



ON THE LEVEL
NEWSLETTER

WINTER 2020

BORN WITHOUT BALANCE

HOW YOU
HELPED
LUKE'S FAMILY
FIND SUPPORT



VEDA

A QUARTERLY NEWSLETTER
OF THE VESTIBULAR
DISORDERS ASSOCIATION

On the Level is a quarterly publication of the Vestibular Disorders Association (VeDA). Information in this newsletter is not intended as a substitute for professional healthcare. VeDA does not recommend any particular course of treatment, clinic, or health care practitioner. The opinions expressed in these articles are those of the authors and not necessarily those of VeDA's staff, medical and scientific advisors, or board of directors. The publisher reserves the right to accept, reject, or edit any materials received for publication. No part of this publication may be reproduced without written permission. © All rights reserved.

BOARD of DIRECTORS

President: Holly Fisher, Ed.D. - Coppell, TX
 Vice President: Kamran Barin, PhD - Columbus, OH
 Treasurer: Jordan Tucker, DPT - Troutville, VA
 Secretary: Kathleen Stross, DPT - Pearland, TX
 Dennis Fitzgerald, MD - Philadelphia, PA
 Rebecca Rubin - Sherman Oaks, CA
 Patricia Gerend, MS - San Francisco, CA
 Robert Rubin, MD, PhD - Oxnard, CA
 Danielle Tate, DPT - Damascus, MD
 Louise Geib, M. Ed - Atlantic Beach, FL (Trustee)
 Bryce Salvador - Westfield, NJ (Honorary)

EXECUTIVE DIRECTOR

Cynthia Ryan, MBA - Portland, OR

MEDICAL & SCIENTIFIC ADVISORS

Chair: P. Ashley Wackym, MD - New Brunswick, NJ
 Richard Clendaniel, PT, PhD - Durham, NC
 Joel A. Goebel, MD, FACS - St. Louis, MO
 Timothy C. Hain, MD - Chicago, IL
 Janet Helmski, PT, PhD - Chicago, IL
 Gary Jacobson, PhD - Nashville, TN
 Jeffrey Kramer, MD - Chicago, IL
 David Newman-Toker, MD, PhD - Baltimore, MD
 James Phillips, PhD - Seattle, WA
 Steven Rauch, MD - Boston, MA
 Jay Rubinstein, MD, PhD - Seattle, WA
 Michael Schubert, PT, PhD - Baltimore, MD
 Alain Semont, PhD, PT - Paris, France
 Neil T. Shepard, PhD - Rochester, MN
 Hinrich Staecker, MD, PhD - Kansas City, MO
 Jack J. Wazen, MD, FACS - Sarasota, FL

WHAT'S INSIDE?

3

BORN WITHOUT BALANCE:
LUKE'S STORY

7

NEW FACES AT VEDA:
MEET ANDI BLOOM

8

LETTER TO MY THERAPIST

10

NEW WEBSITE SNEAK PEEK

11

RESEARCH CORNER

12

WHAT IS A QUALIFIED
CHARITABLE DISTRIBUTION?

13

A CAREGIVER'S JOURNEY



Born Without Balance

By Brooke Montgomery

I am writing this sitting at Luke's bedside in the hospital as he is suffering from yet another one of his "episodes." This makes number twenty-six that require emergency medical treatment. And that doesn't include the five major falls resulting in loss of consciousness, the ambulance rides, or the hundreds of hours of therapy.

Luke has been through more in his four short years than most people endure in a lifetime, and yet, he keeps his infectious smile and a zest for life that few possess.

Luke is a huge fan of fire alarms. Before that, it was elevators, and before that it was ABCs. He taught himself to read at age two and a half. He talks and signs and loves to sing and dance and tell jokes. When he gets sleepy, he asks to "cuddle me up." His favorite animal is a flamingo, and I wonder if he admires their gracefulness and balance.

When Luke was born in 2015, even before we knew he was deaf we knew he didn't like motion. He would scream and flail when lifted from his bassinet. You couldn't even consider rocking him. For the first four months of his life Luke refused to lift his head. Therapists worked tirelessly on his muscles, but every time we would move his head to center he would cry and go back to the side where he felt safe. At three months old an MRI revealed a lesion on his cerebellum, likely scar tissue from an injury in utero.

Despite routine physical therapy, Luke stayed behind on his gross motor skills. He was, however, progressing forward at his

own pace. He sat up at nine months and crawled shortly after. It was somewhere in this time frame, when he was beginning to move, that his episodes began.

In the early days, they would start out with sweaty, clammy skin, and he would grip on to us so tightly you couldn't pull him off if you tried. He would bury his head and cover his right eye with his hand. Eventually, he would beg you to turn the lights off. It would



ABOVE: LUKE HAS BEEN DEAF SINCE BIRTH, AND NOW WEARS A COCHLEAR IMPLANT (PHOTO CREDIT: HAROLD MAHN)

only take a few minutes for the vomiting to begin. Violent, violent vomiting, sometimes thirty or more times an hour, resulting in bleeding, lethargy, and dehydration. We saw specialists in GI, neurosurgery, neurology, ENT, audiology, and cardiology. Everyone had a different theory of what was happening. He underwent testing and tried different medications. Nothing seemed to improve his symptoms, and they were occurring every six to seven weeks, like clockwork.



At twelve months old, Luke began to pull up on things. While it was exciting to see this milestone, he didn't have the balance to stay there, and would often fall. Coupled with the fact that he didn't naturally have a protective response, these falls were often severe. His first bad fall happened the day after his first birthday when he pulled up on a camping chair and it tipped over. He hit his head and immediately lost consciousness. He was stiff and had nystagmus, followed by going completely limp. I thought at that moment that we had



ABOVE: LUKE'S WHOLE FAMILY LEARNED SIGN LANGUAGE SO THEY CAN COMMUNICATE WITH HIM.

lost him. We called an ambulance and he woke up just as they were pulling into the driveway. Neurologically he checked out, and we were sent home with little knowledge and a lot of anxiety.

We always assumed that Luke had impaired vestibular function because it can be related to hearing loss, but doctors were very reluctant to test him or diagnose at such an early age. We began searching for anyone with experience in vestibular therapy for

children, but were told over and over that he was too young. Eventually, we found an occupational therapist who had done her own research in vestibular therapy because she also has a deaf daughter with balance problems. She worked with Luke on joint compression and strategies to calm his vestibular system after lots of stimulation. We began to see improvement in his mood and ability to move without side effects. In that time, we also set up a large area that used to be our dining room with foam tiles and baby gates so that Luke could safely play at home and have the freedom to move around. He sported a helmet for the times he wasn't confined.

At eighteen months, Luke began to walk. His episodes increased in severity. Walking too fast or too much would set him off. Walking on uneven surfaces would set him off. He remained very unsteady, and was limited to a stroller when we left the house, for his safety.

Luke's right eye began to cross at this time, and he got glasses for his strabismus (i.e. misaligned eyes). At nineteen months, Luke had surgery for a cochlear implant. There was some research suggesting

that sound awareness may help improve Luke's vestibular symptoms. Unfortunately, we didn't notice a change for better or worse in that respect.

When Luke was hospitalized in June, 2017 for dehydration from an episode, it was the breaking point for me as a mom. I felt so helpless, and when the neurologist suggested Luke may have a specific mitochondrial disorder that would be fatal and that all three of our boys would have it, my anxiety became out of control. After

six excruciating weeks, the genetic tests were negative, but the feelings of helplessness persisted.

Therapy continued and falls improved over time. Episodes continued, but moved mostly to mornings. At thirty months, we took up the safety floor and gates, and Luke was stable enough to navigate the house, as long as he didn't climb.

Theories about what was going on with Luke still swirled, and we felt no closer to answers. Things like cyclical vomiting and vestibular migraines were at the top of the list, but doctors were baffled because "they usually don't see it in this age group." At thirty-six months we were finally able to get vestibular testing. He lasted thirty seconds before he got sick.

He was diagnosed with "vestibular dysfunction" based on his eye movements. We know his vestibular system is impaired, but no additional information, as they will not do any further testing until he is older because he reacted so poorly to that first test.

It was around this time that we discovered VeDA on Facebook. While it is hard to find other children with vestibular issues, it was nice to know that there was a whole network of vestibular patients with similar symptoms to Luke. It solidified my belief in what he was experiencing, and helped me find solace in knowing we weren't alone. I was able to get practical advice on how to help Luke for the first time.

At around three and a half years old, Luke was finally able to sit in a chair at the kitchen table without falling, and was using



ABOVE: DESPITE LUKE'S VESTIBULAR CHALLENGES, HE IS STILL A PLAYFUL LITTLE BOY (PHOTO CREDIT: JESSICA LEE)

the stroller less and less. We noticed that swimming was extremely helpful for him; he felt independent in the water. There were still low points, like when he missed his first school field trip because of an episode, but we were seeing some progress that we weren't sure would ever happen.

At four, Luke is still having regular episodes. His complaints are changing from stomach pain to more classical headache/migraine symptoms. He is starting to navigate stairs, but still requires one-on-one attention. He is working on dressing himself.

On Halloween of this year, Luke experienced his worst fall to date. He was walking down the hallway at school at the end of the day and tripped over his feet, which is not uncommon for him. The teacher helped him up, and he looked straight up at the ceiling light, lost his balance and fell straight to the ground. He was unconscious for over a minute and the school called the ambulance.



He suffered a concussion and a lot of anxiety about going back to school; he was scared he would fall again, and that Mom wouldn't be there with him. He was fitted for a helmet once again, to be used at school, along with additional safety measures. We are in the process of having our new dog trained to be a service animal for Luke's benefit as well. Luke is also scheduled to have eye surgery for his strabismus in the new year, but there is some concern as to whether this will help or hurt his current situation.

Despite all the ups and downs of the past four years, I realize just how blessed we are to be raising such an extraordinary little boy, and the impact he has made on our family as a whole. He teaches us so much about perseverance, and I am (slowly) learning that some things are out of my control and how to be okay with that. We don't know what the future holds, but for now I will 'cuddle him up' and remind myself how far he has come and how far he will continue to go.



ABOVE: LUKE BRAVELY GETS SUITED UP FOR HIS EEG (ELECTROENCEPHALOGRAPH) TEST.

New Faces at VeDA

By Andi Bloom, Community Support Coordinator

Hi everyone! My name is Andi Bloom and I joined VeDA this past October as the Community Support Coordinator.

I am a new resident of Portland, Oregon, originally from Minneapolis, Minnesota. My background is in patient support, most recently as a Patient Advocate at a women's clinic. I have also spent time as a Family Coach, helping single moms experiencing homelessness get connected with community resources and move into long-term housing.

I have really enjoyed working with VeDA in the few short months I have been a part of this small but mighty team. I have spoken with many vestibular patients who are just starting their journey to find a diagnosis, as well as patients who have been living with a vestibular disorder for many years, and I have been inspired by their resiliency and desire to learn so they can advocate for themselves and their health.

I am excited to continue to learn more about vestibular disorders and help patients and families find vestibular professionals near them. I am also looking forward to collaborating with volunteers and ambassadors to support VeDA's patient education, medical advocacy, legislative advocacy, and outreach programs. Together, we can raise awareness about vestibular disorders worldwide and make vestibular visible so no one has to suffer alone.

What Is Community Support?

VeDA recently changed the name of our "Patient Support Coordinator" position to "Community Support Coordinator" to better reflect our role in supporting patients AND their loved ones through education and advocacy, and by creating support networks. As a community, we can work toward a day when vestibular disorders are widely recognized, rapidly diagnosed, and effectively treated.

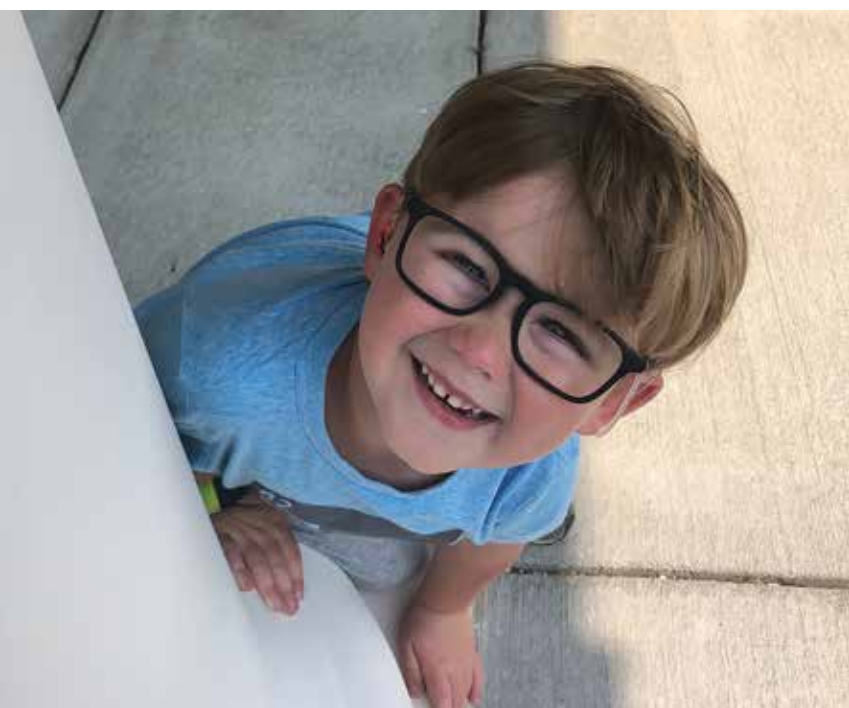


ABOVE: ANDI BIKES TO VEDA'S OFFICES IN PORTLAND, OREGON

In my spare time I enjoy yoga, reading, biking, and hiking with my wife, Ashley, and our dog, Frankie.

Please feel free to give me a call or shoot me an email if I can help you in any way. I look forward to hearing from you!

(800) 837-8428
Andi.Bloom@vestibular.org



"(VEDA) SOLIDIFIED MY BELIEF IN WHAT (LUKE) WAS EXPERIENCING, AND HELPED ME FIND SOLACE IN KNOWING WE WEREN'T ALONE. I WAS ABLE TO GET PRACTICAL ADVICE ON HOW TO HELP LUKE FOR THE FIRST TIME."

- BROOKE MONTGOMERY, LUKE'S MOTHER

Letter To My Therapist

By Kristi DeName, BCB, EMDR II, LMHC
& Cynthia Ryan, MBA

Many vestibular patients experience anxiety, depression, and social isolation, which can contribute to and/or exacerbate your physical symptoms. Counseling can help you manage mental and/or emotional trauma and improve your overall well-being.

One barrier that keeps vestibular patients from seeking out mental health support is that they don't believe a therapist will understand what they are going through.

But there is hope. Many therapists specialize in anxiety, depression, and other challenges common with people with invisible illness.

Here are a few tips for finding a mental health therapist to help you cope with your vestibular disorder:

- Look for a therapist who specializes in anxiety, depression, adjustment issues, chronic illness or chronic pain.
- Psychology Today has an online provider directory with a fantastic filtering system. You can also get a list of referrals from your insurance company and research the provider to learn more about them.
- The patient/therapist relationship is important to the success of therapy. If you are not feeling a connection with your therapist after a couple of sessions it is completely appropriate to seek out a different therapist.

Here is a template you can customize to explain the special issues that accompany your vestibular problems.



To my therapist,

Please know that what I'm going through can be isolating and extremely difficult. I have been diagnosed with (insert your diagnosis) and I'm grieving for my old identity.

I have been seen by a variety of specialized physicians and undergone a full battery of diagnostic tests, many of which were specifically designed to trigger my symptoms. Not knowing what is going on with me and/or receiving an incurable diagnosis is demoralizing. It has taken months or years to finally find a doctor who can provide me with an accurate diagnosis and offer a treatment plan, which may or may not be successful.

My family, friends, and coworkers don't understand what I'm going through because it's invisible. Some of them think I'm making it up or exaggerating my symptoms. This makes me question my sanity.

My mental and physical symptoms are: (insert your symptoms here, e.g. depression, anxiety, irritability, loneliness, brain fog, fatigue, suicidal ideation, etc.).

When my symptoms are at their worst they lower my quality of life, keep me from attending social events, and cause me to call in sick to work (a lot) and/or have resulted in me being unable to work. I am no longer the person I once was. I have sought treatment after treatment to find something to help me feel better and have lost hope. I have no energy, which depresses and frustrates me. I often feel useless because I can't do even simple chores. It especially saddens me when others, including doctors and family, do not understand and say that it's "just stress" or suggest that if I just did things differently I would get better. Sometimes, I feel like a burden to my loved ones and/or my employer.

When my symptoms are lessened I am anxious that they will return. I also feel anxiety around trying out different medications because I have had some bad experiences. I fear aging and my symptoms worsening despite my extreme efforts to heal and manage them. I fear I'll never achieve the goals I had planned for myself. I like being a part of forums to feel less alone, however, sometimes they give me anxiety when I hear about others who have not recovered.

I do my best. On days I feel better I tend to overdo it to compensate for the days I was in bed, restoring myself. Sometimes that leads to a relapse. When symptoms heighten again I feel hopeless. I remind myself that I can get through this. Most days I remain as strong as I can and diligently stay on top of my treatment regime. I am open to new ways to manage my symptoms, both naturally and medicinally.

There are some things I can control, such as eliminating known dietary triggers, modified exercise, physical therapy, moderating my social activity, medication and/or supplements, and stress management. It is difficult to manage symptoms due to triggers outside my control (e.g. hormonal changes, air pressure or altitude changes, weather, bright lights, loud noises, etc.).

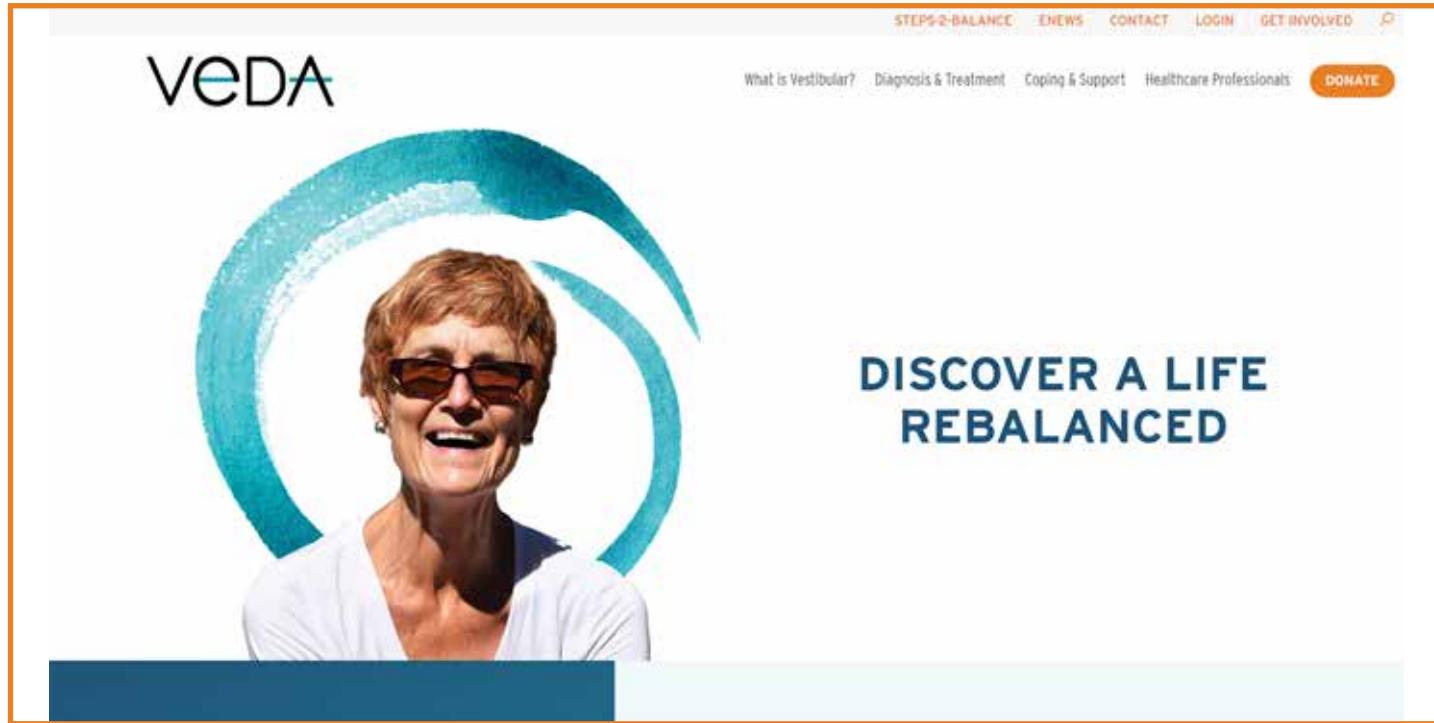
I work hard to find my "new normal." However, I am often exhausted and cognitively fatigued because my brain and body are working triple time.

Please take some time to learn about vestibular disorders so you can understand what I'm going through. The Vestibular Disorders Association (VeDA) has lots of useful articles (vestibular.org).

Thank you so much for your patience and understanding.

NEW WEBSITE COMING SOON!

(SNEAK PEAK)



SPECIAL THANKS!

SPONSOR



WELCOME!

New Balance Benefactors

(>\$250 one-time gift)
Jane Shelby
Bruce Wixson
Jim Hainlen

New Balance Society Member

(>\$5,000 lifetime gifts)
Kathleen Stross

Using Visual Images and Videos to Help Patients with BPPV Describe Vertigo

By Jeremy Grisel, DPT

People who have vestibular disorders usually suffer from vertigo, which is a sensation of spinning or motion. This experience is difficult to describe, which can make communicating it challenging for both the patient and the healthcare provider.

Researchers wanted to see if using pictures or videos that represented a certain sensation of movement experienced during a vertigo attack might help patients with Benign Paroxysmal Positional Vertigo (BPPV) describe their experience.

To do this, people who had been diagnosed by a board-certified physician that they had BPPV were entered into a study. These patients were put into groups that were either shown pictures or videos representing movements that one might experience during an attack of vertigo. These patients were then each put into the Dix-Hallpike position, which was established to reproduce the symptoms of vertigo someone with BPPV experiences. It involves lying backward with the head hanging off the exam table and angled toward the left or right ear. The examiner usually holds the head of the patient and examines the eyes to look for a nystagmus (a rhythmic beating of the eyes) while in the position.

After the maneuver was performed, each person was asked to select the pictures or videos that best described the motion that he or she felt during the Dix-Hallpike maneuver. Each patient was allowed to select as many pictures or videos as needed.

The researchers found that all patients were able to select pictures or videos to describe their vertigo. They also found that the direction the patients described using

the videos matched the direction that the eyes moved during the quick phase of the nystagmus while experiencing vertigo.

The researchers concluded that patients can easily use visual images to describe their experience of vertigo. They also reported that for some, being able to describe the vertigo experience using the videos or pictures had a calming influence on them. It seems that the images gave them a language to explain how they felt.

REFERENCE

Holly JE, Cohen HS, Masood A. Assessing misperception of rotation in benign paroxysmal positional vertigo with static and dynamic images. *Journal of Vestibular Research* 29 (2019) 271-279.



What is a Qualified Charitable Distribution?

By Cynthia Ryan, MBA

Do you have an Individual Retirement Account (IRA)? If so, here's a tip that could help you reduce your tax burden. Once you reach 70 1/2 you are required to withdraw what's known as a "Required Minimum Distribution" (RMD) from your Traditional IRA each year. These distributions are treated as taxable income. However, by gifting your RMD (up to \$100,000) to a qualified charity like VeDA, you can exclude the gifted amount from your taxable income. This strategy is referred to as a Qualified Charitable Distribution (QCD).

(PRO TIP: EVEN THOUGH YOU ARE MAKING A CHARITABLE GIFT, YOU CANNOT INCLUDE THIS AMOUNT IN YOUR ITEMIZED DEDUCTIONS.)

With Congress passing the Tax Cuts and Jobs Act in late 2017, it doubled the standard deduction for individuals and joint filers (\$12,000 and \$24,000, respectively, in 2018). This significantly reduces the number of people who will be itemizing their deductions. If you were itemizing your charitable gifts and are now taking the standard deduction, the tax benefit of the charitable gift is lost.

Here are some benefits you may receive by making a QCD gift:

- Satisfy some or all of your Required Minimum Distribution
- Reduce your taxable income

Reducing your taxable income may provide additional benefits, such as:

- Reduce the amount of tax on your social security benefits
- Reduce the cost of Medicare Part B and Part D premiums
- Help you avoid exposure to the 3.8% net investment income tax
- Allow you to qualify for certain tax credits that have income caps

The distribution must be made directly from your IRA trustee to VeDA.

The QCD can also be accomplished with Inherited IRAs, where the beneficiary receiving the distribution is older than 70 1/2.

If you have questions on whether making a QCD from your IRA is a strategy that may benefit you, we recommend that you speak with your tax professional.

Questions? Contact Michelle Eyres at (800) 837-8428 or michelle.eyres@vestibular.org.



A Caregiver's Journey

By Stephen Haslam

When you accept the challenge of being a caretaker for someone with vestibular issues you may think you know what you are getting into. Many people don't realize that being a caretaker will have a profound impact on your time and energy, your emotional equilibrium, your relationships, and your lifestyle.

Here are a few lessons I like to think I have learned (although I still struggle with them every single day).

HOW I BECAME A CARETAKER

When I was 55 years old my father died and my mother came to live with me and my wife in Houston, Texas. All of her life my mother has had problems with her balance and attacks of vertigo. She has always called herself a "dizzy broad," humor that she uses to lighten a serious situation. Often I'll see her walking across the room and start to lose her balance, upon which she does a little Irish jig to catch herself before she continues slowly onward.



YOU CAN HELP.

DONATE

Your gift helps VeDA support vestibular patients, reduce diagnosis times, and improve treatment outcomes. You can donate online or return your check in the enclosed envelope.

To donate, visit vestibular.org/OTL.

YOUR SUPPORT MATTERS

Luke was born with a damaged vestibular system. Thanks to donors like you, his family was able to get practical advice on how to help Luke, and reassurance that they are not alone.



MEET LUKE, WHO HAS STRUGGLED WITH IMBALANCE SINCE BIRTH.

I thought being a caretaker would amount to such things as helping her make her bed so she would not have to bend over. Doing that kind of thing on a daily basis is quite simple in comparison to grappling with the emotional challenges of caregiving.

NO FAULT, NO BLAME

It took me some time to understand that my mother's vestibular problems are not some burden that came upon her, and as a result, upon me, because of something she did wrong. Regardless of how her condition came about, it is her condition and she has no choice but to live with it.



ABOVE: STEPHEN & MYRRH HAVE LEARNED A LOT ABOUT THE IMPORTANCE OF SELF-CARE AS CAREGIVERS FOR STEPHEN'S MOTHER, EILEENE.

I do have a choice. I could choose to let my brothers or sisters take care of her. I could choose to help her find other support services to look after her special needs. But if I choose to accept her into my life, and play the caregiver role, I can

no longer blame her for burdening me with an imposition into my lifestyle. I made that choice, not her, so I can no longer blame her for the frustrations that come along with it.

IT'S HER PAIN, NOT MINE

She describes her symptoms to me repeatedly. It has taken me many holier-than-thou years to realize that a little empathy can free me as much as it can support my mother. I am not responsible for causing the pain and fear she lives with. I am not required to actually feel it, and I am not responsible for healing it.

UNDERSTANDING

Can I ever truly "understand" a condition that will never go away?

Earlier in my work as a minister, my mentor developed pancreatitis and experienced terrible pain as a result. As I sat with him I remember thinking that when I get sick there's a part of me that knows I'll be well in a few days, or at the outset a few weeks. I began to wonder, "What would it be like to have an actual pain or fear that will never go away, no matter what I think or do, but is only likely to get worse?" It must be terribly debilitating and depressing.

About 15 years ago I ruptured a disc in my lower back. I remember once, while taking steroids for the pain, for an hour or so I experienced a slight attack of vertigo. I hope I never go through that again. Fear of that experience is what my mother lives with every moment of every day.

One of the most frustrating things for my mother is for people to say to her, "I

understand your condition." She shakes her head and tells you that you could not understand. Then she explains her pain and fear, gets a confused look on her face and says, "I guess I can't explain it right." I believe she is trying to tell me, "I desperately want you to understand," while at the same time saying, "You can't understand no matter what I say or do." Both of those are true. She desperately wants understanding and tragically feels no one can understand.

I have found that it works better for me to acknowledge, "Yes, I may not be able to understand what you experience. It must be difficult. So what you and I can focus on is what we can do about this difficult situation." Ironically, when I do that she feels more understood!

WHY IS SHE SO IRRATIONAL?

It is difficult to think rationally and make good decisions when you are in pain or afraid.

I remember that when I broke the disc in my lower back the pain was so excruciating I could not focus on anything else. Pain was everything. All I could do was hope the pain would lessen in an hour or a day or with enough pain killers, although I had no good reason to believe it would change. Seeing ahead into a positive future without that pain was completely impossible.

Once, when she was undergoing some tests, the doctor's assistant put my mother in a position that caused her to have a vertigo attack. Neither the assistant nor I knew how to perform the Epley maneuver that would stop the dizziness. In that moment it was unreasonable for me to expect her to "be positive." All I could do was get the medication she needed, bring it back to her, and wait with her while it took effect.

In such moments, I feel my own frustration

building because I want the uncomfortable moment to be over. But in doing so I am making the situation about me, not about her, which adds more emotional pressure to an already difficult situation. I've learned to take a deep breath, step back, slow down and let her take whatever time she needs to talk through her fear.

SLOWLY LOSING HEARING

My mother has been slowly losing her hearing for many years. Most people think they just need to talk louder, but that only causes more problems. Her hearing aids boost sound, but damage to her inner ear makes it difficult for her brain to understand the sound to be more than just noise.

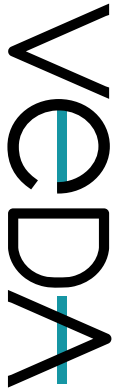
In fact, her brain often reinterprets what we say, so she literally believes we said something else. In the past I thought she just didn't listen. Now I understand that it's a hardware problem, like a short in her circuits. Actually, she can come up with some pretty funny interpretations, so we all get lots of laughs. But we can laugh because we know it's not anyone's fault. It's not her fault for not listening. It's not our fault for not being clearer. I have learned to speak slowly and clearly and look directly at her so she can read my lips.

It must be terribly frustrating to sit with a group of people who are talking and just hear noise. For some reason, in group settings, where there is lots of noise, she will begin to feel dizzy. So we don't go to parties or restaurants often because the noise is physically stressful. As a result, her world has shrunk.

IT'S NOT JUST ABOUT ME

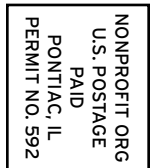
The decision to have my mother live with us affects my wife, Myrrh, as much as it affects me.





5018 NE 15TH AVE, PORTLAND, OR 97211, USA
800.837.8428 | INFO@VESTIBULAR.ORG | VESTIBULAR.ORG

CHANGE SERVICE REQUESTED



When Myrrh and I decided to buy our house we purchased a place with much more room than we needed because we expected at some point to be caretakers for our parents. How lucky am I to have a wife who would make that choice?

I won't go into the dramatic, challenging, and often entertaining mother, son, daughter-in-law dynamics. Suffice it to say that I am always appreciative of the adjustments other people in my life have to make to support my mother.

While her circumstances may require us to adjust our lives for her, my mother doesn't want everything to revolve around her. So we are very conscious to make sure everyone gets support.

Myrrh is a professional artist with a studio (myrrhhaslam.com) in our home. When she needs to focus we let everyone know to stay out of her way. I need physical exercise to keep myself balanced, so we make sure I have time to play pick-up basketball games at the gym. Sometimes I will join Myrrh on a painting trip for about a week so that we can have time together, just the two of us. During this time one of my sisters will fly out to look after our mother. I keep all brothers and sisters informed and up-to-date on how she is doing so they can understand and do whatever they can to help.

WHY DO I DO IT?

I care for my mother because I care about her. I'm sure you have someone in your life who you feel this way about. The caregiver relationship is not always easy, but patience, empathy, and self-care can help you maintain your sanity and build a stronger bond.

(The above article has been abbreviated for space. You can read Stephen's full story at vestibular.org/caregiver.)



“CARERS” PLAY AN IMPORTANT ROLE IN THEIR LOVED ONE’S RECOVERY. THEY, IN TURN, NEED THEIR OWN SUPPORT NETWORK.

LEARN MORE AT VESTIBULAR.ORG/FSN