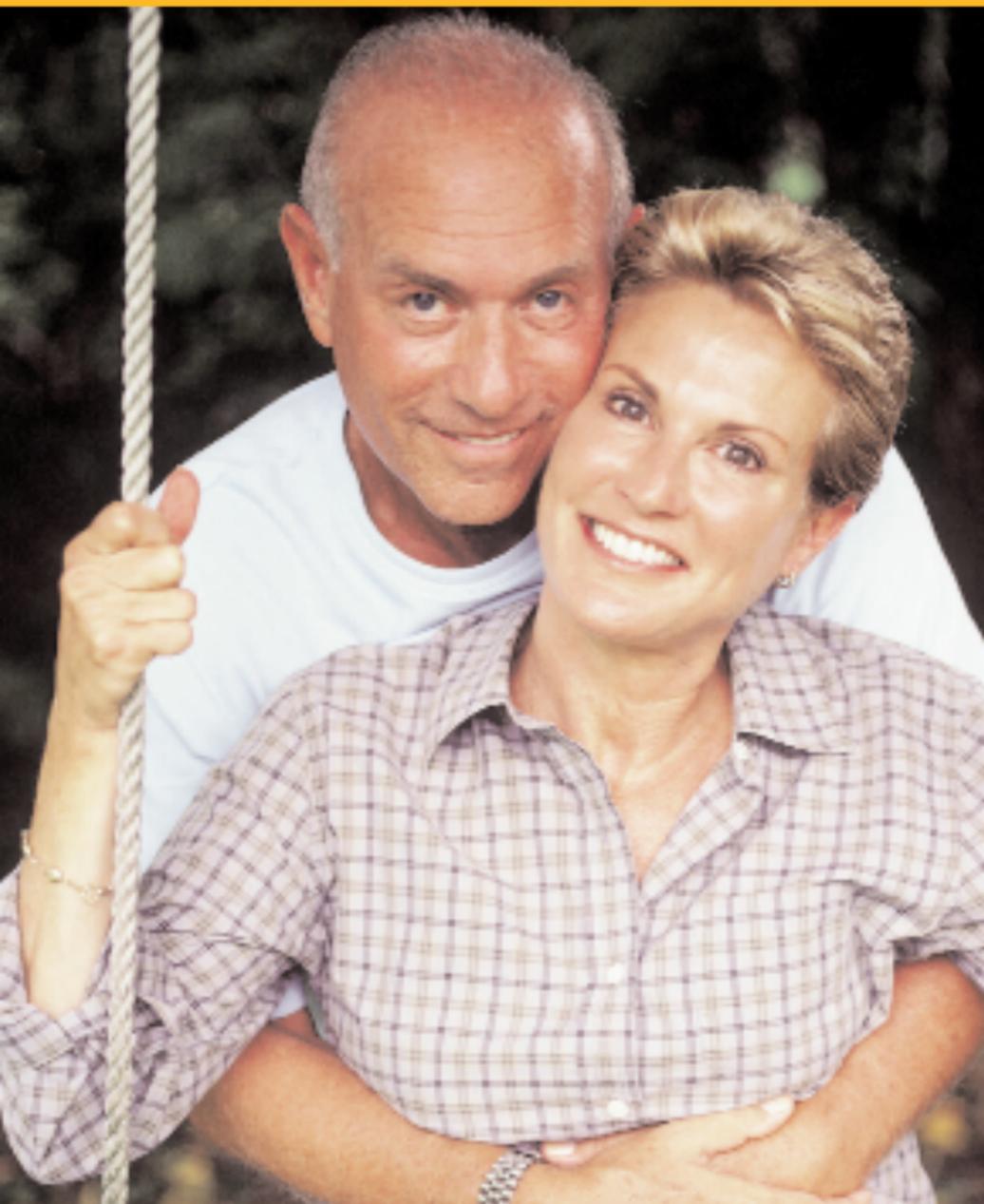




# H.O.P.E.

MENTORING PROGRAM™

Helping Other People with Epilepsy



## Seizures in Adult Life



**EPILEPSY  
FOUNDATION®**

*Not another moment lost to seizures™*

## About the Epilepsy Foundation

The Foundation's mission is to ensure that people with epilepsy have access to all life experiences and to prevent, control and cure epilepsy through research, education, advocacy and services.

The Foundation offers information and assistance to people of all ages who are living with epilepsy, and their families, through its Epilepsy Resource Center.

The Epilepsy Foundation's H.O.P.E. (Helping Other People with Epilepsy) Mentoring Program offers mentoring and presentations on epilepsy to individuals, families and in community living settings.

To find out more about the H.O.P.E. Mentoring Program or the name of a participating Epilepsy Foundation near you, call 1-800-332-1000, or visit [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

© 2003,2009 Epilepsy Foundation of America, Inc.

This pamphlet provides general information about epilepsy to the public. It is not medical advice. People with epilepsy should not make changes in treatment or activities based on this information without first consulting a physician.



*"Nobody had a clue that I, a young mother of three boys, was actually having seizures when I had staring spells. My husband didn't think twice about them when we got married years ago—until after my first convulsion. That was when we realized I needed to get help."*

## Seizures in Adult Life

People tend to think of epilepsy, or seizure disorders, as a condition that usually starts in childhood.

But epilepsy, and the seizures that are its primary symptom, can begin in adult life, too.

It is a much more common condition than most people believe. One in every hundred Americans lives with epilepsy, currently about 3 million people of all ages.

Whether seizures begin at age 10 or 21, adults living with epilepsy face special challenges. Any medical illness can change lives, but a long-term condition such as epilepsy can impact relationships, employment and the individual's sense of self.

This pamphlet will explore some of these issues and offer basic information that we hope will be helpful to adults living with seizures. More in-depth discussion of these issues is available on the Epilepsy Foundation's website at [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org).

# About Epilepsy

Epilepsy is a disorder of the brain that results in sudden, brief changes in the electrical system that controls consciousness and all other physical and mental functions, similar to an electrical lightning storm.

These brief disturbances, called seizures, may temporarily block a person's awareness of time and place. Or they may cause uncontrollable shaking, convulsions, confusion or affect the senses.

Anyone at any age can have a seizure if the brain is stressed enough by injury or disease.

A single seizure isn't epilepsy because a single seizure can result from a temporary condition such as a drug effect or the impact of head trauma.

Epilepsy is the name given to seizures that occur more than once because of an underlying condition in the brain that causes a tendency to have seizures. Some people prefer to call epilepsy a seizure disorder.

# Types of Seizures

The type of seizure a person with epilepsy has depends on where the electrical disturbance happens and how much of the brain is affected. Some people have just one type of seizure; others have more than one type.

In partial seizures, the electrical disturbance is limited to part of the brain. In generalized seizures, the whole brain is affected at once.

**Partial seizures** are the most common type of seizure experienced by people whose seizure disorder begins in adult life.

Partial seizures can be *simple* (during which a person remains awake and aware) or *complex* (during which awareness is clouded and the individual is unable to control his or her actions).

*Sometimes a first seizure is a symptom of another health problem that may need immediate attention. After a first seizure, check with the doctor to rule out other conditions as possible causes.*

# Common Symptoms

## **SIMPLE PARTIAL SEIZURES**

- *Jamais vu (familiar things suddenly seem unfamiliar)*
- *Trembling that moves up one side of the body*
- *Changes in vision and hearing*
- *Odd feelings*
- *Garbled speech*

## **COMPLEX PARTIAL SEIZURES**

- *Staring*
- *Lip smacking*
- *Swallowing*
- *Picking at clothes*
- *Wandering*
- *Lost time*
- *Lack of response to others*
- *Senseless, clumsy movements*
- *Repeating phrases*
- *Taking off clothes*
- *Unaware of danger or pain*
- *"Sleepwalking" appearance*

## **GENERALIZED SEIZURES**

- *Convulsions*
- *Sudden falls*
- *Brief blackouts, staring*
- *Sudden muscle jerks*



*"My greatest challenge related to having epilepsy is dealing with fear and anxiety. The fear is that at any moment, during any activity, I could have a seizure. It's reduced my confidence to a pile of rubble and affects my ability to socialize. What would someone do if I had a seizure?"*

**Generalized seizures** happen when waves of electrical activity swamp the whole brain at once.

The type of seizure most people think of when they hear the word "epilepsy" is the generalized tonic-clonic (grand mal) seizure, also called a convulsion.

It often starts with a cry caused by air being forced out of the lungs. The person falls to the ground, unconscious. The body stiffens briefly and then begins to jerk.

The person may bite his tongue. A frothy saliva may appear around his mouth. Breathing may be very shallow and even stop for a few moments and sometimes the skin turns a bluish color.

After a minute or two, the jerking movements slow down, and the seizure ends naturally.

Bladder or bowel control may be lost as muscles relax after the seizure. The person may be extremely sleepy or even unable to be aroused after a generalized tonic-clonic seizure. Consciousness will then slowly return.

## Seizure First Aid

Seizure first aid involves just a few common-sense steps to protect the person from harm until full awareness returns. What you shouldn't do is just as important as what you should do.

### **FIRST AID FOR GENERALIZED TONIC-CLONIC SEIZURES (grand mal, convulsions)**

- Ease the person having the seizure into a reclining position on the floor or flat surface.
- Put something soft and flat under her head.
- Turn her gently onto one side to prevent choking and keep the airway clear.
- If the person having the seizure is seated, turn her head gently to one side so any fluids drain away from the mouth.

### **What not to do:**

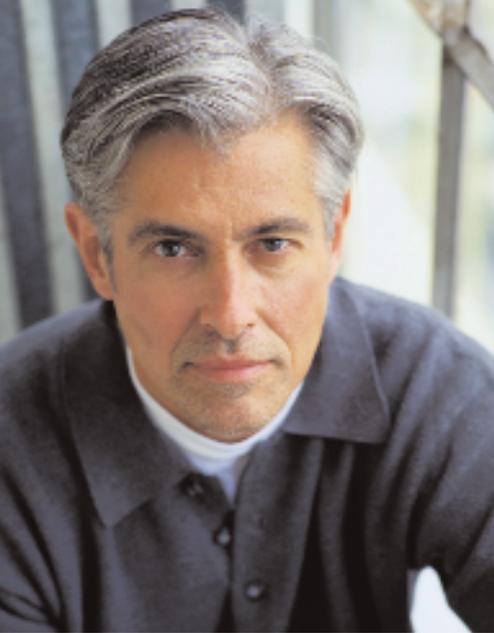
- Don't try to force anything into the mouth. Seizures do not cause people to swallow their tongues.
- Don't try to give fluids or medicine until the seizure is completely over and the person is fully alert again.
- Don't try to restrain the jerking movements. Muscles contract with force during seizures. Applying restraint could cause tears in the muscle or even break a bone.

### **FIRST AID FOR SEIZURE-RELATED CONFUSION**

Confusion and being unable to interact with others may be part of the seizure (particularly complex partial seizures), or it may be part of the recovery period following other types of seizures.

In either case, the same basic rules apply:

- Remove anything from the area that might cause injury or could be a hazard to someone who is temporarily unaware of where he is or what he is doing.



*"I was in the hospital to rule out other causes of my seizures. Once I was diagnosed with epilepsy, I started taking medicine. It took a while to find the right drug, but once we had, I did really well. A couple of years later, I asked the doctor to wean me off. I'm hoping that the seizures will not come back."*

- Don't try to restrain someone who is wandering and confused during a complex partial seizure. If danger threatens, block access or gently guide the person away.
- Be reassuring, comforting and calm as awareness returns.

### **CALL FOR 911?**

Most seizures end naturally without any special treatment after a couple of minutes. When that happens, there's probably no need to call an ambulance.

But sometimes, more serious problems develop. It is advisable to call an ambulance when a convulsion lasts longer than five minutes, or if one seizure follows right after another. An ambulance should also be called if the person appears injured, is having difficulty breathing after the seizure ends, has diabetes or is pregnant.

Also, call for help if consciousness does not return after the seizure ends. People are often confused following a seizure, but confusion lasting more than one hour after a seizure may mean that the seizure is not over.

## *Causes of Epilepsy*

When an adult has lived many years without a diagnosis of epilepsy and then develops the disorder, the first question is often, "Why did this happen to me?"

Although in many cases—as many as five out of ten—there is no good answer, some known causes of epilepsy that begins in adult life include:

- Head injuries
- Brain tumors
- Lack of oxygen to the brain
- Exposure to certain toxins, like lead
- After-effects of infections like meningitis or encephalitis
- Parasites from under-cooked meat (especially pork)
- A seizure that appears to be the first one a person has had may result from a previously undiagnosed seizure disorder.

## *Treating Epilepsy*

The most common form of treatment for epilepsy is daily medication to prevent seizures.

Antiepileptic drugs (also called anticonvulsants) will usually prevent seizures or reduce how often they occur if they are taken every day, on time. Missing doses will make it more likely that seizures will occur. More than 20 drugs are used to treat epilepsy.

People should be especially careful not to stop the medication suddenly. Doing so may cause serious rebound seizures that could even be life threatening.



*"After exhausting nearly every medicine, I was still having two-three seizures a week. I talked it over with my doctor and she suggested that surgery might be an option for me. After many tests, I had a left temporal lobectomy resection. It's now been four and a half years since I had a seizure."*

Physicians consider many things in selecting one medication over the other: its track record with the particular type of seizure a person has, the age and gender of the patient, and the kinds of side effects that may occur.

However, not all people respond to a particular drug in the same way. Some people are more sensitive to side effects than others. And sometimes seizures continue even though the medication is being taken regularly. For all these reasons, finding the most effective epilepsy drug for each individual may take some time.

If the drugs are not successful in controlling seizures, or if people experience uncomfortable side effects, other kinds of treatment may be tried.

These include surgery to remove a small area of the brain, or electrical stimulation of the brain via a large nerve in the neck (vagus nerve stimulation (VNS) therapy).

In children, a strict, calorie-restricted diet high in fats and low in carbohydrates (the ketogenic diet) is often successful in controlling seizures. However, not as much is known about whether it works for adults. It is serious therapy, and must be prescribed by a skilled medical team.

## Living With Epilepsy

Other people's reactions to seizures and epilepsy may be more troubling to people with this condition than the seizures themselves.

Some people with epilepsy worry about how and when to disclose the fact to others, for fear of how other people will react.

People with frequent seizures generally decide to tell others early on so that if a seizure occurs their friends will know what to do. Others may wait until the relationship is on such solid ground that it won't be threatened by the disclosure.

### EMPLOYMENT

Today people with epilepsy are working at thousands of jobs from one end of the country to the other. Many of these people have excellent seizure control, but not all of them do. Having seizures may make the job hunt more difficult, but not impossible.

In general, people with marketable skills who have learned how to discuss epilepsy with employers confidently, emphasizing that it will not interfere with their job performance, have the best chances of success.

When outright discrimination occurs, federal and state laws provide some protection for people with disabilities, including epilepsy. The Americans with Disabilities Act (ADA) requires an employer to provide any reasonable "accommodations" which would enable an otherwise qualified person with an eligible disability to do the job.

Typical accommodations for people with epilepsy might include arranging new work schedules, installing a safety device around machinery, replacing a flickering bulb with a steady light or re-assigning non-essential duties.



*"My friend of many years saw me have a seizure and said it was upsetting. I told her I was sorry and that I felt badly about what happened because I scared everyone so much. She understood. She knows it's just a disorder. I know we're still good friends."*

## **MARRIAGE AND FAMILY**

Men and women who have epilepsy marry and have children just like other people. However, as a group they tend to have a slightly lower marriage rate than the rest of the population.

Fertility, too, appears to be lower in women with epilepsy, possibly as a result of interaction between hormones, seizures and in some cases, certain antiepileptic drugs. Sometimes, women with epilepsy may be unreasonably discouraged from having a baby by doctors or family members.

While it's true that they may find it harder to get pregnant and run a higher risk of having a baby with a birth defect, the overwhelming majority (around 90 percent) of women with epilepsy who become pregnant deliver normal, healthy babies.

Women with seizure disorders who want to become pregnant should discuss their medications with their doctors before the pregnancy begins. If changes are needed they can be made then. Women should ask, too, about how much folic acid they should take to protect against certain problems in the baby.

## **TRANSPORTATION**

Driving a car is the key to self-sufficiency and independence in the United States. But if you blackout while driving, you risk your life and those of others on the road. All states will license people with epilepsy, but only if seizures affecting awareness are completely controlled.

Eligibility requirements vary from state to state, ranging from three months to a year seizure-free. Some states have no specific seizure-free interval, relying instead on a physician's statement of fitness to drive.

## **INSURANCE**

Getting affordable health insurance can be difficult for many people with epilepsy. The best option is group coverage through an employer, but it may exclude or limit coverage of a condition (such as epilepsy) that existed before the person was hired.

The Health Insurance Portability and Accountability Act of 1996 offers some protection for people with pre-existing conditions if their employers offer coverage to other employees.

Under that Act, neither employees with epilepsy nor their children can be excluded completely from coverage. In some cases, people who change jobs may be able to continue existing coverage in the new position, regardless of a pre-existing condition.

Getting life insurance may also be a challenge. Joining a group which offers term life insurance at group rates may be a successful strategy.

## **FINANCIAL ISSUES**

Most people with seizure disorders would rather work and support themselves than receive financial assistance. However, some have seizures and related problems that make it almost impossible to work.

There are two primary sources of financial support for people who cannot work because of disability.

The Social Security Disability Income (SSDI) program helps people who have either paid into the Social Security system while they were working or are the dependents or survivors of someone who paid into Social Security. People on SSDI also receive medical care through Medicare two years after they become eligible for SSDI.

The Supplemental Security Income (SSI) program provides financial aid to people whose epilepsy is disabling and who have limited incomes. Medical care for SSI recipients is provided through Medicaid.

## **RECREATION**

Taking part in sports and vigorous exercise is good for most people and in most cases is unlikely to make seizures worse. Check with your health care team before starting a new sport or activity, since individual reactions may differ.

Some recreational activities call for caution. People with active seizures should not swim alone or in open water, but can enjoy water sports safely so long as they take simple precautions and people with them know about the seizures and are able to help in an emergency.

Walking, running, playing golf or tennis, and team sports such as basketball or touch football are all types of exercise that people with epilepsy participate in and enjoy. Wearing helmets while cycling, playing baseball or football, helps to protect against further injury.

## *How You Feel*

If a person had epilepsy seventy years ago, living a normal life would have been much more difficult than it is today. Prejudice and fear closed many doors.

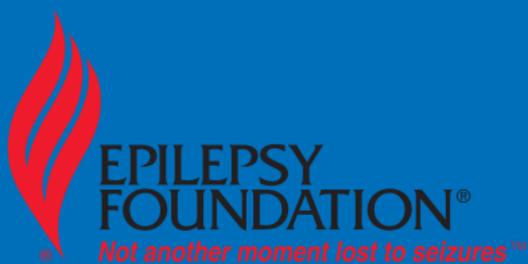
Yet even today, epilepsy can make people feel lonely and isolated. Dealing with an unexpected medical condition, a lengthy search for answers, and a host of new social challenges can be tough. It can be depressing. People often feel overwhelmed and anxious.

If you find yourself experiencing periods of deep unhappiness where nothing seems worth the effort, get medical help. Depression and anxiety can be successfully treated.

At the same time, learning as much as you can about the condition and its treatment and becoming an active partner in your health care can help you move ahead.

Meeting others with epilepsy through the Epilepsy Foundation can make a huge difference to people facing epilepsy for the first time. Support is also available through chat rooms at [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org) where men and women dealing with epilepsy in adult life can share experiences and grow together.

The H.O.P.E. Mentoring program is supported  
by an educational grant from



800-332-1000  
[www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)

465SAL  
Rev. 3/09