

Seizure Disorder

Also called Epilepsy, Convulsions

Description of the Disability

Seizure Disorder is a brain disorder that involves recurring disruptions (called seizures) in the electrical activity in the brain. The brain is a complex electrochemical organ and the body's nerves use electric signals to pass information to and from various parts of the body. Seizures are abnormal electrical discharges in this electrical network, something like a small storm in the brain. They can cause a variety of symptoms including: peculiar sensations (sensory hallucinations - visions, odd smells, odd sounds), involuntary movements, peculiar emotions, peculiar responses, disorientation, muscle spasms (rapid, involuntary contractions of muscles), convulsions (significant spasms of large groups of muscles that shake the person's body), altered consciousness, and loss of consciousness. Which symptoms a person experiences depends on the location, size, and nature of the disturbance.

Many things can cause seizures, including specific genetic conditions, abnormal brain development, brain injuries, pressure on the brain from a tumor or swelling, lack of oxygen to the brain (anoxia), toxins, some medications, surgery, nutritional problems, and birth trauma. However, approximately 75% of the time physicians do not know what causes a particular person to have one or more seizures.

The nature and symptoms of seizures can vary enormously from person to person, but a particular person will usually experience a consistent type of seizures or a small subset (see types listed below). Some people with a seizure disorder have several seizures a day and some have only a few a year. For most people with seizure disorder, it is a stable and chronic condition. Some people "grow out" of their seizure disorder, especially if it starts in childhood or is the result of brain trauma. However, some others experience a progressive increase in the frequency or severity of the seizures as they grow older.

Experiencing a seizure is not always a symptom of a seizure disorder. A Seizure Disorder involves recurring seizures, so the person must experience at least two to be diagnosed. Many people experience a single seizure during their life and never have another.

Seizures are not a sign of mental illness and are not contagious. Having seizures is not necessarily linked to cognitive impairments and problems processing information, although some of the underlying causes (such as a brain injury) may involve coexisting cognitive problems.

There are hundreds of Seizure Disorders or "Epileptic Syndromes" – medical conditions that include seizures as symptoms. Some are called Progressive Epileptic Syndromes because they also cause developmental or neurological problems that get worse over time. Others that do not cause this type of damage are called Benign Epileptic Syndromes. Seizure disorders are also related to a variety of developmental and metabolic disorders, including cerebral palsy, tuberous sclerosis, and autism. In these cases, seizures are just one of a group of associated symptoms.

There are also some medical conditions whose symptoms resemble seizures but are not, including Tourette's Syndrome (a muscle tic disorder), Narcolepsy (a sleep-onset disorder), Cardiac Arrhythmia, and Syncope ("SYNC-o-pee" – fainting).

As part of the process of diagnosing a Seizure Disorder, a neurologist will report on the patterns he or she sees on the person's EEG (Electroencephalogram). The EEG is a reading of the electrical activity in a person's brain and there are characteristic EEG patterns for seizures that help confirm their presence and identify their location, size, and nature. The neurologist's report may also include other measures of brain activity, including CAT scans and MRI scans.

Although seizures rarely cause permanent brain damage or death, there is a rare seizure condition called **Status Epilepticus** that can. In Status Epilepticus, the person experiences repeated seizures without regaining consciousness and normal behavior in between. This is a medical emergency and can lead to brain damage from lack of oxygen. However, most people with a seizure disorder who seek vocational rehabilitation services will have already been cleared by their physician as not at high risk for Status Epilepticus. It is worth noting that more than half the people who experience Status Epilepticus have no history of seizures - so a VR counselor with no seizure history may be nearly as likely to have Status Epilepticus as their client with a seizure disorder.

Types of Seizures

Specialists classify seizures into more than 30 different types, but there are two basic categories based on their location in the brain and how much of the brain they seem to involve: Partial and Generalized. **Partial seizures** seem to stay in one particular region of the brain and not spread very widely. Often the person remains somewhat conscious during partial seizures, but they may feel "foggy" and disconnected. **Generalized seizures** seem to involve many different parts of the brain and usually the person is unaware or only partially aware of their environment during the seizure. However, it is not always easy to distinguish between these two. Some seizures seem to start out as partial and then spread later on. Others seem to be somewhere in between. Below is a description of some of the basic types of seizures:

Partial Seizures (involving a limited (focal) area of the brain)

- **Simple Partial Seizures** (previously called Focal Seizures) – Simple partial seizures start as a jerking movement in the face, arms or legs but can progress into convulsions. The person stays awake and aware of what is going on, but may hear or see things that are not there. The person may also suddenly feel sadness, joy, or fear for no reason. People who have simple partial seizures sometimes report smelling odd smells or having odd feelings before the seizure actually occurs. This advanced warning is sometimes called an "**Aura**." The most common aura is the smell of burnt rubber, but no one knows why.
- **Complex Partial Seizures** (previously called Psychomotor Seizures or Temporal Lobe Seizures) – Complex partial seizures usually start with the person suddenly having a blank stare. Following this, the person exhibits random but "complex", unconscious movements, called Automatisms. These may be a chewing or lip-smacking motion, picking at clothes, swinging a leg, or other random activity. Sometimes this phase may look like organized but

inappropriate behavior, such as pushing other people, trying to kiss other people, undressing, or hitting a wall. The person may or may not be aware of their surroundings during the seizure. It is important not to restrain the person during a complex partial seizure unless absolutely necessary because they may become violent in response. However, the person is usually amenable to suggestions during the seizure and can usually be "steered" away from any dangerous situations. Sometimes individuals have committed "crimes" during a complex partial seizure, such as shoplifting, disorderly conduct, unlawful entry, or resisting arrest. If a person is arrested, being in jail until things are sorted out it can sometimes create significant problems keeping up with their medications. Some people get an advance-warning aura before a complex partial seizure (see simple partial seizures above). Complex partial seizures are the most common of all seizure types.

Generalized Seizures (involving multiple areas of the brain)

- **Generalized Tonic Clonic Seizures** (previously called Grand Mal or Convulsive Seizures) – During a generalizes tonic clonic seizure, a person experiences muscle rigidity, muscle jerks, and shallow breathing, and may temporarily stop breathing. They may have bluish skin and may lose control of their bladder. The person may also experience confusion and fatigue for five or ten minutes after the seizure before returning to full consciousness. In the name, “tonic” refers to muscle tone and body posture, “clonic” is a medical term for spasms. The older term "Grand Mal" is French for “big illness.” Although not the most common type of seizure, this is the stereotypical seizure with which most people are familiar.
- **Generalized Absence Seizures** (previously called Petit Mal Seizures) - These seizures begin and end quickly and may look like a blank stare or like the person is just daydreaming. However, the person has actually lost awareness for a few seconds. They will lose track of what they were doing or what others were saying during and just before the seizure, and may be confused for several minutes afterwards. They may not even be aware the seizure happened. There can also be other behaviors such as eye blinking, muscle twitches, aimless movement, or chewing movements. In the name, the word “absence” is pronounced with a French accent: “ab-SONCE.”
- **Atonic Seizures** (previously called Drop Seizures)- During atonic seizures, the person suddenly loses muscle tone in the muscles that hold the head and body and falls to the ground. The seizure usually lasts between 10 seconds and 1 minute. This type of seizure is rare and is usually a symptom of a serious type of seizure disorder that begins in childhood.
- **Myoclonic Seizures** - Myoclonic seizures involve sudden, major jerks or twitches of the upper body, arms, or legs. The seizures are typically short but intense. The person may be thrown from their chair or may drop whatever they are holding.

In addition to these types of seizures, some people have "**Pseudoseizures**", or "**Psychogenic Seizures**", which are not classified as actual seizures although they share many of the same functional and vocational implications. Pseudoseizures tend to last longer than "true" seizures, have a few technical differences from "true" seizures, and may or may not be related to a “conversion disorder.” (A conversion disorder is the expression of an emotional problem as

physical symptoms when there is no underlying physical illness.) There is no definitive treatment for pseudoseizures but often they have triggers linked to emotionally stressful situations, which can be helped with counseling. It is important to remember that, for the people who have them, pseudoseizures are just as disruptive and involuntary as "true" seizures. In many cases a person has both pseudoseizures and a "true" seizure disorder. A VR Counselor should treat pseudoseizures the same as a "true" seizure disorder in terms of vocational and independent living issues.

Related Concerns:

- **Safety** - There are several safety concerns related to seizures. The first is the possibility of injury from falling or bumping into something during a seizure. Another serious concern is **Aspiration Pneumonia** – a type of pneumonia caused by inhaling fluids into the lungs. In the case of a person having a seizure, there is a danger they could breath in their own drool or vomit.
Also, some things can make seizures worse or destabilize a person’s condition. These include missing doses of anti-seizure medications, being pregnant, drinking alcohol or taking other recreational drugs, smoking cigarettes, and not getting enough sleep.
- **Mental Health** - Due to social pressure, stigma, and misunderstanding, people with seizure disorder are at risk for low self-esteem and depression. They are also at increased risk for suicide. People who witness seizures often misunderstand them, especially non-convulsive seizures, which can appear to be deliberate behavior to those who don’t understand what is happening. When seizures begin in childhood, bullying, teasing, and isolation from other children can be problems. Some people with seizure disorder may also live in fear of the next seizure. In other cases, family members may be overprotective of the person. For some people with seizure disorders, these factors can also reduce normal early vocational experiences such as summer jobs or part-time jobs during high school. These are not problems for everyone who has a seizure disorder, but counselors should be aware of the possibility. Having good support can minimize these issues. Many people find the opportunity to share their experiences in a support group helpful.
- **Driving** - Different states have different rules about issuing a driver's license to a person with a Seizure Disorder that is not well controlled. If the person is considering a career that involves driving or operating heavy equipment, it is important to find out about the laws that might apply and get a physician's report about any limitations or recommendations. If the person will be driving to and from work, these issues should also be discussed. If a person's seizures are well controlled there are usually no restrictions on driving.
- **SUDEP** – There is a mysterious disorder called **Sudden Unexplained Death in Epilepsy** (SUDEP) that can strike without warning, often when the person is alone. Researchers do not know exactly how common it is, but the frequency may be as high as 17% of the deaths of people with a seizure disorder. Research suggests that these deaths are probably triggered by a seizure and usually happen after the seizure has ended. No one knows why it happens, but some researchers speculate that it may involve difficulty with the autonomic regulation of breathing, very much like Sudden Infant Death Syndrome. Others think it may involve problems with the regulation of heartbeat. Since most SUDEP events happen when the person is alone, experts usually recommend staying with a person for 15 to 20 minutes after a seizure just in case (unless the person asks to be alone). Because several risk factors for

SUDEP (listed below) involve the accurate management of anti-seizure drugs, one good preventive measure is frequent follow-up visits with a physician.

For a person with a seizure disorder, risk factors for SUDEP include:

- Drinking alcohol
- Having a severe developmental disability
- Having a brain injury
- Taking more than one anti-seizure drug
- Skipping a dose of anti-seizure medication
- Having poor control of seizures
- Frequent changes in anti-seizure medication
- Lack of sleep

Possible Coexisting Conditions

- Depression
- Substance abuse
- Various disorders for which seizures are a possible symptom
- Traumatic Brain Injury
- Stroke (Cerebrovascular Accident: CVA)

Incidence Statistics

- About 25 percent of working-age people with a seizure disorder are unemployed.
- Seizure disorder is most prevalent in the elderly due to strokes
- In 80% of people with seizure disorder, medicine or surgery can control the seizures. In 20% (about 600,000 people in the US) the seizures do not respond well to treatment.
- 20% of people with seizure disorder experience an “aura” ahead of time, warning that a seizure is about to occur.
- Possible triggers for seizures include repetitive sounds, video games, flashing lights, and touching certain places on the body.
- In 50% of people with seizure disorder, there is no identifiable cause.
- In 75% of people who experience a single seizure, there is no identifiable cause.

Common Treatments, Medications, and Side Effects

Medication

Anti-seizure medication is the most common treatment for seizure disorders. The person's physician will usually choose an anti-seizure drug (or drugs) based on the type of seizure the person reports having. If that drug does not work, the physician will try others. The person can usually reduce and control the seizures, at least to some extent, with anti-seizure drugs. However, anti-seizure drugs are powerful and can often have significant side effects, including fatigue, depression, and a risk for psychosis. They can also have significant interaction effects with other drugs or with alcohol (see Drug entry for more specifics on side effects).

If a person has been seizure free for a long while, they may decide to try stopping or reducing the medication, but they should only do this with close supervision by their physician. It is always very important for people with a seizure disorder to keep in close contact with their physician and stick to their medication regime. Suddenly stopping the medication or missing several doses can trigger seizures and can sometimes trigger an additional type of seizure that is more resistant to treatment than the existing seizures.

Nerve Stimulator

For people with partial seizures, another possible treatment is the **Vagus Nerve Stimulator**. This is a small device that is implanted under the skin of the chest with a wire from the stimulator leading to the vagus nerve. The vagus nerve is a large nerve running through the neck to the brain. For reasons that researchers do not understand, electrically stimulating this nerve seems to help control these seizures. Once the stimulator is in place, the person activates it by passing a small magnet over the device if they feel that a seizure is about to begin. Then the stimulator sends an electric current to the nerve for a few minutes. This approach reduces the frequency of seizures for many people but they must still take anti-seizure drugs as well. Also, the person may have to use the stimulator for several weeks or months before noticing a significant improvement.

Side effects of the Vagus Nerve Stimulator include:

- Pain in the throat
- Hoarseness or slight change in the voice during use
- Cough
- Shortness of breath

Surgery

If a person is having frequent, severe seizures (for example, multiple seizures every day) that do not respond to medications, a physician may choose to try brain surgery. This is a very serious and risky treatment, so physicians usually only try it when all other treatments have failed and the person is not able to function reasonably in daily life.

The least intrusive surgery is a **Cortical Resection** – the removal, isolation, or destruction of a small part of the brain where that person's seizures are starting. Functional implications depend on what part of the brain is involved. The most common cortical resection is a Temporal Lobe Resection, since the temporal lobe seems to be a common trigger point for seizures.

In people with partial seizures, another surgical approach is a "**Lobectomy**" – removing a lobe of the brain. As you might expect, this may or may not have significant functional effects on the person depending on what lobe of the brain is removed. The most common lobectomy involves the Temporal Lobe, and possible functional side effects include partial losses of vision, memory, speech, or coordination. People who have a temporal lobectomy or a temporal resection as a child can often regain some of the skills affected by the surgery later on as other parts of their brain adapt to the change. The brains of adults are not as flexible about adjusting this way.

In children under the age of 13 with significant partial seizures, there is a drastic surgical approach called a "**Hemispherectomy**" – the removal of nearly half of the brain. This is only done in a few specialized treatment centers and only when the seizures are significantly incapacitating the child. Because the brains of children are more adaptable than those of adults, the remaining hemisphere will compensate somewhat for the loss, but there will still be significant functional effects, including lack of control of one side of the body.

For persons with atonic seizures, the surgery is often a "**Corpus Callosotomy**" – the severing of the Corpus Callosum nerve bundle that connects the two hemispheres. This helps keep the seizures from spreading throughout the brain, but partial seizures will remain and may increase in frequency. The person may experience some subtle neurological problems after the surgery, but the functional implications are usually much less than for the other anti-seizure surgeries.

Other Treatments

Some studies have shown that a diet rich in fats and low in carbohydrates (ketogenic diet) may help children experience fewer seizures. However, this diet could lead to serious nutritional problems and should only be done under a doctor's supervision.

Other treatments such as biofeedback, mega-doses of vitamins, and other alternative treatments have not been shown to be effective in decreasing seizures.

What To Do When Someone Is Having A Convulsive Seizure

It is unlikely that a person with a seizure disorder will have a significant convulsive seizure while in your office. But some people, including potential employers and coworkers, may become nervous about what to do if the person has a convulsive seizure. Here are some suggestions.

- **Lay the person down** if possible and roll the person on his or her side to prevent choking.
- **Protect the person's head** from injury- put something soft under their head if possible.
- **Make sure the person's airway stays open.**
- **Remove dangerous objects** (especially hard or sharp objects) away from the person to prevent injury.

- **Do NOT try to restrain** the person to keep them from moving unless they are in danger.
- **NEVER put anything into the person’s mouth.** Liquids or medicine could cause choking and other objects could damage the person’s jaws or teeth. There is no risk of “swallowing their tongue” – it is just an old myth.
- **Keep track of the length** of the seizure(s) and the symptoms so you can report them to emergency personnel or doctor if necessary.
- **Speak calmly and clearly** to the person. They may be able to hear you even if they do not seem to respond. If they can hear you, they are probably very confused and talking to them calmly will help.
- **Stay with the person** until they are completely alert. They may be dazed and disoriented for ten or twenty minutes after the seizure is over (also see SUDEP description above).
- **Call for emergency medical help:**
 - if the person is pregnant or has diabetes
 - if the seizure lasts longer than 5 minutes
 - if the person does not regain consciousness before the next seizure begins (see Status Epilepticus above)
 - if the person does not begin breathing again after the seizure (begin CPR after calling for help)
 - if the person does not wake up after the seizure
 - if the person injures him or herself during the seizure

Possible Functional Issues

- **SAFETY**
 - Driving restrictions or equipment operating restrictions
 - Restrictions on working at great heights
 - Medication side effects, including
 - Difficulty with memory or concentration
 - Depression
 - Fatigue
- **ENVIRONMENTAL**
 - Sensitivity to flickering light or fluorescent lights (possible trigger for seizures)
 - Sensitivity to repetitious sound (possible trigger for seizures)
- **DIFFICULTY IMMEDIATELY AFTER A SEIZURE WITH:**
 - Remembering tasks or events from just before the seizure.
 - Fatigue and disorientation
 - Balance immediately
 - Communicating
- Learning skills are usually not effected

- Dexterity and coordination are usually not effected
- Strength is usually not effected
- Social skills are usually not effected
- Communication skills are usually not effected

Initial Interview Considerations

Initial Questions

- How often do they typically have seizures? When was their last seizure?
- What type of seizures do they have?
- How stable is their condition? Do they expect the frequency or severity of the seizures to change over the next few years?
- When did they last see a physician about the seizure disorder? Does their physician know they are trying to go back to work?
- What triggers, if any, have they noticed for the seizures?
- What is a “typical” seizure experience like for them? How long does it last? How long does it take to recover?
- How often, if ever, do they have a headache or other problems immediately after a seizure? How long do those problems last?
- How satisfied is the person with the effectiveness of the medications they are taking?
- What, if any, side effects of their medications have they noticed that may effect their job choice? Are the side effects different at different times of the day?
- What, if any, accommodations have helped?
- What, if any, warning auras have they noticed before a seizure?
- How anxious do they usually feel about when the next seizure will happen?
- How has the disorder affected their work?
- How often do they drive? Do they have a valid driver's license?
- What restrictions, if any, has their doctor advised about driving?
- How has the disorder affected their home life? Their leisure activities? (gets at other possible impacts)
- How has the disorder affected their friendships? Their family relationships?
- What do they do on a typical weekend? (gets at hobbies, interests, other possible skills)

Initial Observations

- Does the person seem tired or easily confused?
- Does the person seem depressed?

Interview Accommodations (if any)

- Ask beforehand if fluorescent lights or computer monitors cause problems for the person. If so, shut off any in your office before the interview.

Possible Accommodations and Assistive Technology

- It can be helpful to educate coworkers how to recognize and respond to a seizure. In particular, it helps them to understand that any inappropriate behavior is not deliberate but is just part of the temporary seizure.
- Have a plan of action for the possibility of a seizure in the workplace. This will help reduce anxiety and confusion among coworkers about what to do. The plan of action might include emergency information, warning signs, how and when to seek medical attention, who will be the designated responders, and how to provide on-site medical attention.
- Have a “safe” place for the person to go during or after a seizure, where they can recover and not disrupt the work of others. Providing as much privacy as possible during a seizure can also cut down on an employee’s embarrassment about things that may occur during a seizure, such as bladder incontinence, drooling, inappropriate behavior (pushing or trying to kiss others). However, it is also a good idea to have someone with the person in the safe place for a few minutes after a seizure to watch for SUDEP (see discussion above).
- Implement a thorough date book and organizer system that is easy for the person to interpret. This will reduce possible confusion and disorientation immediately after a seizure.
- Have the employer or the person consistently write down job tasks or information. Place prominent and clear labels and directions on work equipment. These will also help reduce possible confusion and disorientation immediately after a seizure.
- Rubber floor mats or soft carpets, padded arms on chairs, and handrails on ladders can help prevent injury from possible falls during seizures.
- Working in teams and providing clear timelines and reminders may help and the person manage time better and meet deadlines even though completing tasks may be difficult right after a seizure.
- Carpooling or rideshare can help with a person with driving restrictions. It may be useful for the person to have multiple alternatives for transportation in case one fails unexpectedly. These alternatives might include a public bus, a neighbor or family member, or a taxi.
- Flexible work schedules and a place to take a nap at lunchtime can help with fatigue issues (a possible trigger for seizures and a possible side effect of medication)
- LCD monitors eliminate the flicker of computer monitors (a possible trigger for seizures).

Career Planning Issues

- For safety reasons, individuals with seizures that are not well controlled should probably avoid careers that include significant driving or operating dangerous equipment. People with controlled seizures do not have to avoid any particular careers.

- If the person has driving restrictions, they will need several alternative transportation options for getting to work in case their main resource is suddenly not available on a particular day. Family, neighbors, and public transportation are possible options.
- Because lack of sleep can trigger seizures, people with seizure disorder should avoid jobs with rotating shifts or overnight shifts.

Emerging Issues

- Processes for monitoring and interrupting the development of seizure disorder
- Gene Therapy for seizure disorders, including stem-cell gene replacement
- Devices to detect brain activity to warn of impending seizure
- Transcranial magnetic stimulation - involves using a strong magnet held outside the head to influence brain activity. There is a theory that this may reduce seizures.

Additional Information Resources

- American Epilepsy Society - www.aesnet.org/
- Job Accommodations Network (has a sample “Plan of Action” that the employee may want to implement at work. *Look under Accommodation Ideas for People with Epilepsy*) - www.jan.wvu.edu/media/Epilepsy.html.
- National Society for Epilepsy - www.epilepsynse.org
- National Institute of Neurological Disorders and Stroke - www.ninds.nih.gov/index.htm.
- Epilepsy Foundation - www.epilepsyfoundation.org