You Are Not Your Diagnosis: Living Well with Chronic Vestibular Conditions

Living with a vestibular disorder can shake the foundation of a person's life. Symptoms such as dizziness, vertigo, brain fog, and imbalance often appear suddenly and can affect work, relationships, identity, and confidence. For many people, the early phase of illness becomes consumed by doctor visits, testing, and searching for answers.

But as speakers emphasized in this session of the Life Rebalanced Live virtual conference, a diagnosis is not the end of the story. The path forward is not only about reducing symptoms—it's about rediscovering identity, rebuilding confidence, and learning how to live well with a chronic condition.

This session brought together two vestibular experts and two patient advocates to explore that journey from both clinical and personal perspectives. The first half featured an interview with vestibular physical therapists and health coaches Dr. Kathleen Stross and Dr. Megan Daly, who discussed how patients can reclaim agency and resilience. The second half featured a patient panel with Adam Lindo, who lives with vestibular neuritis and now works as a health and wellness coach, and Lara Bishop, who lives with vestibular migraine and shares her experiences through her blog Mummy Seeing Double.

Together, their conversation revealed an important truth: learning to live well with vestibular disorders involves both practical strategies and profound shifts in mindset.

Looking at the Whole Person

A key message from the clinicians was that living well with vestibular dysfunction requires stepping back and looking at the whole person, not just the symptoms.

Instead of focusing exclusively on eliminating dizziness, Dr. Stross encourages patients to develop agency and authorship over their lives, even in the presence of symptoms. Living well, she explained, is about restoring confidence, capacity, and connection—not simply chasing a cure.

That shift involves moving away from fear-driven thinking and toward empowerment. Patients begin to focus on:

- Function instead of fear
- Clarity instead of chaos
- Autonomy instead of dependence
- Integration instead of fragmentation
- Identity beyond illness

In other words, the goal is not to erase the challenge but to write a meaningful story that includes it.

When Symptoms Disrupt Identity

Vestibular disorders often create a profound identity crisis. Many patients suddenly cannot perform the roles that once defined them—whether as professionals, parents, athletes, or caregivers.

Dr. Daly described how quickly this loss of stability can knock someone "off their foundation." People may feel overwhelmed by navigating the healthcare system while also dealing with physical symptoms and emotional stress.

Her approach is to help patients return to their core foundation. Instead of focusing on all the things they "should" be doing, patients are encouraged to reconnect with their own needs and values.

The process is deeply individual. What restores stability for one person may look completely different for someone else. But the starting point is the same: identifying what matters most and building forward from there.

Curiosity Instead of Panic

Another powerful idea discussed during the session was learning to approach symptoms with curiosity instead of fear.

When dizziness strikes, the body's instinctive reaction is often panic—fight, flight, or freeze. Dr. Stross encourages patients to interrupt that cycle by pausing and observing what their body is communicating.

Rather than immediately labeling sensations as "bad," patients can acknowledge them with curiosity: What is my body trying to tell me right now?

This shift in mindset helps calm the nervous system and reduces the emotional spiral that can amplify symptoms.

Dr. Stross even recommends reframing the language patients use. Instead of thinking about "symptoms," she suggests viewing them as signals—messages from the body that can guide decision-making.

The Role of Self-Compassion

Self-compassion is another essential part of adapting to chronic illness. Many people blame themselves for worsening symptoms or feel guilty about not functioning the way they once did.

Dr. Daly emphasized that these feelings are extremely common. Patients often criticize themselves for doing “too much” or “not enough.” The goal is not to eliminate those feelings instantly, but to gently redirect them.

Sometimes that means introducing small coping strategies—taking a walk, regulating breathing, or shifting attention toward something enjoyable.

Even small actions can interrupt the cycle of self-criticism and begin to restore emotional balance.

Learning to Pace Activity

One of the most practical strategies discussed by the clinicians was pacing.

Vestibular patients often fall into one of two patterns: pushing too hard and crashing afterward, or avoiding activity altogether out of fear of triggering symptoms.

Dr. Daly uses a traffic light analogy to help patients find the middle ground.

- Green light: Activities that feel manageable
- Yellow light: Early warning signs that it may be time to slow down
- Red light: Signals that it is time to stop or reset

By recognizing these signals, patients can adjust their activity before symptoms escalate.

Dr. Stross complements this with a 0–5 symptom scale, helping patients identify when they are approaching their limits and when to apply coping strategies such as breathing exercises or rest.

Over time, this process allows patients to gradually expand their abilities while maintaining stability.

Building a Toolbox for Flare-Ups

Flare-ups are an inevitable part of living with chronic vestibular disorders.

One of the most important messages from the clinicians was that relapse does not mean failure. In fact, relapse is often part of the recovery process.

Dr. Stross encourages patients to expect that symptoms may return at times—and to prepare a toolbox of strategies to manage those moments.

This toolbox might include:

- Breathing exercises
- Rest or pacing strategies
- Nutritional adjustments
- Support from therapists or support groups
- Reminding oneself that setbacks are temporary

Knowing how to respond to flare-ups helps reduce fear and restores a sense of control.

Patient Experiences: The Emotional Impact

The patient panel highlighted how deeply vestibular disorders can affect mental and emotional well-being.

For Lara Bishop, receiving a diagnosis of vestibular migraine after years of searching for answers brought both relief and overwhelm. She described feeling broken and struggling with guilt as she tried to understand why the condition had developed.

Adam Lindo had a similar experience. At first, he assumed the condition would resolve quickly. But as weeks and months passed, he realized how profoundly it was affecting every aspect of his life—from his relationships to his career.

Both described periods of depression, anxiety, and self-criticism.

Those emotional responses are extremely common among vestibular patients, particularly in the early stages of illness.

The Turning Point

For both panelists, a turning point eventually arrived.

Lara found that working with a cognitive behavioral therapist helped her process anxiety and develop new coping strategies. She learned mindfulness techniques and began practicing meditation, which helped regulate her nervous system and manage stress.

Over time, she reframed her illness as the beginning of a new chapter rather than the end of her previous life.

Adam's shift came during a moment of reflection when he realized he was at a crossroads. He could continue merely surviving—or he could ask a different question: What if there are ways to improve my health and quality of life?

That curiosity led him to explore lifestyle changes and ultimately to build a wellness coaching practice focused on helping others with chronic illness.

Lifestyle Strategies That Made a Difference

Both patients shared the daily habits that now support their stability.

Although their approaches differ, several themes emerged.

Sleep

Maintaining a consistent sleep routine is one of the most important foundations of vestibular health. Both panelists emphasized the importance of going to bed and waking up at regular times.

Diet

Diet also played a significant role in symptom management.

Adam discovered that certain high-histamine foods were worsening his symptoms. Adjusting his diet helped calm his nervous system and improve his overall well-being.

Lara found that reducing caffeine, alcohol, and inflammatory foods helped stabilize her vestibular migraine symptoms.

Exercise

Regular movement—whether strength training, Pilates, or cycling—helped both panelists maintain balance and resilience.

However, they stressed that physical activity must be adapted to each stage of recovery.

What works later in recovery may not be possible in the early stages.

Listening to the Body

Perhaps the most important lesson from the patient panel was the importance of learning to listen to the body.

Patients gradually develop an awareness of their limits and warning signs. This awareness helps them decide when to push forward and when to rest.

Sometimes the best response to a flare-up is gentle movement. Other times it is rest and nervous system regulation.

Finding that balance takes time, experimentation, and patience.

Choosing Hope

Despite the challenges of chronic vestibular disorders, the session ended with a message of encouragement.

Dr. Daly reminded the audience that there are always options and always hope—even when progress feels slow.

Dr. Stross encouraged patients to define themselves not by their illness but by their deeper identity and purpose.

And the patient speakers demonstrated that a meaningful life is still possible, even when symptoms persist.

Vestibular disorders may change the course of a person's life—but they do not erase the possibility of growth, connection, and fulfillment.

As the title of the session reminds us:

You are not your diagnosis.