think you need to glam up that walker, make it something you want to use in the house. Absolutely. Well, on to that. That same general area. I'm curious, Sierra, about your symptoms. They can be a roller coaster. What helps you get through? I know you mentioned your parents and your son kind of keep you motivated. What helps you get through the ups and downs and hold on to that hope? Is it community or is it pretty much. Tell us, tell us what it is

**1:48:02.7 Sarah Page:** I do have a very good support system. I have some very good friends that are willing to do anything really, that I need. They always ask, or I am not hesitant to ask. I guess I'm kind of outspoken in a way... In a good way. But I don't hesitate for that. I do always use a cane anywhere. Not in my home, outside, out in town, anywhere. And I do agree with Jeannette as far as that. People do notice that you have the cane. And especially I look younger than I am. People say that. And I know that's a good thing. I always have. But you do feel the look. And they're wondering to themselves, why is she walking with the cane? Why is he holding on to her like that? Why?

**1:48:58.6 Sarah Page:** So those types of things are okay and you just have to use it anyway, whether you're... Because at first it really scared me. It was not something that I was willing to accept, but I had to. So I do have the support of my parents and my husband, my son, my friends. And we've done a lot around our home to help me, I guess, stay safe. We've added security type things like grab bars and the showers and next to the toilet. And a giant yoga mat in our kitchen. So when I fall in there, at least there's a little cushion. Extra large rugs in the bigger... Like the laundry room and the

kitchen... Excuse me, the bathrooms for those reasons. I have the eye massager that is amazing. I think I have three of them because if one battery needs to be charged, I have one. But I use them every day. They are amazing for the headaches. Amazon, of course. But I have a couple of smaller ones that we... I have a little go bag, I guess I call it whenever we leave the house. So I always have one of those.

**1:50:18.1 Sarah Page:** I have any medications that I might need, some snacks, all sorts of things in there. Have some little identification cards just in case lane's in the bathroom or something that. And something happens to me because I have had major episodes in stores before and have needed help from the staff. And they've always been very helpful. Everyone seems to be very caring, which is good in this kind of world you never know. So I guess just knowing. And I guess that would go into the community too. We have some neighbors and they check on us and that kind of thing. And trying to stay positive can be very difficult sometimes. So I really try hard to do that. That's my nature anyway, is positive, so that's good. I do have a leg up there. But even then it can be very, very sad. I can't even leave my house alone. I can't drive anywhere by myself. Myself. I used to do everything by myself for all of everyone. So just swallowing that is very difficult.

[overlapping conversation]

**1:51:33.8 Sarah Page:** So I am wearing this. Fiona can't see it, just so I don't forget that. But things like that, that make you smile, very important.

**1:51:44.4 Heather Davies:** Well, you're not alone in that, Sarah. A lot of us have been there and we're all wishing the best for you to keep plugging forward and just hold on to those little glimmers, okay?

**1:51:53.3 Sarah Page:** Thank you.

**1:51:54.7 Heather Davies:** I'm sorry I lost our train, my train of thought here, Cynthia.

**1:51:59.6 Cynthia Ryan:** Well, I think that what you were talking about there, Sarah, about what you do to maintain hope during your ups and downs. That kind of also relates to, and I'll bring this part of it into it also. The, the mental and emotional part of having a vestibular disorder. It's very... It's not just physical. There's a lot of mental parts to it. And Sarah, you mentioned that you're naturally optimistic. Excuse me, not everybody is. And I do think that that makes it more difficult for people if you don't not naturally think about, oh, this is going to turn out okay. And I don't want to say that optimism is the only way to go. I think everybody has their own journey. But I do think that focusing on or at least acknowledging the mental and emotional parts of this and finding ways to support those is important. Jeannette, what have you done to support your mental and emotional well-being?

**1:53:18.4 Jeannette Tousignant:** I can't agree with the need more strongly than addressing that for all humans, but definitely if you have a chronic situation and it's an invisible type of illness, it's just... And it's made a world of difference for me to identify that I had this diagnosis in the first place. Because there were a number of years while

I was still working as a clinician where using the electronic medical records documentation system as an example was extremely difficult for me. My vision was not cooperating. I'm 60 years old. I never used a computer at work until the final seven years of my career. And it was extremely humiliating for me to see all the young bucks in my clinic go, oh, it's not that hard, Jeannette. Just go here and do, and click this and click that. I'm like, I had no gestalt for that at all. And I had to really talk myself into keeping on trying. And I was so defeated and so embarrassed because I couldn't do it. And then to finally have gotten the diagnosis of vision misalignment, superior oblique palsy, slow visual reflexes, then it was labeled, and that helped me tremendously.

**1:54:42.9 Jeannette Tousignant:** But the kind of shame that I adopted for being unable to do something that was so simple for everybody else around me was really, really heavy and unfun. And I'm kind of still learning to let that go. So that piece of shame is kind of underlying for me. And I do work on that with my counselor. And I'm getting better at recognizing when my inner voice is going, Jeannette. Well, I have to kind of accept that it's still there and then recognize it and then go, wait a second, let's breathe. And that's been huge for me to finally learn how to breathe. There was a time when I said to my doctor, probably five years ago when I'm standing doing dishes, I catch myself not even breathing. What's that? Well, my vestibular system had my vagus nerve all ramped up and I was so living in a state of fight or flight that my body just forgot to inhale. And like, that's tough news. So it really will play with you on an organic level. Our vestibular system is so intertwined with what our brain does that when you have low mood, when you have those down periods, that's organic.

**1:55:54.4 Jeannette Tousignant:** That's not a flaw. You're not at fault. That's hard-wired. Our vestibular system is designed to help keep us safe. And when we're not, it's going to go, whoa, hold up. No, no, it's going to give us that. And when you live there for a long time, gosh, that's a tough thing. So all of us who are working through that, we have to really give ourselves credit because it's organic, it's not a flaw. And finding the right person and the right tools and cutting yourself some slack as you work through it is essential. And gosh, I'm listening to myself talking, I'm thinking I got to listen to my own medicine more because it's been tough, this post-operative phase for me, and I'm struggling on a lot of days, and that's by design. My brain is trying to learn something new and just really giving ourselves credit for the fact that what we're doing is rewiring. And it takes repetition, and it's not a straight Path and having that support and somebody to talk to you about it is huge. Yeah. Okay. Off my soapbox.

**1:56:52.4 Cynthia Ryan:** Oh, no. It was wonderful. And one things that I took from that is this. The mental and emotional part is physical. It's not. It's not just, you have to overcome what's in your head. There's a real reason these things are happening. So giving yourself grace is a big part of that. I want to just wrap up with one last question for each of you. What would you say to someone who is just beginning vestibular rehabilitation therapy? Especially, someone who's feeling uncertain about whether it's going to make a difference for them or someone who has tried it and hasn't felt like it has helped them. What would you say to them about going forward, how to approach it? Sarah, do you want to start?

**1:57:45.9 Sarah Page:** I would tell them to try to be patient if possible. Give it a chance and know your body. If your body is telling you this is just not for me, then it probably isn't. But give it an extra chance just to check that theory and then research some other options. And don't be afraid to reach out to your doctors, all of them. Send them messages in your MyChart or anything like that. If it's the middle of the night and you can't sleep and you're thinking, I need to send them a message in the morning, send it right now. Say, you know what, I'm up, because I can't sleep. I don't think this part is working out for me. I need your guidance. I need you to help me figure out another path for myself. And if that's a different doctor, okay, if that's another therapy, that's okay, too. Or I wouldn't want anyone to give up just because that first thing isn't really working. Like I said, give it a chance. It's like the medications. You have to give them a chance. And that was really hard for me in the beginning, too, because, oh, they made me feel so bad. You have to just power through it and keep your chin up. That's what my dad always says, keep going, and it will even out. It will get better, and you will figure out something that will help you. And God bless you and good luck, because we're all here with you.

**1:59:28.8 S?:** That's it.

**1:59:30.8 Sarah Page:** And reach out because everyone's here for you, to help you. And this is... Vita is just an amazing place, period.

**1:59:37.0 Cynthia Ryan:** Thank you. Jeannette, any last words of inspiration?

**1:59:42.5 Jeannette Tousignant:** Yeah. I would echo what Sarah is saying. About being your own self-advocate. We're driving our own boat and for many of us here, our boat is constantly rocking right. So it's really critical for us to recognize that vestibular disorders are not generally well understood by our primary care doctors. It takes a rare primary care doctor to really have a handle on how all the symptoms that are part of vestibular disorders are presenting in their office with you. Anxiety and feeling dizzy, and having a hard time describing the other parts of your symptom pattern that looks like a lot of other things to them. So we really have to recognize that as much as we can drive our own boat, do our own research, figure out ways to channel yourself toward the clinicians that are going to make a difference for you is huge. And I know for me personally, just accepting that this is a lifelong journey and keeping the mindset that as long as I'm reaching that point, I know in the earlier session today there was talk about your belief in it getting better.

**2:00:56.0 Jeannette Tousignant:** And when you find that clinician or that friend or that bestie friend that helps you believe and have hope, then whatever you try, when you drive your boat to that next clinician is going to have a greater chance of having impact for you. That placebo effect or that ability for our brains to go, okay, well, I believe that this is worth a try, is just going to, to the nth degree make it potentially more effective. And it's a hard thing to do. But we have to drive our own boat because that just is the facts Jack. Not everybody understands vestibular and we understand our body best. And the more we recognize that we are our best steward and it's up to us to try to give credit to what we're recognizing and just not stop until we find the person that listens and is willing to look under that next rock for us. It's just critical that if

we're down that low, we find somebody and we say... I love what you just said, Sarah, about if it's three in the morning, get on your MyChart and say, hey Doc, I am struggling. I can't keep doing this. My life is not sustainable. This way please. Who can you next direct me to if it's not you? That's a fair question. I would echo that too. Yeah, Sarah, nailed it.

**2:02:09.4 Cynthia Ryan:** Perfect. Perfect. So anyone I know we've got... We have such amazing comments in the chat saying that this has been one of the most... The best patient panel for them. Thank you both to Jeannette and Sarah. And we've got some information if people want to follow our panelists. There's Sarah's blog. You can follow her journey there. And Jeannette, I know you participate in the there's Jeannette's email if you want to follow up with her. Also, for those of you who are looking for a support group, Jeannette participates in the Medically Retired Support group, and there's a lot of activity on the discussion boards from that group. Please check that out. Thank you both so much for sharing your experience with us.

**2:03:02.4 Jeannette Tousignant:** Thank you.

**2:03:03.3 Sarah Page:** Thank you.

**2:03:04.7 Heather Davies:** Yes.

[overlapping conversation]

**2:03:08.7 Cynthia Ryan:** Yes. I'm glad we powered through the technical problems and that everybody just appreciates that we're here today. I just want to give another shout-out to the James D. And Linda B. Hainlin Discovery Fund and the University of Minnesota Department of Otolaryngology for sponsoring this conference, and as one of the attendees in the chat said, making it free and available to everyone.

**2:03:37.0 Heather Davies:** Right. And as a reminder, you can purchase the lifetime access to the recordings and transcripts of this entire conference@vestibular.org LRL recordings. And you can help make sure the valuable information that's presented at the annual event remains free to everyone by making a donation@vestibular.orgLRL... I'm sorry, /LRLdonate. The links are also listed in below.

**2:04:03.5 Cynthia Ryan:** So tomorrow is the final day of the conference. I hope you'll join us and learn about conditions like vestibular migraine, PPPD, and when those and other conditions that are vestibular or not vestibular overlap and how that can affect your nervous system. So join us tomorrow. Thanks everyone. Good night. Bye.

## **Thank you for choosing Scribie!**

Cross-check this transcript against the audio quickly and efficiently using our online Integrated Editor. Please visit the following link and click the Check & Download button to start.

<https://scribie.ai/files/JRVxR2pnJ2Ch>