



On the Level

Quarterly Newsletter of the Vestibular Disorders Association

On The Other Side of Vertigo

By Karla Droste

I woke up Friday morning and the room was violently spinning. I stumbled to the bathroom, holding on to furniture along the way, hoping and praying it would just go away. It didn't. I felt sick in every cell, horribly nauseous and out of control.



Finally I fell mercifully asleep and prayed that everything would be normal when I woke up. It wasn't. The spinning started up again every time I moved my head. Somehow, Rob got me in the car and we drove the hellish couple of miles to East Bay Family Practice. I felt like I was dying with every pothole.

The doctor diagnosed it as benign paroxysmal positional vertigo, BPPV. She explained that the crystals in my inner ear that help govern balance had been dislodged and were free floating in ear fluid. She left the room with a sober message, "This may take a while to resolve."

I slept through most of that nightmare weekend, except the third day when I must confess I mustered up enough energy to go

have my hair done. Vanity wins out, even in the direst of circumstances. My good husband drove me there and waited as I got a color and cut. Poor Rosie, looking very worried, asked me to please not "hurl" in her chair. I'm sure she was relieved to see me go. I went back to bed for three more days. At least my hair looked good.

The wild, spinning vertigo part of it went away after four hellish days, but the dizziness persisted. It is an unsettling, exhausting whirling sensation, kind of like having my cell phone on permanent vibrate mode. There was a very weird pressure at the back of my head and base of my neck. It felt like my head would just roll off at any minute.

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On The Other Side of Vertigo (cont'd. from p.1)

It took so much energy to walk, talk, turn my head, shave my legs, vacuum the cat hair, or prepare a simple meal. Basically it took everything I had just to live. I fell into bed exhausted at the end of the day.

Power walking got me through. I grabbed my water bottle and put my tennis shoes on and out I went. I especially liked the long, clean lanes of the cemetery, figuring even if I'm totally off-balance the worst that can happen is I will just fall over. Unlike driving, I won't kill anyone.

I never understood how a chronic health issue can affect your self-esteem. What happened to me? I'm

"I never understood how a chronic health issue can affect your self-esteem." - Karla Droste

FUN! A major part of my identity is wrapped around my passionate interest in life. But that was all gone. Why would anyone want to be around me? I was sick. I was creepy. I was tainted. In one horrific moment my health had profoundly changed and I was a different person. It was lonely. It messed with my confidence. Had I lost that part of myself forever?

Thanks to the internet, I know everything about vestibular disorders there is to know. I went to a neurologist who tested me for Lyme disease, Vitamin B-12 deficiency and syphilis (negative). He ordered an MRI. The results of my MRI ruled out the scary stuff, like a brain tumor or MS, giving me great peace of mind. After the MRI, everything inside me changed. I didn't have anything life-threatening. I wasn't going to die.

"I didn't have anything life threatening.
I wasn't going to die."
- Karla Droste



Cont'd. on p.3

On The Other Side of Vertigo (cont'd. from p.2)

My neurologist is the best doctor I've ever had. He asked me questions and actually listened. He treated me as a whole person. I walked out of there feeling hopeful, even safer somehow, knowing I was in expert hands. He encouraged me to keep a diary of my symptoms, which I did for many months. I began to see patterns with my dizziness. For example, it got worse if I was in a hurry, or if I was stressed or frustrated about something or didn't get enough sleep.

I also went to several other specialists, including an otolaryngologist. The best part of that appointment was that I finally got a diagnosis. I didn't have BPPV. Instead I had a condition called *vestibular neuritis*. A nasty virus had attacked one of the vestibular nerves in my inner ear. OK, so now I have a diagnosis. When will it go away?

Before I could even think about getting to the *other side* of this condition I had some serious therapy to go through. I love my physical therapist. She has never given up on me. She listened to me and patiently taught me all the exercises meant to help me compensate. Although they have helped – tremendously – I'm still dizzy.

Many months have gone by since my first crazy bout of dizziness and I'm feeling much better. I'm finding a different, more authentic way of being in my life, discovering parts of myself I didn't know I had. I make meaning out of the hard stuff and I emerge stronger and wiser. I'm learning how to stand my ground and be centered in myself - finding my balance.

I'm also learning to shed a lot of "roles." The vertigo released me; it literally took me out of a lot of obligation. The roles that weren't authentic had to go. They were too draining,

even exhausting. I am moving slower and more languorously through the world. I am *gloriously unhurried*, content with a simple day.

Last night we had dinner with friends. After catching up I found myself talking about the vertigo. I shared pretty openly. It felt good but also a little exposing. I hadn't shared at that level while actually *experiencing* the vertigo and the dizziness. I couldn't. It was enough to just survive it.

Just that morning I had watched a couple of people on YouTube share about their experiences with labyrinthitis and vertigo. I'm not



sure why I never looked for these testimonials while I was suffering from the condition. I noticed that most of them were writing and sharing from *the other side of it* too. We all had so much in common. It is an invisible condition. You don't look sick. No one knows there is anything wrong with you. It is intensely isolating. You can be perfectly healthy, spiritually aware, emotion-

ally intelligent, and it can still hit you. I found out these things:

- ◆ I didn't *cause* it.
- ◆ It's not all in my head.
- ◆ It won't last forever.
- ◆ I didn't "go crazy".

It's not that I want to dwell on all of this, but I'm gaining a perspective *from the other side* that I didn't have while in the midst of it, and I am grateful for that perspective. I hope that I have the opportunity to give it back to others suffering from biological or mental/emotional anxiety. My compassion has increased a hundred fold; it has helped make me even more whole. And that is a worthy way to live - growing and expanding into greater wisdom and wholeness.

Karla's blog: reinventingkarla.blogspot.com

A Workplace Dilemma—What to Disclose to Your Employer

By Laurie D. Rainey, M.Ed.

There is a meeting going on, people are talking easily and intelligently about work. There is a flowing nature to the discussion. Problems and ideas are being shared. Individuals appear relaxed yet stimulated and engaged in the constructive and creative process.

Not if you're like me and suffer from a vestibular disorder. We're there but somehow floating above it all, almost dissociated. We're listening. We're attempting to communicate interest nonverbally as the pressure in our head builds. Maintaining the appearance of professionalism and interest takes a vast amount of mental energy, and it's not even 9:00 AM. Do we



"We are attempting to communicate interest nonverbally as the pressure in our head builds."

excuse ourselves once again with the all too familiar, "I feel a migraine coming on," or do we sit and maintain the pretense of good health, hoping no one notices the glazed look in our eyes? Our thoughts are focused on the way we are feeling, not the task at hand. We question whether anyone notices our discomfort or if we are the subject of office gossip because we are always "sick with something" or a chronic complainer.

Many people with chronic medical conditions face these issues daily. Some are lucky enough to have genuinely supportive employers who value their staff and are willing to go to great lengths to make their work environment comfortable and safe while accommodating their needs. Others are not so lucky.

My personal experience was eye opening. I had no choice but to disclose that I had been diagnosed with bilateral semi-circular canal dehiscence. One day I could walk and the next day I couldn't. There was no hiding that.

I was a school counselor in a large Title I elementary school. I had worked for the school district for almost 20 years and had prided myself on my policy of open disclosure in dealing with staff, students, and families. Over the years there were times I needed to inform my supervisor of family issues that needed my attention and I never felt the slightest bit of discomfort because I trusted my employer immensely. I had no reason not to.

After being diagnosed and having surgery my husband and I kept the school informed, sometimes in great detail, as I attempted to recover. I had been assured that my job would be held for me to return to, but in the end it wasn't. I now realize I disclosed too much. My supervisor took it upon himself, based on my own feedback to him, to determine that I was not well enough to return to work, or, as he stated, "there would be too much pressure for me to feel obligated to return to work." I was devastated.

Should I have disclosed my medical issues with

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A Workplace Dilemma (cont'd. from p. 4)

my supervisor in a direct and honest way? Yes. Should I have disclosed details of my recovery, including setbacks and concerns via email? Probably not. I made the mistake of thinking the people I worked for were an extended family. Boundaries became blurred for me as I sank deeper into my prolonged and painful recovery period. I desperately wanted to return to work and thought maintaining open communication with work was necessary. My world had become so small after the surgery that I reached out to the wrong people. Not bad people, just the wrong people.

The truth is, my employer was running a business and I was simply giving him the tools to determine that I was no longer the highly effective professional I was prior to the onset of my condition. Now that I feel better and able to return to work, my beloved job is no longer mine. I take responsibility for my role in this situation, namely my natural inclination to be honest and direct. I am not, however, responsible for the reaction and response of others.

So the dilemma remains: what do you disclose about your medical condition and to whom? The most important issue is to determine if your condition impacts your ability to do your job. Then consider if the condition impacts your ability to do your job without compromising your physical, mental and emotional health. These are not easy questions to answer but necessary to consider as we adjust to life changes brought on by a chronic illness.

Many of us have worked our entire lives, and trying to salvage

"The most important issue is to determine if your condition impacts your ability to do your job." - Laurie Rainey

our professional life amidst a medical crisis can be an extremely unsettling and traumatic experience.

Take some time prior to disclosing to review quietly and carefully how you are feeling, what your prognosis is, and what accommodations may be useful for you. Do this alone or with someone you trust, such as your partner. Write out your thoughts, imagine what it might be like if you were to receive that note. How would you respond? Be honest. Saying too much while in an emotional state is simply not the best way to advocate for yourself. I know this first hand.

Working is a socially engaging, necessary, and validating experience for many people, even more so for those of us who see those opportunities slipping away because of a medical condition. The most important thing we can do is be honest with ourselves, then deal with others as we hopefully become stronger and accustomed to our new way of existing.

"Problems arise in that one has to find a balance between what people need from you and what you need for yourself." - Jessve Norman



Do You Qualify for Disability?

Does your vestibular disorder impact your ability to work to the extent that you've considered applying for disability? Are you worried about whether or not you would qualify?

In a recent online poll 95% of respondents said that their job was affected by their vestibular symptoms. 46% are no longer able to work, and 31% are either on or have applied for disability.

Applying for Social Security Disability can be a complicated and intimidating process, compounded by the insurance industry's lack of understanding

about vestibular disorders. The following articles give you instructions on how to navigate the disability application process, and hints for how to present your condition in a way that clearly demonstrates your limitations and their impact on your ability to perform the duties of your job.



How to Apply for Social Security Disability Insurance

By Ginger Lanigan, Disability Advocate—
Ginger Lanigan & Associates

If you have worked 5 out of the last 10 years, paid FICA, are under 65 years of age, and have a mental or physical disability that looks like it might last a year or more AND prevents you from working any job, you might be eligible for Social Security Disability Insurance (SSDI).

Applications may be filed online (<http://www.ssa.gov/pgm/disability.htm>), taken at the local Social Security office, or completed and filed by an advocate on your behalf.

Medical notes regarding your disability must be obtained and sent to your local Disability Determination office for review by their doctors.

Information regarding your past work must be obtained and sent to your local Disability Determination Services (DDS) for review by

their Vocational Experts.

If the Disability Determination Services denies your application you have a right to file an appeal or reconsideration. New and updated medical information must be sent in and will be reviewed by a new team at DDS.

If your case is approved, congratulations! Social Security will start to send you your monetary benefit monthly. If your case is denied, you can file an appeal. It can take up to a year for your appeal to be heard by an administrative law judge.

If it is very difficult to work your own disability case. Men tend to downplay their medical issues, and women tend to try to do more activities than they should with regard to their specific disability. Because there are certain criteria that must be met, your best chance of winning a disability case is to secure the services of an advocate or lawyer.

Tips on Applying for Disability for a Vestibular Condition

By Claire Haddad, VEDA Board Member & Boston Area Support Group Leader

1. LIST YOUR MAIN SYMPTOMS.

Do not merely state that you have dizziness or vertigo. Does your dizziness include feeling lightheaded and therefore impact your concentration? Do you have a spinning sensation (vertigo) that impacts your gait and therefore you walk with a cane? Include any impact on your vision. Does it impact your driving or the ability to work in an office with fluorescent lights?

2. LIST THE MAIN RESPONSIBILITIES OF YOUR JOB AND THE COGNITIVE SKILLS INVOLVED WITH EACH ONE.

Emphasize that the **brain** is involved with the balance or vestibular system, and that's why your cognitive skills are impacted. The body maintains its balance by using information from the eyes, feet, trunk, spine and the

vestibular system (inner-ear). All of this information is integrated and processed by the brain and in response messages are sent to various muscles of the body to be in perfect balance. When one or more of these information gathering functions is not working well the brain cannot interpret these mixed signals, resulting in imbalance and often an impairment in cognitive functions.

Some typical cognitive impairments include:

- ◆ poor concentration, memory, and word recall
- ◆ impaired ability to track printed words
- ◆ impaired mental stamina
- ◆ Reduced ability to learn & problem-solve because cerebral attention is no longer assigned solely to higher level cognition.
- ◆ Impaired ability to work at a group's pace, making being a team-player impossible

3. LIST THE PHYSICAL IMPAIRMENTS IN YOUR JOB/WORKPLACE.

- ◆ Can you drive to work in heavy traffic and in the dark with oncoming traffic lights? If required, can you travel for your job?
- ◆ Do you have extreme fatigue? Fatigue can be the result of the vestibular system's impairment causing the brain and the body to work overtime because of the mixed signals they receive. Medications that have a sedative effect (e.g. Klonopin) also contribute to fatigue.
- ◆ Can you work without taking significant breaks during the day? How would this impact meeting in groups, interacting with your manager, etc.?
- ◆ Do you have dizziness/imbalance without standing or walking? Do you have symptoms while sitting down at your desk? You can have symptoms of dizziness/vertigo without provoking it by physical movements. If this is true for you, it is crucial that you emphasize it!
- ◆ Do you have bouncing vision with only slight head movements? How does this impact your ability to enter information into a computer

Cont'd. on p.8



"The brain is involved in the balance or vestibular system, and that's why your cognitive skills are impacted."

Tips on Applying for Disability (Cont'd. from p.7)

or complete other office tasks? Does the movement of other people trigger symptoms? (E.g. hand movements of colleagues in a meeting.) Explain how the vestibulo-ocular reflex is often impaired with vestibular disorders which can cause vision problems and exacerbate symptoms of dizziness/vertigo.

Emphasize the unpredictable nature of vestibular disorders.

For example, you may feel fine one day and completely wiped out the next. A good day may **not** be dependent on going home and resting up. A good night's sleep may be followed by a day with symptoms at their worst.

Emphasize how you can no longer carry out certain responsibilities, or how you would need to take frequent breaks to complete these tasks. This would make it impossible to meet deadlines and be an effective and efficient employee.

It's important to include how you cannot think of any reasonable accommodations that your employer/manager can make to allow your return to your position.

4. LIST HOW LONG IT TAKES YOU TO COMPLETE BASIC TASKS THAT ARE NOT NECESSARILY WORK-RELATED, ALTHOUGH THEY REQUIRE THE USE OF YOUR COGNITIVE SKILLS.

List how many breaks it took to complete the disability forms/materials. Emphasize the help of your advocate/lawyer or family member to complete the paperwork of the appeal.

For example, if it takes you longer to pay your bills because writing out checks requires more concentration, then include such a task in your documentation.

5. INCLUDE INFORMATION FROM AN AUTHORITATIVE SOURCE, SUCH AS THE VESTIBULAR DISORDERS ASSOCIATION (VEDA) – VISIT

[HTTPS://VESTIBULAR.ORG](https://vestibular.org) AND DOWNLOAD OUR FREE SHORT PUBLICATIONS.

Choose short articles rather than entire books. An overview on the vestibular system and the impact on cognitive skills are crucial. Also, if your doctor has a website with information on vestibular disorders, consider referencing the doctor's website or provide some information from the site.

6. OTHER TIPS.

Do not feel constrained by the disability form whether it's the first application or an appeal. Include any information that would give a caseworker an accurate depiction of your disability. However, do not overwhelm them.

Do not discuss your abilities. For example, do not discuss that you still enjoy gardening or going to the movies. *Keep the appeal focused on why you cannot work, even with accommodations.*

This advice assumes that the doctor who has diagnosed your vestibular disorder is advocating for you and is also completing disability paperwork on your behalf. If your doctor does not have a good understanding of your job then it is up to you to make him/her aware of the cognitive and physical impairments at your job and ask him/her to incorporate this information into his/her paperwork submitted to the insurance company. Often the disability forms that the doctor is asked to complete focus on a physical impairment that prevents a worker from performing physical tasks (e.g. lifting objects, etc.). If the doctor has already completed the initial disability paperwork, consider asking him/her to write a letter for your appeal. Request a copy of this letter and send it with your appeal package.

Finally, send all communication to the insurance company by registered mail, priority mail with tracking, or by express mail with a signature required.



Research: Diagnostic Criteria for Vestibular Migraine

Establishing clear diagnostic criteria is essential to helping physicians assess and diagnose patients quickly and accurately.

As VEDA's 2011 survey found, the average vestibular patient consulted with 4-5 doctors before receiving a diagnosis. Every day a person remains undiagnosed compounds the negative impacts on their life and livelihood.

VEDA advocates for decreased diagnosis times for people with inner ear balance disorders, and we applaud the work of researchers whose work moves us closer to this goal.

Dr. Thomas Lempert recently published results of his research into developing diagnostic criteria for vestibular migraine in the *Journal of Vestibular Research*. Following is a reproduction of the abstract of this study:

Abstract

This paper presents diagnostic criteria for vestibular migraine, jointly formulated by the Committee for Classification of Vestibular Disorders of the Bárány Society and the Migraine Classification Subcommittee of the International Headache Society (IHS). The classification includes vestibular migraine and

probable vestibular migraine. Vestibular migraine will appear in an appendix of the third edition of the International Classification of Headache Disorders (ICHD) as a first step for new entities, in accordance with the usual IHS procedures. Probable vestibular migraine may be included in a later version of the ICHD, when further evidence has been accumulated. The diagnosis of vestibular migraine is based on recurrent vestibular symptoms, a history of migraine, a temporal association between vestibular symptoms and migraine symptoms and exclusion of other causes of vestibular symptoms. Symptoms that qualify for a diagnosis of vestibular migraine include various types of vertigo as well as head motion-induced dizziness with nausea. Symptoms must be of moderate or severe intensity. Duration of acute episodes is limited to a window of between 5 minutes and 72 hours.

Source:

Thomas Lempert, Jes Olesen, Joseph Furman, John Waterston, Barry Seemungal, John Carey, Alexander Bisdorff, Maurizio Versino, Stefan Evers, David Newman-Toker. *Journal of Vestibular Research*, 2012, Volume 22, Number 4, pg. 167-172. <http://iospress.metapress.com/content/b23w04k64wk2v631/?id=B23W04K64WK2V631>.

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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 at <https://www.vestibular.org/membership>, or send your payment to PO Box 13305, Portland, OR 97213 with the enclosed self-addressed envelope.

Annual Membership:

- Basic \$40 (e-newsletter only) **email required*
- Professional \$110 (e-newsletter only)
- Shipping (optional) \$5 US/\$15 international (if you would like to receive your newsletter in the mail)

Donation:

- \$25 \$50 \$100 \$150 \$200 \$250
 - Other: \$ _____
 - Charge my credit card monthly \$ _____
- Please make my donation anonymous

Method of payment:

- Check (payable to VEDA in U.S. funds)
- Visa MasterCard American Express
- Please send me information about including VEDA in my Will or estate planning.

Name _____

Billing Address _____

City, State Zip _____

E-Mail _____

Phone _____

Credit Card # _____

Exp. date _____

CSV code _____

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.



VESTIBULAR DISORDERS ASSOCIATION

P.O. Box 13305 * Portland, OR 97213-0305 * USA
(800) 837-8428 * info@vestibular.org
www.vestibular.org * EIN: 93-0914340

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.

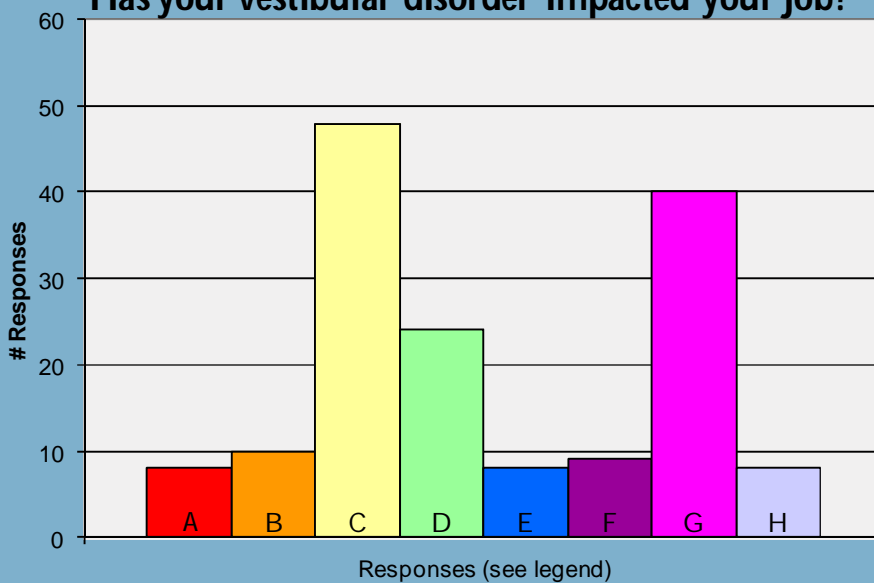
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Attention Professional Members:

If you would like copies of VEDA's free publications co-branded with your clinic's name and address e-mailed to you, contact us at info@vestibular.org

VEDA Online Poll:

Has your vestibular disorder impacted your job?



- A) Yes - I work from home now.
- B) Yes - I've had to reduce my hours.
- C) Yes - I am on or applying for disability.
- D) Yes - I no longer work and do not receive disability.
- E) Yes - I found a different job or started a new career.
- F) Yes - but my employer has provided accommodations for me.
- G) Yes - I still work my normal schedule but struggle to perform the duties of my position.
- H) No - I am able to work a normal schedule without accommodation.