

The following facts must be made available to audience members
during each performance of
The World of Epilepsy: A Caregivers Perspective

Epilepsy Statistics
Center for Disease Control and Prevention
FAQ's*

<http://www.cdc.gov/epilepsy/basics/faq.htm>

Epilepsy Basics

What is epilepsy? What is a seizure?

- **Epilepsy**, which is sometimes called a *seizure disorder*, is a disorder of the brain. A person is diagnosed with epilepsy when they have had two or more seizures.
- A **seizure** is a short change in normal brain activity.
- Seizures are the main sign of epilepsy. Some seizures can look like staring spells. Other seizures cause a person to fall, shake, and lose awareness of what's going on around them.

How long do seizures usually last?

Usually, a seizure lasts from a few seconds to a few minutes. It depends on the type of seizure.

What are the major types of seizures?

Sometimes it is hard to tell when a person is having a seizure. A person having a seizure may seem confused or look like they are staring at something that isn't there. Other seizures can cause a person to fall, shake, and become unaware of what's going on around them. Seizures are classified into two main groups:

- **Generalized seizures** affect both sides of the brain.
- **Focal seizures** affect just one area of the brain. These seizures are also called partial seizures.

However, a person with epilepsy can have more than one kind of seizure.

If I have a seizure, does that mean I have epilepsy?

Not always. Seizures can also happen because of other medical problems. These problems may include:

- High fever.
- Low blood sugar.
- Alcohol or drug withdrawal.

What causes epilepsy?

Epilepsy can be caused by different conditions that affect a person's brain. Some known causes include:

- Stroke.
- Brain tumor.
- Brain infection, like Neurocysticercosis.
- Traumatic brain injury or head injury.

- Loss of oxygen to the brain (for example, during birth).
- Some genetic disorders (such as Down syndrome).
- Other neurologic diseases (such as Alzheimer's Disease).
- For 2 in 3 people, the cause of epilepsy is unknown. This type of epilepsy is called *cryptogenic* or *idiopathic*.

Is epilepsy common?

Epilepsy is one of the most common conditions affecting the brain. When counting both children and adults in the United States:

- About 5.1 million people in the United States have a history of epilepsy.
- About 2.9 million people in the United States have active epilepsy.

How can I prevent epilepsy?

The following are some of the most common ways to reduce your risk of developing epilepsy:

- Have a healthy pregnancy. Some problems during pregnancy and childbirth may lead to epilepsy. Follow a prenatal care plan with your healthcare provider to keep you and your baby healthy.
- Prevent brain injuries.
- Lower the chances of stroke and heart disease.
- Be up-to-date on your vaccinations.
- Wash your hands and prepare food safely to prevent infections such as Cysticercosis.

How is epilepsy diagnosed?

A person who has a seizure for the first time should talk to a healthcare provider, such as a doctor or nurse practitioner. The provider will talk to the person about what happened, and look for the cause of the seizure. Many people who have seizures take tests, such as brain scans for a closer look at what is going on.

How is epilepsy treated?

There are many things a provider and person with epilepsy can do to stop or lessen seizures. The most common treatments for epilepsy include:

- **Medicine.** Anti-seizure drugs are medicines that limit the spread of seizures in the brain. A healthcare provider will change the amount of the medicine or prescribe a new drug if needed to find the best treatment plan. Medicines work for about 2 in 3 people with epilepsy.
- **Surgery.** When seizures come from a single area of the brain (focal seizures), surgery to remove that area may stop future seizures or make them easier to control with medicine. Epilepsy surgery is mostly used when the seizure focus is located in the temporal lobe of the brain.
- **Other treatments.** When medicines do not work and surgery is not possible, other treatments can help. These include Vagus Nerve Stimulation, where an electrical device is placed, or implanted, under the skin on the upper chest to send signals to a large nerve in the neck. Another option is the Ketogenic Diet, a high fat, low carbohydrate diet with limited calories.

Who treats epilepsy?

Many kinds of health providers treat people with epilepsy. Primary care providers, such as family physicians, pediatricians, and nurse practitioners, are often the first people to see a person with epilepsy who has new seizures. These providers may make the diagnosis of epilepsy or they may talk with a neurologist or Epileptologist.

A neurologist is a doctor who specializes in the brain and nervous system. An Epileptologist is a neurologist who specializes in epilepsy. When problems occur, such as seizures or medication side effects, the primary health provider may send the patient to a neurologist or Epileptologist for specialized care.

People who have seizures that are difficult to control or who need advanced care for epilepsy may be referred to an epilepsy centers. Epilepsy centers are staffed by providers who specialize in epilepsy care, such as:

- Epileptologists and neurologists.
- Nurses.
- Psychologists.
- Technicians.
- Many epilepsy centers also work with university hospitals and researchers.

How do I find an epilepsy specialist?

There are several ways you can find a neurologist or an Epileptologist near you. Your primary care or family provider can tell you about types of specialists. The **American Academy of Neurology** and the **American Epilepsy Society** provide a listing of its member neurologists and epilepsy specialists, including Epileptologists. The **National Association of Epilepsy Centers** also provides a list of its member centers, organized by state.

What can I do to manage my epilepsy?

Self-management is what you do to take care of yourself. You can learn how to manage seizures and keep an active and full life. Begin with these tips:

- Take your medicine.
- Talk with your doctor or nurse when you have questions.
- Recognize seizure triggers (such as flashing or bright lights).
- Keep a record of your seizures.
- Get enough sleep.
- Lower stress.
- **WebEase** (Web Epilepsy, Awareness, Support and Education) is a free online self-management program for adults with epilepsy. WebEase helps you set goals and learn skills to better manage your epilepsy. <http://www.webease.org/overview.aspx>

Health and Safety Concerns

Are there special concerns for women who have epilepsy?

Women who have epilepsy face special challenges. Hormonal changes can cause some women with epilepsy to have more seizures during their period.

For women with epilepsy, there are also special concerns about pregnancy, because having a seizure and taking certain drugs during pregnancy may increase the risk of harm to the baby.

If you are a woman with epilepsy who plans to get pregnant, talk with your health team about how to best care for yourself and your baby.

Can a person die from epilepsy?

Most people with epilepsy live a full life. However, the risk of early death is higher for some. We know that the best possible seizure control and living safely can reduce the risk of epilepsy-related death.

Factors that increase the risk of early death include:

- More serious health problems, such as a stroke or a tumor. These conditions carry an increased risk of death and may cause seizures.
- Falls or other injuries that happen because of seizures. These injuries can be life-threatening.
- Seizures that last over 5 minutes. This is a condition called *status epilepticus*. *Status epilepticus* can sometimes happen when a person suddenly stops taking seizure medication.
- Rarely, people with epilepsy can experience Sudden Unexpected Death in Epilepsy (SUDEP). SUDEP is not well understood and experts don't know what causes it, but they suspect that it is sometimes due to a change in heart beats (rhythm) during a seizure. Sudden death due to heart rhythm changes also happens in people who do not have seizures.
- The risk of sudden death is larger for people with major uncontrolled seizures.

If I have epilepsy, can I still drive a car?

Most states and the District of Columbia will not issue a driver's license to someone with epilepsy unless that person provides documentation that he or she has not had a seizure for a specific amount of time. The seizure-free period ranges from a few months to over a year, depending on the state.

Some states need a letter from your health provider to issue a license, showing that your seizures:

- Don't distract you from driving.
- Happen only during sleep. These are called nocturnal seizures.
- Have warning signs that alerts you when a seizure might occur. Sometimes a person feels strange before a seizure. This is called an aura.

If I have epilepsy, can I exercise and play sports?

Sometimes people with epilepsy worry that exercise or sports may worsen their seizures. Exercise is rarely a "trigger" for seizure activity. In fact, regular exercise may improve seizure control. Safely playing sports can also be great for your physical, mental, and emotional well-being. It is always important to avoid sports-related injuries that can increase the risk of seizures.

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