

Steps
-2Balance
May 16-22, 2021

VEDA

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



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JULIE S

A year after a debilitating car accident, Julie is walking again and rediscovering her balance.

For over a year, the world has struggled with the disruption of life and work, increased stress, social isolation, and many more side effects of the coronavirus pandemic.

The physical, mental, social, and emotional challenges are everyday for people like Julie S., who struggles with vestibular dysfunction.

"My vestibular experience started following a brain injury suffered in a car accident. I immediately felt off balance and disconnected.

I went to the emergency room, where they discounted the possibility of a head injury because I did not hit my head. They were wrong.

I immediately scheduled an appointment with my doctor. Her evaluation confirmed neurological dysfunction, and we began a treatment protocol immediately.

My treatments had to start very slowly, and my doctor was careful to tailor them based on what my brain could tolerate.

Almost a year later, I am doing well and slowly regaining function."

THE ROAD AHEAD

Julie's vestibular disorder brought her life to a screeching halt.



\bigvee AMBASSADOR JULIE S.



"I am a veterinarian, but I am not able to practice because of symptoms related to my brain injury," Julie says.

"My husband drives me to my twice-weekly neuro rehab appointments. He does all the shopping, much of the cleaning and cooking, and so much more. It has been a struggle for me to be incapacitated and for him to be responsible for so much while having a full-time job himself.

"Emotionally, it is scary and confusing. I was afraid I would be severely disabled forever. As my treatments have begun to have an impact, I am becoming more functional with each passing month. My progress is excruciatingly slow, but I am finding it easier to have hope for my future."

FINDING HELP

"VeDA has been instrumental in both my diagnosis and recovery. I first learned that both my light and sound sensitivity might be contributing to my vestibular symptoms through VeDA. I also learned about Urban Poling's Activator poles through a VeDA webinar, which have helped me to feel more steady and secure when walking, and contributed to my exercise therapy.

"It has only been the last two months that I have been able to try walking outside. I knew that I needed to start taking walks as part of my vestibular therapy, but I was not feeling stable or safe enough to do so. With my new Urban Poling poles I have progressed from taking a short walk up my driveway to being able to make two trips around the block!

"My walks around the neighborhood have progressed to me being able to walk three blocks now! As a new challenge, my husband and I decided to mix things up and visit a local park this past weekend. I was able to slowly walk 3/4 of a mile on mixed terrain ~

pavement, mulched paths, and raised wooden boardwalks. My Urban Poling poles helped provide stabilization and gave me confidence to try this new environment for my walking rehab. It was a success!

"I am still in formal vestibular rehab as well and continue to make steady progress."

VeDA thanks Julie for sharing her story and for inspiring Fiona Flamingo Bingo! ■

Julie and her Urban Poling walking poles







HOW TO PLAY

Everyone – vestibular patients, family members, and support partners – can play Flamingo Bingo starring Fiona Flamingo! Flamingos are masters of balance something every vestibular patient strives for! The "steps" are meant to be FUN activities for everyone. You know your own limits, so make sure that safety is your top priority when doing an activity.

F1-D0 THE FLAMINGO.

Imitate a flamingo by standing on one foot – use walking poles, a chair, or the wall for support, if needed. For an advanced balance challenge, outstretch your arms to the sides – but only if it is safe to do so! Remain in this position for 10 to 20 seconds, switch your feet, and repeat. Standing on one leg makes you engage your core muscles.

F2-GET SOCIAL. Post your progress on social media. Be proud and show the world what Steps-2-Balance you're taking.

F3-CHOOSE ONE. Don't try to do everything at once. Focus your energy on one thing you can and want to achieve, such as eating more veggies, drinking more water, or waking up earlier.

F4-BE IMPERFECT. There is no such thing as perfection. When you fall short of taking a step but have made an honest attempt, reflect on why it didn't go as planned and learn from the experience.

F5-MEDITATE. Meditation helps calm the mind and reduce anxiety. Because stress is a trigger for many vestibular patients, reducing stress can also lessen symptoms like dizziness and vertigo.



I1-MOVE AFTER A MEAL.

After eating breakfast, lunch, or dinner, go for a walk around the block or do some stretching indoors. The movement will aid your digestion.

12-SET AN ALARM. Every hour, or at the same time each day, remind yourself to get up and move or stretch. Set an alarm on your phone, watch, clock or fitness tracker.

I3-GET CRAFTY. Are there any arts or crafts activities you have been meaning to try? Journaling, watercolor painting, needle felting with yarn, writing poetry - all are ways to focus vour energy and find balance.



14-TRACK YOUR PROGRESS. Every now and again, take a look at your bingo card and appreciate your progress, however big or small. Every step matters!

I5-TRY YOGA. The vestibular ocular reflex (VOR) maintains visual focus when the head is moving in a different direction and/or at a different speed than the body. When practicing yoga poses, picking a focal point while moving the head and body helps to foster the VOR reflex.







Cover as many squares on your bingo card as you are able, and email a photo of your card to **flamingo@vestibular.org**. Everyone who emails a photo of their bingo card by May 22, 2021, will be entered into a drawing for a pair of Activator Poles by Urban Poling.

YOGA

When you post your bingo card on social media, please tag VeDA and use the hashtags **#fionaflamingobingo** and **#urbanpoling**.



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DATE

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TWIST

MEAL

VEDA

O1–STAND, DON'T SIT. Next time you're watching a video or talking on the phone, stand on your feet and stretch or pace the room instead of slouching on the couch. Shake those tail feathers any way you can!

O2–START A CONTEST. Challenge someone to see who can take the most steps in a week, or hold a stretch the longest, or raise the most funds for VeDA. A friendly competition can provide extra incentive.

O3-FREE! The space in the middle of a bingo card is "free" to the player, so feel free to take a day off or choose an activity of your choosing, whether it's a step you've been meaning to take or a day of rest when you need it.



O4–ASK FOR HELP. When balance eludes you, reach out. Someone is bound to have the solution you need to take the next step. You can always visit **vestibular.org/forum** to ask questions of your peers and gain support from the community.

O5–SAVE THE DATE. Put an activity on your calendar and write about it afterwards. Planning ahead is a way to make a commitment, and journaling afterwards is a way to reflect on your journey.



N1-BUDDY UP. Find a "Vestie" (vestibular buddy) and join forces. A Vestie is someone you trust who can remind you to reach your goals or who can do them with you. Establish a daily or weekly time to check in with one another and stay motivated.

N2–GO OUTDOORS. Set foot outside. Whether it's just sitting on your front porch or in your yard, strolling around your neighborhood, or going for a hike, the fresh air will do you good.

N3-REWARD

YOURSELF. Choose one goal that you will achieve this week. Enjoy an extra treat for yourself when you reach that goal to help keep you motivated and energetic. You deserve it!



N4-TREAT YOURSELF. It's important to reward success, and also to soothe yourself after failure. Make the prize proportional to the step you have taken. Celebrate (or apply salve) accordingly.

N5-EAT A HEALTHY MEAL. Many vestibular patients find that modifications in their diet can reduce dizziness and help manage other symptoms. Try not adding extra salt, or reducing the amount of sugar in a recipe to see if it makes a difference.

The A column features activities that take full advantage of Activator Poles by Urban Poling. Urban Poling offers VeDA members 10% off purchases and donates a portion of its proceeds to support balance awareness and patient education. For more information, visit urbanpoling.com/veda.

A1-UP YOUR FIT. Squatting is a terrific exercise to help strengthen the lower body and core muscles. If you have compromised balance, use a sturdy piece of furniture, or even better, a pair of Activator Poles by Urban Poling. Get into squat position, plant





**

Raise \$1,500 or more for Steps-2-Balance and receive a pair of Activator Poles by *Urban Poling!* Learn more at **steps2balance.org**



your poles firmly in front of you at just wider than hip distance apart, and push down through the ledge of the handles into squat position. Don't let your knees go past your toes as you bend! Continue to push through the handles as you come back up to standing. Repeat as many times as you are able.

A2–KICK IT OUT. Single leg abductions are great for strengthening your flamingo stance. For support, use a pair of Activator Poles by Urban Poling. Firmly plant the poles in front of you, press down into the handles, and balance on one leg, kicking out your other leg to the side 5 to 10 times. Repeat on the opposite side.

A3-BREATHE UP. Stretching your chest and shoulder muscles is a good way to breathe deeper. After a walk, place your walking poles (or other sturdy support) at



"We are thrilled to partner with such a wonderful organization like VeDA," says Mandy Shintani, occupational therapist and gerontologist, designer of Activator Poles and managing director of Urban Poling Inc. "Supporting VeDA and the Steps-2-Balance campaign was an easy decision for us as we are also committed to helping those living with balance concerns through our products and programs. Many of our clients have vestibular issues which compromise their balance and have found our unique therapist designed walking poles to be helpful in their journey to better balance, health, and wellness." Thank you, Urban Poling, for your support of the vestibular community!

the 3 o'clock and 9 o'clock positions. Put one leg forward and the other leg back, and bend into it - that's a lunge! Press your chest forward - feel that stretch? Take a deep breath and fluff up those feathers!

A4-PULSE THOSE POLES! Pushing into the ledge of the CoreGrip™ handles of your Activator Poles - whether standing, sitting, or walking - you should feel your core and upper body muscles engage. Before heading out for a walk, stand with your poles and try just pushing down into both handles at the same time. Each time you do, you will feel all those muscles contract. Try doing 20 pulses before and after your walk, and you'll trim up those wings in no time.

A5-DO THE TWIST. Standing with your feet shoulder-width apart, put equal weight on both feet using your walking poles for balance (or other sturdy support), if needed. Keep your legs gently bent at the knees. Now twist your hips from side to side and do a little dance. Gradually bend your knees more as you twist, to lower your body. Hold this position for a few beats, then rise back up by pushing on your poles and raising your knees to the starting position. Both the dropping and rising part of the move should be slow and steady. When going low, it is very important to maintain your balance, so remember to use support.





VeDA partners with the Barany Society and the Journal of Vestibular Research to bring patient-friendly summaries of the most current developments in vestibular medicine.



The Official Journal of the Bárány Society

The Role of Vestibular Cues in Postural Sway

Summary written by Jennifer Robbins, MPT and Suzanne Peters

The purpose of this study was to examine the impact of vestibular cues (such as vision and touch) on postural control (ability to balance).

BACKGROUND

The brain relies on three main sensory systems to control posture and prevent falls:

- The vestibular system in the inner ear;
- The visual system, which relies on input from the eyes; and
- The proprioceptive system, which relies on somatosensory input from the skin.

The vestibular sensory organs include the semicircular canals and the otolith organs. The semicircular canals sense angular rotation (such as turning your head), while the otolith organs sense linear motion and tilting responses (like bending over to grab something).

There are balance tests that are designed to isolate the vestibular system from the proprioceptive system and visual system. For instance, if you are standing on a foam pad with your eyes closed, you cannot rely on either the visual system (you cannot see) or the proprioceptive system (the ground below you is not firm), so you must use your vestibular system. Therefore, "failing" tests under these conditions may indicate a problem with your vestibular system.

When you are standing, your body has to pick which system to "listen" to. When the body makes the wrong decision or a system is impaired, increased sway in standing (imbalance) occurs, which can lead to falls. "Sensory reweighting" refers to the process your body uses to fix this excess postural sway. It is important to remember that postural sway.

is natural, but excess sway could indicate a problem.

When the sensory signals sent to the brain don't represent a physical stimulus it results in "sensory noise." In other words, one system in the body may distract another system that should be responding to the natural tilting and re-centering process we call postural sway. These distracting messages can come from the muscles, brain, eyes or inner ear. If the brain is not able to cancel out this sensory noise, it can result in imbalance.

METHODS AND FINDINGS

This study used standing balance tests that focus on the vestibular system and took them a step further to examine the direction of movement that was causing people to fall most often. They performed two separate studies.

Study A looked at the relationship between vestibular thresholds (the smallest motion that can be correctly sensed as being a certain direction) and postural sway, specifically lateral translations (movement parallel to the ground.) They found that side-to-side sway and lateral translation vestibular thresholds are positively correlated and play an important role in postural control. Note that the participants in this study did not have diagnosed vestibular problems.

Study B measured thresholds for rolling, forward-backwards and diagonal movement. They did not find statistically significant results in this study.

This paper also provided information about how much of a balance challenge a person accepts based on how big of a threat he/she finds the situation to be. If he/she has more confidence in their balance, they accept a larger balance challenge. The person will put forth a big effort to try to reduce postural sway and prevent a fall if the balance challenge appears to be very threatening.

CONCLUSION

Overall, the paper showed that the conditions that require the brain to rely heavily upon the vestibular system (a foam pad and little to no light) caused the most difference in postural sway between subjects, even in healthy people without vestibular conditions. This means the tests used to assess the vestibular system are doing their job.

Furthermore, based on the sway measured in healthy people on all versions of the test (those that rely on vision, proprioception, and vestibular, respectively), when the vestibular system is used in isolation, people show the most sway (remember that increased sway is correlated with falls). Finally, the study also validates thresholds as a good way to study sensory function.

Although the study only found significant results correlating side-to-side sway and sensory feedback, the study has potential implications for vestibular implants, balance prostheses, and physical therapy exercises, i.e. physical therapy exercises and vestibular implants that focus on cuing control of side-to-side sway with feedback may be more beneficial than previously thought.

There were some limitations of this study. There were fewer than 30 test subjects, and some of them were unable to complete all of the test scenarios. The design also lacks randomization and blinding, two aspects that make experimental results much more robust. However, it does suggest that more research needs to be done to answer the question about the mechanisms by which sensory noise could relate to falls.

SOURCE: Faisal Karmali, Adam D. Goodworth, Yulia Valko, Tania Leeder, Robert J. Peterka, and Daniel M. Merfeld. Feb. 25, 2021; https://doi.org/10.1152/jn.00168.2020.

Jennifer Robbins, MPT, is a physical therapist at Integration Physical Therapy in Old Greenwich, Greenwich, Connecticut.

Suzanne Peters is a student physical therapist at Regis University in Denver, Colorado.

YOUR SUPPORT MATTERS

Your support makes it possible for VeDA to document the advances made in vestibular science and research.



VeDA's mission is to support vestibular patients, reduce diagnosis times, and improve treatment outcomes.

Send a check in the enclosed envelope or donate online at **vestibular.org/donate**





Mindset & Living With Chronic Health Conditions

By Karen R. Mizrach, B.S.W, M.Ed. Counseling

Coping successfully with a chronic illness is rarely about finding ways to return to a pre-illness state, but instead signifies establishing long-lasting ways to adjust to a new sense of self.

Chronic illness presents an often complicated, overwhelming set of circumstances into a person's life. There are unending doctor's appointments, intimidating and expensive tests, treatments and therapies that may or may not work, and difficult limitations that are forced onto lifestyles. It is not an easy process learning to live with an illness that cannot be cured and will likely be lifelong. Yet, there is evidence that a person's mindset can have a profound impact on quality of life and ability to adjust to such challenges. Also good news is that mindset, unlike genetically set personality, is an aspect of ourselves that can be enhanced by learning new skills. For those of us with chronic conditions this offers hope as we wrestle with our symptoms and changing realities.

First, it's important to understand what "mindset" means. Mindset is a set of attitudes, beliefs, and habits that guide a person's emotional and cognitive behaviors. It can determine how effectively someone confronts and deals with

many types of life occurrences. Mindset can be positive or negative, but most people tend to fall somewhere in between. A positive mindset does not equal having a "pollyanna response." It simply allows a person to move forward, within reality, rather than getting stuck in hopelessness. Mindset has been equated to psychological flexibility.

The concept of mindset has been studied in relation to chronic illness adaptation, and has been found to be a significant element in how well (or not) a person copes with a new, challenging reality. Adjustment is an ongoing process complete with setbacks and periods of hope. It develops as a patient explores medical help, receives a diagnosis. tries out treatment options and undergoes various testing. Even someone with the most positive outlook usually

struggles with the initial

phases of dealing with a chronic illness. This is normal as life's realities and routines are disrupted. As with many types of loss, eventually people come to a time of acceptance and interest in moving ahead. With acceptance comes a new mindset possibility and a path forward.

Acceptance is key in order to begin adjusting to a new life situation. This is not the same as passive resignation or giving up. Rather, it is understanding limitations and needs, and being ready to incorporate them into a new version of your life. Acceptance is empowering rather than defeating. Validating – not minimizing or negating – your experience can help you to honestly assess your condition, your options, and your choices. Then the process of taking some control can begin.

As people with chronic conditions begin to take charge of their situations, there are overlapping life areas that are crucial to address. An interesting model called **THRIVE** examines how these factors work together and affect a person's ultimate quality of life. Therapeutic Intervention, Habit and Routine, Relationships, Individual Differences, Values and Beliefs, and **E**motional Factors (THRIVE) are components that contribute to mindset. These areas can be addressed and improved and adapted to increase coping ability.

Each person's situation, diagnosis, and resources are different, so the path to creating a healthy mindset will vary. There are several counseling types that can be useful in helping flexible thinking and problem solving. Several studies show that social relationships are crucial in predicting how someone will cope with a chronic illness. It's very important to find at least one person who will listen to you and let you be yourself. They don't have to have the same illness. There is also evidence that participating

> in groups for support, sharing, and education is a strong predictor of resilience in the process of adapting to a chronic condition.

So, in considering your particular life situation and might seem like a daunting, resources, take some time to evaluate where vou might be in this process of adapting and accepting. And take stock of what vour mindset tends to be overall. Small tweaks in perspective – nurturing a few key relationships, and reaching out for help - can make a huge difference in moving forward with

> health challenges. It's a life commitment to take as much control as possible in a situation where there was no choice. A positive mindset might just be the ultimate in self-care.

Karen Mizrach is a retired reading teacher, former social worker, and yoga teacher, who is adapting to life with a vestibular disorder. A personal goal is to reach out and support others who struggle with similar challenges. Karen lives, writes, and wobbles in Richmond, Virginia.

RESOURCES:

While becoming more

psychologically flexible

if not impossible task, it

is a skill, and any skill can

be learned by just about

anyone with enough

practice.

How mindset helps heal chronic illness. By Julie Killion, MA, LPC, LCAS, NCC: healthandhealingonline.com.

The THRIVE model: A framework and review of internal and external predictors of coping with chronic illness. By Katherine White, Marianne SM Issac, Claire Kamoun, Jessica Leygues, and Simon Cohn: journals.sagepub.com.

Resilience in the chronic illness experience. By Debbie Kralik, Antonia van Loon, and Kate Visenti: tandfonline.com.

Q&A with psychologist Vicki Helgeson: Living with chronic illness: Why some cope and others don't: knowablemagazine.org.

The best life possible. By Joseph Trunzo: aeon.co.

A simple mindset shift that will change your life! By Jennifer Ellis-Schuetz: www.empoweredtoheal.com.



2021-2023 Strategic Plan

By Cynthia Ryan, MBA, Executive Director

It's 2021, and here we are, a world completely out of balance as a result of the COVID crisis. Amidst this turmoil, the Vestibular Disorders Association (VeDA) remains committed to continuing its support of people living with the debilitating effects of vestibular dysfunction by providing scientifically validated information to help people find a diagnosis, and helping people navigate an increasingly complicated and over-burdened medical system.

Most importantly, VeDA connects vestibular patients with a global community of people who understand what they are going through - because they have gone through it themselves.

VeDA is facing challenges to continue its 30-year legacy as champions of the vestibular patient experience. But I believe VeDA's longevity is a testament to the resilience of our supporters, people who know what it means to fight an invisible illness.

Faced with uncertainty, late last year VeDA's Board of Directors took steps to chart the organization's path forward. I'm excited to share with you our insights and a vision for how we can create a world where vestibular disorders are widely recognized, rapidly diagnosed, and effectively treated.

THE NEW NORMAL

When I started with VeDA nine years ago, I was fired up with a passion to reshape the medical system. I wanted physicians to recognize vestibular disorders as the devastating conditions they are, not just some incurable, mysterious illness. Funding was needed to focus research on improved diagnostic protocols and treatments, and to ensure that vestibular specialists are adequately reimbursed for the care they provide. A safety net was also needed for people who can no longer work due to their vestibular impairment. Some of these goals are within sight, but we are far short of others.

Over the years, VeDA has developed a solid reputation as a leading voice in the global vestibular community. Major medical institutions and professional associations look to us. We have a powerful platform to represent the needs of the vestibular community.

OPPORTUNITIES

Ironically, many of the restrictions imposed by COVID-19 have created unexpected opportunities. As people have become more comfortable with virtual gatherings, the vestibular community has grown exponentially. Through social media, online support groups, and our website's discussion forum, people struggling with vestibular dysfunction have been able to connect with each other and share their experiences.

In 2020, VeDA held its first Virtual Vestibular Conference, bringing together more than 1,200 people from around the world to watch presentations by vestibular experts and patient panel discussions. We were able to make this event accessible to people regardless of their location or ability (or lack thereof) to travel. Plans are underway for another, even better conference in 2022.

Telehealth is another opportunity. For many, the path to diagnosis and treatment is delayed, either because there is no vestibular healthcare specialist within close proximity to them, or simply because they cannot drive due to their condition. This causes unnecessary and prolonged suffering. Telehealth overcomes a big barrier to care, thereby reducing diagnosis times and improving treatment outcomes. We see this trend continuing to grow among our community of professional healthcare members.

CHALLENGES

Normally, VeDA's Board of Directors meets once a year in person to discuss the issues facing the vestibular community and set goals. However, due to travel restrictions and social distancing mandates, we were forced to devise a new strategic planning process.

Rather than one long weekend of intense discussion, we focused on one initiative at a time over several weeks of virtual meetings. While we missed seeing each other in person, we found an appreciation for the space to sit with our ideas between meetings, to research and explore, and ultimately to develop a plan that is clear, thoughtful, and full of hope.

STRATEGIES & PLANNING

VeDA's mission remains steadfast: to support and empower vestibular patients on their journey back to balance. The four pillars that support our strategic plan are as follows:

- **1. Building Community:** By building a diverse and influential community of people who suffer from vestibular dysfunction, their support partners, and the healthcare professionals who treat them, VeDA fosters collaborative actions that advance the shared goals of the vestibular community.
- **2. Increasing Awareness:** As a trusted source of information, VeDA raises awareness of vestibular disorders to a global audience through public outreach and educational resources, which help people who are suffering from undiagnosed dizziness, imbalance, and other devastating consequences of vestibular dysfunction.
- **3. Advocating for Change:** VeDA collects and disseminates data on the vestibular patient experience, promotes education and tools for healthcare professionals, fosters reciprocal relationships with government, regulatory and academic agencies and institutions, advocates for improved diagnosis, treatment and management for people with vestibular dysfunction, and encourages funding to support these efforts.
- **4. Developing Resources:** In addition to donations and professional memberships, VeDA seeks to diversify its funding sources, manage paid and volunteer human resources, embrace continuous process improvements, and minimize risk to ensure a robust, sustainable organization.

VEDA FOR EVERYONE

Some of you may know that I have a personal investment in helping VeDA. My mother suffers from Meniere's disease, vestibular migraine, and BPPV. Her life and the lives of my family have been immeasurably affected by her invisible illnesses. I know from firsthand experience how much the community VeDA provides has meant to her. She has not had to struggle alone. But sadly, there are many others who are not as fortunate as her to have supportive families.

I believe in the power of many, and that together we are stronger. I believe our efforts truly make a difference. I invite you to join me on this journey to make vestibular visible and help others find a life rebalanced.



THANK YOU TO BALANCE SOCIETY MEMBER PATTY GEREND

(Lifetime Donor of \$5,000)

About 15 years ago, I began having sporadic vertigo attacks. Not only were they terrifying, but I had no luck getting help from the healthcare practitioners I saw. When I found VeDA, I discovered I was not the only one suffering from a vestibular disorder. I have been donating to VeDA regularly ever since in the knowledge that they strive to help patients understand and address their experiences, and that they pursue avenues in the healthcare industry toward better visibility, diagnoses, and treatments for vestibular patients.

THANK YOU TO **NEW**BALANCE BENFACTORS

(\$250 or more)

DON BESTWICK, PT ROBERT GOLDEN DAVID SCHRADER

Every year, more than 2 million people visit VeDA's website looking for answers. Our Facebook posts reach nearly 4 million people, and our Patient & Family Resource Coordinator provides one-on-one coaching to hundreds more.

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