

## SEIZURE FIRST AID

### HOW CAN I HELP SOMEONE EXPERIENCING A SEIZURE?

- Note the time that the seizure begins. The duration of the seizure matters to first responders and doctors.
- Roll the person on their side to keep their airway clear and to prevent choking.
- Cushion the person's head.
- Loosen any tight neckwear, such as a tie or scarf.
- Protect the person by clearing the space around them, or by gently holding the person to prevent them from coming into contact with any objects.

- If the person is a relative or close friend and you feel they are protected, consider capturing a video of the seizure to share with their neurologist, maintaining utmost privacy.
- Know the response plan for family and friends. This may include rescue medications for seizures that last longer than a specified duration.
- Stay calm. The person seizing needs your help.
- Stay with the person until they are fully reoriented.

### STEPS TO AVOID:

- DO NOT attempt to force open the mouth of the person seizing, or try put anything inside their mouth.

- DO NOT give oral medications during the seizure, unless instructed by a doctor.
- DO NOT restrain the person or attempt to rouse the person by shouting or shaking them.
- DO NOT administer food or drink until the person is completely conscious.

### CALL FOR MEDICAL HELP IF:

- A seizure lasts for more than five minutes.
- The person does not resume breathing after the seizure (regardless of how long the seizure lasted).
- The person has one seizure after another.
- The person is injured, pregnant or diabetic.

## WHICH DOCTORS TREAT EPILEPSY?

Neurologists, general practitioners, pediatricians and pediatric neurologists are among the medical professionals that treat epilepsy. An epileptologist is a neurologist who specializes in the treatment of epilepsy. Whether you're going in for your first appointment or you have already been to several, it is beneficial to prepare in advance to help make the best use of the visit.

### AT THE DOCTOR'S OFFICE: QUESTIONS TO ASK

- What is the exact diagnosis?
- What is likely causing the seizures?
- What are the treatment options and what are some alternative approaches?
- What side effects can be expected with treatment, and how can they be managed?
- What kinds of tests do we need and would more frequent testing help?
- Should we see an epileptologist?
- Ask about nocturnal seizures.
- What types of devices exist that can alert a caregiver when seizure activity occurs?
- Ask about MRI tests, both with and without contrast

- What should prompt a call between visits?
- Ask the doctor to discuss the risks presented by epilepsy, including SUDEP.
- Seek another doctor referral if you want a second opinion.

## ABOUT DANNY DID: WE CAN HELP

Founded by Chicagoans Mike and Mariann Stanton in 2010 after the sudden death of their four-year-old son Danny, the Danny Did Foundation's primary mission is to prevent deaths caused by seizures. The Foundation is dedicated to advancing public awareness of epilepsy and Sudden Unexpected Death in Epilepsy (SUDEP), enhancing the SUDEP communication model between medical professionals and families impacted by seizures, and gaining mainstream acceptance and use of seizure detection and prediction devices that may assist in preventing seizure-related deaths. Epilepsy affects nearly 3.5 million people in the United States and 65 million people worldwide. One in 26 Americans will develop epilepsy during their lifetime.

The name of the Danny Did Foundation originates from the last line of Danny Stanton's obituary, written by his dad: **"Please go and enjoy your life. Danny did."**

If we can help, please be in touch.



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Danny Did is a non-profit corporation organized in Illinois and recognized by the IRS as a 501c(3) tax-exempt organization.

All content contained in this publication is for informational purposes only. Do not make changes in your or your child's medication, lifestyle, or seizure management process without consulting your physician.

# EPILEPSY: KNOWING YOUR RISKS

*A publication for individuals and families facing the challenges of seizures*



Protecting Kids With Epilepsy

Epilepsy is a complicated disorder that exists along a wide spectrum of severity—what may be applicable to one situation may be inappropriate for another. For that reason, we encourage you to communicate openly and regularly with your doctor. The most important thing, however, is not to give up. It's easy to feel overwhelmed, but you are not alone. The Danny Did Foundation provides this informational piece to empower you, and maximize your family's safety.

## 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 may 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 a 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.



200,000 people are diagnosed with epilepsy annually



## 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

- Leave 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.

### OUTSIDE THE HOUSE

- 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 'buddy system.'
- Adhere to your driving restrictions, and if you're unable to drive due to seizures, investigate public transportation options.

### OTHER PRECAUTIONS

- Make sure everyone in the family knows how to respond to a seizure (see back page).
- Wear a medical ID bracelet or necklace that indicates you have epilepsy.
- Ensure that you get enough sleep and rest, and takes measures to reduce your stress.
- Make sure 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 help prevent injuries.
- When friends, family, or others watch your child, share this brochure or post a list of first aid tips where they're easy to see. Send this list with your child on sleepovers, too.
- When your child is bike riding, make sure he or she is protected with a helmet, knee pads, and elbow pads.
- Provide a cell phone for your child (or people they are with) to use in case of an emergency.

Epilepsy doesn't have to mean that you need to stop doing things, going places, or having fun. But it does require forethought, proactive thinking, and smart precautions. These changes can help you to increase your safety while doing things you enjoy.

## LEARN ABOUT SUDEP: SUDDEN UNEXPECTED DEATH IN EPILEPSY

*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 sudden 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 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.*

### Q: 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.

### Q: How often does SUDEP occur?

**A:** The incidence of SUDEP differs greatly depending upon the population studied. One challenge in pinpointing the numbers behind SUDEP is that information from county and state mortality registries is sometimes incomplete. Some physicians are unfamiliar with SUDEP, and do not list SUDEP on a death certificate. To become educated on the risk level for yourself or your loved one, talk with your doctor.

### Q: What causes SUDEP?

**A:** At this time, the precise cause or causes of SUDEP are not known, although research is underway to study this. Most theories about SUDEP focus on

breathing (respiration), heart rhythms and brain function, or some combination of those three factors. What role seizures play in SUDEP is currently being studied. The majority of SUDEP cases follow tonic-clonic (grand mal) seizures.

### Q: What are the risk factors for SUDEP?

**A:** While SUDEP is a risk for anyone with epilepsy, some people are at higher risk than others. It is important to discuss your individual risk level with your doctor. Risk factors that are most consistently associated with SUDEP are:

- Seizures that can't be controlled
- Long-standing chronic epilepsy
- Generalized tonic-clonic (grand mal) seizures
- Seizures that happen during sleep
- Not taking anticonvulsant medicine as prescribed
- Stopping the use of anti-convulsant medicine abruptly
- Developmental delays
- Onset of epilepsy at a young age

### Q: 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 can advocate for increase SUDEP awareness among the public and the medical community;
- Seek maximum seizure control via strict treatment adherence;
- Lead a healthy lifestyle, with regular physical activity and modifications that reduce stress and seizure activity;



Seizure-related deaths strike families like the Stantons every year. Epilepsy is a massive health crisis and must

be treated as such. Take steps to 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;

- Ensure that family members and caretakers have knowledge of seizure first aid and of emergency resuscitation measures, including CPR and defibrillator use.

### Q: How do I talk with my doctor about SUDEP?

**A:** 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 to minimize the epilepsy-related risks for your loved one. Remember, no one can or will advocate for your loved one better than you.

### Q: 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 be helpful in alerting to certain types of seizures and enabling early intervention. Some of them are listed at our website: [Dannydid.org](http://Dannydid.org), along with a brochure that outlines details to consider when selecting a device. 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 to date, no commercially available seizure detection/monitoring devices have been proven to predict or prevent SUDEP.* If you find a device that seems like a fit for your needs, but financial constraints are a barrier to access, you can email us at [info@dannydid.org](mailto:info@dannydid.org) to request our grant funding application.

### Q: Is there a heightened risk of mortality for people with epilepsy?

**A:** Most people with epilepsy live a full life span. However, there are potential 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 (called 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 SUDEP.

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. Education and advice from a medical professional that knows your specific case background is the best source.