

## Frequently Asked Questions About Epilepsy/Seizures

### **Q. What is epilepsy?**

Epilepsy is a neurological disorder that produces sudden, brief changes in how brain cells (neurons) function. When brain cells are not working properly, a person's consciousness, movements or actions may be altered for a short time. Those physical changes are called seizures. Epilepsy is sometimes called a seizure disorder.

### **Q. When does epilepsy usually develop?**

Epilepsy can begin at any time of life. One in four of the 200,000 new cases of epilepsy diagnosed each year in the U.S. begin under the age of 14; one in three begins in people over the age of 65. The remaining 41 percent of new cases start between the ages of 15 and 64.

### **Q. How many people in the U.S. have epilepsy?**

Almost one percent of the population, or nearly 3 million people, have epilepsy.

### **Q. What causes a person to develop epilepsy?**

Sometimes no cause can be found. Among the rest, epilepsy may be caused by head injuries, strokes, brain tumors, genetics, lead poisoning, problems in brain development before birth, illnesses that affect the brain like meningitis or encephalitis, or even severe cases of measles.

### **Q. Can epilepsy be prevented?**

Epilepsy can be prevented by reducing risks of head injury and stroke, or by developing new vaccines to prevent seizure-producing illnesses. For example, safety belts and air bags, motorcycle helmets, and safety seats for infants in automobiles protect against epilepsy as a result of auto accidents.

### **Q. Is epilepsy ever contagious?**

No, you cannot catch epilepsy from another person.

### **Q. Is epilepsy an inherited condition?**

Some types of epilepsy are definitely associated with genetic factors. At the same time, epilepsy usually develops with no family history of the condition at all. It may be that all of us inherit some susceptibility to seizures, but that many people with a high susceptibility never develop the condition unless something happens to injure the brain. Children of a parent with epilepsy have a slightly greater probability of developing the condition than the rest of the population, but it is still much more likely that they will not.

### **Q. What causes epilepsy or seizures?**

The brain is the control center for the body. Normal electrical signals between cells make the brain and body work correctly. The cells work like little switches, turning electrical charges on and off automatically. But sometimes it is as if some cells get stuck in the "on" position, and keep firing. This continuous firing affects neighboring cells and spreads to other parts of the brain, or throughout the brain. The excessive electrical charges prevent those cells from performing their normal functions. It may change the way the world looks, or may make our bodies move automatically.

Sometimes they may cause a convulsion. Seizures usually last a short time (a matter of seconds or a minute or two), and then end naturally as brain cell activity returns to normal.

## **Q. What kinds of seizures do people with epilepsy have?**

Several different kinds of seizures may occur. Generalized tonic clonic seizures (also called grand mal or convulsions) are the most noticeable kind. They happen when the whole brain is suddenly swamped with electrical energy. The seizure often starts with a cry caused by air being suddenly forced out of the lungs. The person falls to the ground, unconscious. The body stiffens, and then begins to jerk. The tongue may be bitten. A frothy saliva may appear around the mouth. Breathing may get very shallow and even stop for a few moments, causing the skin to turn a bluish color. The jerking movements then slow down, and the seizure ends naturally after a minute or two. Bladder or bowel control is sometimes lost. When consciousness returns the person who had the seizure may feel confused and sleepy. In some cases only a very short recovery period is required, after which people can go back to their normal activities. If the seizure is prolonged, or the person is injured, medical attention is essential. Absence seizures (also called petit mal) look like daydreaming or blank staring. They begin and end abruptly, last only a few seconds, and are most often seen in children. A child having this kind of seizure is unaware of people and things around him for a few seconds, but quickly returns to full awareness. These "little" seizures happen so quickly that the child (and sometimes other people around him) may not notice them.

Sometimes these seizures also produce blinking or chewing movements, turning of the head, or waving of the arms. Atonic seizures, or drop attacks, cause sudden falls. Myoclonic seizures produce massive muscle jerks. And infantile spasms are characterized by head drops or body spasms. Simple partial seizures produce changes in sensation, movement or feeling without alteration of consciousness. Sometimes the movements start in one area of the body and then slowly progress upwards to involve one whole side. The seizure may make things look strange, or the person may see people or things that are not really there. He or she may hear strange sounds or have a feeling that what is happening around him or her has somehow happened before (deja vu). He or she may feel strange sensations on one side of the body or a rising felling in the abdomen. These feelings may last several seconds up to a minute or so. The cause of these disturbances (which may be frightening and upsetting to someone who doesn't know what is causing them) is seizure activity taking place in parts of the brain that control movement, seeing, hearing, memory, or feeling. Complex partial seizures (sometimes called psychomotor or temporal lobe seizures) affect awareness. A complex partial seizure makes a person appear to be in a trance and go through a series of movements over which he has no control. Although the kind of movements may vary from individual to individual, there may be a distinctive pattern of actions that each person follows every time a seizure happens. A seizure of this type may start with a warning, termed the aura, which is actually the simple partial seizure that precedes impairment of consciousness: a strange sensation, a feeling of fear, perhaps, or a sudden sick feeling in the stomach, or even seeing or hearing something that is not really there. The person stares blankly, and may make chewing movements with the mouth. He or she may move an arm, pull at clothing, get up and walk around, all the time looking dazed and out of touch with the environment. Although not completely aware of things and people around him, a person having this kind of seizure, may follow simple directions if they are given in a calm, friendly voice. Sometimes complex partial seizures produce more dramatic changes in behavior, including

screaming, crying, moaning, laughing, disrobing, running, or apparent fear. Although most seizures last for only a minute or two, full awareness may not return for some time afterwards. Confusion and irritability may follow, and the person will not remember what happened or what he or she did while the seizure was going on. Both simple or complex partial seizures may affect enough brain cells to spread and become a generalized tonic clonic (grand mal) seizure. Doctors describe these as partial seizures secondarily generalized.

### **Q. What is an aura?**

An aura is a feeling or experience that may warn the person that a more severe seizure is about to begin. The aura is, in fact, the start of a simple partial seizure before it spreads to other areas (see above).

Examples include a feeling of fear or sickness or an odd smell or taste, as described above. People who have this warning may have time to move away from possible hazards. Sometimes the expected seizure does not follow and all that happens is the aura.

### **Q. Do seizures injure the brain?**

The average seizure does not seem to have any lasting effect on the brain. Many people with epilepsy have had dozens or even hundreds of seizures in their lives without noticeable changes in intelligence or alertness; others say that lots of seizures over time do have some negative effects. Seizures which last an unusually long time may injure the brain.

### **Q. Is there any danger of a person dying during a seizure?**

A seizure is seldom a cause of death, but it can happen. There is a chance of accidental death if someone has a seizure in water, or near heights, or while driving a car. Occasionally, a person may fall in such a way that breathing is blocked, or may suffer a heart attack as a result of the stress of the seizure. In rare cases, breathing may not start again when a convulsive seizure is over, in which case artificial respiration should be given. Death may also occur as a result of a series of non-stop seizures that may last for hours if not treated in a hospital. People suffering more than one convulsive seizure in a short period should also receive immediate medical care. Young adults with hard-to-control seizures may be at higher risk of sudden, unexplained death. This rare but troubling phenomenon is not yet well understood.

### **Q. Could a person with epilepsy harm someone else during a seizure?**

A person who is having a seizure cannot control his or her actions and is therefore not capable of carrying out a planned attack on someone while it is going on. If a person having a seizure is grabbed or held down during an episode of automatic behavior, the person might lash out instinctively at whoever is restraining him or her.

### **Q. Are seizures with fever related to epilepsy?**

In most cases, infants and children who have fever-triggered (febrile) seizures do not go on to develop epilepsy. Although you can't always prevent seizures with fever in very young children, there may be some things that will help and that you should ask your doctor about. Parents should get medical attention immediately if a baby has a convulsion.

## FIRST AID

### **Q. What should you do if someone has a generalized tonic clonic (grand mal) seizure?**

[link to Seizure First Aid]

### **Q. What should you do if someone has one of the other types of seizures?**

You don't have to do anything if a person has brief periods of staring or shaking of the limbs. If someone has the kind of seizure that produces a dazed state and automatic behavior, the best thing to do is:

- Watch the person carefully and explain to others what is happening. Often people who don't recognize this kind of behavior as a seizure think that the dazed person is drunk or on drugs.
- Speak quietly and calmly in a friendly way.
- Guide the person gently away from any danger, such as a steep flight of steps, a busy highway, or a hot stove. Do not grab hold, however, unless some immediate danger threatens. People having this kind of seizure are an "automatic pilot" so far as their movements are concerned. Instinct may make them struggle or lash out at the person who is trying to hold them.
- Stay with the person until full consciousness returns, and offer help in returning home.

### **Q. Should an ambulance be called?**

If you know someone has epilepsy, it is usually not necessary to call an ambulance unless the seizure lasts longer than five minutes, or another seizure begins soon after the first, or the person cannot be awakened after the jerking movements have stopped. If someone having a convulsive seizure seems ill, injured, is pregnant or has diabetes or the seizure happened in water an ambulance should be called.

## TREATMENT

### **Q. Where can a person get medical care for epilepsy?**

Neurologists, pediatric neurologists, pediatricians, internists and family physicians all provide treatment for epilepsy. Specialized care for people whose seizures are difficult to control is available in large medical centers, neurological clinics, at university and other hospitals, and from neurological specialists in private practice.

### **Q. What kinds of tests are used in the evaluation of a person who may have epilepsy?**

The doctor's main tool in diagnosing epilepsy is a careful medical history and as much information as he or she can get about what the seizures looked like and what happened just before they began. A second major tool is an electroencephalograph (EEG). This is a test that records brain waves picked up by tiny wires (electrodes) pasted on the scalp. The brain waves may show special patterns which help the doctor identify epilepsy. CT or MRI machines take pictures of the inside of the brain to see if there are any growths, scars, or other physical conditions that may be causing the seizures.

### **Q. Can a person whose EEG is normal still have epilepsy?**

Yes. Electrical changes may be taking place so deep in the brain that the electrodes on the scalp don't pick them up. Second, there may not have been any unusual activity while the EEG recording was being made. Twenty-four hour recordings with a home monitor may pick up signs of epilepsy that would not be found during the half-hour or so that is usually recorded as part of a

routine EEG study. Sometimes, patients are admitted to an epilepsy monitoring unit for even more prolonged recording, during which medication doses may be reduced.

**Q. How is epilepsy treated?**

Epilepsy treatment is designed to prevent seizures. It includes medication, surgery, vagus nerve stimulation or special diet. Of these treatments, regular use of seizure-preventing drugs is by far the most common, and the first to be tried. Different drugs control different types of seizures. A medication that helps one person may not be effective for someone else. Whenever possible, doctors try to control seizures with just one drug.

**Q. Do drugs cure epilepsy?**

Not in the same sense that penicillin can cure an infection. But for many people with epilepsy, the drugs will prevent seizures so long as they are taken regularly. After someone has been free of seizures for a few years, the physician may recommend a slow withdrawal from the medication to see whether he or she will remain seizure free without medication. For many people with epilepsy, however, taking antiepileptic medication will be something that has to continue over many years.

**Q. How successful is treatment?**

Of the 200,000 new cases of seizures and epilepsy that occur each year in the United States, about 2/3 will achieve seizure remission, and many of these people will be able to withdraw from medication at some point. The remaining one-third will continue to have seizures, despite treatment. Currently, more than 2.7 million Americans are living with seizures. Hopefully, research will develop new ways of controlling seizures so that all Americans with epilepsy will be able to live seizure-free.

**Q. Can a person become addicted to antiepileptic drugs?**

This is unlikely to happen. A person taking drugs for epilepsy depends on them to prevent seizures. If he or she stops taking them suddenly, a seizure or a series of seizures is the likely result. These medications are not prescribed in quantities to produce a high, and are seldom abused in the sense that more than the prescribed dose is taken.

**Q. When is epilepsy treated by surgery?**

Surgery may be considered if medication fails to control the seizures and if the seizures are caused by an abnormality in a limited part of the brain. If such an area can be found and taken out safely, the surgeon will remove it. In many cases the seizures will then stop, or be greatly reduced. Surgeons will only operate when the possible benefits outweigh the risks, other types of surgery may be considered in some cases.

**Q. What sort of diet is used to treat epilepsy?**

The diet is called a ketogenic diet. It is a strict diet, very high in fats and very low in carbohydrates, with restricted calories. It produces a chemical change in the body, called ketosis, which in some people, especially children, prevents seizures. A ketogenic diet is usually tried after medications have failed to stop the seizures. Like other treatments for epilepsy, it must be prescribed and monitored by a physician. There's no evidence that any other type of special diet is of benefit to

people with epilepsy, although some that require milder forms of carbohydrate restriction than the ketogenic diet are being studied.

**Q. What is the vagus nerve stimulation treatment?**

Vagus nerve stimulation (VNS) is a type of treatment in which short bursts of electrical energy are directed into the brain via the vagus nerve, a large nerve in the neck. The energy comes from a battery, about the size of a silver dollar, which is surgically implanted under the skin, usually on the chest. Leads are threaded under the skin and attached to the vagus nerve in the same procedure. The physician programs the device to deliver small bursts of electrical stimulation every few minutes. This is a relatively new type of treatment. It may be tried when other treatment is not effective. Just how it works to prevent seizures is still being studied.

**Q. Can extra vitamins and minerals prevent seizures?**

Lack of vitamin B and magnesium can lead to seizures in rare cases, but it is unwise to try to self-medicate with high dose vitamins without a physician's advice. However, a daily multiple vitamin with folic acid may be taken. Sometimes supplemental vitamins will be prescribed by the doctor, but these are usually used to make up for vitamins lost through the effect of the seizure drugs rather than to prevent seizures.

## DAILY LIFE

**Q. Does epilepsy affect mental ability?**

Intelligence tests of people with epilepsy generally show a normal range of intelligence. Some people with epilepsy are very intelligent, some are not, and most rank somewhere in the middle. At the same time, some children with epilepsy who are of normal intelligence do not perform in school as well as expected. There is also a higher frequency of epilepsy in people with other neurological disorders, such as some forms of developmental delay or cerebral palsy, that may have associated cognitive limitations. This may be due to a number of factors. Some brain processes may be affected by the medication. Sometimes these children may be having small seizures that interrupt attention or affect memory. On the other hand, epilepsy can be caused by many different conditions, some of which themselves may reduce mental ability or create specific learning disabilities.

**Q. What are the chances of outgrowing epilepsy?**

In some forms of childhood epilepsy, the chances are quite good. It is difficult to predict whether an individual child will be one of those in whom the condition disappears in later life. However, in the specific conditions of benign childhood epilepsy (Rolandic), the seizures almost always disappear after adolescence. Some forms of epilepsy begin in adolescence and are unlikely to be outgrown.

**Q. Does epilepsy get worse with age?**

Generally not, unless the seizures are caused by an underlying brain problem that worsens with time, such as a tumor. If anything, seizure frequency seems to decrease as a person grows older. However, new cases of epilepsy may develop in older people, often as the result of stroke.

**Q. Is epilepsy linked to mental illness?**

Epilepsy and mental illness are separate conditions, although it is possible for them to exist in the same person. Sometimes people with epilepsy who experience sensory seizures (hallucinations of sight and sound) fear that they may be mentally ill, and are relieved to learn that what is happening to them is merely the result of epileptic activity in the brain. However, the experience of having epilepsy can have a negative effect on psychological well being, and brain injuries that produce seizures may sometimes affect mood and behavior.

**Q. Can someone with epilepsy get a driver's license?**

Yes, if the seizures are under reliable control and he or she is under a physician's care. Individual states have different laws that specify the length of time a person must be seizure free before being allowed to drive.

**Q. Can people with epilepsy be employed?**

Yes. People whose seizures are completely controlled on medication can work at most jobs. Others may still have seizures, but can be valuable employees when placed in the right job or when accommodations are made. Each person's abilities and/or limitations should be considered individually.

**Q. Is it illegal for an employer to refuse to hire a qualified person just because he or she has epilepsy?**

Yes. The Americans with Disabilities Act outlaws this type of discrimination against otherwise qualified people who have disabilities that amount to a significant impairment. Also, many states have passed special laws which forbid discrimination against qualified people with disabilities. Federal regulations also forbid employers who receive federal contracts or agencies which receive federal funds to discriminate in this way.

**Q. Can people with epilepsy drink alcohol?**

Some can and some can't. Heavy use of alcohol is likely to make seizures worse and should be avoided. Moderate use depends on the reaction of the individual: There may also be a risk in the use of alcohol when anti-seizure medications are being taken. Many doctors advise their patients with epilepsy to avoid alcohol altogether.

**Q. Is a person with epilepsy eligible to serve in the armed forces?**

Young men with epilepsy have to register for the draft, but at the present time are not eligible for military duty. There are some exceptions to this general rule for those whose special skills (such as doctors and dentists) are needed by the Services. A person who has been seizure free and off medication for five years prior to enlistment may be accepted for service, however.

**Q. Can people with epilepsy take part in sports or other vigorous activities?**

In most cases, the answer is yes, although a lot depends on the degree of seizure control, the type of sport, and what the doctor recommends. Research suggests that people are likely to have fewer seizures when actively occupied.

## **Q. What about swimming?**

This is also dependent on the quality of seizure control and the doctor's recommendation. A child or adult with good, reliable control should be able to swim safely, so long as he or she does so in the company of others who are aware of the epilepsy and are sufficiently good swimmers themselves to help if a seizure should occur. A seizure-prone person should probably limit swimming only to those occasions when close supervision is available. Water sports are always a potential hazard when a person has epilepsy, but with proper attention to safety, participation is possible.

## **Q. Can people with epilepsy get insurance?**

It depends on the type of insurance and the state in which the person is living. Historically, insurance companies have been reluctant to offer life, health, or auto coverage to people with epilepsy, regarding them as a higher risk than the rest of the population. In some areas this is beginning to change, although many people still find themselves turned down, subject to exclusions for any claims relating to epilepsy, or offered coverage only at very high rates. Most states offer pool insurance for those regarded as "high risk" who have been denied by private insurance companies.

## **Q. How does the Epilepsy Foundation help people with epilepsy?**

The Epilepsy Foundation nationwide provides information, referral, public education, employment assistance, advocacy, and support group programs. The national office, located in the Washington, D.C. metropolitan area, supports medical research, works with government agencies and with Congress, speaks out on behalf of people with epilepsy, operates a National Epilepsy Library and a highly rated website ([www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)). The Foundation is a tax exempt non-profit organization.

## **Q. How can I help the Foundation make a difference for people with epilepsy?**

Get involved! For further information, contact your local affiliate – Epilepsy Foundation of Greater Los Angeles at [ENDEPILEPSY.org](http://ENDEPILEPSY.org) or 800.564.0445.