



Danny Did[®]

FOUNDATION

EPILEPSY: KNOWING YOUR RISKS

Information for people and families who face seizures.

Epilepsy is a complicated neurological disease that encompasses a range of disorders that vary in type and severity, sometimes referred to as “the epilepsies.” Almost every situation is unique, and you will likely have more questions beyond the scope of this brochure. For that reason, we encourage you to communicate openly and regularly with your healthcare provider. It is easy to feel overwhelmed and underprepared while navigating your epilepsy journey, but you are not alone. The Danny Did Foundation provides this informational piece as a head start toward empowering yourself and maximizing your family’s safety. We are committed to raising awareness and preventing injuries and deaths caused by epilepsy, and we welcome you to join our effort. The most important thing is not to give up.

A DIAGNOSIS OF EPILEPSY - A Basic Overview

If a person has two or more unprovoked seizures, they are typically diagnosed with epilepsy. Sometimes doctors refer to this condition as a “seizure disorder.” And yes, it can be overwhelming. But armed with the right information and support, you can make choices that maximize your safety and quality of life, and leave you feeling educated and empowered.

A diagnosis of epilepsy can be a life changing experience. It is normal to wonder, what does this mean, and how will our lives

be impacted? The reality is that most people living with epilepsy do go about their daily routines just like those who are not affected by epilepsy. They are able to go to school, play sports, work, and participate in activities that make life enjoyable. However, they also live and cope with uncertainty, knowing that the timing of seizures can be unpredictable. The quality of life for some living with epilepsy may be affected by the frequency and severity of their seizures, and potentially by the side effects of their medications.

WHAT IS EPILEPSY?

Epilepsy is a neurological 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 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. According to the American Academy of Neurology, 1 in 26 people will develop epilepsy during their lives. Chances are, we all know someone with epilepsy.

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 eliminated by standard treatment with medication.

Epilepsy is characterized by seizures that can differ in type, cause, frequency and severity. In most cases seizures are unpredictable, but for some, they occur in regular patterns or certain settings. Taking safety precautions is important for all people with epilepsy. Whether around the house, at school, at work, out with friends, or especially while sleeping, planning ahead can make a 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.





LEARN ABOUT SUDEP: SUDDEN UNEXPECTED DEATH IN EPILEPSY

FOLLOW THESE TIPS TO HELP KEEP ‘SEIZURE SAFE’

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

An important component of safety in epilepsy is the knowledge that 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 mortality risk for people with epilepsy is called Sudden Unexpected Death in Epilepsy, or SUDEP. It is one of the least talked about risks, but because of its tragic consequences, it is an aspect of epilepsy that people have many questions about. This next section represents some of the most commonly asked questions when it comes to SUDEP.

AROUND THE HOUSE

- Leave bathroom doors unlocked for easy access for your loved one in the event of a seizure.
- A softer surface is safer in the event of a fall. Put padding around tables and other furniture with sharp edges, 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, and investigate emergency shower shut off valves.
- 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.
- When exercising, take regular breaks, stay hydrated and 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

- Ensure all medications are taken on time, as prescribed.
- Ensure everyone in your family, school and workplace knows how to respond to a seizure (see back page).
- Wear a medical ID bracelet or necklace that indicates you have epilepsy.
- Learn to recognize pre-seizure warning signs, if applicable.
- Lead a healthy lifestyle and avoid conditions and activities that can trigger seizures, like alcohol and recreational drugs.
- Ensure that you get enough sleep and rest, and take measures to reduce your stress.
- Investigate seizure alarm devices and technologies that can help notify others of seizure activity.

FOR CHILDREN WITH EPILEPSY

- 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.
- Meet with your provider to develop a seizure action plan (SAP) for your child’s school.
- When your child is bike riding, make sure he or she is protected with a helmet, knee pads, and elbow pads.
- If your child has ‘drop’ seizures, a helmet and face guard may help prevent injuries.
- Provide a cell phone for your child (or people they are with) and enable location apps to use in case of an emergency.

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.

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 order to be certain, 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 recurring unprovoked seizures.
- A person with epilepsy died unexpectedly, who was otherwise healthy.
- The death occurred suddenly and during

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

normal activity (often during sleep).

- No obvious medical cause of death could be determined at autopsy.
- The death was not the direct result of status epilepticus.

Q: How often does SUDEP occur?

A: The frequency of SUDEP differs 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 and death investigators 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, speak with your provider.

Q: What causes SUDEP?

A: At this time, the precise cause or causes of SUDEP are not known, but are the focus of much research. According to the Centers for Disease Control and Prevention (CDC), research into the cause of SUDEP focuses on breathing changes, heart rhythms, brain function, as well as the possibility of mixed causes. It is believed that most cases of SUDEP happen during or right after a seizure, but exactly how SUDEP causes death is still being studied.

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 provider. Risk factors that are most consistently associated with SUDEP are:

- Convulsive seizures (Generalized tonic-clonic – or GTCs seizures) that are not controlled by treatment;
- GTCs that happen during sleep;
- Not taking anticonvulsant medicine as prescribed;
- Stopping the use of anticonvulsant medicine abruptly;
- Onset of epilepsy at a young age.

Q: What can I do to reduce the risk of SUDEP?

A: According to the CDC, these are measures that people with epilepsy and their families can take to minimize their risk:

- Seek maximum seizure control via strict treatment adherence, and avoid seizure triggers.
- Lead a healthy lifestyle, with regular physical

activity and modifications that reduce stress and seizure activity;

- Visit with your doctor regularly, especially if convulsive seizures are not completely controlled.
- Ensure that family members and caretakers have knowledge of seizure first aid and of emergency resuscitation measures, including CPR and defibrillator use.

The Danny Did Foundation also encourages these additional steps:

- Consider supervision or monitoring during sleep hours to identify seizure activity;
- Consider the use of alternative therapies such as dietary options, surgical options, or devices/ technologies that detect certain seizures and



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.

alert caretakers, to enable early intervention;

- Ask your doctor annually about new information they have learned about SUDEP, and whether your treatment plan includes all possible steps to reduce your risk.

- Inquire about and advocate for research that enables a better understanding of the causes of SUDEP;
- Become an advocate to increase SUDEP awareness among the public and the medical community.

Q: How do I talk with my healthcare provider about SUDEP?

A: If your provider 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 purpose to enhance communication and to minimize the epilepsy-related risks for your loved one. Mortality in epilepsy is a difficult topic, but no one can or will advocate for your loved one better than you.

Q: What should I know about seizure detection devices and seizure-safety products?

A: A variety of options exist, from implanted technologies to worn devices to non-invasive systems, that can be helpful in alerting your loved ones to certain types of seizures and enabling early intervention. Some are listed at our website: dannydid.org, along with factors 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. To date, no seizure detection/monitoring devices have been proven to predict or prevent SUDEP. If you find a system that seems like a fit for your needs, but financial constraints are a barrier to access, you can visit dannydid.org to find our grant funding application.

More research is needed to answer the 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 healthcare team. SUDEP is a topic that should be re-visited and discussed with your healthcare team on an ongoing basis. Information from a medical professional that knows your specific case background is the best source.

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SEIZURE FIRST AID

HOW TO 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, 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 and do not panic.
- Stay with the person until they are fully awake and reoriented.

STEPS TO AVOID:

- DO NOT attempt to force open the mouth of the person seizing, or try to 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 HEALTHCARE PROFESSIONALS TREAT EPILEPSY?

General practitioners, pediatricians, pediatric neurologists and adult 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.

QUESTIONS TO ASK AT A DOCTOR'S VISIT

- What is the exact diagnosis?
- Is there a known cause for 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 seizures that occur during sleep.
- 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 provider to discuss the risks presented by epilepsy, including SUDEP.
- Seek another provider 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 passing 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 advancing the acceptance, use and insurance coverage for seizure detection devices that may assist in preventing seizure-related deaths. Danny Did is a collaborative partner to the Epilepsy Pipeline Conference, the Epilepsy Foundation Device Accelerator Course, the North American SUDEP Registry, and the Partners Against Mortality in Epilepsy initiative.



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." We celebrate Danny's life through every person and family we reach. If we can help, please be in touch.



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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.