



On the Level

Quarterly Newsletter of the Vestibular Disorders Association

Two Poles & a Vestibular Disorder— My Portland Marathon Story

By Melissa Bosserman, MS, CCC-SLP

“HEY! Where’s the snow?” I hear for the umpteenth time. I crack a wry smile, but inside I’m not laughing. If only they knew.

People stare at me when I walk. At first, it made me uncomfortable, until I decided to stare right back just as intently as if *they* were the strange sight.

It’s true—I am quite the strange sight with my black spandex shorts, green tank top, black gloves, and bright red Leki Nordic walking poles. It’s really the poles people are staring at, not me. They are simply curious and wondering why I am walking strangely with what appears to be ski poles.

In the summer of 1997, I was a typical thirteen year old girl, excited about traveling to visit family on the East coast. My world was shattered on June 5th, when



Melissa Bosserman—who suffers from multiple vestibular disorders—completes the Portland Marathon!

my ears did not “pop” as they should while flying on a commercial airplane. Instead, the round and oval windows of both ears ruptured. I had boarded the airplane with excellent balance, only to leave the same airplane with terrible dizziness and nausea.

Continued on pg. 2



VEDA goes “social”

- VEDA Tweets! Follow us on Twitter (@vestibularveda)
- Connect with VEDA on LinkedIn!
- VEDA on Facebook—if you like VEDA, “Like” us on Facebook! VEDA has almost 3,500 Facebook followers already—help us top the 4,000 mark! Go to facebook.com/vestibulardisorders.

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Nordic Walking (continued from page 1)

I was diagnosed with bilateral perilymph fistulas (PLFs) and endolymphatic hydrops. At first, I could not function because of the constant dizziness, nausea, visual disturbances, brain fog, ear pain, tinnitus, and headaches. I



Melissa Bosserman after surgery related to her vestibular disorders.

missed three years of school and ended up dropping out because I could not even do the work at home. My symptoms gradually improved, allowing me to slowly increase my activity. Treatment consisted of multiple rounds of bed rest, bi-

lateral surgical repair of the PLFs, endolymphatic sac decompression, vestibular therapy, medications, and dietary modifications. By the summer of 2000, I began taking classes at the local community college with the assistance of disabled student services, a tape recorder for note taking, and anti-nausea medication. My motto that kept me going through the worst days was this: "You can vomit at home and do nothing, or you can vomit out there and accomplish something."

Ten years after my injury, I graduated with a Master of Science in Speech and Hearing Sciences from Portland State University and began working full time as a speech-language pathologist. Even after all this time, I still have symptoms, mostly a constant mild dizziness. There are good days and bad days, but I have learned how to adapt and manage the symptoms.

As a younger individual with a vestibular disorder, it was frustrating and difficult to find a form of exercise that felt safe (low risk of fal-

ling or re-injury), provided good cardio, and was fun. My doctor had encouraged me multiple times to try walking—it was the safest form of exercise, he said. Unfortunately, the horizon bounced up and down with each step; I felt like I was going to fall when I got tired; and it was boring. As I browsed a sporting goods store in 2008, the solution came to me—two hiking poles. I bought them and taught myself the Nordic walking technique through instructional videos and articles on the Internet. When I walked with the poles, it felt more secure and interesting, burned more calories, and engaged my abdominal and arm muscles.

"YOU CAN VOMIT AT HOME AND DO NOTHING, OR YOU CAN VOMIT OUT THERE AND ACCOMPLISH SOMETHING."

For the past three years, I have been an avid Nordic walker. I joined a local walking club, entered races, and gradually increased my distance and speed. I find that when I don't get out and walk, the dizziness and visual disturbances increase; whereas, if I do get my walk, I am better. Last year, I walked my first full length marathon—26.2 miles.



Melissa's medals... and motto!

This year, I competed in the Nordic Walk division of Portland Marathon for a second time. I walked 26.2 miles in 5 hours, 50 minutes. I won first place in the women's

Nordic Walking (continued from page 2)

Nordic Walk division and second place overall for the Nordic Walk division. It was not easy! I was so terribly dizzy when I finished that I had to lie down on the sidewalk. After a couple of glasses of orange juice and a brief rest, the dizziness went back to “normal.” My muscles, on the other hand, were very sore and stiff for four days afterward!

People say that completing a marathon is life changing. In a way, it isn’t—I am still me, and I still have a vestibular disorder. Yet in another way, it is because I regained the confidence in myself that I will persevere and have the inner strength to push myself beyond the barriers.

The 2011 Portland Marathon was my last race as a Nordic walker. Over the summer, I discovered that I no longer needed to rely on the poles for balance and I increased my speed by learning “race-walk technique.” I have recently begun to compete at local Track and Field race-walking competitions and am training with hopes of qualifying to compete in the Team USA Olympic Trials held in Eugene, Oregon this summer.



Until then, happy walking!

“I regained the confidence in myself that I will persevere and have the inner strength to push myself beyond the barriers.”

About Nordic Walking

As a person with a vestibular disorder, I have found Nordic Walking to be a safe and enjoyable method of exercise that promotes greater feelings of stability. Nordic walking involves actively using two poles, similar to trekking and ski poles, which have a slanted foot. The poles should be long enough to be held comfortably with the arms bent at a 90 degree angle when planted by the feet. The motions of Nordic walking involve an alternating rhythm and trunk rotation. The opposing arm swings forward and plants the pole at an angle slightly behind the leading foot. As the walker rolls through the foot, she pushes off with the pole, extending the arm behind and propelling herself forward. This results in an increased stride length¹.

The benefits of Nordic walking when compared to regular walking are increased heart rate, increased oxygen consumption, increased caloric consumption, decreased perceived effort, reduced fatigue, improved aerobic capacity, better mental health, improved endurance, and improved coordination of movements^{1,2,3}. No studies have been conducted on balance and Nordic walking to date, although Church et al (2002) notes, “The use of Nordic walking poles is particularly promising, as the poles provide stability that may promote physical activity among older individuals and those with orthopedic and balance concerns.”

References:

- ¹ Kocur P, Wilk M. Nordic Walking—a new form of exercise in rehabilitation. *Medical Rehabilitation*. 2006;10(2): 1–8.
- ² Church T, Earnest C, Morss G. Field Testing of Physiological Responses Associated with Nordic Walking. *Res Q Exerc Sport*. 2002;73(3):296–300.
- ³ Strombeck BE, Theander E, Jacobsson LT. Effects of exercise on aerobic capacity and fatigue in women with primary Sjogren's syndrome. *Rheumatology*. 2007;46(5):868–871.

Tips on Increasing Your Activity Level and Managing Fatigue



By Claire Haddad,
VEDA Board Member

Fatigue is a common symptom of vestibular dysfunction because your body's system is working hard to keep you balanced. Here are some tips to help manage your fatigue so you can live a happy and productive life.

Know your energy level: How much energy do you have on a typical day?

Some people may have a relatively stable energy level, while others may find that it fluctuates within a range based on weather changes, allergies, diet (influences of salt, alcohol, caffeine, etc.), and even unknown factors. Some may have a “good day energy level” and a “poor day energy level.”

Understanding one's limits is the best way to maximize your energy. The key to feeling well on most days is to make sure your activity level does not exceed your energy level.

Know what depletes your energy: How do you avoid the energy zappers?

Many people experience increased vestibular symptoms (e.g. dizziness, brain fog, sensation of movement, visual disturbances, etc.) when they are exposed to a lot of stimulation. These situations might include: going to the shopping mall, the grocery store, or a crowded/loud restaurant or looking at busy environments such as patterned carpets, venetian blinds, windshield wipers, ceiling fans, passing cars, fluorescent lights, etc.

While you don't want to isolate yourself, there are some activities that aren't worth zapping your energy, especially if you are trying to accomplish something that is more important. For example, shopping on-line is a good alternative to going to the shopping mall. If you must go shopping, pick a time when the mall is not so busy, either when it opens in the morning, or just before closing.

How to conserve energy: Plan your day/week well.

It sounds simple: planning your activities is key to staying within your energy level. “Pushing through” each day beyond your energy level will likely overwhelm you and lead to increased symptoms with longer recovery times.

Determine the best time of the day to complete activities. Some people feel better in the mornings when they are fresh, others feel better in the afternoons once they've been up for a while and have acclimated to being upright against gravity. Schedule activities in the part of the day that you feel your strongest.

If you work, organize yourself the night before (lay out clothing, put car keys in a central place, make a lunch) to minimize running around in the morning and zapping your energy before you even get out the door.

How to restore energy: Pull back when you've overdone it.

Even before you bump up against your energy limit, take short, restorative breaks, such as lying down and listening to music or meditating for 15 minutes. Do not watch TV – it is a stimulating activity. If you work, periodically go to the restroom just to take a “rest.”

Extra energy for a special event

Going to a very challenging/unusual event requires special planning. Never plan an activity for which you do not have an exit plan. Make certain that you can leave or quit if you become overwhelmed; take breaks at a restroom or quiet side room.

If you have to go to a challenging event (e.g. going to the airport, a wedding, a large party, etc.), many people benefit from resting very well the day before and allowing plenty of time for recovery the following day.

Tips on Increasing Your Activity Level - continued from page 4

Increase your energy level: Increasing tolerances and endurance

Strengthening your vestibular system may allow you to tolerate better the situations that exacerbate symptoms and deplete energy. If you have been recommended to do vestibular exercises, try to complete them at least 3-5 times weekly to increase your tolerances and endurance. Walking is a good vestibular rehab exercise and keeps the muscular-skeletal system strong.

Many physical therapists have started to incorporate the the Wii Fit (an interactive video game) to strengthen balance. You can begin these activities slowly to increase strength, endurance, balance, eye-foot coordination and reaction times. Tai Chi is another physical exercise that has been shown to improve balance. If you can't get to a class, Dr. Timothy Hain sells a DVD for home use.



Make sure to eat a balanced diet and drink lots of water for hydration; reduce/avoid caffeine and alcohol.

How to increase your energy level/reduce stress with alternative therapies

Alternative therapies, such as acupuncture, reiki (energy healing), and cranial sacral work (done by a chiropractor), may reduce stress levels and even improve vestibular symptoms. With fewer symptoms, people generally feel an energy increase or can tolerate stimuli better. Not every therapy may have an effect and you may have to do them frequently (maybe 6-8 sessions in 2-3 months) to have a noticeable effect.

Other energy drains: Vision trouble and sleep difficulties.

People with vestibular disorders often become more dependent on their eyes for balance. As a result, any problems with vision will exacerbate vestibular problems and add to the energy drain. Make sure to have your eyes checked regularly. Even if your vision is fine, you may consider seeing a behavioral optometrist if you believe vision issues are contributing to your vestibular problems. Also, any sleep difficulty (e.g. insomnia, sleep apnea etc.) that prevents a restful, restorative night sleep should be investigated.

Clarify your energy level: Keep a diary

Keep a diary for a month and document your activity level and your energy level each day. Is your activity level exceeding your energy level? What can you change? If your symptoms are particularly influenced by diet (especially Meniere's Disease), then track your diet as well.

Sue Hickey's book *Finding Balance: Healing from a Decade of Vestibular Disorders* is the best example of someone who successfully kept a diary, not only to better manage her energy level, but to discuss her symptoms with her doctor. This resulted in better treatment and outcomes.

Explain your energy limits to friends and family

Talk to family members and friends about how you are trying to increase your activity level when possible. You may be willing to be more social, but you know you risk disappointing them if you have to cancel on them as a result of increased symptoms. Educating your friends and family in advance about vestibular disorders and the often unpredictable nature of symptoms will likely result in greater understanding and less frustration. Refer them to the Vestibular Disorders Association's website (www.vestibular.org) for many free articles to help educate your loved ones about vestibular disorders.

New Technologies: The Balance Belt

Many people who suffer from vestibular disorders – especially seniors – have difficulty maintaining their balance. With unsteadiness comes an increased risk of falling and injury, the result of which is often that the sufferer becomes reclusive to avoid this risk and the unpleasant embarrassment that accompanies it.

However, balance-impaired individuals may soon be on the move again! Researchers are developing new technologies to help keep patients upright, encouraging them to exercise and remain active.

Conrad Wall III, director of the Jenks Vestibular Diagnostic Laboratory at Massachusetts Eye and Ear Infirmary and a Medical Advisor for VEDA, has developed a “balance belt” designed to help people stay mobile longer by enhancing their sense of balance.



This two-pound belt is equipped with motion sensors that trigger a vibration when the wearer begins to tilt to one side. The person intuitively leans away from the vibration, causing them to return to their “normal” vertical position.

In a Boston Globe article, Wall reports that

THE BALANCE BELT IS DESIGNED TO HELP PEOPLE STAY MOBILE LONGER BY ENHANCING THEIR SENSE OF BALANCE.

the belt was able to reduce the risk of falling among seniors who were trained to walk with it from 80% to 20%. Wall says that Balance Tek - the company he created to market the belt—will initially make the belts available to physical therapists, who will use them in a clinic setting before sending them home with patients.

Fay Horak, a physical therapist and professor of neurology at Oregon Health & Science University and a Scientific Advisor for VEDA, has developed a similar type of belt that will emit audible signals to alert the wearer that they are tilting left, right, forward or backward.

For the thousands of people afraid to leave their homes for fear of falling, these tools lend hope that they can get back on their feet and begin to explore the world once more!

Lazar, Kay. "Learning to Restore Balance." *The Boston Globe* 16 Jan. 2012: 1-5. Web. 26 Jan. 2012.

Balance Tek. <http://www.balancetek.com>. Updated Sept. 17, 2010. Accessed Jan. 27, 2012.

**"THE LAST OF HUMAN FREEDOMS
IS TO CHOOSE ONE'S ATTITUDE
IN ANY GIVEN SET OF
CIRCUMSTANCES."**

**VICTOR E.
FRANKL**



A New Face at VEDA

Dear VEDA Members,

It is my pleasure to join with you, the VEDA staff and Board of Directors to elevate awareness for vestibular disorders worldwide and to help affect real change in the medical community to reduce the time it takes to diagnose a vestibular disorder and improve treatment outcomes for people suffering from inner ear balance problems.

I know I have some big shoes to fill. Our former executive director, Lisa Haven, was (and is) a dedicated advocate for people with vestibular disorders, possessing a deep understanding for, and scientific knowledge of, the many cognitive, physical and emotional ailments people suffering from vestibular disorders are subject to. I am fortunate to have had the opportunity to learn from her, if only for a short time.

My own experience with vestibular disorders goes back 30 years. I remember waking up in the middle of the night to my mother calling for help. Her bedroom had begun to spin around her, and with my father out of town on a business trip it was up to me and my older sister to call 911. Needless to say, the sight of a half a dozen fireman surrounding my mother's bed was imprinted on my impressionable teenage mind.

It was years before my mother was accurately diagnosed with Meniere's Disease. Over the past 30+ years she has endured an endless series of tests and treatments, with varying degrees of success. She has continued to have periodic spinning "episodes," and over the last decade or so her hearing and balance have decreased dramatically.

I've seen how this disease has impacted a close member of my family. My earliest memories of my mother are of an energetic, outgoing woman who loved to engage with people. But with the loss her hearing and increasing unsteadiness, she most often retreats into a book rather than going to the coffee

shop or taking a walk.

No doubt this story is familiar to many of you. Likely you are reading this because you or someone you know suffers from a vestibular disorder and your life has been changed as a result. I know it hasn't been easy. But do you know what? It can get better!

For over 29 years VEDA has advocated for people with vestibular disorders, providing information and support, and engaging the medical community to help improve services for patients. We have a strong base of supporters (you!), but there are still hundreds of thousands of people out there who don't understand what it means for "dizzy" to be one's normal state of being. Looks like we have our work cut out for us.

Change is in the air at VEDA, and we look forward to working with you to help make "vestibular" a household name.

Best Wishes for a Happy and Healthful Year,

Cynthia Ryan, MBA
Executive Director



Come On Everybody, Do Your Exercise!

Staying fit is an important part of a person's ability to compensate for imbalance due to a chronic vestibular disorder. Participating in sporting activities can be a great way to stay active and can be very helpful as a sort of vestibular rehabilitation therapy (VRT), as long as it is an activity you and your doctor agree is OK for you to do.

You can also incorporate VRT-type exercises into your daily routine. One VEDA member describes how she found ways to turn household chores into an opportunity to practice her vestibular exercises.

"After 6 months of doing the VRT exercises exactly as they told me, I started to find how to do the same motions within my life instead of in addition to my life. The key is to find that motion in something you like to do, and then repeat it the number of times your VRT treatment dictates.

"For example, one of my prescribed exercises was to toss playing cards on the floor and turn before picking each up...ho hum! Before long I found that I was so bored I put off doing the exercise, or simply skipped it all together!

"But when I realized that I could go outside and pick up weeds or leaves in the garden, turning 1/2 turn between each and 10 turns in a row (per my VRT plan) it became part of my life. I can't pick up all the leaves, but I can help my family with them and get my exercise done at the same time.

THE KEY TO VRT EXERCISES IS REPETITION: YOU MUST REPEAT THE MOTION OVER AND OVER TO ADAPT, WITH THE GOAL THAT EVENTUALLY YOU CAN REDUCE OR ELIMINATE THE TROUBLING SYMPTOMS.

"Try picking one exercise for each location in the house and/or at work. For example, in the bathroom I have a paper in front of me that looks like a checkerboard with black and white intermittent squares. There I do my vestibular exercise where I move my head while looking at one square to help my visual stability. (The goal is to decrease the squares from appearing to move when I turn my head.)

"Yes, I still skip them now and then, but without making them part of my life, I would not have been able to keep them up."

What motivates you to practice vestibular rehab therapy? Send your ideas, input and questions to: info@vestibular.org. You can also join in on related discussions on our Facebook page at <http://www.facebook.com/vestibulardisorders>.

**Always make sure to consult with your physician before attempting a new exercise or adjusting your prescribed exercises to fit your lifestyle. If a particular activity or movement is causing you problems, stop and talk to your doctor before continuing.*



The Artistic Expression of Vestibular Disorders

How do you express creativity? Have you ever tried picking up a paint brush, or molding a piece of clay?

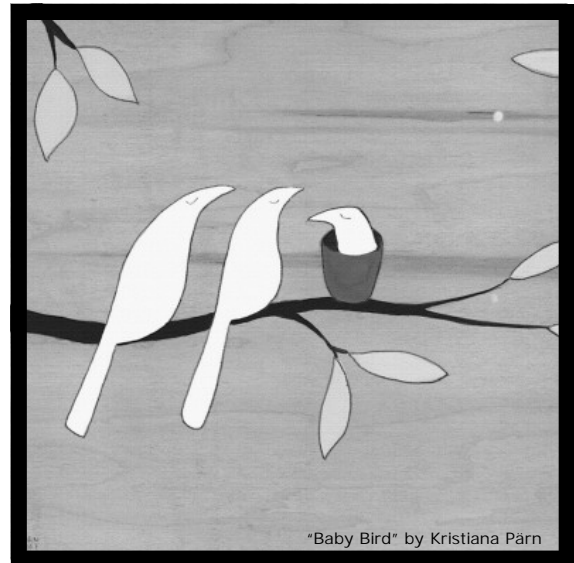
An article in the Los Angeles Times¹ reported that people who have suffered migraines, strokes, and other brain-related injuries often exhibit new-found artistic tendencies, while artists may experience a shift in style after the onset of symptoms.

Researchers have begun to study the interconnectedness of biology and creativity, including the contributions of inhibition, obsession, and other personality traits.

"There are virtually no situations where brain damage makes things better," says Anjan Chatterjee, a neurologist at the University of Pennsylvania. "But art is one of the few complex aspects of human cognition that doesn't necessarily get worse."

In some cases, it becomes more beautiful.

1 Sohn, Emily. "After brain damage, the creative juices flow for some." *Los Angeles Times* 20 May 2011: 1-2. Web. 26 Jan. 2012. <<http://articles.latimes.com/2011/may/20/health/la-he-diseases-art-20110516>>.



They Don't Believe Me When I Say I'm Dizzy!

Many vestibular patients report that people don't believe them when they describe their physical symptoms or explain why they have persisted for so long. Even friends and family just don't "get" it, and may even imply (or outright proclaim!) that they're "faking it."

Here are some direct quotes from people who responded to VEDA's recent survey describing what it feels like to have a vestibular disorder:

It's like being in a weightless place.

To me it's like losing part of your GPS system.

Think of a time you woke up and you were still drunk...minus the party...

I DESCRIBE IT LIKE A CAT WITHOUT THEIR WHISKERS—FELINES RELY ON THEIR WHISKERS FOR BALANCE, JUST LIKE WE RELY ON OUR VESTIBULAR SYSTEM.

I feel like I'm on the Tea Cup ride at Disneyland!

I feel like I'm a bobble-head doll, where everything bounces and moves inside my head.

Imagine you just stepped off a boat or a merry-go-round. If you've ever felt motion-sickness you'll know what I mean!

"Causes of Dizziness" is a publication that can help you define your dizzy symptoms. Visit the online store on our website at vestibular.org to download your free copy.

Thank You!

We thank the following individuals and organizations for their generous donations and pledges to VEDA received August 2, 2011 through December 31, 2011.

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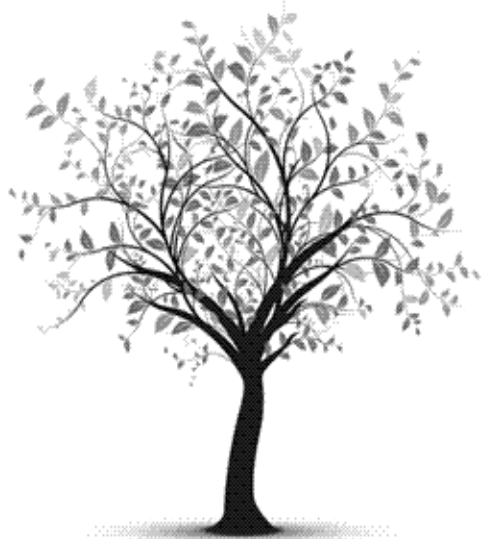
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What Will Your Legacy Be?



Jeanette Welch—a founding VEDA board member—was dedicated to supporting the mission of the Vestibular Disorders Association during her lifetime, and beyond. As a charter member of VEDA's "Balance Society," Jeanette left a legacy that will continue to help people suffering from vestibular disorders now and into the future.

When you make a planned gift to the Vestibular Disorders Association, you'll become a member of our "Balance Society" - a memorial to your commitment to improve the lives of people with vestibular disorders.

For more information about including VEDA in your Will or estate plan, contact executive director, Cynthia Ryan, at 800.837-8428 or via e-mail at Cynthia@vestibular.org.

Yes! I want to help people suffering from vestibular disorders.

Your membership with VEDA helps us provide information on vestibular disorders to thousands of people every year. Thank you!

You can renew your membership and make an additional gift to support VEDA's life-changing work online at <https://www.vestibular.org>, or send your payment with the enclosed self-addressed envelope.

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- Basic \$45 (International)
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Thank you for supporting the Vestibular Disorders Association! With your help we can reduce the time it takes to accurately diagnose vestibular disorders and improve treatment outcomes, helping patients live happy, productive lives.



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The Vestibular Disorders Association (VEDA) is a 501(c)(3) nonprofit organization with a mission to serve people with vestibular disorders by providing access to information, offering a support network, and elevating awareness of the challenges associated with these disorders.

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DID YOU KNOW?

Many artists experience a shift in style after the onset of vestibular symptoms.

Vincent Van Gogh is reported to have suffered from Meniere's Disease. His famous painting titled, "Starry Night" is allegedly a representation of his perception of dizziness.

