

# SUDEP



**Most people with epilepsy live long and healthy lives. But, you might be surprised to learn that some people die from epilepsy, and not just from obvious causes, such as accidents.**

**There are times when people with epilepsy die without warning and no cause is found. This is known as Sudden Unexpected Death in Epilepsy or SUDEP. The risk is low, but real. And although it's a difficult issue to face, it's important to consider when making lifestyle choices, so you can lower your risk of SUDEP.**

## INFORMATION FOR

# Young Adults and Teens with Epilepsy

### WHAT IS SUDEP?

**Sudden Unexpected Death in Epilepsy (SUDEP) refers to the death of a person with epilepsy, without warning and where no cause of death could be found.**



### HOW COMMON IS SUDEP?

It's estimated that about one in 1,000 people with epilepsy die from SUDEP each year. In people with uncontrolled, difficult to treat seizures the rate may be as high as 1 in 100 per year.

It's believed these rates are underestimates because poor awareness of SUDEP results in inaccurate recording of these deaths.

### WHAT CAUSES SUDEP?

The cause of SUDEP is unknown. It usually happens at night or during sleep. There's often, but not always, evidence of a seizure before death. A seizure before death isn't needed for a diagnosis of SUDEP.

Researchers are looking at problems with breathing, heart rhythm and brain function as possible causes of SUDEP. During seizures there is often a change in breathing and heart rhythm. This isn't dangerous for most people living with epilepsy. Sometimes, a more serious drop in oxygen levels in the blood or changes in heart rhythm may occur. Seizures may also affect the brain's influence on breathing and the heart. In addition, researchers are exploring genetic links between seizures and heart rhythm abnormalities.

It's unlikely that a single cause will explain all SUDEP deaths. Advances in research are identifying critical risk factors and a number of potential mechanisms for SUDEP. As researchers learn more, this new knowledge will help people with epilepsy do more to lower their risk and possibly prevent SUDEP.

### WHAT ARE THE RISK FACTORS FOR SUDEP?

The strongest risk factor for SUDEP is having frequent **generalized tonic-clonic (grand mal) seizures**. The more frequent these seizures are, the higher the risk of SUDEP.

Other risk factors are being investigated. To help minimize your risk, it's important to discuss SUDEP with your doctor and remember that low risk is not the same as no risk. There are things you can do.

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## INFORMATION FOR

## Young Adults and Teens with Epilepsy (continued)

### WHAT YOU CAN DO

- ☑ Discuss SUDEP and any concerns you might have with your doctor.
- ☑ Work with your doctor to have as few seizures as possible. This includes taking medications as prescribed and avoiding seizure triggers (such as lack of sleep or drinking alcohol) to lower your risk of SUDEP.
- ☑ Confide in your friends and let others around you know you have epilepsy. Teach them what they can do to help you recover during and after a seizure.
- ☑ Talk about seizures and the risk of SUDEP with people living with epilepsy. To connect with others and for a listing of local resources, see the Making Sense of SUDEP website.
- ☑ Sign up for the campaign eNewsletter and keep up-to-date with news and research about SUDEP by visiting the Making Sense of SUDEP website.

### HOW TO LOWER THE RISK

The best way to reduce the risk of SUDEP is to have as few seizures as possible.

- Take your prescribed seizure meds regularly and reliably. If you have trouble remembering to take your meds, try using a smart phone app. 
- Identify and avoid triggers for seizures (such as not sleeping enough, drinking too much alcohol or using recreational drugs).
- Keep regular appointments with your doctor. If you have concerns about side effects, it's important not to stop your meds or make any adjustments without talking to your doctor first.
- Discuss other epilepsy treatments with your doctor (such as surgery) when meds aren't enough to control seizures.

### SEIZURE SAFETY

Seizures put you at risk of injury and accidents. Take some simple steps to keep yourself safe:

- Modify your home and work environment to avoid seizure-related injuries.
- Take extra precautions around water, including swimming and bathing.
- If you have frequent seizures during sleep, consider using a monitoring device or sharing a room to alert family members when you're having a seizure.

### WHAT TO DO IF A PERSON HAS A SEIZURE:

1. Time the seizure
2. Loosen tight clothing and place something soft under the head
3. Turn on side to prevent choking
4. NEVER put anything in the mouth
5. NEVER restrain
6. Call an ambulance if the seizure lasts longer than 5 minutes
7. After the seizure, stay until the person is awake and alert, or help arrives.

### AWARENESS IS THE FIRST STEP TOWARDS FINDING THE CAUSE AND PREVENTION OF SUDEP

Everyone with epilepsy should know about SUDEP and its risk factors. It's just as important as learning about the risks from injuries or accidents that can happen during a seizure. Knowing about SUDEP lets you make informed decisions and take charge of your health.

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