

ON THE LEVEL VEDA

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION

LIFE REBALANCED



My Labyrinthine Journey

By Coral Armstrong, DVM

In March 2008, my busy life, which included full-time work as a veterinarian for small and large animals, helping my husband on our ranch with the horses and cattle, and training my own horses for ranch work and competition, was derailed by the shock of a cancer diagnosis. I was 49 years old at the time and had considered myself healthy. A routine mammogram changed all that, and I was plunged into a novel environment, the world of oncology.

After 18 months of treatment that involved multiple surgeries, dozens of blood tests, many imaging sessions, a year of chemo and biologic therapy infusions, and 7 weeks of daily radiation treatments, I was officially declared NED (no evidence of disease), which is the closest an oncologist will come to saying you are cured. Although I was fortunate to tolerate this arduous process better than most in my situation, it took a long time for me to completely recover my health and even longer to figure out why some things weren't quite the same as before. It was literally years before we figured out that most of my ongoing problems were caused by bilateral vestibular hypofunction. The entire

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UPPER LEFT: CORAL ON A HOUSE CALL; LOWER LEFT: HORSEBACK RIDING IS CORAL'S PASSION; LOWER RIGHT: CORAL'S VETERINARY TEAM

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experience made me learn and grow in some unexpected ways, not the least of which was getting to know so many wonderful and caring people whom I would not otherwise have met.

Many others have described their cancer treatment experiences in great detail. I will just focus on what is pertinent to vestibular problems. It is my opinion that vestibular dysfunction is pretty common yet under-recognized in cancer survivors because it shares symptoms with so many other disease- and treatment-related issues, which can be very difficult to sort out.

Riding horses and working with large animals is dependent on having good balance. I largely took these attributes for granted until there was a problem.

I got through the first couple of surgeries trouble-free, then started infusions of Taxotere, Carboplatin, and Herceptin at the chemotherapy center. Like everyone else, I was pretty scared of the whole process and leery of side effects. The first all-day infusion session went off without a hitch, and I went back to work two days later. I tried to cut back my workload some, and only scheduled routine cases until we knew how I was going to react. I can't say I felt great but I thought I was OK, considering.

On day three, I was in the middle of a very simple procedure that I have done thousands of times, when I suddenly became disoriented, dizzy, had blurred vision, heard ringing in my ears, and felt weak on the right side of my body. Everything looked fuzzy, but I was able to finish and went home.

I called my triage nurse, but had a hard time describing what I was experiencing because I could not think clearly. It was all pretty scary. My oncologist determined it was probably just "chemo brain," and I got better after a few days. My medications were adjusted and I was able to complete all of my infusions on schedule. I had similar, but less intense episodes a few days after each treatment, and accepted this as just part of the deal. I often felt weak, dizzy, and nauseated, but was still able to function pretty well, and of course we all thought it was normal considering the medications I was on. I recall being asked repeatedly by my nurses if I felt any numbness or tingling in my hands or feet (signs of neurotoxicity) but I did not.

Once I finished the chemo I felt a lot better, but kept falling unexpectedly and wasn't very coordinated. I frequently veered when walking, especially if I moved my head, and bumped into doorframes, mostly on the right. I thought I was weak after all I had been through, so I started a self-designed home exercise program with stretching and yoga-type moves, and it seemed to help.

One thing I found particularly vexing was the blurry vision, which

seemed to come on literally overnight, and gradually worsened after completion of treatment. I had always had very acute eyesight and had never worn glasses, so I had a lot of trouble coping. Cancer patients are told they will have some mild visual changes that get better after treatment is finished, but mine did not resolve and seemed a lot worse than I was told to expect. Because I had no experience with this sort of problem, I thought maybe I was just exaggerating its significance.

Finally, I went to an ophthalmologist, who seemed genuinely puzzled by my concerns that the chemo had somehow damaged my sight, declared my eyes healthy, and wrote me a prescription for bifocals.

As part of the exam, I was asked if I had double vision, which I denied.

My eyes had been dilated and I was completely unprepared for how disorienting this would feel. I could not keep my balance walking out of the office, down an unfamiliar long hallway, and had a panic attack (also a new experience for me). I am sure the office staff thought I was crazy or chemically impaired. I was later fitted with contact lenses, which better matched my activity level, and although improved, I still could not see in "real life" as well as I could during testing in the optometrist's office. I found this frustrating but did not know what else to do.

In June 2012, I spent a long and stressful day outdoors in very windy conditions. I woke up the next morning so dizzy that I decided to seek medical attention. I went to my primary care physician, who told me I had "labyrinthitis." She told me to take it easy, avoid windy conditions (difficult where I live) and place cotton in my ears when outside. She expected the problem to improve within a few days, but it did not.

A couple of weeks later I had a routine follow-up

appointment with my oncologist. She told me the problem was likely related to the chemo drugs I had received a few years before, although symptoms usually show up right away during treatment. At that time it did not occur to me that the chronic imbalance and tinnitus that had started soon after my first infusion was related to my current severe dizziness. The doctor expressed sympathy, but did not have any options to offer for relief, so I went back to my primary care physician, who declared this unacceptable. She did not know how to help me, but she sent me to an otolaryngologist whom she thought might. That doctor noted that I had nystagmus and did some basic balance testing in his exam room. He concluded that I had a

vestibular disorder caused by the chemotherapy drugs, and said that he actually saw this problem pretty frequently. Because I did not also have numbness and tingling in my hands and feet, which would indicate peripheral neuropathy, my vestibular problem had gone undetected until it became bad enough that I felt dizzy and sought medical attention. His next words were, "I am sorry, but there is no cure for this. All we have is physical therapy." It seems he didn't think it would be very helpful. However, my previous experiences with physical therapy had been positive, so that sounded pretty good to me. An intervention

that did not involve invasive surgery and toxic drug therapy? Where could I sign up?

I was sent to a hospital-based vestibular therapy rehabilitation program for evaluation. Finally, I felt like I was getting somewhere. I will note here that throughout my cancer treatments and subsequent recovery period, I had been very proactive in my care due to my extensive medical training, and was quite persistent and assertive if I did not feel my needs were being met. Still, once I decided to seek care for the dizziness, it took me five months and consultations with three different physicians before I was referred to someone who could help me.

"MY PREVIOUS EXPERIENCES WITH PHYSICAL THERAPY HAD BEEN POSITIVE...AN INTERVENTION THAT DID NOT INVOLVE INVASIVE SURGERY AND TOXIC DRUG THERAPY? WHERE COULD I SIGN UP?"

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MY LABYRINTHING JOURNEY...CONTINUED FROM PAGE 3:

I soon learned from my vestibular rehab therapist that my issues with falling, fatigue, nausea, foggy thinking, visual problems, and what I thought was weakness were all related. I finally realized that the problem had actually started in 2008. I just did not recognize it until it worsened enough in 2012 that I became overtly dizzy. I learned that my vestibular hypofunction impaired my ability to visually track and coordinate with moving targets, which is an important skill for a veterinarian, since our patients rarely hold perfectly still. Large animal work became especially difficult because I often have to tip my head back to look into the eyes or mouths of horses, all the while maintaining my balance as the patient moves around me. Additionally, I always found myself explaining my condition to owners because I was afraid they would think I was intoxicated.

My therapist initially thought I had left lateral canal BPPV in addition to bilateral peripheral vestibular hypofunction. She explained that it was necessary to first resolve the BPPV and then we could focus on the other problem because otherwise it could make the BPPV worse. However, after three months we weren't getting anywhere.

I was discharged and sent back to the ear, nose and throat doctor. He ordered a brain MRI, which was normal, then sent me to a specialty clinic in the San Francisco Bay area where I had an extensive evaluation that included skull base CT, posturography, electronystagmography, and caloric testing. Their diagnosis was "central and bilateral peripheral vestibular hypofunction, worse on the right." Translation: I had brain involvement in addition to the more external portions of the vestibular system located in the inner ear. That explained the BPPV treatment not helping. Apparently, central vestibular hypofunction can mimic lateral canal BPPV, but is not helped by the typically used BPPV therapeutic maneuvers.

Once this was established, I went back to my original therapist for ongoing treatment of the vestibular hypofunction. This basically consists of retraining your nervous system to its "new normal" and learning subtle tricks to maintain your balance, such as resting one hand on a shopping cart even if you aren't the one pushing it, keeping one knee bent so as to make contact

with vertical surfaces, such as kitchen cabinets, while cooking, and touching walls and doorframes as needed while walking.

I made rapid progress and felt much better after three more months of therapy! Finally, I was discharged with a home exercise program, which I continue to do faithfully to prevent relapse. Today, despite my chronic neurologic condition, I can function normally in most situations and no longer find myself needing to make explanations to avoid embarrassment. There are still some things I find very challenging, such as noisy, visually stimulating environments. I went to the county fair with my husband and we walked through the midway at night. What a mistake! I could not look at the moving carnival rides and I once again found myself explaining my condition to security to avoid being detained for presumed drunkenness.

I have difficulty with more mundane things, such as hanging laundry out on a breezy day, but I can still do them. Every morning, I am dizzy for the first hour after I get out of bed and have to be especially careful to avoid falling if I get up quickly at night. If I lie down on my back for more than a few minutes



during the day, I will be dizzy all over again. This makes leaving the building after medical procedures and dental appointments challenging. I avoid lying down to nap because it isn't worth being dizzy afterwards.

It is interesting to note that I never had any difficulty riding horses, and continued to do so even when I felt pretty bad. It took me a while to figure out why this was the case. I finally realized that the physical contact between my legs and the saddle allowed my still-intact proprioception to come into play, just as when you are seated in a chair. The horse was doing all the work of maintaining his own balance and taking over that function for me. Also, while riding you don't move your head much except to look in the direction you want the horse to go. Stepping off the horse was another story, as I made the transition to being responsible for staying upright. My own horses were quite tolerant of my keeping a hand on them as a balance reference point and they learned not to be alarmed by my inconsistent lurching gait, but this remained a problem for those that were my patients, so until I got better I had to be pretty careful around them.

As time went by, I was satisfied with the extent of my improvement and accepted my limitations. My visual problems remained frustrating but I did not think anything more could be done because I knew my difficulties were related to a brain lesion rather than a typical eye problem. So things looked blurry a lot of the time even when I had what should have been the correct vision prescription.

One day in the fall of 2016, I read an article about binocular vision dysfunction in the VeDA newsletter. I found it quite interesting because I like neurology but did not really think it applied to me. It was a slow day at work, so I took the online quiz that went with the article. I submitted my answers, figuring I would get a generic email reply in a week, and went back to work. An hour later, I received a phone call from Dr. Debby Feinberg in Michigan. She told me that I had scored very high on the test for VH (vertical heterophoria) and was a candidate for treatment that involved realigning my visual axis using eyeglasses that incorporated optical prisms. I told her that I had a chronic vestibular disorder that caused blurred, but not double vision, so I was pretty skeptical. I was so much better from the interventions I had already

had, I did not think there was room for improvement, and in any case I wasn't going to travel to Michigan to find out. She said that Dr. Vincent Penza in San Francisco could evaluate and treat me there.

He called me the next day, and after I spoke to him I decided to give it a try. I figured that even if I did not have VH, I would probably at least get a better vision prescription. I was particularly resistant to the concept of wearing glasses instead of contact lenses because I had not done well in them previously.

I read Dr. Feinberg's research papers to better understand what vertical heterophoria is. Humans and other predatory animal species have highly developed binocular vision, which means our two eyes work together to give us depth perception and other visual benefits. If the two eyes don't work together properly, double vision can result. This in turn leads to reading difficulties, eyestrain, headaches, nausea, fatigue, and neck pain caused by holding the head tilted to one side. People can be born with a subtle anatomical misalignment or the problem can be acquired, most commonly as the result of a traumatic brain injury. The two eyes do not quite point in the same direction, resulting in two images, one slightly above the other, rather than a single image, as is seen with normal binocular vision. A person so affected may be aware they have double vision or, more commonly, the two not-quite superimposed images are perceived as blurred due to the brain's efforts to merge them. In my case, I answered in the affirmative to a lot of the questions about symptoms of VH, but these are also symptoms of vestibular disorders and so I discounted my high score on Dr. Feinberg's test.

I traveled to San Francisco and underwent a full day of neuro-optometric testing. I was very surprised when Dr. Penza noted that I had slight right head tilt. I had denied it on the VH questionnaire. I was shocked to realize during the Maddox Rod test that I really was seeing double. Remember, I had been asked repeatedly over the years by care providers about it and I always said no. In my mind, double vision (diplopia) literally meant seeing two side-by-side, completely separate images. My brain's attempts to merge the slight vertical discrepancy between my two eyes just seemed blurry to me. At last I understood why I could not see as well in daily life as I could during optometric testing, where each eye

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MY LABYRINTHING JOURNEY...CONTINUED FROM PAGE 5:

was tested and corrected separately, but when used together the images did not line up! After this I was fitted with prescription eyeglasses that incorporate prisms to compensate for the discrepancy between the way my eyes are aligned and thus correct the diplopia.

I soon regained my previous reading speed, which had been impaired because I kept losing my place on the page. My gait stabilized and my head tilt disappeared. With it went the neck pain, headaches, and most of the travel-related nausea. The head tilt is a strategy people with binocular vision dysfunction use to help reduce the perception of double images, often without realizing they are doing so. I was tilting my head because I could see a little more clearly that way. As a veterinarian, I have seen and treated many dogs, cats and horses with vestibular problems and they generally recover well on their own except that a head tilt usually remains. No one knows why this is, but now I have an idea. They, too, may be trying to compensate for impaired binocular vision.

My new glasses seemed to be a great success at first. I could see clearly and they worked perfectly when I was indoors. However, outdoor activities were another story. As directed by Dr. Penza, I had stopped wearing my old contacts and exclusively wore the prism eyeglasses for three months so I would adapt to them. Wearing the glasses resolved my diplopia and its associated discomforts, but my vestibular symptoms were worse if I was moving around much, particularly outside on uneven terrain. As spring came and I was doing more outside, it became unbearable. One day we were repairing a fence on a hillside, which required a lot of head movement in a visually busy environment with a challenging balance situation. I had to put my old contacts back in as the double vision was preferable to the way I was feeling. I had given it a good try but just could not adapt to wearing the glasses if I was walking around or had to move my head much.

I went back to Dr. Penza and he presented an elegant solution: custom multifocal contact lenses with prisms! Wearing these, my vestibular system was able to function at its previously well-compensated level, with the added benefit of eliminated diplopia. There are limitations to the degree of optical clarity that can be obtained with contacts, so I don't quite have the visual acuity I have with the glasses, but I can always use them if I really need that. It seems that at least some of the visual difficulties well-known to afflict vestibular patients can be attributed to

binocular vision dysfunction, and I think that others may benefit as I did. It's a non-invasive intervention, so certainly worth trying.

I realize that everyone's story is unique. I decided to share mine hoping to inspire others in their efforts to get better. I think the first thing is to be PERSISTENT in finding someone who can help you, and have confidence in yourself that it's not all in your head. It's also really important to accurately describe your symptoms to the best of your ability. I kept telling my doctors that I felt "dizzy." I

still use that term because of its brevity, but what I really was experiencing was disequilibrium, which is a general feeling of being off-balance, along with a strange whirling heaviness that seemed to originate in the upper one-third of my head. Dizzy is such a catch-all term that it is often discounted by medical practitioners, especially if it is chronic, since it's unlikely to be immediately life-threatening (unless you happen to fall off a cliff!).

Vestibular hypofunction in particular can be devastating due to the fact that it is generally irreversible. I feel fortunate that my condition was relatively mild, but I also attribute my degree of recovery to the fact that I was very motivated to remain active and continue as many of my normal routines as possible. The practitioners who treated me all expressed surprise to find me functioning

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as well as I was. I cannot stress enough how helpful the vestibular rehab therapy was in my adaptation. Then, even after I was satisfied that I had recovered as much as possible, my visual problems were further helped by specific, recently-perfected interventions.

Modern medicine has given us some amazing resources; so many, in fact, that no single physician can possibly be aware of all therapies that are available to their patients. Most doctors are not

“IT IS UP TO PATIENTS TO ADVOCATE FOR THEMSELVES AND OTHERS AND TRY TO SPREAD THE WORD THAT HELP IS AVAILABLE.”

very informed about vestibular disorders in general so they also don't know the extent of what is available to treat them. It is up to patients to advocate for themselves and others and try to spread the word that help is available.

Thank you to VeDA for being the leading international organization that people turn to for information on vestibular disorders, publishing articles that are clear, reliable, and scientifically objective.

VEDA

DIZZY DASH

SAVE THE DATE!

May 18th, 2018

WALK YOUR OWN PATH

Dizzy Dash is a virtual event—you decide what to do, when and where. It was created by vestibular patients to encourage you to set a goal that supports your recovery. Participants register for the “event” and are encouraged to create a personal campaign page to share their story and invite friends and family to support VeDA. Some patients have set a goal to walk 2 miles, while others aim to make it around the block. The most important thing is to set a goal that works for YOU and let the people around you share the journey.

STAY TUNED FOR MORE DETAILS!

TeleRehab: Vestibular Physical Therapy Access to Everyone

By Sarah Gallagher, PT, DPT, NCS



DR. SARAH GALLAGHER

As a patient who suffers from dizziness, one of the most basic challenges you may encounter is finding a therapy clinic to receive appropriate treatment. There may not be a vestibular expert in your area, you may be too dizzy to drive to your appointments, or you simply do not know how a vestibular physical therapist

can help you. Receiving vestibular therapy via videoconferencing, or telerehabilitation, can solve many of these barriers to receiving the excellent care you need.

To provide you some background, telehealth or telemedicine are terms used to describe any health care service delivered through videoconferencing. Telerehabilitation (or telerehab for short) is specific to rehab therapy services and is intended to provide the same therapy that you would receive in the clinic, delivered via videoconferencing. Telehealth has been available to some patients for decades, especially patients in rural areas; however, it is now becoming more available to all patients.

As a physical therapist, I have been treating patients with vestibular disorders for 10 years, and practice at a clinic that specializes in the treatment of patients with vestibular disorders in Denver, Colorado. Soon after starting in my position, I realized there was a challenge for patients to receive the care they needed for improvement, as many of my patients had previously tried vestibular therapy without success. When patients were fortunate enough to find a therapist who could provide the vestibular expertise they needed, they often had barriers to access such as needing to commute several hours, or driving in heavy urban traffic, or arranging a ride to receive this specialized care.

Due to the challenges that I witnessed with patients having difficulty getting to their appointments with

me, I explored and began to treat patients over videoconferencing. When these patients experienced successful outcomes, I realized the potential for telerehab to be used as a tool to more easily connect with patients who truly need expert care, which isn't always available for them locally.

WHY CHOOSE TELEREHAB FOR YOUR VESTIBULAR PHYSICAL THERAPY?

Telerehab provides access to the most expert providers rather than being restricted to therapists who are located in your community. Telerehab also provides some advantages for vestibular patients over receiving in-clinic therapy. Barriers to treatment that are avoided by care being delivered through video conferencing include being too dizzy to travel to the clinic, not having transportation, no time to attend frequent appointments, the time commitment to commute is too disruptive to life, or commuting increases symptoms, limiting participation and resulting in prolonged recovery.

In addition to avoiding the barriers listed above, telerehab care allows patients to recover from treatments immediately at home, avoiding commuting after the appointments, which can increase dizziness. Other practical benefits are that the patient learns how to perform their exercises in their home environment with the guidance and feedback of a vestibular trained physical therapist, which improves the quality and compliance of the



home program.

Lastly, a practical benefit of telerehab is that it can reduce costs for patients, due to spending less time away from work or home responsibilities since there is no commute time.

In terms of the logistics of telerehab, there are many technology platforms that have been designed to ensure privacy and protection of personal health information. It will depend on your therapist as to which platform is used, but there are many user-friendly products on the market. These products require basic computer literacy, and access to a computer with a camera, or a device such as tablet or a smartphone that has a camera built in.

Research that has explored the benefits of telerehab has been compelling. This includes outstanding patient satisfaction, effective patient outcomes, and healthcare cost savings.

Key points about telerehab for dizzy patients are that it is the same therapy that you would receive in the clinic and has the potential to improve the quality of your care. Not all patients are ideal candidates for telerehab. The physical therapist must decide who is best suited. Some patients may benefit from a combination of clinic and videoconference, as hands-on care may often be the most effective treatment. Telerehab is regulated by each state, and legislation

has not been introduced in all states addressing telerehab as of yet.

To summarize, telerehab has excellent potential to reach patients with vestibular disorders, and aid in optimizing their access to expert care. Ask your therapist if telerehab is an option for your care, and if so, speak to your insurance about covering this service.

ABOUT SARAH GALLAGHER

In early 2017 I started a videoconferencing vestibular physical therapy practice and we introduced videoconferencing services from our clinic to treat patients in the state of Colorado. I collaborate with other national leaders in telerehab to promote the legislation to support telehealth, provide education about patient benefits, and collect data on patient outcomes. I also lecture at the University of Colorado PT school about the practice of vestibular therapy and telerehab and am the chair of the vestibular special interest group telehealth task for the American Physical Therapy Association (APTA).

ATTENTION HEALTHCARE PROVIDERS:

You can add “Telemedicine” as a specialty to your provider directory listing. Contact Michelle Eyres at 503.294.9085 or via email at mcihelle.eyres@vestibular.org if you have questions.

When you join VeDA's Sustaining Circle, you ensure that vestibular patients who are seeking information and support get the help they need, when they need it. Making a monthly gift to VeDA is an easy way to budget your philanthropic giving, and helps us with our budgeting, too!

THANK YOU FOR YOUR GENEROSITY!



The Effect of Fear of Falling on Vestibular Feedback Control

By Nicole Acerra, PhD P.T., BScP.T., BA



DR. NICOLE ACERRA

Vestibular therapists often ask patients if they have fallen or if they are afraid of falling (fear of falling = FOF). Healthcare providers have long known that FOF is important. FOF causes movements to be more cautious and rigid. People who are afraid of falling tend to fall more often. Many people will self-limit their physical activity

and social outings. This may in turn lead to social isolation or deconditioning (such as a loss of physical strength or balance).

Keeping our balance is no easy task. Balance is constantly being re-calculated and uses up a lot of our brain energy. Research is slowly piecing together how we calculate balance day-to-day and the impact of FOF on our balance. Many research studies are being conducted to help us better understand how we keep balance, what factors affect balance, and how balance is impaired with vestibular disorders. Below is a summary of some of the key points of one such study.

PURPOSE

This study looked at how balance is affected by anxiety. In particular, they investigated if there was a difference in balance reflexes between walking with anxiety compared to walking without anxiety. The researchers created anxiety by having participants walk on a thin walkway (like a balance beam) at a great height and compared that to walking on ground level.

METHODS

Sixteen young healthy adults volunteered to walk along a thin walkway (22 cm wide) near ground level and again on an elevated walkway (3.85 meters above ground level). They wore a safety harness and rated their anxiety on the two walkways. Researchers measured body movement at 52 points on their bodies to relate body movement to levels of anxiety.

MAIN FINDINGS

The main study finding is that fear influences some vestibular balance reflexes in young, healthy adults. This study is in keeping with previous studies in healthy adults. The study also noted that different balance reflex pathways are differently affected by being fearful of falling.

LIMITATIONS

All research studies have limitations. At this time, we can't be sure if this research can be generalized to older adults, children, or people living with vestibular disorders. We also aren't sure if these changes in balance reflexes are helpful or harmful - such as, do these changes lead to more or less falls?

Fears and anxieties are personal and can change based on the situation. In this study, 'anxiety' was created by walking at a height and was measured by asking people to rate their anxiety. Because anxiety can't be seen or touched, the researchers had to depend on self-reports of fear of heights during the task. It's hard to know if all fears and anxieties cause the same changes in balance reflexes - such as, would the fear of slipping on ice cause the same changes in balance?

NEXT STEPS

More research is needed to better understand how fear affects falling as we age and in people with vestibular disorders. Also, what does this mean for fall prevention? Can specific home-based exercises improve balance reactions or reduce falls?

TAKE HOME MESSAGE

This study adds to our understanding of how the vestibular balance reflexes are influenced by anxiety or fear. It confirms that heightened anxiety changes the way we move.

SOURCE

De Melker Worms JLA, Stins JF, Beek PJ, Loram ID. The effect of fear of falling on vestibular feedback control of balance. *Physiological Reports*. 2017;5(18). doi:10.14814/phy2.13391.

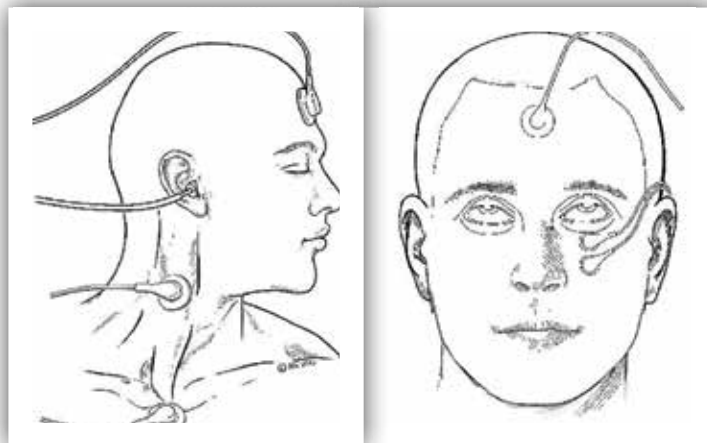
Guideline Addresses Vestibular Evoked Myogenic Potential (VEMP) Testing of Inner Ear Function

By Terry Fife, MD

VEMP studies are electrophysiological studies done by applying a sound stimulus to one ear and measuring for muscle electrical activity over a neck muscle (cervical VEMP, cVEMP) on the same side or an eye muscle (ocular VEMP, oVEMP) on the opposite side. It is painless and causes no dizziness and recordings can be obtained fairly easily especially in those < 65 years of age. This testing method received FDA approval in October 2015. Because VEMP testing is relatively new, Medicare and most insurance companies do not yet cover these studies. This new Guideline now provides evidence for VEMP testing at least in selected situations.

A recently published Practice Guideline by the American Academy of Neurology reviewed the published literature on the use of cervical vestibular evoked myogenic potentials (cVEMPs) and ocular vestibular evoked myogenic potentials (oVEMPs) as tests to help diagnose vestibular disorders. The evidence supported the use of both cVEMP and oVEMP in affirming the diagnosis of superior canal dehiscence syndrome (SCDS). SCDS occurs when there is an abnormal opening (dehiscence) in a small area of the temporal bone around the superior semicircular canal of the inner ear that causes sensations of dizziness and may cause autophony (increased hearing of one's own voice and bodily sounds), sensitivity to vibration and certain sounds, and sometimes conductive hearing loss. VEMP responses are extra-large (larger amplitudes) and can be elicited at lower levels of sound stimulation (lower thresholds) on the side with SCDS compared to normal. VEMP testing may be added to temporal bone CT to assure the diagnosis of SCDS is correct.

Animal studies support the widely held belief that cVEMP responses reflect function mainly of the saccule (the inner ear gravity sensor) and oVEMP reflects mainly function of the utricle (inner ear horizontal acceleration sensor). However, the Guideline did not find any studies in humans that could prove this point, but concedes that such studies would be hard to perform in humans.



CERVICAL VEMP ELECTRODE SET UP OCULAR VEMP ELECTRODE SET UP

For other vestibular disease they found insufficient evidence that cVEMPs and oVEMPs are able to diagnose Ménière's disease. The evidence did not support the recommendation of using VEMP studies to make the diagnosis of benign paroxysmal positional vertigo or to diagnose vestibular migraine. Even though the Guideline did not find published articles in humans to prove its accuracy in assessing utricle and saccule function, many clinicians use cVEMP or oVEMP to assess the function of these inner ear structures.

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2. Position Statement: Vestibular Myogenic Potential (VEMP) Testing. American Academy of Otolaryngology-Head and Neck Surgery. <http://www.entnet.org/content/position-statement-vestibular-myogenic-potential-vemp-testing>, 9/20/2014, last accessed 12/12/17.

Letter to the Editor

Dear VeDA,

I am already a member of your organization but I wanted to send an extra donation for a very specific reason.

Recently I had extensive knee/leg surgery to replace a total knee replacement that was the wrong size. In the four years that it took me to find a surgeon who would take on the revision and repair work I fell 32 times, all due to the wonky knee. To make matters worse, I have had several vestibular disorders for years. They include bilateral superior canal dehiscence and migraine associated vertigo/disequilibrium. As you know, both of these contain seemingly multitudes of bizarre symptoms that one must learn to live with.

I discussed my vestibular disorders in detail - before the surgery - with the orthopedic surgeon because my vestibular symptoms do affect what I can and cannot do for postop orthopedic related physical therapy. He seemed very receptive and said he would work with me. Sadly, that did not happen. At my last appointment two weeks ago he accused me of being a liar when I told him I could not go to any gym (too noisy, too much movement, too much light) and I could not use any kind of cardio machine (extreme disequilibrium and sometimes vomiting within ten minutes - I know as I've tested this multiple times). He told me four times to just "make yourself deal with it and get on that recumbent bike at a gym." Sigh.


Today I sent him a letter concerning his rudeness and, because of your wonderful website, I included a total of nine articles that covered the basics of the vestibular system as well as on the four vestibular disorders that I have been diagnosed with. That felt really good. (Woo-hoo! I've soooo had it with doctors saying that I am "just an anxious woman who maybe gets dizzy sometimes" or who call me a liar.)

This donation is to say thank you for having all those well-written and well-researched articles available on the spot. Thank you. Thank you.

Respectfully, B.K.

Thank you, B.K., for your support and feedback!

Donors like B.K. help VeDA keep our educational library up-to-date. You can ensure that these resources are available to future vestibular patients by making a secure donation at vestibular.org/donate.



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Volunteer Spotlight

By James Janakowski

On Christmas Eve 2002, I was diagnosed with a 6cm x 4cm acoustic neuroma (vestibular schwannoma). I was an ironworker and superintendent, working long hours and traveling all over the country. When I came home I thought I was just tired. My wife and children noticed that I was bumping into things and was deaf in my left ear. They insisted I see a doctor.

My 14-year old son, Matt, accompanied me to all my doctor appointments, taking notes and asking questions. He was a big help.

The surgeon told me I needed to have the operation right away because the tumor was pressing on my brain stem. I had surgery on Valentine's Day.

My vestibular symptoms didn't start in earnest until after my first surgery - hearing loss, fullness in the ear, tinnitus, dizziness, unsteadiness, facial numbness, headaches, and mental confusion. I had a scar going from my forehead to behind my ear, and I couldn't walk or talk. We joked that I looked like Jack Nicholson in One Flew Over the Cuckoo's Nest. You have to be able to laugh at yourself.

The nurse helped me learn to use a walker; I held onto it like I was balancing on a beam 50 floors up! My thinking was if I keep walking and moving I would get better, so every few hours I got up and, with help, made it a little further. When the doctor came to check on me he asked if I could stand; boy did I surprise him!

In 2015, I was diagnosed with another acoustic neuroma. We watched it for one year and it grew to 3mm x 4mm. I had surgery in February and everything went well, but three months later I was so sick I thought I was a goner. I was more dizzy and nauseated than I had ever been. My eyes hurt, and the headaches I'd had since the first surgery were worse.

This is my condition now. I have two grandchildren, three great kids, a wonderful wife, and yet I can't enjoy a thing. But I try. Every day I get up at 8am and I try, and I won't stop until I get better.

I went to a rehab center for vestibular therapy, which was a challenge. I had to get into something

like a "Jolly Jumper." Do you remember those? We hung them over the door for our children so they could jump around. It was quite funny to me so I could not stop laughing when I got into it. The therapist said, you will not be laughing in a day or so. She was right. While hanging there they move the walls until you're about to throw up. Then they move the floors. This goes on for weeks. Then they move everything together until you are not as dizzy as when you started. I recommend everyone go to vestibular therapy if you have not. It really helps. DO IT.



JAMES AT WORK BEFORE SURGERY.

This disorder has ruined my career. I was 43 years old when I had my first surgery. I had two daughters going to college and I could not work. My son, Matt, played Lacrosse and was top rated; I never missed a game. I loved my job, the men and woman that worked for me were such a big part of my life. I tried to go back to work but I only lasted a few months. Thank God for my Union. I'd saved money, and all my brothers took up a collection to help.

I am a member of VeDA because of the support I receive. I love VeDA's Facebook page. The people interact with one another, talk about the issues they have and what they do to cope. I love being part of this wonderful group of people that understand what I deal with every day.

Never give up on yourself. If you need help, reach out to someone that knows what you're going through. Try every day. Don't quit. Work at it one step at a time and know your limits. When you're down, smile!

James recently joined VeDA's Ambassador Board, where he volunteers to raise awareness about vestibular disorders online and in his local community.

Got Magnesium?

By Sandy Egge, MSACN



SANDY EGGE

A vital micronutrient that plays an important role in electrolyte and fluid balance as well as bone integrity, muscle contraction, heart rhythm, cell division, and nerve health, magnesium contributes to well over 300 biochemical processes in the body. And, you want another crazy, impressive number? It's

reported that we have in excess of 3,700 binding sites for this nutrient as well. This is one important mineral! A mineral found in nature, it's vital to our life, and to our balance.

Because magnesium plays a part in electrolyte and fluid balance, it's important to review this nutrient when thinking about vestibular disorders. While true magnesium deficiency is rare in most healthy individuals, it is thought that the majority of Americans do not get the recommended daily amount, and that 'magnesium reserves' may not be sufficient. Deficiencies may be brought on as a result of poor dietary intake, chronic and prolonged digestive and intestinal health issues, antibiotic and drug use, diuretic use, malabsorption, excessive exercise and sweating, and more. The Food and Nutrition Board at the Institute of Medicine supports an average daily intake of magnesium for men ages 19-30 at 400 mg/day, increased to 420mg after age 31, and women ages 19-30 at 310 mg/day, increased to 320 mg after age 31.

Did you know that if you have low dietary magnesium intake, your body will take magnesium from your bones, compromising bone health, to support the tightly regulated magnesium levels in the blood (serum levels)?

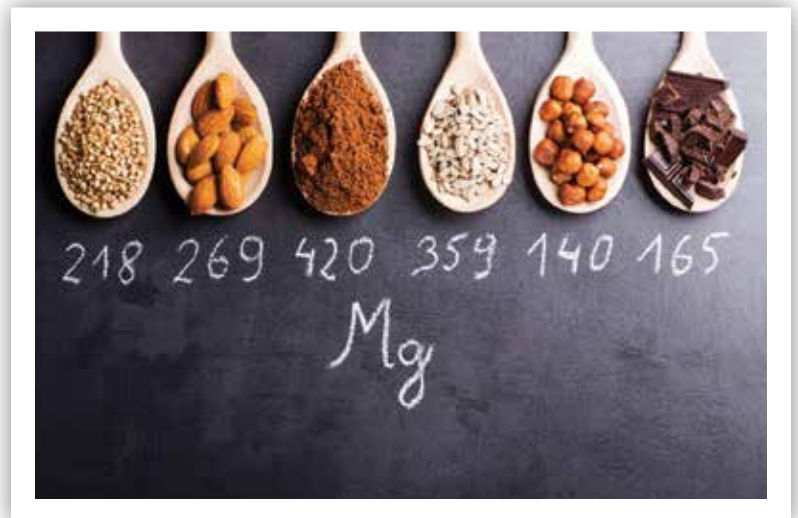
Some symptoms that have been reported with those experiencing prolonged low magnesium levels are dizziness and imbalance, especially when standing up suddenly. It is thought that low magnesium may contribute to a reduction in messaging of sensory

nerves, or misinterpretation of messages from the inner ear around movement or lack of movement, contributing to feelings of dizziness and imbalance. As part of the electrolyte family of nutrients, magnesium also contributes to proper protein-fluid balance which is important in supporting body equilibrium.

Another reported symptom related to low magnesium intake is migraine headaches. While migraines and headaches can have different triggers, such as muscle tension, stress, inadequate sleep, poor diet, hormonal imbalances, and food sensitivities, it is thought that magnesium deficiency could also play a role. It has been suggested that low magnesium creates an environment where there is inadequate relaxation of muscles - think neck and shoulders - which means there is continuous contraction at some level of these muscles creating tightness and tension. It is also considered a possibility that this continuous tension may contribute to restriction of blood vessels in the brain, triggering a potential migraine.

So, what can you do? Where do you find magnesium in food? What is the best magnesium supplement to take?

The first thing you can do is review your dietary intake. What foods are you eating? Some magnesium-rich foods are dark green leafy vegetables, avocados, bananas, nuts, dried peas and beans, meat and eggs.



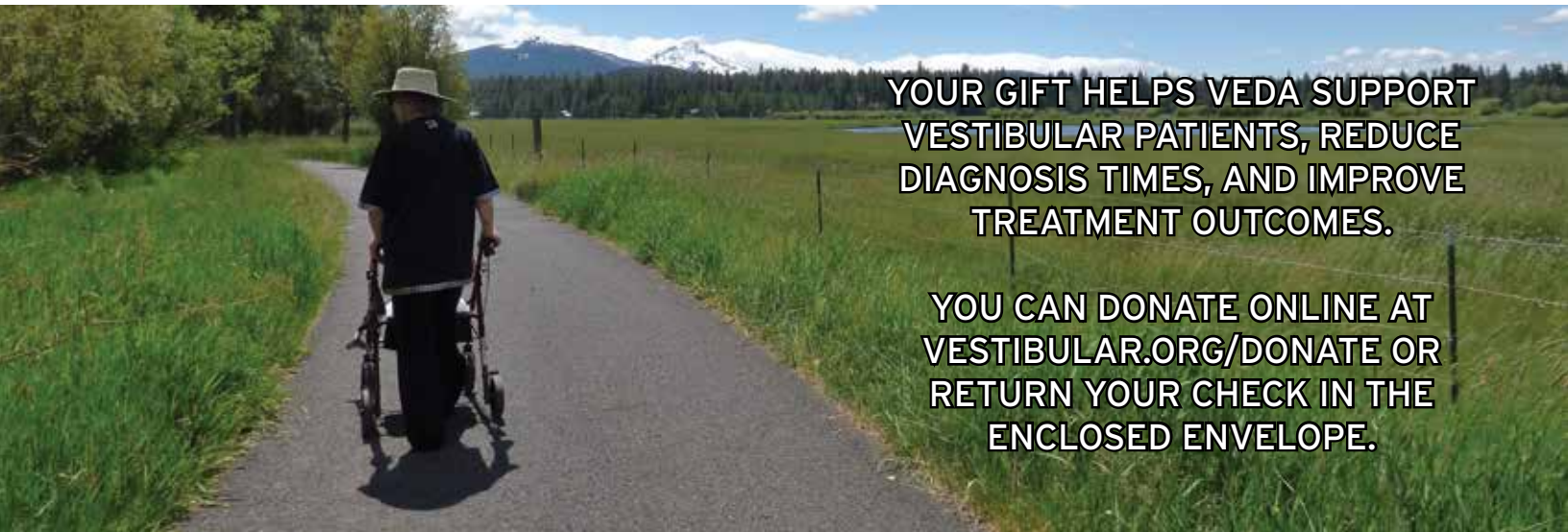
You might also consider a magnesium supplement. Magnesium is available in a few forms. Magnesium malate is a good form to take early in the day, as it supports muscle relaxation and reduction of tension but also helps to energize your cells. Magnesium citrate is an easy form to take in the evening. It is also the most common form found. It is easily absorbed and promotes relaxation and rest. However, be aware to not overdo it, as you may experience diarrhea the next morning. Magnesium glycinate also supports good sleep and relaxation without the side effect of diarrhea.

Lastly, it is necessary to remember that while this mineral is essential to life, it still sits in a delicate

balance and works in synergy with other minerals such as sodium, potassium, chloride, phosphorus, and calcium - all of which contribute to proper electrolyte and fluid balance in the body.

If you think that magnesium deficiency may play a role in your vestibular disorder, ask your licensed healthcare provider for nutrient deficiency testing. In order for your provider to better assess you, it's important to be specific about your symptoms, diet, and lifestyle habits. You might want to journal the details so that you can accurately share them. VeDA has patient logs available for you to download on their website at vestibular.org/patient-logs.

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2018 Action Plan Highlights

By Cynthia Ryan, Executive Director

VeDA's mission is to support and empower vestibular patients on their journey back to balance. As a VeDA member, you help us accomplish this goal by supporting our patient support and education programs, medical and legislative advocacy efforts, and public awareness campaigns.

Here are some of our goals for 2018:

ENSURE PATIENTS HAVE EASY ACCESS TO EDUCATIONAL ARTICLES AND TOOLS

Our website is so jam-packed with information that it can sometimes be hard to find what you're looking for. We will be reformatting our website so you can access up-to-date resources quickly.

SUPPORT VESTIBULAR RESEARCH

We will be launching a new research grants program to help emerging clinicians present their research at professional conferences.

EDUCATE PRIMARY CARE PROVIDERS

We're working on a systematic review paper analyzing diagnostic protocols for dizzy patients, and introducing our own vestibular triage protocols.

TAKE IT TO WASHINGTON

The focus of our new grassroots legislative advocacy program will be to contact public policy decision-makers about issues that impact insurance coverage for vestibular testing and treatment.

Thank you for supporting this important work!

Wishing you balance,



Cynthia Ryan, MBA

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