



Observations on Cognitive and Psychological Aspects of Vestibular Disorders

This article includes comments compiled from VEDA's videotaped interviews with Carolyn Bennett, ACSW, social worker; Alexander J. Schleuning II, MD, otolaryngologist; and Mark D. Tilson, PhD, neuropsychologist.

Cognitive functioning

Mark D. Tilson, PhD: The vestibular system is responsible for coordinating your position in space and your position relative to gravity, for the purpose of allowing you to move forward in time and space with what you are planning to do. The vestibular system is closely linked to parts of the brain involved with planning and sequencing and attention and concentration, which you need [in order] to function and to interpret information.

Because of the linkages of the vestibular system with multiple other parts of the brain, people with vestibular disorders typically experience all kinds of cognitive problems. They have problems with visual and motor coordination, so they have trouble with depth perception. That translates to problems with reading—they feel their eyes are skipping lines, and reading can become very frustrating. When one part of the system is out of whack, it affects everything.

Anxiety and depression

Alexander J. Schleuning II, MD: Dizziness, unsteadiness, and vertigo are

very emotionally trying. They're frightening, and they carry with them great threats to the individual—threat of loss of job, threat of inability to do the things they enjoy doing, such as playing tennis or golf, or caring for their children appropriately. Patients wonder if they will ever be able to be functional again. [There is] fear of not having a very clearly defined diagnosis, never having certainty as to the prognosis, because we are never absolute in the prognosis. Many patients develop severe depression because of their inability to perform their normal tasks.

Tilson: People who even on good days don't function as well as they are used to almost always get discouraged, depressed, worried, or anxious about it. And it typically becomes a blow to your self-esteem. You're used to being able to function, to do things, to deal with problems effectively. And when you find over and over that you start in on something but you get confused or you get fatigued easily, it pulls the rug out from under you emotionally. Your sense that you can cope with life, not surprisingly, goes down.

Lack of family support

Tilson: Typically, in the early stages of this kind of problem, family is very sympathetic and understanding. But most diseases tend to clear up after a while; we are not used to disorders that go on and on and on. Even loving families will often begin to get frustrated, irritated, and fed up with the patient. If your family is getting fed up with you and the physicians are getting frustrated with you, your self-esteem is going to have a hard time.

Schleuning: Over a period of time, people who have balance disorders lose the support of their family or others, because in many cases it's a silent, non-visible disorder. They might see a parent or family member who seems to be able to get around all right but has these complaints that they are going to fall or that they are unstable. And it's not something they can see, so their sympathies tend to be lost over a period of time.

Carolyn Bennett, ACSW: Another thing that is awkward for families to understand is, why can someone with a vestibular disorder do something one day, and the next day not be able to do it? People often will tell you that they have good days and bad days. Symptoms that people with vestibular disorders may complain of—being dizzy, feeling nauseated—don't in and of themselves sound all that bad. Most of us have experienced dizziness for a few moments,

and it may be a little uncomfortable, but it certainly doesn't impact our day. When you're dizzy for 24 hours, you have no time of the day when you feel like you can walk down the hall and know where you are. It's terribly disabling. The same goes with nausea. Nausea is something that most of us have experienced, but we don't experience it for the whole day, day after day.

Many people with vestibular disorders are very sensitive to their environment. For example, fluorescent lights may be really distracting for some people. Light that comes through windows, Venetian blinds, can make someone very tense and actually make their symptoms worse. Brightly colored or patterned clothing, wallpaper, or carpets may make them feel so symptomatic they have to go to bed. This is hard for families to understand. Other things that can be difficult to live with are loud noises. The kids come in, they go out, they call to each other—that can be very difficult for somebody who is sound-sensitive. It's hard for a family to remember that those things are setting off symptoms that they can't see.

Disability evaluation

Schleuning: We occasionally encounter individuals in whom we desire neuropsychiatry, or psychological testing. One of the problems is that patients consider that as a threat to their integrity, a threat to their story, and that it is [a sign] of disbelief. But most frequently, testing of this nature is an attempt to determine

the amount of disability that [a vestibular disorder] is creating in their lives.

Tilson: There are two reasons why a psychiatrist or psychologist would become involved with a person with vestibular problems. People with vestibular disorders essentially always have some cognitive problems—with attention, concentration, visual and spatial perception. And because of the disruption in their lives, it also leads to emotional problems—depression, frustration, all kinds of problems with the family. For either or both of those reasons, it's going to make sense to consult a professional in psychiatry or psychology. There are three kinds of psychological service professionals who might be involved; any or all of those three may be appropriate at various points in dealing with the problem.

Psychiatrists are MDs (medical doctors). They can prescribe medications, and they can provide psychological treatment—talk therapy, behavior therapy. *Psychologists* are not MDs; the degree is PhD. So psychologists can't prescribe medications. Psychologists typically provide detailed psychological counseling, behavioral treatment, and talk therapy. A *neuropsychologist* is a PhD psychologist, but with an additional specialty area dealing with people who have neurological and brain-related problems in addition to, or rather than, simply emotional problems.

Neuropsychological testing

Neuropsychological testing—frequently requested by a physician for [persons] with various types of vestibular disorders—is different from what people usually think of as psychological testing [for example, personality assessments].

Neuropsychological testing involves testing a person's mental functions, almost like circuit-testing of the brain. You're testing a person's attention, concentration, short-term memory, visual skills, thinking and reasoning skills, their ability to plan and solve problems—all the different mental functions that we use in daily life. The information that we get is essentially a profile of the person's strengths and weaknesses in terms of their mental function. Neuropsychological testing can tease out which areas the person is functioning normally in, and in which areas the person is having problems. The value of that information to the physician, the patient, and their family is first of all to understand. And second, that information can give you some leads on how you might be able to get around those problems, adjust to them over time, work around them or even make them less severe.

After neuropsychological evaluation is done, typically the follow-up treatment is provided by either occupational therapists or speech and language pathologists who are specially trained in cognitive rehabilitation therapy.

Neuropsychological testing results actually can help with disability-

determination issues and legal issues. Deficits that people experience with attention, memory, and functioning are not necessarily visible. The person looks good, they sound good; they're still intelligent and speak well. So it's easy for even physicians and family and others to discount a person's problems.

Neuropsychological testing documents that the person really does have this problem, and it documents how severe the problems are and to what extent they might be disabling. That can be helpful in quantifying a disability.

Adapting to a vestibular disorder

Tilson: Adaptation to living with a vestibular disorder is a long-term process. In the early [acute] stages, people may be consumed with rock-bottom physical and medical issues, struggling just to get under control things like balance, nausea, vomiting, and headaches. They're not going to be ready to, and shouldn't necessarily be expected to, deal with the fine points of memory and attention problems, coping with things emotionally beyond the immediate issues. At that stage, people can be pretty distraught, wondering if it can go on like this forever. It doesn't go on like that forever; sooner or later the basic physical symptoms, with trial and error and ongoing treatment, will be brought under at least adequate control. Then you are in for the longer haul, dealing with the cognitive, memory, and attention problems, the impact on your life, the limitations on activity you may have at some times.

There are two kinds of general strategies to try to cope with and live well with the vestibular disorder. One is dealing with the cognitive problem; the other is dealing with the emotional reactions to [the disorder] and the long-term issues.

Addressing the cognitive issues

Tilson: There are cognitive rehabilitation programs and exercises to learn how to cope with the cognitive deficits. One approach is to teach the person specific tricks and exercises that may help them learn to focus their attention better, focus their vision more effectively on the page, etc. The other approach for the cognitive problems is what you might call a compensation approach—where you can't necessarily make the problem better directly, but you can learn all types of tricks and ways to get around the problem. For example, if you have short-term memory problems, writing things down, using a tape recorder, asking people to tell you one thing and wait while you get it until they tell you the next thing—those can be very effective in helping you get through your day much more easily.

Addressing the psychological issues

Tilson: Dealing with the emotional strategy is a big topic. People go through almost a grieving process, of understanding that they have lost the functioning and the way of being that they previously had. Most people go through what we have heard of as the stages of grieving. There is denial

initially—feeling that “this will get better tomorrow,” or “if only I could take the right herb or medicine, I’ll get better”; then beginning to have some sort of acceptance, and there is some depression and sadness associated with that. Ideally, a person can move through those stages and get to the point where they at some level, grudgingly (and that’s okay), make peace with the fact that they are not functioning the way they used to, and then learn how to manage effectively. There are lots of things people need to learn to do: dealing with fatigue, pacing themselves, learning to set more realistic goals as to what they can accomplish.

Another thing that is important for a person to learn emotionally is to avoid what I would call a learned-helplessness reaction. That’s understandable, but not helpful. It is helpful for people to learn to recognize that they’re sinking into this learned-helplessness reaction and to combat the reaction using some coping techniques. If you refuse to let yourself get beaten down, you can develop a habit of expecting that you’re going to get back up and it’s going to happen quicker, so that you can get along with your life and push the vestibular [disorder] into the background.

Schleuning: There are individuals who would benefit from counseling because of great anxiety or depression. Counseling is an immense help, and perhaps antidepressant medications, which are often used in patients who have long-standing dizziness.

Bennett: This is a time when it is appropriate to ask for outside help. Professional counseling [can] help the person with the vestibular disorder, or their family, cope and deal with the changes. In some communities, support groups are available for persons with vestibular disorders and their family members. The most powerful [function] for support groups is to hear other people explain what their experiences are. Most families have only met one person with a vestibular disorder. When you have an opportunity to meet a number of people with vestibular disorders, you get a better understanding that this really is a problem that impacts people. It helps the family support the person better.

Educating the family

Bennett: A vestibular disorder has a profound impact on the family—emotionally, physically, financially. Many families find that they need to make adjustments. It’s really important for families to understand that a vestibular disorder is a medical condition.

Certainly, education plays a major role. I usually encourage family members to go with the person to the doctor’s office so they can hear the information first-hand. There’s a lot of information available on vestibular disorders, and I would encourage family members to read that information so they can understand what these are like.

A key for families is learning how to communicate. Families generally are really good with communicating, “What are we going to have for dinner?” “Did you do the laundry yet?” But sometimes talking about “How are you feeling?” or “What’s going on with you?” is a little more difficult. It’s important for the person with the vestibular disorder to explain to their family what it’s like. It’s also important for them to explain what they need. And it’s really important for the families to touch base with the person and ask them questions: “What is today like? Is today a good day? If today is not such a good day, how can I help you?” It’s a real give-and-take, just like family life. It doesn’t always go smoothly, but communication can be a big plus in getting through the process.

It’s also important to maintain a sense of humor, to remember to have fun with each other and on those good days enjoy them, and on the bad days know that a good day is going to come again.

Schleuning: The family members and the patient have to understand that many of these disorders do not change in a week or a month; and certainly after a head trauma, it could be two or three years before a person clears the fuzziness—occasionally even longer. Since it is a long-term disease that is not very visible, it takes a great deal of patience, both on the part of the individual and the family.

© Vestibular Disorders Association

VEDA’s publications are protected under copyright. For more information, see our permissions guide at www.vestibular.org.

This document is not intended as a substitute for professional health care.



VESTIBULAR DISORDERS ASSOCIATION

PO Box 13305 · PORTLAND, OR 97213 · FAX: (503) 229-8064 · (800) 837-8428 · INFO@VESTIBULAR.ORG · WWW.VESTIBULAR.ORG

Did this free publication from VEDA help you?

Thanks to VEDA, vestibular disorders are becoming recognized for their impacts on lives and our economy. We see new diagnostic tools and research studies, more accessible treatments, and a growing respect for how life-changing vestibular disorders can be.

VEDA provides tools to help people have a better quality of life: educational materials, support networks, professional resources, and elevated public awareness.

Your support of VEDA matters. Please help us to continue providing such great help by becoming a member or donor.

Members receive an information packet; discounts on purchases; a subscription to VEDA's newsletter, *On the Level*, containing information on diagnosis, treatment, research, and coping strategies; and the option of communicating directly with others who understand the personal impacts of a vestibular disorder. Professional members also receive the option to list training opportunities on our site, bulk-discounted prices on patient education materials, and a listing on VEDA's provider directory, the only of its kind serving patients seeking help from a vestibular specialist.

SUPPORT VEDA

Membership, 1-year

\$ 40 ... Basic
\$110 ... Professional

Memberships include electronic & online newsletter & free publications. For hard copies, include optional shipping fees.

\$ 5 ... Shipping (domestic)
\$ 15 ... Shipping (international)

\$ _____ Please indicate your desired subscription amount here.

Optional Contribution

I'd to support VEDA with a donation (instead of or in addition to membership).

\$ _____ Please indicate your desired subscription amount here.

Check this box if you prefer that your donation remain anonymous.

\$ _____

Total

PAYMENT INFORMATION

If you prefer, you can make your purchases online at <http://www.vestibular.org>.

Check or money order in US funds, payable to VEDA (enclosed)

Visa _____
 MC _____ Card number _____ Exp. date (mo./yr.) _____
 Amex _____

_____ Billing address of card (if different from mailing information)

MAILING INFORMATION

Name _____

Address _____ City _____

State/Province _____ Zip/Postal code _____ Country _____

Telephone _____ E-mail _____