



# VESTIBULAR

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## DISORDERS ASSOCIATION

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## Coping with a Vestibular Disorder

This document combines two VEDA publications: *Coping with a Chronic Vestibular Disorder and Other Physical Illnesses* (written in 2007 by a social worker) and *Learning to Cope with Vestibular Disorders* (tips offered by support group leaders on adjusting to the daily challenges of a vestibular disorder).

### I. Coping with a Chronic Vestibular Disorder and Other Physical Illnesses (Beyond “Learn to Live with It”)

By Molly-Jane Isaacson Rubinger, MSW, LICSW with the Vestibular Disorders Association

Upon receiving a diagnosis of a vestibular disorder, a person may be relieved at having a name for what is wrong and in learning that the illness is not degenerative or fatal. (“The good news is that you are not going to die from this.”) However, this relief may be accompanied by the sobering and overwhelming news that the debilitating symptoms may possibly remain or recur indefinitely. (“The bad news is that you just need to learn to live with it.”) In order to move forward from this point, the patient and his or her family need to grieve.

#### **The grieving process**

In our culture, it is most common to associate grieving with death. So when the necessity of grieving is introduced to persons with a vestibular disorder, they sometimes comment: “But no one has died.” While this is true, an equally profound loss has occurred—the loss of previously held hopes, dreams, and future plans for both the patient

and his or her family. Nevertheless, daily life does not need to grind to a halt while one wallows in grief. However, it *is* important to recognize that a loss has occurred and that some or all of the stages associated with grieving will be experienced (shock, denial, anger, bargaining, and depression) in moving toward acceptance. These stages don’t always follow each other in a neat progression—it is not uncommon to revisit a stage after having moved on to another one.

Without addressing the need to grieve, a person with a chronic illness gets stuck and is unable to move forward. Successful coping is impeded by denial and anger resulting from attempts to get one’s “old self” back or to live as if the disorder were not present. That’s not to say that anger and denial disappear with the grieving process—but that grieving allows them to be recognized for what they are.

#### **Expectations of others**

Upon experiencing the death of someone close, a person usually receives an outpouring of comfort and support from others, followed relatively quickly by the expectation that bereavement will fade and the person will begin the business of getting on with life. Such expectations occur because prolonged grieving makes people uncomfortable. This process is complicated when the grieving is about loss caused by an invisible and chronic illness. Even though initial expressions of support and comfort may be forthcoming, emotional support and comprehension of the need to grieve are often lacking.

### **Framework for coping with a chronic vestibular disorder**

A vestibular disorder can rob you of a sense of control over your life—so the goal of coping is to find every way possible to take back that control. To do this, you need a frame of mind for thinking about the disorder in a way that allows you to impose restrictions on how it will affect you.

It is important to recognize that a chronic illness is an entity unto itself and that it assumes a presence in your life. This entity has been referred to as an *uninvited guest* by Mildred Flashman, professor of social work at Boston University. The illness makes demands on resources of physical and emotional energy,

time, and money—much like an uninvited guest. By acknowledging the illness as a separate entity, you take it outside of yourself so that it doesn't define who you are and so that you can determine how you are going to relate to it.

For example, if you have fragile control over your symptoms and you want to attend an event on a Wednesday, you might address your illness as follows: "In order for me to feel well on Wednesday, you need me to take it easy on Tuesday and also not to plan something too strenuous for Thursday. I will choose to honor that need." This way of thinking provides you with better control over the illness than you would have if you were to attempt to ignore its presence and then find yourself at the mercy of its symptoms.

The goal of this strategy is to create a positive frame of reference. Tools to exercise that control can include the following items that you might consider in a "toolbox" for coping:

Measure time in long, rather than short, spans: If you ask yourself, "Do I feel better today than I did yesterday?" the answer is likely to be "no." However, if you ask "Was this holiday season better than last year?" there is a higher likelihood that you can answer "yes." For example, one support-group

member used to cherish her winter beach vacation, yet she couldn't tolerate looking at the constant motion of the ocean's waves during the first year after she became ill. One year later, she was able to sit on the porch and gaze at the water. In the third year, she could walk on the beach. Her annual vacation provided an effective way for her to mark her progress.

Prepare a disaster plan: A person with a vestibular disorder may plan to do something and then get very anxious about the possibility of becoming ill while participating in the event or activity. Or worse, anxiety may prevent the person from making any plans, thus leading to increasing social isolation. Having a disaster plan can be helpful for managing such anxiety.

To form a disaster plan, determine the worst-case scenario that could occur at an event you are planning to attend; then plan what you would do about that scenario. There is a good chance that you won't need the plan; however, if a disaster does occur, you are prepared to manage it.

Employ imagery: This inventive technique involves finding a personal image that helps you handle your particular concern. For example, when a woman returned to

her interviewing job after a year's absence, she was very worried that she would get dizzy and fall out of her chair. So, before she began an interview, she would imagine fastening a seatbelt around herself and then she'd recite "I'm strapped in now and I won't fall out." Even though no actual seatbelt existed, the image helped support her.

Reframe your thoughts: This tool is otherwise known as "is the glass half empty or half full?" Reframing gives you control in choosing how you will view a given situation. For example, a woman with a passion for gardening was unable to do it for a long while. When she finally returned to her garden, she began to feel dizzy after spending only an hour planting bulbs. She realized, however, that she had a choice—she could become angry and frustrated at being dizzy or she could tell herself that the dizziness was a reminder that she had just spent an hour doing something that she had been unable to do for a long time. Focusing on the latter gave her a feeling of being in control rather than being at the mercy of her symptom.

Educate yourself and use the knowledge to help you communicate: Knowledge is empowering. You need to know as much as possible in order to be an informed consumer and to advocate

for yourself. Also consider that using the word “dizzy” to describe how you feel may produce an unintended interpretation because of how this word sometimes appears in other forms of usage, such as “dizzy dame” or “dizzy drunk.” You may be taken more seriously if, instead of telling someone that “I get dizzy when I move my head,” you say “I get lightheaded and unsteady when I move my head” or “I have benign positional vertigo and here is a pamphlet that will tell you more about it.”

Find a support group: It is extremely validating to talk with other people who know exactly how you feel. Most people who have not experienced a vestibular disorder don’t understand what you are experiencing, even though they may say something like, “oh, I’ve been dizzy before.” To know that you are not alone with your thoughts and feelings is invaluable.

Maintain a balance between coping and hoping: Learning to live with a vestibular disorder does not mean giving up the hope that your symptoms will reduce or that you will have a long remission. Many people with a vestibular disorder get better.

Hoping and coping need to exist side by side. Hope cannot take the place of coping; committing to the process

of coping does not infer that you are giving up hope. That being said, coping is very hard work—you may find yourself tempted to stop the effort. This is natural and not harmful, as long as you limit the length of your respite from coping to a day or two before you get back on track.

Using these tools takes practice. They don’t work one hundred percent of the time—yet they work often. If you have a tool to apply to a situation, you are more likely to be in control of your illness rather than allowing it to control you.

### **The context of coping with illness**

You are not a blank slate when you develop a vestibular disorder. Thus it is not uncommon for old and unresolved issues to be stirred up—particularly those associated with earlier losses. If there were personal issues or family problems that existed prior to your illness, they could be displaced onto the illness instead of being dealt with in their own right. Professional assistance can help you understand the impact that an illness has on you and your family.

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## II. Learning to Cope with Vestibular Disorders

Tips offered by the Vestibular Disorders Association and support-group leaders for the person who is new to vestibular disorders.

With or without a diagnosis, a dizzy person can be overwhelmed and confused. Many people need guidance about how to self-educate and how to help family members and friends understand.

### **Educate yourself**

Knowledge is powerful. According to former United States Surgeon General Dr. C. Everett Koop:

"No prescription is better than knowledge."

The Vestibular Disorders Association

(VEDA) has a considerable amount of information on its Web site ([www.vestibular.org](http://www.vestibular.org)) about a broad spectrum of topics, including the vestibular system in general, specific types of vestibular disorders, diagnosis and treatment options, and more. VEDA also has a [provider directory](#) of health professionals who specialize in treating vestibular disorders, as well as other support resources and literature.

### **Pace yourself**

If you are not feeling well, evaluate what activities and chores are crucial for you to do. Ask yourself if any of

them can wait until another day. Or consider whether they can be delegated to others.

Know your limitations and refrain from overdoing the things that aggravate your symptoms excessively. It is not uncommon for people with a vestibular disorder to be unaware of their level of fatigue and the degree of effort involved with functioning until they stop to rest. The effort required in compensating for vertigo or dizziness can increase so gradually that its magnitude is not obvious until it becomes overwhelming. As desirable as it may be to stick to a task in order to complete it, taking a rest might make the difference between having an “OK” day the next day and feeling totally wiped out.

Use relaxation exercises each day: sit in a comfortable place with support for your head. Clear your head of any distractions and replace them with helpful, peaceful, quiet images; breathe deeply and relax. Consider assuring yourself that better days will arrive. They will.

### **Take steps to reduce stress**

If you are no longer able to work, explore whether you can take a leave of absence from your job. In the U.S., [www.disability.gov](http://www.disability.gov) can help you to inform yourself about long-term disability support programs such as Social Security disability. Become familiar with the Americans with Disabilities Act. If you are applying for disability, make sure you keep well-documented records of phone

calls you make and copies of letters and forms that you've submitted (including submission dates and addresses). Make sure you meet all deadlines and requests by the agency.

### **Make time for daily physical activity**

Getting out of the house daily is a good idea. If approved by your physician, go for a short walk, even if it is just around your yard. Use a cane when necessary to give you some vital proprioceptive feedback. If you are hesitant to go out alone, enlist a companion to accompany you.

### **Eat well**

A healthy diet is important. Enlist the help of a nutritional expert at your local hospital if your illness requires a particular diet. Your doctor can provide a referral for you. Also, VEDA has information on dietary considerations for people with certain types of vestibular disorders (see [www.vestibular.org/](http://www.vestibular.org/) for *Dietary Considerations with Endolymphatic Hydrops, Ménière's Disease, and Vestibular Migraine*, which includes tips about dining out.)

### **Adjust to difficulties with reading**

If reading is possible but effortful, take periodic breaks. If you can, stand up, stretch, and move while focusing on something in the distance. Many people with vestibular disorders find that books on tape—talking books—offer the wonderful option of reading a book while resting with closed eyes. This resource allows the mind to remain active and

distracted from symptoms while the dizziness subsides and the body recovers.

Local public libraries may have information about free books on tape. In addition, the National Library Service (NLS) for the Blind and Physically Handicapped loans books, magazines, and listening devices to individuals who have problems reading because of temporary or permanent visual or physical limitations. No postage is required to borrow or return books and equipment. A brief eligibility form must be submitted, however. For a list of the NLS resources in each state, visit [www.loc.gov/nls/reference/directories/resources.html#states](http://www.loc.gov/nls/reference/directories/resources.html#states).

DVDs can provide additional information and entertainment. VEDA has a helpful DVD that features patients and health care professionals who discuss diagnosis, treatment, symptoms, and issues of communicating with family and friends. For ordering information, please contact VEDA directly ([www.vestibular.org](http://www.vestibular.org)).

### **Seek transportation help**

If your physical condition does not allow you to drive a car safely, arrange transportation assistance. Do not feel embarrassed or afraid to ask for help. Sometimes people close to you want to help but are not sure how. They are often relieved to know that they can offer a particular type of assistance such as providing transportation. If friends are not available, inform yourself about the

public transportation options that exist in your city or town.

### **Seek help with physical, emotional, or financial problems**

Ask for help with activities such as shopping or being in crowds. If you are enduring financial hardship because of your condition, write to your creditors and explain your situation. Try to work out a plan with them. Many businesses are flexible if they observe that you are making an honest effort.

### **Maintain confidence, self-esteem, and perspective**

Focus on things you can do and accomplish rather than dwelling on what you cannot do. With treatment and experience in managing your symptoms, you will be able to add more activities. A sense of humor can help limit downward emotional spirals. Try not to let the consequences of dizziness change your internal sense of worth. You may not always be able to access your former capabilities when you want to, but your wisdom from those capabilities is still there.

The symptoms of vestibular disorders can be “invisible” to others, sometimes leading people to assume that your strategies for accommodating symptoms are a result of a psychological problem. Reassure yourself about the physical basis of your symptoms. And yes, some cognitive and emotional difficulties can result from the physical struggle with balance disorders. Do not hesitate to

seek out counseling if you're feeling overwhelmed or depressed. These feelings are natural.

### **Avoid becoming isolated**

Vestibular disorders can produce symptoms and limitations that others might have difficulty understanding. Thus it is vital to maintain communications among friends and family members. Find ways to explain to others how your vestibular disorder affects you. Be clear in telling them what they can do for you. Let them know that you are not trying to alienate yourself from them.

Invite close friends for a visit. Getting together in small groups or with one person at a time is easier than meeting in large groups. Select meeting places where you can control the environment. You might also consider attending a local [support group](#). Such groups provide an opportunity to learn about vestibular disorders and meet with people who understand what you are experiencing. Because participants do not need to define or prove their disability, or to defend themselves, communication is more productive, sometimes revealing common feelings of anger, grief, loss, and even humor. Some attendees find that it is helpful to bring family members and/or friends to these meetings so they gain a better understanding of what you

are dealing with by listening to others.

If you feel well enough to do so, consider starting a group, if none exist near you. Enlist the help of another person if it seems to be too much of a challenge to do on your own. Some resources to help support group leaders with meeting formats, structure, and topic ideas are available through [VEDA](#), which is an international organization founded in 1983 and is dedicated to educating and supporting people with vestibular system impairments and the people who treat them.

If joining a group is not possible or comfortable for you, another option is to participate in a communication network such as [VEDA's Facebook page](#).

Living with dizziness, vertigo, or imbalance can be very frustrating. Remember that you do not have to endure this alone.

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## Did this free publication from VEDA help you?

**Thanks to VEDA**, vestibular disorders are becoming widely recognized, rapidly diagnosed, and effectively treated.

**VEDA's mission** is to inform, support, and advocate for the vestibular community.

**You can help!** Your tax-deductible gift makes sure that VEDA's valuable resources reach the people who can benefit from them most – vestibular patients like you!

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**Members receive** a Patient Toolkit, a subscription to VEDA's newsletter, *On the Level* - containing information on diagnosis, treatment, research, and coping strategies - access to VEDA's online member forum, the opportunity to join V-PALS, a pen-pals network for vestibular patients, and more!

**For healthcare professionals:** Individual and clinic/hospital memberships are available. Professional members receive a subscription to VEDA's newsletter, a listing in VEDA's provider directory, co-branded educational publications for their patients, access to a multi-specialty online forum, and the opportunity to publish articles on VEDA's website. For details, call (800) 837-8428, email [info@vestibular.org](mailto:info@vestibular.org) or visit <https://vestibular.org/membership>.

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