

# ON THE LEVEL

A QUARTERLY NEWSLETTER OF THE VESTIBULAR DISORDERS ASSOCIATION



INFORMATION

SUPPORT

AWARENESS

ADVOCACY



## Vestibular Disorders Mess with Your Brain

By Anne Kirchheimer

Nine years ago, a month after my 60th birthday, I was hospitalized with extreme vertigo and nausea – so severe that I couldn't walk 5 steps to a telephone for help. Diagnosed with labyrinthitis from a virus that damaged the nerve in my inner ear, hospital neurologists assured me I'd fully recuperate and be back to normal.

The extreme vertigo and nausea dissipated, to be replaced by complete imbalance, cognitive difficulties, severe fatigue, neck pain and excruciating headaches. I thought I was dying, going crazy, or had burned out. I continued to go to work but assumed I would soon be fired from my job as a writer. Used to churning out business plans, proposals and abstracts, I could not write a simple letter, or follow what was going on in a meeting much less run one.

A gregarious, social person, I needed to spend a lot of time alone. I still do. Interacting with even two or three people is exhausting. It's not easy getting used to the "new me."

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(TOP LEFT) ANNE IN HER OFFICE (BOTTOM LEFT) ANNE & SON KENNY AT A BASEBALL GAME  
(BOTTOM RIGHT) ANNE - SELF PORTRAIT

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BRAIN CONTINUED FROM PAGE 1:

Despite the neurologist’s assurance of 100% recovery I had to leave my job two and a half months after being hospitalized. After a few months on medical leave it was clear that I would not be able to return to work. I applied for long-term disability insurance through the private insurance company that I was obliged to pay into through my employer. That company required me to apply for social security disability. I was denied disability compensation by both. From the explanations in the denials it was evident that neither the private insurance company nor Social Security workers fully comprehended what a vestibular disorder was.

Granted, it is not easy to understand. My family and friends try to accept the new me, but from things they say I know they don’t get the ramifications of a vestibular disorder. How would anyone really understand how tiring, exasperating and disconcerting it is to go through the day seeing every object in a moving state? It’s like being in an amusement park fun house with the floors tilting and moving, mirrors distorting everything, but believe me it is NOT FUN. I hired a lawyer for help with the disability insurance issue. Finally, after a year and a half I was awarded long-term disability insurance from the private company and then from Social Security after an appeal that required a hearing before a judge.

I have to treat myself as a delicate hothouse flower – an orchid or something – in order to function at even my compromised level. Enough sleep and resting are mandatory, and I cannot multi-task at all. I can’t even talk on the phone while preparing the dog’s breakfast, which is not rocket science or a meal at the Ritz!

Today I spent a lot of time on the couch. Resting is a necessity if I expect to function in what is my new vestibular normal. People say I look good. Who wouldn’t after spending so much time resting? Having a vestibular disorder takes a toll. It has impacted my career, social life, travel, hobbies and simple pleasures like going to a ballgame or to a club to hear music or dance. My fatigue prevents day trips to beautiful spots in New England that I once enjoyed. The meditative and relaxing pastime as a self-taught painter and collage artist has had to take a back burner. The dizziness, faulty concentration and fatigue were too much.

My heart goes out to people in my vestibular support group, particularly the younger people who are launching careers, raising children, or trying to socialize and meet a life partner while coping with their vestibular disorder.

Most days I don’t feel very well, but I try to keep going, try not to get down. A friend in New York City gave me the best piece of advice: “Try to keep your spirits up.” Sometimes it is not easy.

On an annual visit to the radiation oncologist who treated me for cancer nearly 20 years ago, I was asked to fill out a form prior to examination. The answers enable the doctor to best assess a patient’s cancer treatment side effects and post-cancer quality of life status.

To certain questions I circled yes. I suffer from fatigue, joint and muscle pain, headaches, and dizziness. In parenthesis I wrote vestibular disorder, indicating the symptoms were not a result of my previous cancer.

Upon entering the exam room the doctor immediately spoke to me in the comforting tone I had grown accustomed to during my cancer treatment and further cancer scares over the years. “I am so sorry to hear about your vestibular problems. That is such a debilitating disorder.”



This is a man who sees breast cancer patients all day long – some on the brink of death – and yet he understands what I am living with now that I have a vestibular disorder, I thought. Eternally grateful for his wonderful “bedside manner” and excellent cancer care over the years, I also appreciated his empathy for this invisible chronic illness.

I am among the fortunate to have health care professionals who understand the effects of living with a vestibular disorder. They are kinder to me than I sometimes am to myself.

I am a long-term cancer survivor and am supremely grateful for my life. Today I am working on being a vestibular disorder survivor. It may not be life-threatening, but this damned disorder can sure kill your spirit if you let it.

Cognitive Aspects of Vestibular Disorders

*By Rachel Bilgrei, PsyD*  
Vestibular disorders affect individuals physically AND psychologically. These disorders are variable not only in their physical manifestation, but in their psychological manifestation as well. And while it is important to understand your physical symptoms, it is equally important to understand your psychological symptoms because they can often trigger and/or exacerbate your physical symptoms.

Cognitive is just a fancy word for thinking. When I use the phrase *cognitive aspects of vestibular disorders* I am referring to how your vestibular disorder affects your ability to think, specifically to pay attention and concentrate, to remember, to reason and to problem solve.

DISORIENTATION AND CONFUSION ARE COMMON DURING ACUTE STAGES OF VESTIBULAR DISORDERS.  
In these very frightening and disturbing moments, knowing who and where you are, the time of

day, etc., may not be readily available to you. Fortunately, these moments are relatively short-lived. As the physical symptoms fade, clarity and comprehension return.

VESTIBULAR DISORDERS INTERFERE WITH COGNITIVE STAMINA/ENERGY.  
Cognitive energy is finite for everyone. If you are using a great deal of this energy to maintain equilibrium and stay steady (something that is normally done automatically), it is unlikely that you will have very much left over for other activities. As a result, cognitive fatigue sets in. Activities that you used to be able to perform with ease and very little effort now require much more effort, leaving you drained of energy and requiring rest/naps. Spontaneity goes right out the window.

VESTIBULAR DISORDERS IMPAIR ATTENTION AND CONCENTRATION.  
Vestibular disorders interfere with your ability to

pay attention and concentrate. You may find that it is difficult to sustain focus for a significant length of time. You may find you are easily distracted – both by external stimuli (the noise of other people talking, the TV) and internal stimuli (your thoughts and feelings). Multi-tasking, the ability to do and keep track of two processes at the same time can also be compromised. Another area of attention/concentration that is often affected in people who have vestibular disorders is sequencing. For example: You may find yourself mixing up sounds while speaking, or reversing numbers or letters when speaking or writing. You may have trouble following directions, filling out forms, following a recipe, or tracking conversation or plot in a movie.

VISUAL SKILLS INTERFERE WITH PERCEPTUAL ASPECTS OF COGNITIVE FUNCTIONING.

Because of the intricate link between the vestibular system and the visual system, problems with visual-spatial tasks are common in people suffering from vestibular disorders. Eye-hand coordination may not be very coordinated. Depth perception may also be thrown off-course.

THE PROBLEM WITH MEMORY.

The most common cognitive complaint I have heard in my clinical experience working with people suffering from vestibular disorders has been difficulties with memory. And the problem seems to be more with short-term memory (remembering what you had for breakfast this morning) rather than long-term memory (recalling the name of your best childhood friend). Often, but not always, what is perceived as a memory problem is really a problem with attention. I like to use a bank model of memory to explain this phenomenon. To deposit money into your bank account, there are a series of steps that you need to execute in order to ensure your money is properly deposited so that at some later date, it will be there for you to withdraw. The same is true for your brain and processing

information to be stored in memory. There are specific steps it goes through to ensure that information gets “deposited” so that it is available for retrieval or “withdrawal” at some later point. At the bank as well as in your brain, if the steps are not followed properly, the money/information gets lost and thus is not available for future use. The cognitive strain of a vestibular disorder can interfere with this “depositing” or encoding process of information. As such, if the information is never properly encoded, there is no way it will be available at some later date for retrieval.

YOUR EXECUTIVE MAY NOT BE FUNCTIONING.

Imagine that sitting just inside your forehead is a very important person sitting at a very large desk. This person is the executive of your brain, the person in charge of managing, overseeing and coordinating all the functions of your brain. Specifically, this person is responsible for organization, problem-solving, decision-making and self-monitoring. In addition, this person provides you with a sense of internal certainty, that thoughts get organized and plans get executed, seemingly automatically. These abilities are referred to as executive functioning. Unfortunately, in the presence of a vestibular disorder, your executive functioning may not be functioning very well. This person is asleep under the desk! Overworked, under-resourced, he/she is just too overwhelmed, and this automaticity that you so readily rely on is gone. Plans, even the simplest ones, such as getting yourself dressed in the morning, may be completely disorganized ... and disorganizing. You may find it difficult deciding what to have for breakfast. Activities that were automatic, that you never had to even think twice about, now have to be meticulously focused on and thought about.

The difficulties described above can, and unfortunately often do, significantly interfere with day-to-day life. In response to these cognitive changes you may feel that your abilities have

diminished, both at home and at work. However, it is not your abilities that are diminished. It is your cognitive stamina that is depleted because it is being used for a function that, prior to having a vestibular disorder, your body handled easily. Reading is laborious, using the computer is painful and frustrating, balancing your checkbook is near impossible. Or if it is possible, you are doing things very differently than you did before. For example, you may find you operate at a slower pace, needing a lot more time to accomplish tasks than you used to, or with help from others. You may have found a more simplistic approach to accomplishing tasks, one that gets the job done but not nearly as satisfactorily. You may also have trouble navigating large supermarkets or department stores.

COPING STRATEGIES.


Thankfully, there are ways to combat and overcome these difficulties and improve functioning. The chart to the right pairs each problem area discussed above with a variety of coping skills you can utilize to minimize and/or compensate for these difficulties. **Rest, proper nutrition and appropriate exercise are also key components to managing areas of cognitive difficulty.**

TREATMENT.

Participating in treatment offers individualized attention to your specific problem areas while also providing normalization, validation and support. Sometimes professional help begins with a neuropsychological evaluation. This evaluation can provide detailed information about your cognitive functions. It identifies your strengths and weaknesses, areas in which you are functioning normally and areas in which you are having problems. With the results of this evaluation, treatment recommendations are made, usually for a course of cognitive rehabilitation. Cognitive rehabilitation can be done by an occupational therapist, a speech therapist or a psychologist. A first step is increasing awareness and self-monitoring of difficulties. Once problems are clearly identified and understood, there are two routes available: (1) cognitive retraining (a physical therapy for the brain) to remediate problem areas and (2) learning compensatory strategies. In cognitive retraining, skills (such as attention and

AREA OF DIFFICULTY	COPING STRATEGY
Disorientation and confusion	Just BREATHE. Repeat the mantra: “This will pass. I’m OK.”
Cognitive fatigue	Self-monitor: Conduct self-checks of your mental energy. PACE YOURSELF. TAKE BREAKS.
Attention/concentration	Enlist all sense modes to take in information. Listen to what is being said, write it down, read it, and say it out loud.
Visual skills	Visit large stores at off-peak hours. Read from a printout rather than from a computer screen. Listen to information rather than reading it (when possible).
Memory	Make lists. And check them. Often.
Executive functioning	Create a structure and routine to your day and follow it consistently every day. Use an organizer/daily planner. Prioritize.

concentration) are practiced and strengthened through a variety of exercises. Learning compensatory strategies involves utilizing strengths to overcome weaknesses, and developing a “bag of tricks” that you can employ to get around problem areas.



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# Annual Report

## 2013 - A YEAR IN REVIEW

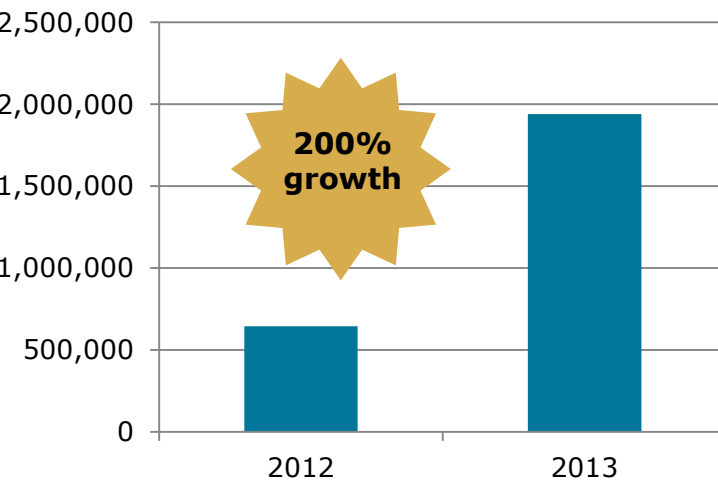
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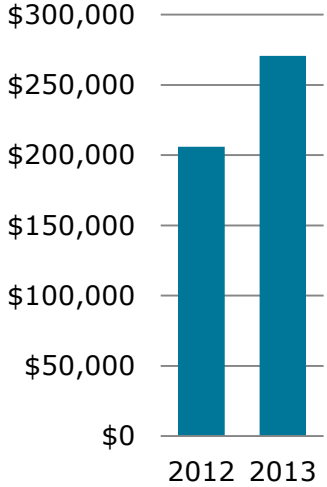
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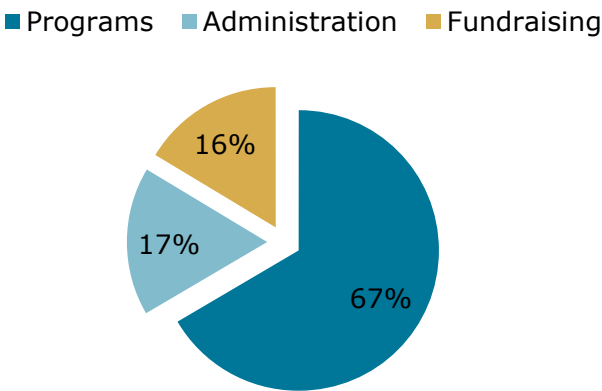
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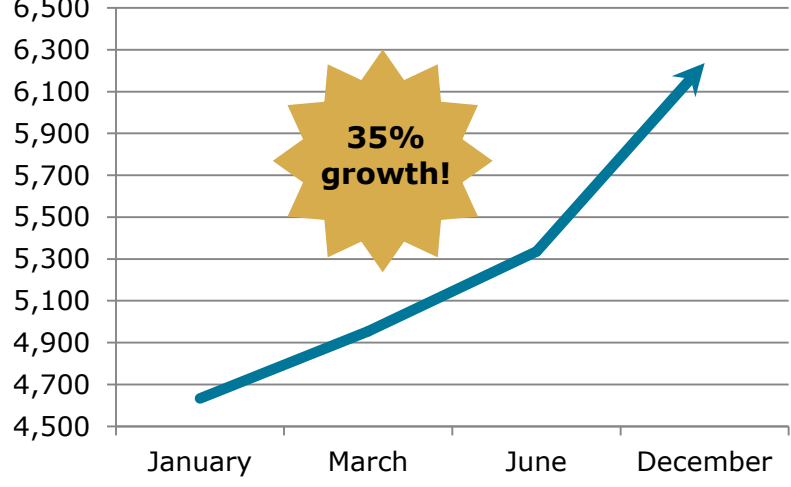
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CREATED A PLAN

DEVELOPED A  
MARKETING PLAN



LAUNCHED THE  
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AWARENESS WEEK  
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Thank you for supporting the Vestibular Disorders Association! With your help we can reduce the time it takes to accurately diagnose vestibular disorders and improve treatment outcomes, helping patients live happy, productive lives.

A MESSAGE FROM VEDA'S EXECUTIVE DIRECTOR



2013 has been a year of tremendous growth for VEDA. Not only did we hire our first development director and, as a result, hold our most successful Balance Awareness Week, we reached more vestibular patients than ever before with information and support, raising awareness and moving closer to a day when vestibular disorders are widely recognized, rapidly diagnosed, and effectively treated. And the credit goes to YOU, our supporters: YOU renewed your membership; YOU made an additional gift; YOU participated in Balance Awareness Week; YOU shared VEDA's message with your social networks. It is only together that we can achieve our goal of reducing diagnosis times for vestibular patients - and thanks to YOU we're on our way! Here's to an equally successful 2014!

~ Cynthia Ryan, MBA

VISIT VESTIBULAR.ORG/FEEDBACK TO SEND US YOUR FEEDBACK.



Balance Awareness Week - September 15-21, 2014



# VESTIBULAR

## DISORDERS ASSOCIATION

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### CHANGE SERVICE REQUESTED

#### The Vestibular Disorders

**Association (VEDA)** is a 501(c)(3) nonprofit organization whose mission is to inform, support and advocate for the vestibular community.

### Low-Sodium Recipe by Dr. Maggie Bloom, PhD

## Rainbow Veggie Stir-Fry



This delicious veggie dish can be used as a side dish or an entire meal. While it already has beans in it, you can add another protein of choice like fish, eggs, tofu, chicken, turkey or lean meat. You can also sprinkle on a ¼ cup low-sodium cheese.

Feel free to pair this dish with grains like brown rice, quinoa, buckwheat/kasha or whole grain pasta. You can also serve it chilled in a low-sodium pita.

Coat large frying pan with olive oil spray. Warm the pan (medium heat). Add vegetables, starting with those that take the longest to cook (carrots, onions, eggplant and zucchini). As they begin to brown and soften, add the cabbage, then bok choy, tomatoes, celery, spinach and kale. Stir every few minutes to keep all ingredients tossed to the bottom. Lastly, add beans, olive oil, lime juice, spices and herbs.

Be sure not to overcook this dish. It is healthiest and tastes best when it is al dente. Use the juices made by the veggies when serving as they are chock full of nutrients. Enjoy!

**VISIT [VESTIBULAR.ORG](http://VESTIBULAR.ORG) TO READ MORE ABOUT DIETARY CONSIDERATIONS FOR VESTIBULAR DISORDERS UNDER 'EDUCATIONAL RESOURCES.'**

## INGREDIENTS

olive oil spray  
1 Tbsp. of olive oil  
12 oz. chopped kale  
2 carrots chopped  
12 oz. chopped cabbage (red and green)  
1 medium white eggplant cubed  
4-5 bok choy leaves with stems chopped

baby spinach leaves  
15 oz. can of cannellini beans- no salt added (white kidney beans)  
15 oz. can of fire-roasted tomatoes (no salt added)  
2 small zucchinis chopped  
1 celery stalk chopped  
8 oz. chopped red or sweet onion  
cilantro

parsley  
juice of a ½ lime  
black coarse pepper  
paprika or chili powder  
celery seed  
Spike (no salt added)  
basil  
oregano  
garlic powder  
2 Tbsp. Brewer's Yeast