

# SUDEP



Although most people with epilepsy live long and healthy lives, their increased risk of death compared to the general population is a serious concern. Some people with epilepsy may die due to accidents or the underlying cause of their epilepsy, such as tumors or genetic conditions. It is less known that people with epilepsy are also at risk of sudden and unexpected death (SUDEP). Being aware of SUDEP, learning more about it and discussing the risk with healthcare providers are all positive ways to face this difficult issue.

SUDEP should be considered along with other factors, when making decisions about your epilepsy. The cause of SUDEP may be unknown but there are measures that can be taken, such as controlling your seizures, to lower your risk.

## INFORMATION FOR People 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?

Recent studies estimate the rate of SUDEP at about one death per 1,000 people with epilepsy per year. This may be an underestimate because of poor case identification due to lack of awareness, and inconsistencies in the investigation and recording of the deaths. In people with frequent epileptic convulsions that are poorly controlled with medications, the rate may approach 1 in 100 per year.

### WHAT CAUSES SUDEP?

The cause of SUDEP is unknown. It usually occurs at night or during sleep, and this makes it hard to find out exactly what happened during the last moments of life. There is often, but not always, evidence of a seizure before death. A seizure at the time of death is not needed for diagnosis of SUDEP.

It is 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.

Researchers are investigating 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. In most people with epilepsy, this is not dangerous. Sometimes, a more serious drop in blood oxygen levels or changes in heart rhythm may occur. Seizures may also affect the brain's control of breathing and heart function. In addition, researchers are exploring genetic links between seizures and heart rhythm abnormalities. Further research is urgently needed to reveal these possible causes of death and to help people with epilepsy understand how to lower their risk of 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 is important to discuss SUDEP with your healthcare provider and remember that low risk is not the same as no risk. There are things you can do.

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## WHAT YOU CAN DO

- ☑ Talk to your healthcare provider about SUDEP and share this information with your family and caregivers.
- ☑ Work with your healthcare provider to find the best way to treat your seizures, identify your seizure triggers and lower your risk.
- ☑ Make sure those around you know that you have epilepsy and what they can do to help you during and after your seizure.
- ☑ Visit the Making Sense of SUDEP website to get the latest news and research, a list of available resources and to sign up for the campaign eNewsletter.

## INFORMATION FOR

# People with Epilepsy (continued)

## HOW TO LOWER THE RISK

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

- Keep regular appointments with your healthcare provider.
- Take your seizure medications regularly and reliably. If you have concerns about side effects, it is important not to make changes to your medications without talking to your healthcare provider.
- Identify and avoid triggers for seizures (such as lack of sleep, drinking too much alcohol or using recreational drugs).
- Ask your healthcare provider about other epilepsy treatments (such as surgery) when medications are not 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 are 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

People with epilepsy should be informed about all the risks of their condition and how to lower those risks. Having this information allows them to make decisions that could possibly save their life.

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PWE/APR 12