



ON THE LEVEL
NEWSLETTER

FALL 2019

DECOMPENSATION

JOHN WAS ON THE ROAD TO RECOVERY.
THEN HE FELL BACK TO SQUARE ONE.

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VEDA

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OF THE VESTIBULAR
DISORDERS ASSOCIATION

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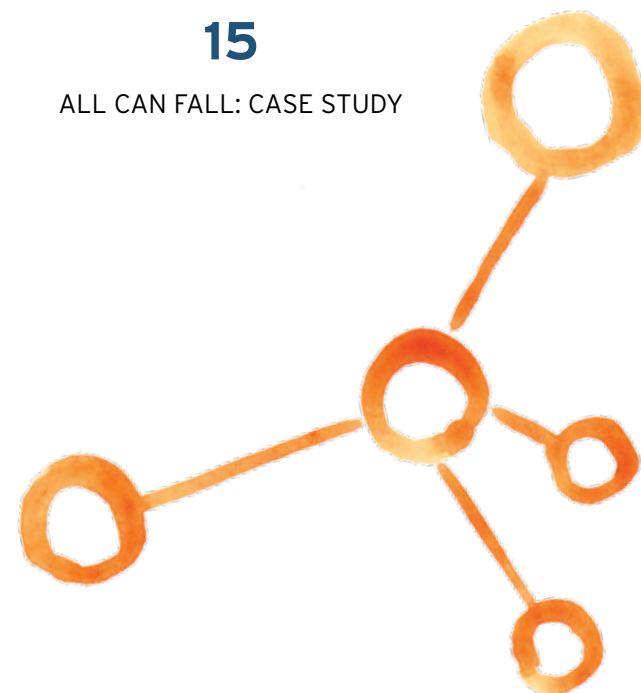
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Tenacious Perseverance & Optimism Keep Me Going

By Michelle Eyres & Cynthia Ryan

John Vetter attended the University of California, Berkley and graduated with bachelor and master's degrees in chemical engineering. He went on to graduate from law school and practiced intellectual property/patent law. Anxiety is something he has struggled with all of his life. Adding a vestibular disorder to the mix has caused that anxiety to increase.

In March 2016, John began losing vision in his right eye. A sort of gray shield would lower, blocking out all vision, then would gradually disappear.

In November 2016, John was diagnosed with an arteriovenous malformation (AVM) in the occipital lobe of his brain. Blood normally flows through arteries into capillaries, and then into veins. In an AVM, an artery is directly connected to a vein. Veins cannot handle the high pressure the way an artery can.

In December 2016, John was told the AVM was causing seizures, which manifested in what he described as "the gray shield." He was prescribed the generic equivalent to Dilantin, which made him feel drunk and hungover.

In order to correct the AVM John opted for non-invasive, gamma knife radiation treatment. This procedure was performed in January 2017. The combination of a steroid with generic Dilantin left him incapacitated. It was all he could do to lie on the bed and breathe.

Because the drugs were making it impossible to execute activities of daily living, John asked for a different anti-seizure drug. The new drug also made him feel drunk. Finally, his neurologist took over his medication management and prescribed Vimpat. Now he didn't feel drunk, but

he developed allergic skin rashes on his extremities, so he stopped taking the drug.

After about a month John told his neurologist that he was still dizzy, plus he had gained 30 pounds. John's cardiologist put him on a drug containing a stimulant, which allowed him to get through more of his activities of daily living but caused his anxiety to flourish.



ABOVE: JOHN HAD TO RETIRE FROM HIS JOB AS A PATENT ATTORNEY.

The neurologist referred him to an ENT, who diagnosed him with "chronic vertigo" and sent him for balance testing in July 2017. After undergoing a regimen of balance tests, including the "whirling chair," the results showed that nerves in his middle ear were not communicating enough information to other parts of his brain, causing him to feel dizzy and imbalanced. At this time, if John wanted to walk somewhere he would look at his destination and somehow he would get there. John did not know what his feet were doing. Soon thereafter, he felt like he had



large pieces of plywood strapped to his feet and he was walking on water.

During all of this, John had to go on medical leave from his practice and felt he probably would never return. "I cannot adequately represent my client when a three minute presentation at a city council meeting causes me to hang onto the podium for dear life," he said.



ABOVE: BEFORE HIS VESTIBULAR PROBLEMS, JOHN WAS AN ACTIVE TRAVELER.

John was prescribed 30 vestibular rehabilitation sessions, which he completed between August 15 and December 8, 2017. He was fortunate that the local hospital had two vestibular therapists and provided transportation for outpatient rehab. He would get dizzy on the ride to the hospital, dizzier from the rehab exercises, and dizzier still on the ride home. Fortunately, he was making progress.

Eventually his AVN dissipated and his vision began to improve. However, this meant that

his vestibular status regressed. When he resumed vestibular therapy in January 2018, John discovered he had decompensated and would become nauseous from doing the same exercises he had done successfully many times before. His gait was still wild and uneven and his vision needed to stabilize before vestibular rehab would again be effective. He was, almost, back to square one.

Then John began having double vision in his right eye in all but bright sunlight conditions. He was finally diagnosed with a cataract and damaged eye nerves. Periodically, he experiences vertigo where his surroundings are moving. Each episode lasts for about four minutes and he is not sure whether it is caused by seizure, panic attack, or something else.

John had surgery on his right eye, then a week later on his left. After the first eye was fixed, he felt like his vision was back to when he was a child. At his November 2018 post-surgery follow-up appointment, eye exercises were prescribed as well as unlimited vestibular rehab. John visits FYZICAL North Miami for vestibular rehab three times each week, which has helped him tremendously.

John's wife, Cynthia has been a tremendous help. As a nurse, she knows just what to do. "She goes to appointments with me and asks all the questions I forget to ask," he said, "I'm just glad I was able to care for her when she had heart surgery."

Last year John and his fraternity brothers gathered at Lake Tahoe. Some of his friends went out on a boat but John was not eager to walk onto a moving dock and get into a swaying boat. His fraternity brothers understood and helped him get into the boat, kept the boat speed slow and took a

GO TO "VESTIBULAR REHAB AND DO IT RELIGIOUSLY. OTHERWISE YOU WILL DECOMPENSATE."

route where there were not as many wakes from other boats so the ride was smoother. "I would not have been able to go without their support," he said.

While John can no longer drive on the freeway, he can drive on small, one lane roads close to home. He discovered VeDA's resources during an internet search, and

has found them to be the best source of information on the internet. He likes to study and learn when he is exposed to new information, ideas or diseases. VeDA's articles are written in a way patients can understand—not too easy and not too hard.

When asked what advice he would give to someone just starting their vestibular journey, he replied:

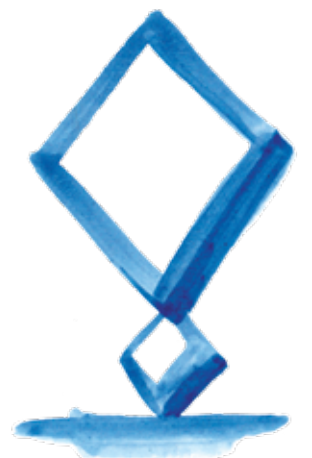
- Learn to relax and let it pass—the dizziness comes and goes faster if you can relax and just get through it.
- Have thorough balance testing done no matter how awful it makes you feel.
- Get a diagnosis!
- Go to vestibular rehab and do it religiously—otherwise you will decompensate.
- Good disability insurance is a must.
- Reduce your stress!

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Whenever You Call Me, I'll Be There

By Nikole Records, MSW

"I've seen seven doctors and no one can tell me what's wrong with me."

"I can't function at work. My coworkers think I'm drunk because I'm stumbling around."

"My family can't understand why one day I feel fine, and the next I can't get out of bed."

These are just some of the horror stories I hear every day from people who call VeDA because they are at the end of their rope and don't know where to turn.

"I understand, and I'm here to help." When I say this, many people break down in tears because it's the first time their experience has been validated.

I'm not a vestibular healthcare provider. I can't answer all their medical questions. But when I send them VeDA's scientifically-validated articles about vestibular diagnosis, testing and treatment, they can better understand their condition, and everything starts to make sense. This is the point where they begin to feel a little less afraid.

The next step is getting them connected to a qualified vestibular specialist. This is the key to getting an accurate diagnosis and effective treatment.

As a trained counselor, I know how important it is for people to get support to help them cope with the emotional impacts of living with an invisible chronic illness.

Sometimes people just need to talk with someone else who has been through what they are going through. Unfortunately, sometimes their family, friends or coworkers don't "get it."

The good news is that there are many ways VeDA can help vestibular patients get connected to their peers.

Sometimes you just need a good one-on-one with someone who will listen to you. In this case, I reach out to one of our volunteer Patient Support Callers (learn more about this program on pg. 7).

For face-to-face support, we have a network of in-person support groups across the U.S. If there isn't a support group near you, we have online support groups that meet virtually.

Social media plays a role in patient support as well. Any time of the day or night you can go to one of the many groups on Facebook dedicated to vestibular illnesses. We especially recommend the "Vestibular Disorders Support Group."

It is my honor to help vestibular patients during one of the scariest and most challenging times in their lives. I feel like I'm truly making a difference.

You Don't Get it 'Till You Get It

By Cynthia Ryan, MBA

Until you have been in another person's shoes, you cannot understand what they are going through.

That's why it's so important for vestibular patients to be able to connect with people who have shared their experience.

VeDA facilitates this connection through our Patient Support Caller Program.

When someone calls VeDA looking for information and support, one of the tools our Community Support Coordinator has is a cadre of volunteers willing to pick up the phone, make a call, and listen. This simple act can make a world of difference to someone who is struggling alone and feels misunderstood.

Recently Nancy, one of VeDA's volunteer

Patient Support Callers, reached out to Doreen, who was having a bad vestibular day.

"I was feeling dizzy and off balance. I couldn't concentrate and was totally worn out. My doctor told me it was just stress, but I knew it was more than that. My family has been getting frustrated with me because I've been having 'off' days more often. Nancy totally understood what I was going through and gave me some tips on how to cope. I am so thankful she was there to listen and support me."

"IF WE CAN SHARE OUR STORY WITH SOMEONE WHO RESPONDS WITH EMPATHY AND UNDERSTANDING, SHAME CANNOT SURVIVE."

- BRENE BROWN

YOU CAN HELP.

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

To donate, visit vestibular.org/OTL.

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"MAKE MELODIES" - ORIGINAL ARTWORK BY VESTIBULAR PATIENT, NICOLLE CURE

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BECAUSE OF YOU, WE REACHED >614,000 PEOPLE ON FACEBOOK.

Chemotherapy and Cochlear Toxicity

By Michelle Eyres

Platinum-based chemotherapy is used to inhibit the growth of tumors in many types of cancer. It is well documented that this type of chemotherapy causes irreversible hearing loss. Less known is its affect on the structures of the inner ear.

The hearing and vestibular organs share the same blood, nerve, and fluid supplies, which could imply that they share the same toxic effects.

The organs of the inner ear (three semi-circular canals and two otolith organs) play a crucial role in the human balance system. Currently, no test exists that can measure how well a patient's inner ear is functioning. Rather, vestibular function is inferred based on the "downstream processes," such as the vestibulo-ocular reflex (VOR), which control head and eye movement.

Balance is not restricted to vestibular function, but is an integration of "visual, somatosensory and vestibular inputs to the central nervous system." Studies in this area are hampered by the fact that many vestibular symptoms are dismissed as side effects of chemotherapy and/or radiation treatment, or as symptoms of the cancer.

A recent literature review assessed the side effects of platinum-based chemotherapy. As of September 2018 there were more than 15.5 million cancer survivors in the United States. By 2026, this number is estimated to rise to 20 million. Cancers are being detected earlier, treatments are improving, and survivors are living longer. Because of this, it is important to understand the long-term effects of chemotherapy drugs on the inner ear.

Over 2,600 articles were identified in the initial literature search. 75 articles fit the final review criteria. The studies selected had sample sizes ranging from one to 952

participants, with ages from 11 to 83 years who were being treated for cancers, including head and neck, testicular, gynecologic, pulmonary, breast, brain, and more.

Five areas of interest were identified:

1. Objective tests of vestibular and/or balance function
2. Patients' symptoms
3. Physical examination
4. Associated factors, such as dosage, pre-existing vestibular loss, and cochlear toxicity
5. General considerations

Objective tests include the caloric test, rotational test, vestibular autorotation test (VAT) and horizontal video head impulse test (vHIT). All of these tests detect issues in the horizontal VOR.

Investigators divided their conclusions into two categories:

- Conclusions based on established knowledge
- Knowledge gaps

CONCLUSIONS BASED ON ESTABLISHED KNOWLEDGE

- The existing information in the literature examined only the horizontal semicircular canal, which is one of five peripheral vestibular sensory organs. A more comprehensive test or series of tests needs to be used to better evaluate exactly where the damage has occurred.
- Vestibular function loss may not be

FALLS AND MOBILITY ISSUES ARE MORE COMMON IN CANCER SURVIVORS THAN THE GENERAL POPULATION.

recognized until the patient loses other balance cues, such as when walking in the dark, or develops peripheral neuropathy.

- Posturography is a better measure of overall balance system health.
- If vestibular damage is not known until other symptoms appear this can "lead to an earlier onset of age-related vestibular impairment."
- The distinction between objective tests, which can be measured by the clinicians, and subjective symptoms, which can only be reported by the patients, should be emphasized.
- Multiple studies reported abnormal tests in patients without obvious symptoms.
- Clinicians cannot rely solely on patient-reported symptoms to detect vestibular toxicity. Patients are sometimes unaware they have damage because, in the normal course of the day, they have not noticed the effects.
- Dizziness and other balance problems can be difficult for the patient to describe, and for the physician to categorize. Clarification of the terminology used is important.
- Nonspecific symptoms, such as nausea, vomiting, dizziness, and/or brain fog, might be associated with cancer diseases and general deconditioning of patients.
- Aging, the cumulative dose of chemotherapy, poor renal function, and co-administration of other ototoxic medications can lead to cochlear damage.
- Vestibular toxicity occurred as the cumulative dose of cisplatin increased.

KNOWLEDGE GAPS

- More research needs to be conducted because the literature reviewed had too few patients, variable methods and/or widely ranging results.
- No study evaluated patients using

vHIT, which tests all six semicircular canals, or vestibular evoked myogenic potentials (VEMPs), which tests otolith organs.

- Patient symptom evaluation needs to be less varied. More surveillance by investigators using specific questioning could yield better results.
- The association between cochlear impairment and vestibular toxicity is still unknown.
- Cochlear function impairment is more common, or it is recognized earlier and before vestibular impairment.
- BPPV is common in the general population, so assumptions might be made that its occurrence is not related to ototoxic drugs being used.
- Many cancer treatments are a combination of drugs, one or more of which might be ototoxic. Therefore, more research into individual drugs needs to be undertaken.

SUMMARY

Platinum-based chemotherapy drugs can cause damage to the inner ear. However, symptoms may be dismissed as a side effect of the treatment. Vestibular toxicity needs more research and a higher quality of research (i.e. more in-depth testing and physical examination) so cancer patients can be better informed about treatment options and their potential side effects. Knowing if a patient's vestibular system is being damaged during treatment might lead to a different choice of treatment being made.

REFERENCE

Prayuenyong P, Taylor JA, Pearson SE, Gomez R, Patel PM, Hall DA, Kasbekar AV and Baguley DM (2018) Vestibulotoxicity Associated with Platinum-Based Chemotherapy in Survivors of Cancer: A Scoping Review. *Front. Oncol.* 8:363. doi: 10.3389/fonc.2018.00363.

Fall Prevention & Home Safety

By Kathleen Stross, PT, MS, CHC

For those with vestibular disorders, falls are a real problem. No longer just for the elderly, losing balance can occur without warning when dizziness or imbalance strikes, resulting in injury, disability or isolation. Even if a person has never had an actual fall, the fear itself can lead to social withdrawal, anxiety, depression, and decreased activity.

Medications, vestibular rehab exercises, and safety strategies are among the important preventative measures for those with vertigo and imbalance. In addition to that, fall-proofing your home could add confidence and security, and reduce the risk of falling or injury if a fall occurs.

Basics: Vestibular patients benefit from environments that allow them to use their vision and somatosensation/proprioception to compensate for their vestibular weakness. So, keeping your environment safe means creating an environment where you can stay grounded, and see what's going on, using all your senses for better equilibrium.

Do a home survey, walking around the outside and inside of your home looking in three different zones.

Walk around the house three times, making notes as you go. Each time you will be focusing on a particular zone, as shown below. Be sure to include not only the inside of your home but the outside area as well, including all doors, gates, and steps to enter or exit the home.

The first time, walk around looking at everything in Zone 1, eye level and above. Can you see enough to walk around during the daytime and at night? Could you see if the power went out? Is everything overhead within reach without needing to climb?

Walking around for Zone 2 requires that you walk and stop every 5-7 feet. Each time you stop, think about what would happen if you a) got dizzy and started to fall, or b) needed to sit down. Is there something close by to grab onto or a chair (without wheels) if you needed to quickly sit down?

During the third walk around your home, focus on Zone 3. Do you have a clear path

in every room? Are there newspapers, throw rugs, or other items on the floor? Although rugs may be decorative, they can be a trip hazard. Firm, stable surfaces are best for balance. If you prefer carpet, then wall-to-wall carpeting is best, with a low pile and minimal to no padding. A thick padding underneath your carpet can have you feeling particularly unsteady when your body is not able to feel connected to the floor. Outside, make sure you have a level walking path (wide enough for walking with a cane or walker) through the grass or garden area. Minimize the grade of sloping surfaces or add a handrail.

THINGS I CAN DO TO REDUCE MY RISK OF FALLING

- Wear nonskid shoes that are secure on my feet
- Make sure my clothes fit well so they won't catch on something or trip me
- Get regular exercise to maintain strength and flexibility
- Have my vision checked every two years and maintain a current eyeglass prescription
- Maintain healthy blood pressure
- Pay attention to new medications and possible side effects or drug-drug interactions that can cause dizziness
- Limit alcohol

Making changes in your home may be difficult. There are many reasons why people don't take the recommended preventative measures, and later have regrets when they feel their fall could have been prevented.

Don't make excuses. If you are off balance, nothing is more important than keeping your home safe to prevent falls.

- Install grab bars
- Add a ramp or handrails
- Get a cane or walker

- Consider a bedside commode or shower chair
- Visit the doctor or therapist to discuss your balance concerns

Ask others for help.

Invite a friend to help you complete your safety walk-through, and take notes or make a To-Do list.

Have someone else come and complete jobs that require climbing or reaching high overhead.

SAFETY CONSIDERATIONS BY AREA

There are specific challenges that come with each area in your home. Here are some examples and recommendations that can be applied to specific areas of your home.

Entrances to the home: Look at all the doors for clearance and safety. Every home should have multiple ways to exit. Make sure you look at every door for safe passage. Are locks easy enough to open with one hand? Fire or storm damage can make your favorite exit impassable; make sure you are able to leave out of any door, in a hurry.

3-ZONE HOME SAFETY ASSESSMENT

ZONE 1: EYE LEVEL

Head and eyes: optimal vision depends on good lighting and minimizing head movements

ZONE 2: HANDS AND SEAT LEVEL

Arms and hips: need to be able to grab ahold, or sit down on a moment's notice

ZONE 3: GROUND LEVEL

Legs and feet: need firm, level surfaces, free of obstacles or unexpected changes



CONSIDER INSTALLING A RAILING AT ALL ENTRANCES TO YOUR HOME.
FROM THIS → TO THIS

Watch for anything that can cause you to trip, like a high step, edge, or mat. If you have steps up to the door, consider installing a railing. If you have gates, make sure they are able to be unlocked quickly in the event of an emergency exit.

Kitchen: Keep paths clear. Low profile rubber mats are ok in front of the sink and refrigerator if you dispense water from the fridge door. Consider a rolling cart to help you move items around during meal prep.

Bathroom: Pay special attention here. An elevated toilet seat and grab bars make toileting safer and more energy-efficient. If you step into the shower, place a grab bar where you can hold on while stepping over the edge. Install grab bar(s) for assistance getting up and down from the toilet.



Bedroom: waking up in the morning can be especially difficult, and dangerous. Sit

on the side of the bed for a few moments before you stand up. Say good morning to your vestibular system by turning your head up/down, and side-to-side a couple of times. Make sure you can see clearly. Once you stand up, stretch to stand up really straight, look to make sure you have enough light and a clear path before you start walking. Keep your cane or walker at the bedside.

Lights are essential. Whether in the daytime or during the nighttime, adequate overhead and floor lighting can make things easier for you to get around the house.

Upgrade your bulbs to save on energy costs. But be careful when you shop. Some LED bulbs take a few minutes to produce full light when turned on. You want an energy efficient bulb that produces full light immediately upon turning on.

Car/garage: Garages tend to be dark. Consider installing additional fluorescent lighting. This is usually a simple task for a handyman because a fluorescent lighting kit can easily plug into the power from the garage door opener. Maintain a clear path for safe and easy access to the trashcan or car. If you store things in the garage, keep the items you use the most at chest or waist level, so you have easy access to them without having to climb, bend, or reach.

If you use a cane or walker: it may be helpful to have more than one. If you live in a two-story house, you may want to keep one upstairs and downstairs. That way you can walk to the stairs, leave your walker, ascend using the handrails, and pick up your second walker that you left near the top of the stairs. When it's time to go downstairs, park your walker at the top of the stairs, descend carefully using the handrails, and rejoin the walker you left at the foot of the stairs. If you use a cane, consider adding a strap so that you can keep it on your wrist in case you need to hold something in that hand while gripping the railing in the other hand.

Yard/garden: if you love to garden, it's worth it to clear and level out a path around the yard. Stepping stones or pavers, while lovely, are not the best option here. Consider a concrete path, or a tightly laid brick path. The goal is to have a path that has plenty of room for your feet to land (without requiring precise foot placement) and is stable and

level. Crushed gravel/limestone is better than rounded pebbles because they can be tamped down to provide a more secure surface.

For further tips, use VeDA's provider directory to find a physical or occupational therapist near you.



CONSIDER INSTALLING A CONCRETE PATH AROUND YOUR YARD.

FROM THIS



TO THIS

Falling Down On The Job

By Cindy Price

If you've had a vestibular disorder for a while, you may start to think of being dizzy as your new normal. When that happens, it's easy to let your guard down. And when you do that, you become more susceptible to falls, no matter what your age.

When I fell recently, I explained away my knee injury as the result of "not paying attention" and missing a stair step, but it was so much more than that. After all, I'd dismissed the idea years ago that I could fall on these stairs. The relative safety of the home's staircases was a key factor in my decision to buy my house.

Here are the factors that actually led to my fall:

- My baseline dizziness. I always have a general sense of dizziness that's easily worsened by movement.
- I was adjusting to a new medication. I was experiencing several temporary side effects from this prescription, which blurred my vision, made me dizzy than usual, and made me constantly anxious.
- I was distracted. My husband and I were installing a light outside, and I knew he was still on the ladder as I went downstairs to flip the breaker switch. Normally, this wouldn't make me anxious, but my new medication left me nervous knowing he was on the ladder without me holding

it. I was distracted as I tried to go downstairs and return as quickly as possible.

- Lack of safety features. As safe as I considered this staircase to be—with wide stairs and non-slip gripping—it doesn't have a hand rail.
- Poor lighting. I hadn't turned on every light possible. That, combined with my slightly blurred vision, created just enough room for error for me to miss the final step.

I bruised three bones that day. My knee specialist said the damage to my femur was severe, and he would have recommended I keep all weight off that leg for several weeks had he seen me earlier.

Most falls are preventable, but it's up to us as patients with chronic dizziness and/or imbalance to take the steps to prevent them.

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CINDY OFTEN USES HIKING POLES OR EVEN A WHEELCHAIR WHEN SHE KNOWS SHE IS HAVING A "BAD BALANCE DAY."