

# SUDEP



**Most people with epilepsy live long and healthy lives. However, people with epilepsy have an increased risk of death compared to those living without epilepsy.**

**For children with epilepsy, the majority of deaths are not related to seizures. Research shows that most of the increased rate of death in children with epilepsy is in children with epilepsy and neurological disability. In these children, death is usually due to severe infection or complications of their brain disease.**

## INFORMATION FOR PARENTS & CAREGIVERS OF CHILDREN WITH EPILEPSY

### WHAT IS SUDEP?

Sometimes people with epilepsy die unexpectedly. Sudden Unexpected Death in Epilepsy (SUDEP) refers to the death of an adult or child with epilepsy, where no cause of death could be found. Being aware of SUDEP, learning more about it and discussing the risk with your child's healthcare providers are all positive ways to face this difficult issue.



### HOW COMMON IS SUDEP?

Recent studies estimate the rate of SUDEP among adults and children at about one death per 1,000 people with epilepsy per year. However, the rates of SUDEP in children appear to be much lower, in the range of 2 deaths per 10,000 children per year. It is not understood why the rate of SUDEP is lower in children. It may be related to factors such as the better general health of children compared to adults, plus parents and caregivers helping to ensure that children take their seizure medications.

### WHAT CAUSES SUDEP?

The cause of SUDEP is unknown. Like Sudden Infant Death Syndrome (SIDS), SUDEP appears to occur more often at night. 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 child's risk, it is important to discuss SUDEP with your child's healthcare provider. There are things you can do to reduce your child's risk.

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## WHAT YOU CAN DO

- Talk to your child's healthcare provider about SUDEP and share this information with your family and child's caregivers.
- Work with your child's healthcare provider to find the best way to treat his or her seizures, identify seizure triggers and lower their risk.
- Make sure those around your child know he or she has epilepsy and what they can do to help your child during and after their seizure.
- Visit our website to get the latest news and research, a list of available resources and to sign up for our eNewsletter.

## INFORMATION FOR PARENTS & CAREGIVERS OF CHILDREN WITH EPILEPSY (continued)

### HOW TO LOWER THE RISK

**The best way to reduce the risk of SUDEP is to help your child to have as few seizures as possible:**

- Keep regular appointments with your child's healthcare provider.
- Help your child to take his or her seizure medications regularly and reliably. If you have concerns about side effects, talk to your healthcare provider. Do not make changes to your child's medications without talking to your child's healthcare provider.
- Identify and avoid triggers for seizures (such as lack of sleep).
- Ask your child's healthcare provider about other epilepsy treatments (such as surgery and the ketogenic diet) when medications are not enough to control seizures.

### SEIZURE SAFETY

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

- Modify your home or other daily environment to avoid seizure-related injuries.
- Take extra precautions around water, including swimming and bathing.
- If your child has frequent seizures during sleep, consider using a monitoring device. During times of uncontrolled seizures, consider sharing a room with your child to be aware of seizure activity.

### 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.

**If you find yourself worrying about the risk of SUDEP and how best to balance the need to keep your child safe with the need to encourage your child's growth and independence, speak to a member of your child's healthcare team for support.**

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