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.”

CONTINUED ON PAGE 2
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 rest are mandatory, and I cannot multi-task at all. I can’t even talk on the phone while preparing the dog’s breakfast, something – in order to function at even my compromised level. 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. 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
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 to decide 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.

COPIING 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 and deficits, including 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 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.

COPING STRATEGIES.

<table>
<thead>
<tr>
<th>AREA OF DIFFICULTY</th>
<th>COPING STRATEGY</th>
</tr>
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<tbody>
<tr>
<td>Disorientation and confusion</td>
<td>Just BREATHE. Repeat the mantra: “This will pass. I’m OK.”</td>
</tr>
<tr>
<td>Cognitive fatigue</td>
<td>Self-monitor: Conduct self-checks of your mental energy. PACE YOURSELF. TAKE BREAKS.</td>
</tr>
<tr>
<td>Attention/concentration</td>
<td>Enlist all sense modes to take in information. Listen to what is being said, write it down, read it, and say it out loud.</td>
</tr>
<tr>
<td>Visual skills</td>
<td>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).</td>
</tr>
<tr>
<td>Memory</td>
<td>Make lists. And check them. Often.</td>
</tr>
<tr>
<td>Executive functioning</td>
<td>Create a structure and routine to your day and follow it consistently every day. Use an organizer/daily planner. Prioritize.</td>
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</tbody>
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Rachel Bilgrey, PsyD, is a clinical psychologist in private practice in NYC. Previously she worked as the vestibular psychology coordinator at the Rush Institute of Rehabilitation Medicine. Currently, Dr. Bilgrey is completing her psychoanalytic training at the NYU postdoctoral program in psychotherapy and psychoanalysis. Rachel is a long time VEDA member.
Annual Report
2013 - A YEAR IN REVIEW

ACHIEVEMENTS

HIRED FIRST DEVELOPMENT DIRECTOR
FORMED ADVOCACY COMMITTEE & CREATED A PLAN
DEVELOPED A MARKETING PLAN
LAUNCHED THE VEDA SUPPORT GROUP NETWORK
BALANCE AWARENESS WEEK REVENUE UP 152%
337 MEDIA IMPRESSIONS = 23 MILLION VIEWERS

INFORMATION | SUPPORT | AWARENESS | ADVOCACY

Website Visitors

2013 - 2,500,000
2012 - 1,250,000

200% growth

Revenues

2013 - $300,000
2012 - $150,000

Expenses

67% Programs
16% Administration
17% Fundraising

Facebook Followers

January - 4,500
March - 5,300
June - 6,100
December - 6,900

35% growth!

Website Visitors Growth: 200%
Revenues Growth: 2013 vs. 2012
Expenses Breakdown: Programs, Administration, Fundraising
Facebook Followers Increase: 35%
Thank you to our 2013 Donors!

$250 TO $499
Sue Fisher Seeger
General Atomics
Larry Bowman
Stephen Fisher
Michael Sperlinga
Gerda Wassermann
Eloise Erdman
Steve Rosenberg
Caren Backus
Jorja Black
Jennifer Briscoe
Allan Butchman
Shear Resources
Matthew J Donachio
Karla Droste
Jeffrey Dunn
Rebecca Gale
Mark Gallagher
Wendy Golden
Diane Gregg
Stephanie Hagen
Jonathan Harti
David & Amy Jaffe
Ellis Kern
Victoria LeeFevre
Mike Malloy
Brandie Miles
Carol Murphy
Sita Nazarian
Donna Runklet
Donald Rusciuc
Gary Rogers
Annie Rorimer
Donnal Selz
Cheri Smith
Nancy Waliszek
Willow Grove Physical Therapy, LLC
Betsy Cammerford

ASSOCIATES
$100 TO $249
Frank Bonnell
Nina Cohen
Jeffrey Fuchs
Kendra Gilkes
Ronald Jewell
Richard Jorgenson
Susan Kelley
Walter Lyon
Sarah Martel
Beth Masterman
Hug McLean
Paul Olson
Helene Raab
Luis Rey
Bill Schmitt
Mary Schollhammer
Dean Smith
Mary Stucky-Walsa
Lawrence Stone
Rudy Thomasson
Ian Ball
Oris Graf

GUARDIANS
$500 TO $1,000
Suzie Hickey & Sheldon Klapner
Cheri Haddad
Phyllis Schwartz
Gary Brentbild
Sheehan Shooshouse
Grand Valley State University
OFT Class of 2014
Louise Gelb
Dr. David Beal
Gary Bowen
Gail Gallagher
Alice Hirsch
Merilee Holst
Lester & Becky Knight
John Miller
Robert Reyes
Alex Schmelzer
Roggiero Spillere
Laura Sanford
Susan Weiner
The Capital Group
Companies Charitable Foundation

FRIENDS
$500 TO 1,999
Lisa Biotik
Dr. Grayson Rodgers
The Mildred M. Voelker Memorial Fund
Betsy Cammerford
Deanne Bonnar
Lawrence Krencher
Dr. Stacey Buckner
Amol Tembe
Dr. Stacey Buckner
Deanne Bonnar
Gary Rogers

SUPPORTERS
$10,000 TO $19,999
Molly-Jane Rubinger
Dennis Robinson
Laura Ritchie
Gary Pitts
Kathy Perigloisi-Miller
Raymond Pasquale
John Paljug
Alice Owen
Lynda Oros
Timothy O’Brien
Mary Jeanne McPaul
Keavy McNaughton-James
Frederic Marks
John Hadden
Robert LaRusso
Kathleen McCluskey
Catherine Miller
Mary McManus
Brian McLaughlin
Sara McRae
Richard Marder
Molly-Mae Martin
Lora McQuaide
Jennifer McCord
Wendy McElroy
Robert Mees
Robert Meuser
Susan Meuser
Robert Meuser
Kim McRae
Tom Meuser
Jill Meldrum
Carolyn Mercanta
Mark Merullo
Robert Mesina
Molly Merchant
Gina Merchant
Sara Merchant
Marcia Mahar
Jay Meador
Linda Mainieri
Deirdre Maffey
Lisa Maines
Barbara Madigan
Martha Magee
Nancy Magill
Melissa Magee
Barbara Mann
Renee Manley
Marcie Mandel
Marcie Mandel
Vivie Mann
Marcie Mandel
Dr. John Mann
Marcie Mandel
Dr. Laura Mandel
Marcie Mandel
Dr. Bonne Kline
Kenneth Koehler
Joan Landy
Anne Lavelle
Diane Lee
Robert Lenkauskas
Kay Long
Edith Lord-Wolf
Thomas Lyall
Jeffrey Gray
Lynne Zank
Pirjo Tuomi
Ian Street
Karen Steinberg
Loretta Siciliano
Rebecca Rubin
Gary Rogers

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YES! I WANT TO HELP PEOPLE SUFFERING FROM VESTIBULAR DISORDERS.

You can renew your membership or make a donation to support VEDA’s life-changing work online at vestibular.org or send your payment to 5108 NE 15th Ave, Portland, OR 97211 with the enclosed self-addressed envelope.

Annual Membership:
- Basic $40 (e-newsletter only-mail required)
- Professional $110 (e-newsletter only-mail required)

I would like to receive your newsletter in the mail for $5 US/$15 International

Donation:
- $25
- $50
- $100
- $150
- $200
- $250

Other

Please make my donation anonymous

Method of Payment:
- Check (payable to VEDA in US Dollars)
- Visa
- MasterCard
- American Express

Please send me information about including VEDA in my Will or Estate Planning.

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.

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

A MESSAGE FROM VEDA’S EXECUTIVE DIRECTOR
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 TO READ MORE ABOUT DIETARY CONSIDERATIONS FOR VESTIBULAR DISORDERS UNDER ‘EDUCATIONAL RESOURCES.’

INGREDIENTS

<table>
<thead>
<tr>
<th>olive oil spray</th>
<th>baby spinach leaves</th>
<th>parsley</th>
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</thead>
<tbody>
<tr>
<td>1 Tbsp. of olive oil</td>
<td>15 oz. can of cannellini beans-no salt added (white kidney beans)</td>
<td>juice of a ½ lime</td>
</tr>
<tr>
<td>12 oz. chopped kale</td>
<td>15 oz. can of fire-roasted tomatoes (no salt added)</td>
<td>black coarse pepper</td>
</tr>
<tr>
<td>2 carrots chopped</td>
<td>2 small zucchinis chopped</td>
<td>paprika or chili powder</td>
</tr>
<tr>
<td>12 oz. chopped cabbage (red and green)</td>
<td>1 celery stalk chopped</td>
<td>celery seed</td>
</tr>
<tr>
<td>1 medium white eggplant cubed</td>
<td>8 oz. chopped red or sweet onion cilantro</td>
<td>Spike (no salt added)</td>
</tr>
<tr>
<td>4-5 bok choy leaves with stems chopped</td>
<td></td>
<td>basil</td>
</tr>
<tr>
<td></td>
<td></td>
<td>oregano</td>
</tr>
<tr>
<td></td>
<td></td>
<td>garlic powder</td>
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<tr>
<td></td>
<td></td>
<td>2 Tbsp. Brewer’s Yeast</td>
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