Epilepsy: Knowing Your Risks

A publication for individuals and families facing the challenges of seizures

A Diagnosis of Epilepsy—A Basic Overview

You may have heard epilepsy called different things. Because the word “epilepsy” can be a scary thing to hear, some doctors may refer to a “seizure disorder” or—quite often—just “seizures”. If a person has two or more unprovoked seizures, however, they are typically diagnosed with epilepsy. And yes, it can be overwhelming. But armed with the right information, you can make choices that maximize your safety and quality of life—and leave you feeling educated and empowered. A diagnosis of epilepsy is a life-changing experience, both for the person receiving the diagnosis and for their loved ones.

Questions abound: What does this mean? Will our lives—and our loved one’s life—ever be the same again? The answer is that most people living with epilepsy do go about their daily routines just like those who are not affected by epilepsy. They go to school, they play sports, they have jobs, they participate in activities that make life enjoyable. However, they also live with the knowledge that at any moment they could have a seizure, and that the quality of their lives may be affected by the frequency and severity of their seizures, as well as by the effects of their medications.

What is Epilepsy?

Epilepsy is a disorder of the nervous system characterized by recurring seizures that result in sudden, brief changes in the way the brain works. Seizures are a symptom of epilepsy. Epilepsy is not a mental illness, and it is not contagious. But it is far more common than you might think.

Nearly 3.5 million people in the United States have epilepsy, an amount equal to the number of people with cerebral palsy, multiple sclerosis, and Parkinson’s disease combined. Approximately 1 in 26 people will develop epilepsy at some point in their lives.

Maximizing Safety

Within epilepsy, there is a wide range of syndromes and disorders that affect people in various ways. For about one-third of people with epilepsy, their seizures are not controlled by medication. Epilepsy is characterized by seizures that can differ in type, cause, frequency and severity. In most case seizures are unpredictable, but for some, they occur in regular patterns or certain settings. Safety is of the utmost importance for all people with epilepsy. Whether around the house, at school, at work, out with friends, or even asleep in bed, keeping safe by planning ahead can make a huge difference. In this publication, we offer information that can help to keep you or your loved one as safe as possible while coping with seizures.
An important component of safety in epilepsy is the knowledge seizures can sometimes be fatal. More people die as a result of seizures than from any infant death syndrome (SIDS) and house fires combined. One way a person can die due to a seizure is Sudden Unexpected Death in Epilepsy, or SUDEP. It is one of the least talked about risks within epilepsy, but because of its tragic consequences, it is an aspect of epilepsy that people have many questions about. Remember, good seizure control and the use of safety measures can reduce the risk of seizure-related death.

**What is SUDEP?**

**A:** A death is referred to as SUDEP when a seemingly healthy person with epilepsy dies unexpectedly and no clear reason for the death can be determined. In most cases, an autopsy is required to rule out other causes of death. The most common criteria used to determine whether a death is due to SUDEP are:

- The person has epilepsy, which is defined as recurrent unprovoked seizures.
- The person died unexpectedly while in a reasonable state of health.
- The death occurred suddenly and during normal activity (often during sleep).
- An obvious medical cause of death could not be determined at autopsy.

The death was not the direct result of status epilepticus.

**What can I do to reduce the risk of SUDEP?**

**A:** The full understanding of SUDEP is still unfolding, but there are measures people with epilepsy and their families can take to minimize their risk:

- Become aware of the public and community facilities that provide assistance.
- Be aware of the local emergency response.
- Learn the features of your local health system.
- Be aware of your local community resources.
- Be aware of your local hospital system.
- Be aware of your local medical community.
- Be aware of your local medical facilities.
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**What should I know about seizure detection devices and resources?**

**A:** A variety of options exist, from implanted technologies to worn devices to non-invasive systems, that can help in alerting to certain types of seizures and enabling early intervention. Some of them are listed at our website: [DannyDid.org](http://DannyDid.org).

**Leaves bathroom doors unlocked for easy access in the event of a seizure.**

- A softer surface is safer in the event of a fall—put padding and carpeting on the floor where possible.

**Consider showers instead of baths to reduce the risk of drowning in the event of a seizure.**

- Consider limiting the water temperature to prevent burns.

**Use paper or plastic plates and cups in place of glass to decrease the possibilities of cuts or other injuries during a seizure.**

**When bike riding, keep to side roads to reduce the risk of traffic incidents, and always wear a helmet.**

**When waiting for buses or trains, stand back from the road, tracks, or train platform, in order to reduce the chance of injury in the event of a fall.**

- Make sure that exercise is accompanied by lots of breaks, hydration and chances to stay cool.

**When swimming, wear a life jacket and use the "no fade" zone.**

**Consider taking showers instead of baths to reduce the risk of injury in the event of a fall.**

**To reduce stress and seizure activity; communicate with your doctor to minimize your risks.**

**Patients should visit with their doctor regularly, especially if convulsive seizures are not completely controlled.**

**Consider the use of alternative therapies such as dietary options, research trials, surgical options, dietary options, or devices/technologies that detect certain seizures and alert caretakers, to enable early intervention.**

**Consider supervision or monitoring during sleep hours to identify seizure activity; inquire about and advocate for research that enables a better understanding of the causes of SUDEP.**

**FOLLOW THESE SIMPLE TIPS TO HELP KEEP ‘SEIZURE SAFE’**

The issue of safety should be discussed with your doctor—not only after the initial diagnosis, but regularly and ongoing. Here is a selection of tips for maximizing safety.

**AROUND THE HOUSE**

- Ensure that all medications are taken on time, as prescribed.

- Learn to recognize pre-seizure warning signs.

- Lead a healthy lifestyle and avoid conditions and activities that can trigger seizures, like alcohol and recreational drugs.

- Investigate seizure alarm devices and technologies that can help notify others of seizure activity.

**SAFETY TIPS REGARDING CHILDREN WITH EPILEPSY**

- Put padding around tables and other furniture with sharp edges.

- If your child has ‘drop’ seizures, a helmet and face guard may be needed.

- When friends, family, or others watch your child, share this brochure or post a list of first aid tips enabling early intervention. Some of them are listed at our website: [DannyDid.org](http://DannyDid.org).