




SEIZURES

AND

EPILEPSY



**BASIC
FACTS
ABOUT
SEIZURE
DISORDER**

WHAT IS A SEIZURE?

A seizure is a temporary change in a person's movements, sensations, or consciousness caused by an abnormal electrical discharge of the nerve cells in the brain. A seizure can take many forms depending on where in the brain it starts and where it spreads. While there are many different types of seizures, not all are convulsions.

WHAT IS EPILEPSY?

Epilepsy is a disorder of the brain characterized by two or more unprovoked seizures. Epilepsy sometimes is also referred to as a seizure disorder. Although the word "epilepsy" is frightening, it shouldn't be.

SEIZURES AND EPILEPSY DON'T SOUND VERY DIFFERENT. ARE THEY?

THEY AREN'T!

Many people will have a seizure only once in their lifetime. We don't call that epilepsy. Sometimes a child has seizures only with fever, and we don't call that epilepsy.

THEN HOW MANY PEOPLE HAVE EPILEPSY?

In the United States, it is estimated that more than 1 out of 100 people or 1% have epilepsy. That is over 2.7 million Americans who have seizure disorders.

WHY ARE PEOPLE SO AFRAID OF THE WORD "EPILEPSY"?

Because there are many myths and misunderstandings about epilepsy, some people continue to fear epilepsy. Until recently there were people who thought seizures had something to do with demons or mental illness. Today we know that epilepsy is a medical problem, not a psychiatric or emotional disorder and we know that most epilepsy can be controlled with medications. Most people with epilepsy lead perfectly typical lives except during the brief time when they have a seizure.

WHAT CAUSES SEIZURES?

Many different things can cause seizures. Low blood sugar, chemical imbalances, abnormal brain development, head injury, stroke, and drug and alcohol abuse to name a few. But many times, especially in children, doctors cannot find a cause and will say the seizures are "idiopathic" (id-eo-path-ic) which means the cause cannot be found. Families told that by physicians often become very frustrated. But it's actually good news. Idiopathic seizures are far more likely to be outgrown or controlled than seizures with a known cause.

ARE YOU BORN WITH EPILEPSY?

Some people do begin having seizures at birth, but people can develop epilepsy at any time during their lives. Three-quarters of the more than 180,000 newly diagnosed cases of epilepsy begin in childhood. It becomes more common again in the elderly.

IS EPILEPSY INHERITED?

People who have a history of seizures in their family have a slightly higher chance of developing seizures, yet most do not develop epilepsy. More often, people who do develop seizures have no family history of epilepsy. If there is a strong family history, the neurologist should be notified.

CAN EPILEPSY REALLY BE TREATED AND CONTROLLED?

Yes. More than half of the people with epilepsy can have their seizures completely controlled with medication and without side effects. Another 30 percent can have their seizures partially controlled. Unfortunately, there are still some people who have poor seizure control, but medication can reduce the frequency and severity of their seizures.

WHAT ARE THE DIFFERENT TYPES OF SEIZURES?

Neurologists categorize seizures into two types:

- *focal* or *partial* seizures which start in just one area of the brain, and
- *generalized* seizures involving the whole brain.

Under these two categories are many, many types of seizures. The center table has more information.

Focal or *partial* seizures may involve just the part of the brain that causes movement such as a finger or hand to twitch, an arm or leg to shake, or may involve the whole side of the body. A partial seizure also may occur in the part of the brain that controls the senses and may cause an abnormal sensation, such as an odd taste, a smell, or sensations in the hand or in the stomach.

Simple partial seizures do not impair consciousness.

Complex partial seizures impair consciousness.

Generalized seizures seem to involve the whole brain at once. One type, called *absence* seizures, cause clouding of consciousness, often a blank stare lasting just a few seconds. The individual seems to be absent. This type used to be called *petit mal*.

Another type of generalized seizure is the *tonic-clonic* or “grand mal” seizure during which a person loses consciousness, falls to the ground and shakes all over. There is often stiffening of the body at the start (the “tonic” phase), and the person sometimes turns blue. Although during a tonic-clonic seizure, individuals may have their face and lips turn blue, this does not mean there is a lack of oxygen to the brain. Seizures probably do not damage the brain unless they go on for hours. The person may also lose bladder or bowel control. This type of seizure is also known as a convulsion. After the stiffening, there is usually jerking of the arms and legs (the “clonic” phase).

WHAT SHOULD I DO IF I SEE SOMEONE HAVING A TONIC-CLONIC SEIZURE?

The most upsetting thing about seeing someone have a generalized tonic-clonic (grand mal) seizure is that there is very little that you can or need to do. The most important thing to do is to stay calm and help those around to be calm also. Remember, the person having the seizure is unconscious. He or she will not remember the seizure, is not suffering, and will begin to breathe on his or her own.

Remember:

- Loosen a tie, collar, or tight clothing around the neck.
- Place something soft, like a folded jacket, under the head so that it doesn't bang on a hard surface.
- When you are able, turn the person on his/her side to allow saliva to drain and to ease breathing.
- After the seizure, let the person rest, if necessary.
- *Never* restrain the person's movement.
- *Never* force anything into the mouth.

Once it was thought that the person was going to swallow his or her tongue and choke. Bystanders would try to place something in the mouth to hold down the tongue. Now we know that:

- the tongue cannot be swallowed, and
- the person will start breathing on his/her own; they do *not* need mouth-to-mouth resuscitation.

Most seizures end on their own in a few minutes. The jerking of the arms and legs becomes slower and finally stops at the end of the seizure. Usually the person lets out a loud sigh and becomes limp and goes to sleep. The seizure is over and this is the “post-ictal” (after seizure) recovery period. In a few minutes the person can be aroused, although they are often sleepy and confused.

You *do not* need to call an ambulance unless:

- this is the first known seizure
- the seizure is followed by other seizures, (status epilepticus - a very serious situation)
- the seizure lasts more than five minutes
- the person sustains an injury that might require medical attention, or
- the person is pregnant or has diabetes.

You can look for a medical alert bracelet or necklace which most people with epilepsy should wear.

WHAT ABOUT THE OTHER KINDS OF SEIZURES? WHAT DO I DO FOR THEM?

Little or no first aid will be required for most seizures. During *simple partial* seizures which affect movement or senses, the person does not lose consciousness and is aware of the seizure. There is nothing you need to do.

During *complex partial* seizures, the individual is not only confused, but may make automatic movements such as smacking lips, picking at clothes, or wandering around. The person is not aware of what he or she is doing. If you try to restrain the person, he or she may struggle or fight back (out of misunderstanding and confusion). The best thing to do is to stay close and make sure the person does not injure him or herself. These seizures rarely last more than a minute or two, and there may be brief confusion afterward.

During *absence* seizures which are generalized throughout the brain, the person does lose awareness. Often they just stop and stare for a few seconds. During this type of seizure, there is nothing you need to do except protect the person from harm.

WHAT ARE “FEVER SEIZURES?” ARE THEY THE SAME THING AS EPILEPSY?”

“Fever” or *febrile* seizures are seizures that occur with a high fever. They occur in three to four percent of all children, and are usually outgrown by the age of five years. Most children have only one, occasionally a few. Very few children with febrile seizures have epilepsy later in life, and most do not require treatment with antiepileptic medications. Obtaining tests is generally not necessary.

DOES A PERSON KNOW THEY ARE GOING TO HAVE A SEIZURE?

Some people have what is called an *aura*. They may feel, smell, or see something that appears unusual. This is the beginning of seizure activity in the brain. Most people, however, do not get auras and have no warning that a seizure is about to occur.

WHAT ARE THE MEDICATIONS USED TO TREAT EPILEPSY?

There are many “antiepileptic” also known as “anti-convulsant” medicines used to treat seizures. These medications usually have two different names - a brand name given by the manufacturer and a generic name.

| Brand Name | Generic Name |
|-------------|---------------------|
| Ativan | lorazepam |
| Carbatrol | carbamazepine |
| Depakene | valproic acid |
| Depakote | divalproex sodium |
| Depakote ER | divalproex sodium |
| Diamox | acetazolamide |
| Diastat | diazepam rectal gel |
| Dilantin | phenytoin |
| Felbatol | felbamate |
| Gabitril | tiagabine |
| Keppra | levetiracetam |
| Klonopin | clonazepam |
| Lamictal | lamotrigine |
| Luminal | phenobarbital |
| Lyrica | pregabalin |
| Mysoline | primidone |
| Neurontin | gabapentin |
| Phenytek | phenytoin |
| Tegretol | carbamazepine |
| Tegretol-XR | carbamazepine |
| Topamax | topiramate |
| Tranxene | clorazepate |
| Trileptal | oxcarbazepine |
| Zonegran | zonisamide |

SEIZURE IDENTIFICATION CHART

| Type | What seizures look like | Do | Don't |
|------|-------------------------|----|-------|
|------|-------------------------|----|-------|

Generalized Tonic Clonic (Grand Mal)

- Aura - (warming, start of seizure)
- Fall to ground
- Tonic phase - stiffening
- Clonic phase - jerking
- May have shallow breathing and skin may be slightly blue
- Lasts 1 to 2 minutes
- Recovery - tired, confused, may need to rest
- Stay calm
- Protect head from injury
- Place person on side (to keep airway clear)
- Look for medical identification
- Note the time
- Loosen collar
- Clear the area
- Stay with person until seizure is over and reassure them
- Do not put anything in mouth
- Do not call ambulance unless more than 5 minutes have elapsed or the person has injured him/herself, is pregnant, has diabetes or has a series of seizures.
- Do not perform artificial respiration

Absence (Petit Mal)

- Looks like blank stare/daydreaming
- Brief (few seconds), blinking, chewing
- Person Unaware
- No first aid needed
- Family/person should be made aware that seizure took place

Complex Partial (Psychomotor, Temporal Lobe)

- Blank stare, disoriented, chewing movements, confusion, may wander, pick at clothes, not respond
- Lasts several seconds to a few minutes, no memory of event
- Seizure may be confused with drugs or drunkenness, mental illness, disorderly conduct
- Speak calmly, reorient person
- Reassure person who has had seizure
- Guide away from dangerous objects
- Stay with person until consciousness returns
- Do not restrain

Other Seizure Types

Simple Partial

Atonic

Myoclonic

Infantile Spasms

- Local jerks, a local sensation
- Drop attacks
- Sudden jerks
- Cluster of quick jerks
- No first aid needed
- Family/person should be made aware that seizure took place
- Notify physician
- Make sure they are safe

Some of the commonly used antiepileptic drugs are listed in the insert section of this brochure, including some of the most recent ones. There are many other excellent drugs that are used less commonly. Remember, all antiepileptic medications are effective, or they would not be licensed, but some are more effective than others for controlling certain types of seizures. Some anticonvulsants are also used for pain, migraine, and mood disorders.

Choosing the correct medication for a person's seizures is done on an individual basis. The physician and the person with seizures try to find the correct amount of medicine that controls the seizures while trying to minimize the side effects. Doctors will monitor the levels of the medicine in the blood to make sure there is enough medicine to control the seizures and not too much so that the person may become toxic and have severe side effects.

WHAT ARE THE SIDE EFFECTS?

Side effects are the unwanted or unintended effects of a medicine. Sleepiness, unsteadiness, changes in behavior, poor performance at work or in school are all possible side effects of these antiepileptic medications. Often they occur for the first few weeks, then improve. These are what physicians call "dose-related side effects" because they can usually be controlled by reducing the dose.

Rashes, hives, bruising, yellowing of the skin, are not common and should be promptly reported to and discussed with the doctor. These side effects can be serious. All patients on medication should take a multivitamin and calcium every day.

Whenever someone takes medicine, he/she must be aware that there are risks. People should evaluate the risks of taking the medicine against the benefits of controlling the condition and make their decisions with the advice of their doctors. Every patient is different.

AREN'T THERE ANY SAFE MEDICINES?

All of these medicines are safe, but some are safer than others. All medications have side effects, but some have more severe effects than others. The person who has the seizures (or the parent when a child is involved) and the physician should discuss the risks and the benefits of treatment, as well as the side effects of the medicine they are considering using. Treatment of seizures will work best when the patient and the physician are working together to solve potential problems.

CAN SURGERY STOP SEIZURES?

Sometimes. If the seizures are focal and start from just one part of the brain, and if that part of the brain can be safely removed, then surgery can often eliminate seizures. With new techniques such as video-monitoring and special ways of mapping both the brain and the origin of the seizures, doctors can safely operate on many more people.

It is always worth asking the physician. Most people with seizures do not need surgery since their seizures are controlled with medicine.

In 1997, a new device called a *vagus nerve stimulator* was federally approved for use in patients with partial seizures. This silver-dollar sized device is surgically implanted near the left collarbone and gives off periodic electrical impulses through a wire wrapped around the vagus nerve in the neck. It has been shown to decrease seizure frequency in some patients, with fewer side effects than medication. People with epilepsy may want to discuss the new device further with their physicians.

IS THERE ANYTHING WHICH CAN BE DONE TO PREVENT SEIZURES?

Yes. Anything which prevents head injuries will also prevent seizures. Wearing seat belts and wearing helmets when riding bikes or motorcycles all help to prevent epilepsy.

In general, people with epilepsy, like people without epilepsy, do best when leading a life without too much excess of anything. A healthy and routine life-style, with a reasonable amount of rest, seems to decrease seizures. For some, stress, excitement, lack of sleep, or alcohol and drug use may trigger seizures.

WHAT ABOUT DIET? CAN WHAT A PERSON EATS CAUSE SEIZURES?

No. Not unless a person is on a fad diet. There are occasional chemical problems such as blood sugar or calcium problems which may cause seizures and even rarer chemical problems where a person needs extra vitamins. If there is any doubt, consult a physician.

There is a special diet called the ketogenic diet which is used to treat difficult seizures in children. The diet is very high in fat and low in carbohydrates and produces a condition called ketosis. This diet must be prescribed and closely monitored by a doctor and nutritionist working together. While not easy to follow, nor free of side effects, this diet can be very helpful. The Atkins diet can also help, but needs to be followed with supervision.

CAN A WOMAN WITH EPILEPSY GET PREGNANT?

Yes. A woman with epilepsy can get pregnant like any other woman. Some birth control pills may be slightly less effective in the woman who is taking antiepileptic medication. She should discuss this with her physician.

Most women with epilepsy who are taking antiepileptic medications will have perfectly normal children. There is a somewhat increased risk of birth defects in children born to women with epilepsy due to antiepileptic medication. A woman should discuss the risks to the fetus and benefits for herself with her physician before getting pregnant. All women of child-bearing age should take folic acid daily.

CAN PEOPLE WITH EPILEPSY DRIVE, SWIM, ETC.? WHAT CAN'T THEY DO?

The laws regarding driving vary from state to state, but when a person's seizures are controlled for the required period of time, they can drive.

No one should swim alone, but for the person with infrequent seizures, the risk of a seizure while swimming is very low. If they are swimming with the appropriate supervision or with a friend, then swimming can be even safer. Showers are probably safer than baths.

People with epilepsy *can* work, *can* live in the community and *can* have families and friends just like anyone else. Depending on the nature of the seizures, life need not be restricted. Common sense and precautions should always be taken, however.

IS IT COMMON TO OVERPROTECT PEOPLE WITH EPILEPSY?

Parents and families often become overprotective because of the uncertainties connected with epilepsy. Overprotection itself may become a greater problem than the person's seizures. It is important for everyone dealing with children and adults with epilepsy to be certain that the protection is in proportion to the severity of epilepsy. For the majority of individuals whose seizures are controlled or who have only occasional seizures, the risks are not much greater than the risks we all take every day.

IS THERE ANYTHING ELSE TO KNOW ABOUT EPILEPSY?

These are the basic questions people ask about epilepsy. There are many other questions that could be asked. If you have more questions, call the Epilepsy Foundation of the Chesapeake Region at 410-828-7700 or 800-492-2523, or call the Epilepsy Foundation's National Office at 800-EFA-1000 where further information can be obtained.

Remember, a good, caring physician should either be willing to answer a person's questions or be able to refer them to a place where they can get answers. The Epilepsy Foundation of the Chesapeake Region is usually a good place to start.

This booklet provides general information. It does not give medical advice. Decisions about seizures, treatment, and risks should only be made together with a neurologist.

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WHAT IS THE EPILEPSY FOUNDATION OF THE CHESAPEAKE REGION?

The Epilepsy Foundation of the Chesapeake Region is a private, non-profit organization that has been serving the over 50,000 Marylanders with epilepsy for over 40 years. Additionally, EFCR provides services for persons with other disabilities. Services offered include counseling, information and referral, advocacy, employment assistance, housing and community living assistance, family and children's services, public, professional, and school education, and consultative services.

I WOULD LIKE TO KNOW MORE ABOUT.

- Epilepsy
- EFCR's programs and services
- Volunteer opportunities at EFCR

I WOULD LIKE TO HELP...

With EFCR's efforts on behalf of the over 50,000 Marylanders with epilepsy. Here is a donation for:

- \$10 \$25 \$50 \$100 Other

I WOULD LIKE TO BECOME A MEMBER OF ERCR.

Membership includes:

- Subscription to "Epilepsy Monitor," EFCR's newsletter.
- Membership in the Epilepsy Foundation of America.
- Subscription to "Epilepsy USA," EFA's newsletter.
- Access to mail order drug discount program offered through EFA.
- Invitation to annual membership meeting and voting privileges

Annual dues are \$25. Enclosed is \$ _____ for _____ tax-deductible memberships.

Name: _____

Address: _____

City: _____

State: _____ Zip: _____

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