

For further information and details of helplines for people with epilepsy, please visit [sudep.org](http://sudep.org) or call 01235 772850.

SUDEP.ORG

SUDEP Action 



## SUDEP - understanding the risk

Information and guidance for people with epilepsy

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Epilepsy Bereaved (founded 1995) is part of SUDEP Action

This information is produced in alliance with SUDEP Aware, a North American partner organisation.

Although Sudden Unexpected Death in Epilepsy (SUDEP) is thankfully rare, it's not a condition that can be ignored. If you have frequent tonic-clonic seizures, it might be that you're more vulnerable. This leaflet is designed to tell you more about SUDEP and some of the lifestyle choices you can take to help reduce the risk.



## What is SUDEP?

Each year, roughly one in every thousand people with epilepsy will die suddenly with no obvious cause. The risk may be greater for a small number of people, which is why it's important to talk to your medical team about your own condition.

SUDEP usually occurs at night or during sleep. It's often the case that the affected person will have had a seizure just before their death, although this isn't universal.

## Why does it happen?

Researchers are still investigating the causes of SUDEP and it's unlikely there's a single cause. During seizures, people may often see a change in their breathing or heart rhythm. Normally, this isn't a problem, but if more serious changes occur – a major drop in oxygen levels in the blood, for example – then this might be a trigger for SUDEP.

Seizures may also affect the brain's influence on breathing and the heart. Another possibility is that there is a genetic link between seizures and heart rhythm abnormalities. Advances in research mean that we're getting closer to identifying the critical risk factors.

## HOW CAN YOU REDUCE YOUR RISK?

The strongest risk factor is a generalised tonic-clonic seizure (which some people call a 'grand mal'). The more frequent these convulsive seizures are, the higher the likelihood of SUDEP. As a result, the most important step you can take to avoid SUDEP is to minimise the number of seizures you have.

### **Read our *Epilepsy. Be smart, be safe* leaflet.**

It gives a lot of practical advice about living with epilepsy that you can discuss with your family, friends and medical team.

### **Take your prescribed medication regularly and reliably.**

Try a diary or smartphone app if you have trouble remembering.

### **Keep regular appointments with your doctor and attend your annual review.**

Don't make adjustments to your medication or stop taking it, without talking to a doctor first. If you're making changes in your life – thinking about starting a family or moving somewhere new – see if your epilepsy care plan needs to change.

Consider using EpSMon, a smartphone app to help you regularly assess and monitor your epilepsy, risks and wellbeing so you are aware of any changes. Find out more at [www.epsmmon.com](http://www.epsmmon.com). You could also tell your health professionals about the SUDEP and Seizure Safety Checklist, a communication tool to help them discuss and monitor your risks and wellbeing during your annual review. They can find out more at [www.sudep.org/checklist](http://www.sudep.org/checklist).

### **Identify the triggers for your seizures.**

Do you find that your epilepsy is particularly affected by not sleeping enough, drinking too much alcohol or taking recreational drugs? If so, try to avoid the trigger.

### **Discuss other epilepsy treatments with your doctor.**

If you feel your medication isn't doing enough to control your seizures, there may be other options such as surgery.

### **Confide in your friends.**

Tell them that you have epilepsy and explain what they should do if you have a seizure.

There is some evidence that it's safer to be with someone when you have a seizure, so it might be worth discussing sharing a room with a family member if you are affected during your sleep. Alternatively, you might want to consider, with your doctor, a monitoring device that may alert them if you have a seizure.

*“Don't make adjustments to your medication or stop taking it, without talking to a doctor first.”*