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DIAGNOSIS

TESTING

While testing can be inconclusive, your doctor may be able to treat your symptoms with or without a diagnosis

ARTICLE

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# Trouble Getting a Diagnosis?

By the Vestibular Disorders Association, revised by Dr. Neil Shepard, PhD & Dr. Dennis Fitzgerald

Many people who suffer from dizziness, imbalance, or vertigo have trouble finding out why. Dizziness and vertigo are not actually "diagnoses," they are symptoms of a diagnosis. However, many physicians will use these terms as if they were a diagnosis. Vertigo is the most specific symptom and has a specific definition. Vertigo is an illusion (feeling) of movement. That movement may be felt inside of the person or that person may have the perception of movement of the environment around them. The movement may be perceived as spinning, up and down, or side to side dizziness, giddiness, floating, light-headedness, or a less easily defined feeling. If you suffer from these problems, you may visit doctor after doctor and undergo test after test without receiving a diagnosis. And since the first step to getting better is getting a diagnosis, you may become exhausted and frustrated in the search for relief.

Every case of dizziness is unique, and there may be reasons why your case is especially hard to diagnose. But there are also reasons that are common to almost all sufferers. In the material that follows, we outline some of the most common reasons and provide suggestions for speeding up the process.

## MANY DIFFERENT DISORDERS CAN CAUSE DIZZINESS

80% of patients with the symptom of vertigo have an inner ear disorder.

Although inner ear disorders can be a cause of dizziness, dizziness can also be caused by problems that have nothing to do with the inner ear. Some of these problems include anxiety, arrhythmia, stroke, heart attack, defective heart valves, orthostatic hypotension, hardening of the arteries, hypothyroidism, hypoglycemia, epilepsy, brain tumors, and congenital malformations of the brain or skull.

Dizziness is also a common side-effect of certain drugs, and it can be caused by exposure to toxic chemicals.

Since many of these conditions are life-threatening, your doctor must be careful to rule them out first.

Even if your doctor is able to determine the cause of your dizziness originates from your inner ear's balance system, which is called the vestibular system, there are many different possibilities. Inner ear

disorders that cause vertigo are most commonly caused by Benign Paroxysmal Positional Vertigo (BPPV). Less common inner ear disorders include Ménière's disease, vestibular neuritis, otosclerosis, labyrinthitis, acoustic neuroma and perilymph fistula. Other diseases that can affect the inner ear or the parts of the brain devoted to balance include migraine, allergies, multiple sclerosis, syphilis and other bacterial and viral infections, and diabetes. The inner ear can also be damaged by blows to the head or whiplash injuries. Even anxiety can cause dizziness. Determining exactly which one or which combination of these disorders is causing your problem can take a great deal of time and can require visits to many different specialists who may order and sometimes repeat many different specialized tests.

Development of secondary conditions related to anxiety or conditioned responses can cause prolongation of symptoms once the initial inner ear disorder has resolved. A recently described condition, Chronic Subjective Dizziness Syndrome, is now felt to be associated with migraine. To the lay public, migraine means "migraine headache." However, migraine symptoms can include vertigo, temporary blindness, other ocular symptoms, and even stroke-like symptoms. These migraine symptoms occur usually in patients who have known migraine headaches but may not be accompanied by the typical headache at the time of these other symptoms. A family history of migraine makes a patient more prone to have a migraine disorder, even without any history of migraine headaches.

### THE SIGNS AND SYMPTOMS OF VESTIBULAR DISORDERS ARE SOMETIMES DIFFICULT TO RECOGNIZE

Dizziness is a symptom that is real to you but is not observable by your doctor. In order to diagnose a vestibular system disorder, your doctor must rely on signs that he or she can observe, such as abnormal eye or body movements. In the early stages of many vestibular disorders these signs may be absent or present only weakly or occasionally. As a result, your doctor may not be able to easily determine whether your dizziness is being caused by a vestibular disorder.

Also, the term "dizziness" can be used to describe many different sensations. While most doctors are trained to suspect inner ear disorders if a patient complains of violent nausea and whirling sensations, such strong symptoms do not always occur in the early stages of inner ear disorders. If you report that you feel off-balance, unsteady, light-headed, spacey, or that you feel as if you are rocking or floating, all of which may be perfectly true, your doctor may not suspect an inner ear disorder right away.

### DISORDERS OF THE PERIPHERAL VESTIBULAR SYSTEM CAN BE HARD TO DISTINGUISH FROM CENTRAL VESTIBULAR DISORDERS

The vestibular system consists both of sense organs in the inner ear and of the parts of the brain that receive information from the inner ear. The vestibular sense organs of the inner ear are called the peripheral vestibular system. The parts of the vestibular system located inside the brain are called the central vestibular system.

| DEFINITIONS | |
|---|---|
| **Central Vestibular System** | The vestibular sense organs of the inner ear. |
| **Peripheral Vestibular Disorders** | The parts of the vestibular system located inside the brain. |

When the whole vestibular system is working properly, the peripheral vestibular system detects head motion and sends accurate information about how the head is moving to the central vestibular system (which includes the vestibular nuclei and parts of the cerebellum and brainstem). The central vestibular system uses the information from the peripheral vestibular system to coordinate balance and eye movements and our sensations of motion.

Diseases can affect the peripheral vestibular system alone, the central vestibular system alone, or some combination of peripheral and central structures. Unfortunately, the symptoms of central and peripheral vestibular disorders can be very hard to distinguish between. Sophisticated testing is often required to determine whether symptoms of dizziness or imbalance are being caused by damage to the peripheral or the central nervous system.

Despite the fact that it can be hard to determine whether the peripheral or the central vestibular system is the source of the problem, it is very important to try to make that distinction. Treatments directed at the peripheral vestibular system are of no use against disorders of the central vestibular system and vice versa. Also, treating the peripheral vestibular system when the disease is actually in the central vestibular system can cause more harm than good.

For example, when symptoms of peripheral vestibular disorders are severe and uncontrollable many doctors recommend destroying the function of structures in the inner ear or severing the nerve that leads from the inner ear to the brain. These surgical procedures can relieve the symptoms of peripheral vestibular disorders, but they also destroy vestibular function forever. If such destructive procedures were carried out on a patient who had a central, rather than a peripheral, vestibular disorder, the patient's symptoms could end up worse rather than better.

## VESTIBULAR SYSTEM TESTS REQUIRE SPECIALIZED EQUIPMENT AND EXPERTISE TO INTERPRET

Even if your doctor has been able to detect the signs of a vestibular disorder, most general practitioners do not have the equipment and expertise to deter-mine which particular vestibular disorder is causing your problem. This is why you may be referred to a specialist (an oto-laryngologist, otologist, or neurotologist) who will order diagnostic tests performed by an audiologist that measure hearing, eye movement, and peripheral vestibular function. In addition, the specialist will order an assessment of balance and functional impairments. These evaluations are typically performed by physical and occupational therapists with advanced training in balance disorders.

However, especially in the early stages of many vestibular disorders, even these tests can be inconclusive. They can show that there is damage in the vestibular system, but they may not show conclusively which disorder is causing the problem, whether one or both ears are involved, or whether the damage is in the inner ear itself or the parts of the brain that receive the signals from the inner ear.

## SOME DOCTORS ADOPT A "WAIT AND SEE" APPROACH

Dizziness is a very common problem, and many vestibular disorders resolve completely on their own without any treatment at all. If your doctor is relatively sure that your dizziness is caused by an uncomplicated vestibular disorder, she or he may simply wait to see if your symptoms improve or resolve on their own. Some resolve within a matter of days or weeks; others may take longer. Another reason for waiting is that your doctor may be hoping that your signs and symptoms will become clear enough to point to a particular diagnosis. If symptoms haven't improved significantly by the end of six months, spontaneous recovery is unlikely and you should return to your doctor for further analysis.

## SUGGESTIONS

Here are some suggestions for speeding up the diagnostic process:

- Provide your doctor with as much information as you can.
- Make sure you understand what your doctor is trying to do, and follow the doctor's instructions.
- Be prepared to seek a second opinion.



## PROVIDE YOUR DOCTOR WITH AS MUCH INFORMATION AS YOU CAN

Compile records of your medical history and the histories of your closest blood relatives. Inform your doctor of all the medications you take, including over-the-counter drugs and drugs like alcohol and tobacco. Keep track of allergies and exposure to toxic chemicals like paints, glues, solvents, and petroleum products. Observe your own symptoms and ask your family to help observe them with you. When does your dizziness occur? Is there anything that seems to make it better or worse? You may want to use VEDA's patient logs and/or medical history form, available for download at vestibular.org/diagnosis_treatment.

## MAKE SURE YOU UNDERSTAND WHAT YOUR DOCTOR IS TRYING TO DO, AND FOLLOW THE DOCTOR'S INSTRUCTIONS

Ask your doctor to explain what she or he thinks is causing the problem. Be sure to insist that the doctor explain in language you can understand. Understand why the doctor is referring you to another doctor or asking you to undergo another set of tests. If you have trouble asking these questions, ask a family member to go with you, ask questions, and take notes. If your doctor appears to be doing nothing, find out why. If your doctor orders a treatment, or asks you to change your diet or lifestyle, be sure to give it a fair trial. Medications, diets, and exercise regimens can sometimes take six weeks to three months to show results. Above all, become your own healthcare advocate. Learn as much as you can about vestibular disorders so you can ask relevant questions and better understand any technical language your doctor might use. Visit vestibular.org/educational-resources for further information.

## BE PREPARED TO SEEK A SECOND OPINION

Not all doctors are equally good at diagnosing vestibular disorders. If your doctor is not answering your questions, not actively trying to diagnose your case, or asking you to undergo treatments that don't work, you may need to seek out a doctor who specializes in dizziness and balance disorders. These doctors are typically otolaryngologists, neurologists, otologists, or neuro-otologists with specialized training in vestibular disorders. If you are already seeing a specialist, you may still need to seek another, depending on your type of vestibular disorder. Getting to a specialty center for dizziness and balance disorders may be your best opportunity for getting the help you need. The Vestibular Disorders Association (VEDA) can supply the names of specialists and/or clinics in your region. See VEDA's online provider directory at vestibular.org.

## A FINAL COMMENT

Getting a diagnosis does not always lead to a cure. Scientists and doctors are only just beginning to understand the complex mechanisms of the vestibular system. Much more research will be needed to discover the exact cause of many vestibular disorders, and it will not be possible to develop treatments that really cure the disorders until the causes are discovered.

Most of the treatments that are available now can only relieve symptoms, not cure the disorder, and unfortunately, not all of the available treatments work for all patients. Regardless of whether or not your doctor can actually cure your disorder, she or he should be able to help you learn to manage your symptoms and improve your quality of life.

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**NOTES:**

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