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, that’s epilepsy. And yes, it can be scary. But armed with the right information, you can make choices that maximize your safety and quality of life—and leave you feeling empowered and as prepared as you can be.

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, play sports, have jobs, and participate in activities that make life enjoyable. However, they also live with the knowledge that a seizure could strike at any moment, and that their quality of life may be affected by their seizure frequency and severity, as well as by medication side effects.

WHAT IS EPILEPSY?
Epilepsy is a brain disorder 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 may think. Nearly three million people in the United States have epilepsy, more than those with cerebral palsy, multiple sclerosis, and Parkinson’s disease combined. Approximately 1 in 26 people will develop epilepsy at some point in their lives. Chances are, we all know someone with epilepsy.

SAFETY IS KEY
Epilepsy is a complex spectrum of disorders that affects 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 differ in type, cause, and severity. In most cases seizures are unpredictable, but for some they often occur in regular patterns or certain settings. Safety is 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 thinking and planning ahead can make a huge difference. In this publication, we offer some steps and information that can help to keep you or your loved one with epilepsy safe and leading a healthy and active life.
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 fires and sudden infant death syndrome (SIDS) combined. One way a person can die due to a seizure is Sudden Unexpected Death in Epilepsy, or SUDEP. SUDEP is one of the least talked about aspects of epilepsy, yet because of its tragic consequences, it is the one aspect of epilepsy about which people have the most questions. Remember, good seizure control and the use of safety measures can reduce the risk of seizure-related death.

Q: Can people die from epilepsy?
A: Yes. Most people with epilepsy live a full life span. However, there are potential risk factors associated with living with epilepsy and seizures that may increase the risk of early death:

- Accidents such as drowning, burning, choking, or falling can occur during a seizure, and may result in injuries that are serious or life threatening.
- Very long seizures, or seizures that happen quickly and one after another, status epilepticus, can be life-threatening. Ask your doctor about the scenarios under which status epilepticus could occur.
- People with epilepsy are more prone to experience depression and anxiety. In extreme cases, this can increase the risk for suicide.
- Some people with epilepsy may die suddenly and without explanation. This is called SUDEP.

Q: What causes SUDEP?
A: The incidence of SUDEP occurs greatly depending upon the population studied. One challenge in pinpointing the numbers behind SUDEP is that information from frequency and state mortality registries is sometimes incomplete. Some coroners, medical examiners and other physicians are unfamiliar with SUDEP, and so would not list SUDEP on a death certificate. Persons with absence or myoclonic seizures are not known to have increased risk for SUDEP, whereas the risk of sudden death seems to be higher among people with convulsive seizures. Talk with your doctor, neurologist or epileptologist to access the risks factors of SUDEP as they relate to you or your loved one.

Q: What are the risk factors for SUDEP?
A: SUDEP can happen to anyone with epilepsy. Some people are at higher risk than others, and you should discuss your individual risks with your doctor. Risk factors that are most consistently associated with SUDEP are:

- Seizures that can’t be controlled
- Not taking anticonvulsant medicine as prescribed
- A higher number of anticonvulsant medications, at high doses
- Seizures that happen during sleep
- Seizures that can be controlled
- Not taking anticonvulsant medicine as prescribed
- A higher number of anticonvulsant medications, at high doses
- Seizures occurring during sleep
- Seizures occurring during sleep
- Seizures occurring during sleep

Q: How can I do to reduce the risk of SUDEP?
A: SUDEP can happen to anyone with epilepsy. Some people are at higher risk than others, and you should discuss your individual risks with your doctor. Risk factors that are most consistently associated with SUDEP are:

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Q: What should I know about seizure detection devices and resources?
A: A range of options exist, from implanted technologies to worn devices to non-invasive devices, that can be helpful in alerting to certain types of seizures and enabling early intervention. Some undergo clinical trials to provide data on their ability to detect certain seizure types. Some of these resources are listed at our website: www.dannydid.org. Danny Did does not endorse any one device over others. We simply encourage you to investigate which option could be a fit for you and your loved one. Please note that what data is currently being proven to predict or prevent SUDEP. That remains unknown. If you find a device that seems like a fit for your needs, ask the manufacturer if they can provide data that supports its usefulness, and consult your doctor for their feedback.

Q: How do I talk with my doctor about SUDEP?
A: As if your doctor has not spoken with you about the health risks associated with epilepsy, including SUDEP, schedule an appointment to meet with them. We suggest some questions to ask on the back page, designed with the goal to enhance communication and empowerment and to minimize the epilepsy-related risks for your loved one. Remember, no one can or will advocate for your loved one better than you.

More research and studies are needed to answer the many questions that remain about SUDEP. The topics listed above address some of the basic and frequently asked questions. For information related to your individual situation, consult with your doctor. Information from a medical professional that knows your background medical health is the best source.