



ON THE LEVEL  
NEWSLETTER

SPRING 2019

## BLOSSOMING

EMILY DISCOVERS HER  
VERSION OF "RECOVERY"

A large background image of a field of purple lavender flowers in bloom, with a soft-focus effect. The flowers are in various stages of bloom, and the background is a mix of green and purple hues.

**VEDA**

A QUARTERLY NEWSLETTER  
OF THE VESTIBULAR  
DISORDERS ASSOCIATION

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

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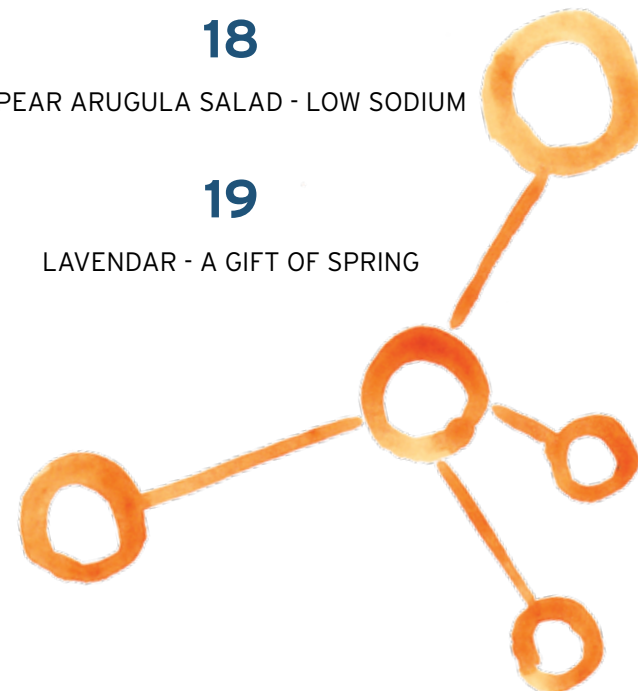
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## Vestibular Warrior

By Emily Englert

October 31<sup>st</sup>, 2016 was the scariest Halloween ever. But not because of goblins or zombies. It was on this day that my world flipped upside down. I had no warning, and I was totally unprepared to deal with what was happening to me.

I was just sitting at my desk at work, when suddenly everything went sideways. In an instant I felt disconnected from my body. My eyes wouldn't focus, and I felt like I was walking on a trampoline. I was terrified.

I'd had a cold with an ear infection the week before but didn't think anything of it. I expected that my body would heal and I would just be fine. That night I took my two young boys (Sage, age 2 years, and Emerson, age 3 months) out trick-or-treating. I felt awful, with anxiety coursing through my system, but I was determined to be a part of their holiday ritual.

The next day I felt worse. I could barely walk and was reduced to crawling around my house. The doctor said it was just a cold. I thought, "I'll just take a few days off to rest and recuperate." After a week I was in no way ready to return to work, but that's the beauty and curse of an invisible condition - you don't look sick, so you are expected to perform. What else could I do?

On the road to recovery I went to see my general practitioner and genuinely thought that she would know what was wrong and be able to help me. That first week I spent hours in her office, and I quickly realized this was not the case. I knew at this point that I would have to advocate for myself. I saw two ENTs, neurologists, several other general practitioners, a physical therapist, a gynecologist, a holistic doctor and a chiropractor. They all had something to offer, often not what I wanted to hear.

There is so much emotion wrapped up in the early months of my vestibular journey. It was all so terrifying, confusing and heartbreaking. I pleaded with the universe, "Please let me just wake up and feel normal again." I can't pinpoint exactly when I accepted that this wasn't going to go away overnight, but eventually reality set in.

This is when my "fight" mechanism kicked in. I wasn't going to let this vestibular



**ABOVE:** EMILY POWERED THROUGH TRICK-OR-TREATING WITH SONS, SAGE (PICTURED) AND EMERSON, DESPITE FEELING DISCONNECTED WITH HER BODY.

monster take me down. I cried a lot (and sobbed harder), then I picked myself up and took action.

About three months into this nightmare I started doing my own research. I learned about vestibular neuritis and vestibular migraine. I started going into doctors' offices with questions. I let them know that I wasn't going anywhere. Some of the things I heard



from doctors honestly make me laugh at this point, not because they were funny, but because it's absolutely ridiculous some of the suggestions I was offered. You know your body and what your symptoms feel like. Remember that.

I went to physical therapy but I didn't feel like it was helping. Getting back out into the world, where my vestibular system is challetruly felt like therapy for me. That's when I turned to a holistic approach. I paid closer attention to what I was eating. I



**ABOVE:** THE LOVE EMILY SHARES WITH HER CHILDREN WAS A "GUIDING LIGHT" IN HER RECOVERY.

researched supplements and I worked with a holistic doctor. Since March I've done yoga and meditation a few times each week and it's been such a game changer for both my physical and mental health.

If someone had told me two and a half years ago that I would still be dealing with vestibular symptoms on a daily basis, I would have said, "No way, I can't. It's awful." But here I am doing just that. And I'm leading a happy life. Not without its challenges, but

I'm grateful for it all at this point. It's been a journey of really getting to know myself and finding happiness in dark moments, because it certainly exists.

I've seen many doctors, had many tests, explored both western medicine and more holistic approaches, and learned a lot. And I'm still constantly learning. I'm not entirely without symptoms, but I am at peace with this condition and empowered to support myself along the way.

I've found that being honest with myself and the people in my life about what I'm going through has made a world of difference. They may not fully get it, but at least I'm being honest. There are times when my health has to come first. If there is an event or something else happening that is going to cause more stress than it's worth, I don't participate. It's that simple. I no longer apologize for what I'm going through. It's a part of me, but it's not all of me.

When my vestibular disorder first hit, my sons were very young and they needed their mom to be there for them. I often had to stay up half the night with my baby; it's such

a blur. I just told myself that they need love and if I just show up that's all that matters. I remember sitting on the ground watching Emerson play on the mat while Sage drove trains around. I felt like I was floating on a moving dock, totally disconnected from my body, but I was still there with them. That's what they needed. In many ways I feel like I missed out on the first year of my youngest's life. But I know I did the best I could.

My kids were my guiding light. They saved



me. They were too young to know what was happening, but their love was everything to me.

My husband, Kristian, has been my rock. In the beginning, neither of us understood what I was going through. He supported me as I saw countless doctors and then embraced a holistic approach. He has let me fall to pieces when I needed to, just cry and let it all out, and then he has encouraged me to keep pushing forward. It's been hard for him to see me at my worst and I'm sure he was scared. But together we stayed positive.

Finding happiness with a vestibular disorder is really hard at times. I can't quite see right. The ground underneath me feels like it's moving. I would think things like, "I'm disconnected from my body and you want me to be happy?" Then I would tell myself, "Yeah, figure it out." And so I started searching. It requires finding happiness and joy in small things, everyday things. The first time I put away laundry and I didn't feel my body swaying as I bent up and down, that's happiness.

Let's talk about the biggest mountain you'll ever climb: perspective. This is your attitude toward your vestibular stuff, how you talk about it and think about it. This is how you let it define you. This mountain is really big, and when you think you've made it to the top there will be another stretch (maybe a long one). That's OK. Take a big breath and keep climbing. Chug some water. Your perspective is going to play a big role here, so take a moment before you land on it.

These days I'm running again. Running has always been my happy place. In the beginning and into the messy middle of life

**YOU KNOW YOUR BODY AND WHAT YOUR SYMPTOMS FEEL LIKE.**

**REMEMBER THAT.**

with a vestibular disorder and just showing up every day was all I could do. Running brought me back my life. It's such a different experience now because I'm so beyond grateful that I can run. I found joy on the trails and rediscovered me again. This is my version of recovery. Recovery for me means that most days I feel pretty great. I know this is not the end, and I will continue to expand my knowledge to fully

understand the roots of this vestibular disorder. I am truly grateful to be part of VeDA's community of support, where we can inspire one another and flourish.



**ABOVE:** EMILY IS A VEDA AMBASSADOR AND VESTIBULAR WARRIOR. SHE SUPPORTS AND EMPOWERS VESTIBULAR PATIENTS IN DISCOVERING THEIR WELLNESS USING A HOLISTIC APPROACH THROUGH HER BLOG, [WWW.BLISS-OUT.CO](http://WWW.BLISS-OUT.CO).

## The Spectrum of Vestibular Migraine

By Michelle Eyres

In the journal *Headache* printed by the American Headache Society, researchers looked at the symptoms during and between vestibular migraines (VM) as well as any psychiatric or physical exam findings in patients who experience VM.

VM is not as common as “regular” migraine but it is the most common cause of vertigo. Migraines affect approximately 16% of the adult population, whereas VM affects between 1% and 2.7%. Many VM sufferers seek medical attention. However, it remains a very under-recognized condition.

The challenge of VM lies in the spectrum of symptoms, the absence of “typical” migraine pain and its recent definition as a disease. A review was conducted of VM patients’ charts at the UT Southwestern Vestibular and Neuro-Visual Disorders clinic. These patients were seen between August 2014 and March 2018.

The International Headache Society and the Barany Society define VM as:

- At least 5 episodes of vestibular symptoms of moderate or severe intensity, lasting 5 minutes to 72 hours.
- Current or previous history of migraine with or without aura.
- One or more migraine features (symptoms) with at least 50% of vestibular episodes.
- Headache with at least two of the following characteristics: unilateral (one sided), pulsating, moderate or severe pain intensity, aggravated by routine physical activity.
- Photophobia or phonophobia (i.e. sensitivity to light or sound).
- Visual aura.

Charts of 131 patients were reviewed. Women accounted for the majority of VM patients by a ratio of 4:1. The average age of the first VM

was 44.3 years. Over half of the patients had a history of migraine and 42.7% had vestibular and migraine symptoms.

A family history of migraine was reported by half the patients while one-third of the patients had a family history of vestibular symptoms. 120 of the patients had a brain MRI or CT, but no remarkable findings were discovered.

VM patients’ symptoms ranged from one at a time to six different sensations simultaneously. The predominant symptom was “triggered vertigo” due to head motion or visual stimuli. It was reported that lying in a recliner with the head supported helped to relieve the symptom. The second most frequent symptom was “spontaneous vertigo.” One-third of the patients reported unsteadiness on their feet. 90% of the patients experienced light or sound sensitivity. Only 50% experienced a painful headache. Over one third of patients experienced “brain fog,” fatigue and/or word-finding difficulty. Many people had “Alice in Wonderland syndrome” as well as out-of-body experiences.

In between VM episodes, a vast majority of patients (88.6%) described visually induced dizziness brought on by supermarket aisles, busy patterns, movies, video games and/or scrolling on electronic screens of any size. Quick head movements also brought on dizziness in over half the patients. Visually induced dizziness and head movement dizziness in between VM were blamed by many patients’ for job difficulties, social isolation and difficulty with daily chores.

Over half of the patients described their dizziness as “persistent, almost constant.” Of those, 64% had PPPD (Persistent Postural Perceptual Dizziness) and 13% had MdDS (Mal de Debarquement Syndrome).

Once vestibular symptoms began, 70% of

patients were diagnosed with anxiety and 40% with depression. VM attacks were reported to be brought on by stress, bright lights, lack of sleep and weather changes. Missing meals, engaging in activities which require excessive head movements and exercise also triggered VM attacks. The usual culprits (alcohol and caffeine) also were triggers.

Acrophobia, claustrophobia, susceptibility to motion sickness and visually induced dizziness seem to indicate that VM patients have a hypersensitivity to the mixed messages their brains are receiving via their eyes and vestibular system. The high rate of anxiety, as well as other psychiatric disorders, reinforces the relationship between vestibular and mood disorders.

One trigger that VM patients suffer from, but which is not reported by “typical” migraine patients, is activities involving excessive head movements, e.g. house cleaning, driving in traffic and playing with “rambunctious” children. Combine house cleaning, menses (33% reported it a trigger) and stress and you have a VM cocktail.

The review concludes that the wide variety of VM symptoms and between VM episode symptoms, along with some psychiatric co-occurring issues, “may mislead clinicians into attributing VM patients’ symptoms to a purely psychiatric” origin. “It is vital for neurologists to recognize the clues that can help them correctly diagnose and treat this common disorder,” concluded the study authors.



**SOURCE:**  
*Beh SC, et al. The spectrum of vestibular migraine: Clinical features, triggers, and examination findings. Headache: The Journal of Head and Face Pain. Headache 2019; 0:1-14. February 12, 2019.*



## My Journey Toward Recovery and Paying it Forward

By Don Needham

**DON VOLUNTEERS AS A PATIENT SUPPORT MENTOR BY CALLING PEOPLE WHO CONTACT VEDA, AND WHO ARE DESPERATE TO TALK WITH SOMEONE WHO UNDERSTANDS WHAT THEY ARE GOING THROUGH. HE AND ALL OUR VOLUNTEERS PLAY A VITAL ROLE IN HELPING VEDA IN OUR MISSION TO SUPPORT AND EMPOWER VESTIBULAR PATIENTS ON THEIR JOURNEY BACK TO BALANCE.**

I am semi-retired, and at age 65 was thoroughly enjoying life one beautiful spring day in May, 2016. It had rained during the night so I was walking in the pasture to check the water gaps (for city folks, that's where a fence crosses a creek or waterway). The runoff from the rain can wash the water gap out and livestock can get out onto the neighbors' place. I got about 100 yards from the house when out of the blue I experienced incredible spinning vertigo and started throwing up. I fell to my knees and it felt like someone was pushing or sitting on my right shoulder. I figured out if I closed my eyes I would stop throwing up. So I crawled back to the house like this, throwing up every time I opened my eyes to see where I was going. I didn't know if I was going to make it.

I spent 12 days in the hospital. For four days I could not walk. I had continuous migraines with extreme double vision. They thought I had a stroke but tests proved negative.

Finally, I was released with a walker and told not to drive. No diagnosis. I decided to see if I could get some idea of what this was online. It didn't take long to figure out it had to be vestibular.

I figured out that I needed to see a neurotologist, which was three hours away. My family had to drive me. He told me I had

Meniere's and that I needed a steroid shot in my ear or surgery. By the time he diagnosed me I had been having some success with vestibular rehabilitation therapy (VRT), so I refused his offer. I continued with VRT for 6 months and was released at 95%. I thought I was home free.

Life was good until June, 2017. Again, with no warning, my dizziness increased, along with nystagmus and bad head pressure. This time I went to another neurotologist. He prescribed a light diuretic, told me to reduce my sodium intake, and warned me that allergies make the symptoms worse. I get allergy shots and take an antihistamine every day.

I read everything I could find and learned that I really needed to clean up my diet of processed foods. A few months later I was diagnosed with vestibular migraines (VM). I have learned it is important to figure out the triggers for both Meniere's and VM. This is very much trial and error. Sleep and rest are so very important.

In October, 2017 I started having trouble with my eyes. I couldn't read more than five minutes, couldn't judge distances while driving, and it felt like I was seeing with binoculars with no peripheral vision. I found a neuro-visual optometrist, and sure enough I have both horizontal and vertical heterophoria caused by a concussion

playing football 50 years ago. This was the final piece of the puzzle for me.

I am doing well now and even have some trips planned in the coming months. It has been a long and rough journey but I made it. Am I cured? No. But I figure around 80% with mostly good days. My faith in God sustains me and gives me great peace through all of this. For me, it is about taking it one day at a time, always learning, always seeking, never giving up, and staying positive. I hope and pray that someday there will be a cure, but until then I will keep putting one foot in front of the other.

It is very clear to me that only people who have been through what I have understand it. In the beginning, there are

so many emotions and questions, so many frustrations about things we have no control over. I compare it to the grief from losing a loved one. Our lives can be changed forever. Many of us will never fully recover, and that is sometimes difficult to accept.

I wanted to volunteer to let others know that I care and I understand. Sometimes we just need someone to talk to. We tend to want to withdraw and isolate ourselves, which doesn't help. I want to encourage and support others to be an advocate for their own health by learning as much as they can about their vestibular condition. I want to tell them that there is hope, no matter what their circumstances. So many people have helped me. Volunteering with VeDA will help me pay it forward.

**I WANTED TO VOLUNTEER TO LET OTHERS KNOW THAT I CARE AND I UNDERSTAND.**

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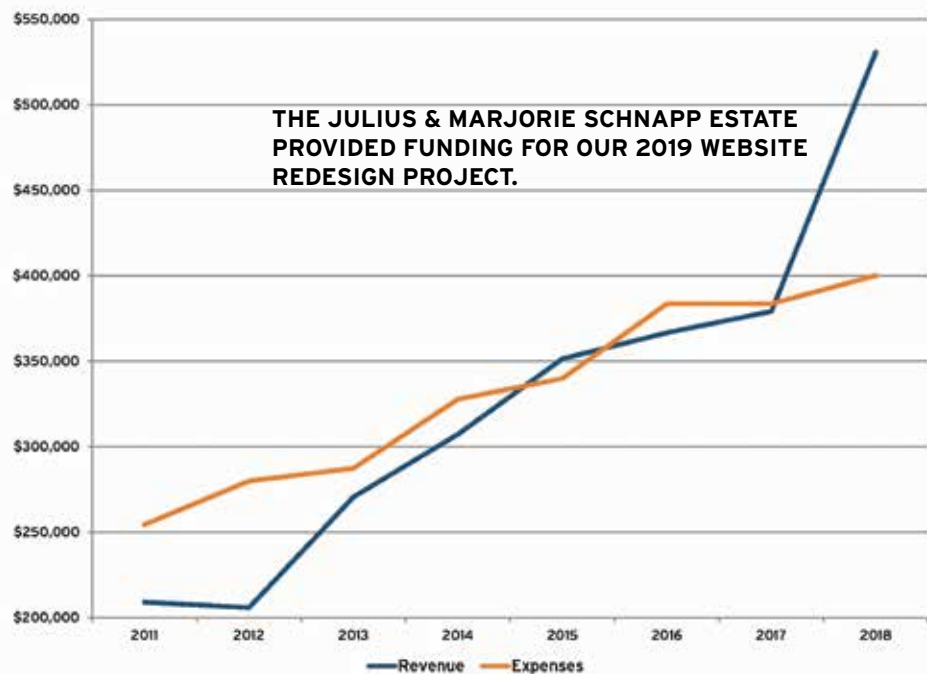
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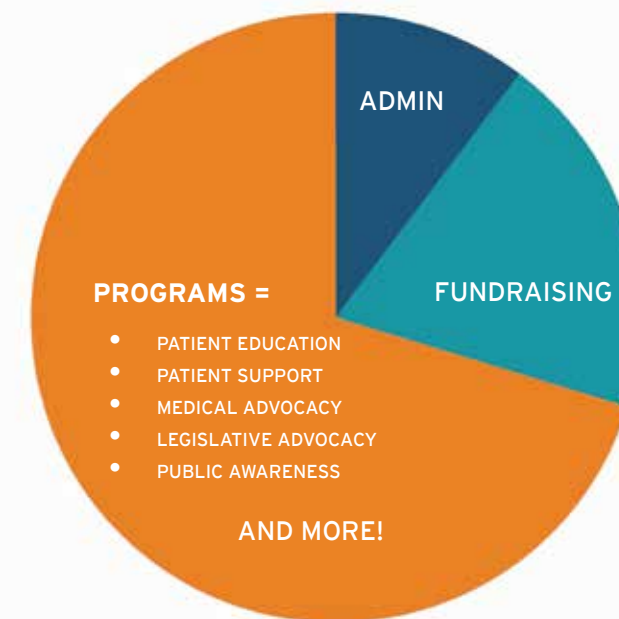
Thanks to you, VeDA is able to provide one-on-one support to over 160 patients and their loved ones every month.

# 2018 ANNUAL REPORT

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## VeDA Volunteer Goes to D.C.

By Cynthia Ryan, Executive Director

Danielle Tate represented VeDA during RDLA's (Rare Disease Legislative Advocates) Rare Disease Week on Capitol Hill.

Danielle is a physical therapist and a volunteer member of VeDA's Advocacy Committee. Recently, she had the opportunity to join other rare disease advocates in Washington D.C. to raise awareness about vestibular disorders and learn how we can best effect change that will reduce diagnosis times and improve treatment outcomes for vestibular patients. Here is what Danielle said about her trip:

"EveryLife Foundation for Rare Diseases has designed a program to support the advocacy of all rare disease patients and organizations (including vestibular dysfunction patients!). I consider myself extremely fortunate to have been a part of the Rare Disease Week on Capitol Hill while spreading the word about VeDA. More than 550 advocates took part in a Legislative Conference where we heard from experts from Capitol Hill about how to support 2019 legislative priorities, build effective relationships with Members of Congress, and how to introduce our own legislation.

The next day, I could barely contain my excitement as I joined over 550 other advocates on Capitol Hill to meet with Members of Congress. Thanks to our efforts, at least six Members of Congress joined the Rare Disease Caucus, which provides a forum for Members of Congress to voice constituent concerns, collaborate on ideas, facilitate conversations between the medical and patient community and build support for legislation that will improve the lives of people with rare diseases. Throughout the week, I was amazed to hear directly from representatives of Congress and the Senate

who have personal connections to rare diseases in their lives. The entire experience made me extremely proud and excited to see what the future has in store for VeDA's Legislative Advocacy Committee."

If you are interested in becoming involved in legislative advocacy, let us know at [vestibular.org/Advocate](http://vestibular.org/Advocate).



## HOW YOU CAN HELP

### DONATE

- Online
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### VOLUNTEER

- Join a committee
- Become an Ambassador
- Share your skills (writing, graphic design, etc.)

### ADVOCATE

- Write your legislator
- Share your story
- Join VeDA's advocacy team

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## Pear Arugula Salad

By Alicia Wolf, a.k.a. "The Dizzy Cook"

### PREP TIME - 15 MINUTES

A vegan and nut free salad, this is a recipe that you'll definitely want to have seconds of. It's easy to throw together with pantry ingredients, and elegant yet simple.

Servings: 4 people

### SALAD INGREDIENTS:

- 1/2 5oz package of fresh arugula
- 1 watermelon radish, washed and roots trimmed, chopped small. If you can't find a watermelon radish, red radishes would be fine.
- 1 pear - royal riviera or comice are preferred, sliced
- 1/4 cup lightly toasted pepitas (pumpkin seeds)

### MAPLE VINAIGRETTE

- 3 tbsp extra virgin olive oil
- 1.5 tbsp white vinegar
- 1 tbsp maple syrup
- 1 small clove of garlic, peeled and minced
- 2 tsp whole grain or dijon mustard
- Kosher salt and pepper to taste

### INSTRUCTIONS

1. To lightly toast your pepitas, warm a clean pan (no oil) over medium low heat. Add pepitas and toast, stirring occasionally for roughly 3-5 minutes. Check often to make

sure they do not burn.

2. In a small bowl, whisk together the salad dressing ingredients. Taste and adjust for more salt and pepper. In a large bowl, add the fresh arugula and toss with as much dressing as you'd like (there might be a bit leftover for a future salad). Add pears, pepitas, and radish to the top.
3. If not ready to serve immediately, store the salad, undressed and covered, in the fridge. Pears will brown after a while, so cut those right before serving.



## Lavender - A Gift of Spring

By Karen Mizrach

One thing you learn rather quickly when you struggle with a complicated health condition is to embrace any new idea, no matter how small, and to treasure any little joy that comes your way. While you are busy searching for the big answers (the cures, the therapies, the doctors, the medications), take time to also look for the smaller daily gifts you can give yourself. Nature is a great healer, whether it's a walk in the woods, sitting on a bench in your yard or learning about a special plant that can give you a lift.

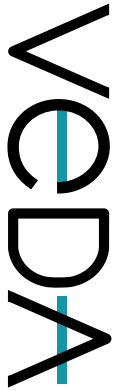
This spring, a beautiful, fragrant flowering herb may offer you a bit of peace and relaxation. Lavender has been used for centuries as a health and wellness aide. The small, purple flower has a powerful scent that is believed to induce a sense of well-being and restfulness. Its origin is in the Mediterranean region, where it has a long history of being used in baths and ointments. The fragrance can often help with stress reduction and relaxation, which are important goals for those who struggle with balance issues.

Stress and anxiety are unfortunate companions to vestibular disorders. They interweave so much with our other symptoms that it's often hard to separate them to determine what causes what. The telltale signs of anxiety, pounding heart, trembling, and shallow breathing (among others) can arise at any time, even without obvious cause. There is evidence that lavender has a quality that can assist in lowering your anxiety response and create a feeling of relaxation. In fact, there have been many studies that measure this response. One study focused on dental patients who were anxious before their check-up. Lavender was used in a diffuser (candle warmer) in the waiting area. Patients who

were exposed to the aroma were markedly more relaxed during their dental procedures (source: <https://www.ncbi.nlm.nih.gov/pubmed/25328900>).

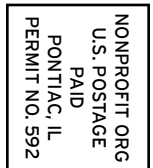
The first step in trying an essential oil like lavender is to establish that the scent is pleasing to you and doesn't cause a negative reaction. Locate a store that sells essential oils. Usually the best stores to try are health and wellness ones. Using the tester bottle, wave the bottle of lavender oil under your nose. It's not recommended to take a big whiff before you know if the fragrance appeals to you. If lavender causes you any negative reaction, even if you just don't like the smell, there is no need to explore it further. If it is appealing, dab a little on your wrist and live with it for a few hours. Once you've decided it doesn't irritate your nose, skin or mood, it's time to learn how to use the oil for the best results.

While not an FDA approved treatment for anxiety, lavender has been shown through history to be a calming therapy for many people. There are many ways to use lavender to experience its therapeutic qualities. The most common way to use a fragrance such as lavender is through an essential oil. This is a concentrated extract taken directly from the flower. Oils can be inhaled, topically applied, or diffused into the air. Essential oils are most often mixed with carrier oils to allow the most effective absorption and most gentle application. Some common carrier oils are sweet almond, grape seed, coconut, sesame and sunflower oils. It's best to use dark glass for storage and a cool, dark place to keep your oils. To make an oil blend, try about 10 drops of the lavender oil mixed in with 1/2 ounce of a carrier oil. This can be massaged in small amounts on your temples, the



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back of your neck or on the forehead. Lie down in a dark, quiet place and simply relax, breathing in the aroma and letting your muscles release their tension. As you become familiar with your reaction to lavender you can play with other uses of the oil. Putting some on a cloth and inhaling it, or investing in an aromatherapy diffuser can be other ways to enjoy the fragrance. Also, dropping some oil into a bath is an age proven luxury.

So, as you collect bits of wisdom, medical treatments and therapies for treating and coping with your vestibular disorder, give the power of lavender a try this spring. If you don't love the scent up close, maybe grow a plant in your yard and just enjoy its beauty. As with any plant or natural substance, some people will be allergic or experience negative sensations from the aroma. If lavender is not for you, try peppermint, lemongrass/balm or chamomile oils. There is probably one you will find enjoyable and relaxing. If you take medicines for anxiety please ask your doctor about using herbs in addition.

A couple of good, clearly written books to use as you are learning about essential oils are *Essential Oils For Beginners*, published by Althea Press, 2013, and *Just The Essentials* by Adina Grigore, 2017. ■

