

About SUDEP

For many people, epilepsy is a condition which can be well-managed and has little or no impact on their life. For others, ongoing seizures mean that epilepsy has a long-term impact on them. Like some other medical conditions, epilepsy is occasionally associated with premature death in some individuals, although this is not common. SUDEP is when someone who has epilepsy dies suddenly and no other cause of death can be found.

There are more than half a million people with epilepsy in the UK. Approximately 1 in 1,000 adults, and 1 in 4,500 children with epilepsy, lose their lives to (SUDEP) every year. The percentage of the population affected by SUDEP is relatively low, and there are things that can be done to reduce risk.

SUDEP is a research priority for Epilepsy Society, and researchers have made an important breakthrough in discovering that an individual's genetic makeup may contribute to the risk of SUDEP.

Visit [epilepsysociety.org.uk/research](https://www.epilepsysociety.org.uk/research)



SUDEP can be upsetting or worrying to think about. Knowing about SUDEP, and the risks around seizures, might help you to work out what risks apply to you, and how to reduce them so you can feel more in control.

Visit [epilepsysociety.org.uk/living-epilepsy/risk](https://www.epilepsysociety.org.uk/living-epilepsy/risk)

Why does SUDEP happen?

It is not clear why SUDEP happens. Because SUDEP is thought to happen either during or following a seizure, it is possible that it is due to a problem with the person's heart, or breathing, during or following the seizure.

Sometimes a person with epilepsy dies suddenly for no obvious reason. Sudden Unexpected Death in Epilepsy (SUDEP) is rare and there may be some things you can do to reduce your risk.

The risk factors around SUDEP

We don't know why SUDEP happens, but some situations are thought to make it more likely in certain people:

- As SUDEP is thought to happen during or following a seizure, uncontrolled or poorly controlled seizures are a risk.
- SUDEP is thought to be more likely in people with frequent seizures, particularly convulsive seizures, than in people with infrequent seizures.

It is worth remembering that the risk of SUDEP varies from one person to another but some of the risks around SUDEP can be reduced.

Reducing risk

As SUDEP is thought to be linked to seizures, getting the best seizure control possible may be a way to reduce risks, including accidents, injury, and SUDEP.

Taking anti-seizure medication (ASM) as prescribed and around the same time or times each day can help with seizure control. If you have difficulties taking your medication (for example, if you find it difficult to remember to take it), aids such as pill boxes (drug wallets) might be helpful.



Helpline 01494 601400
Confidential, national call rate.
Information and emotional support.
Visit [epilepsysociety.org.uk/helpline](https://www.epilepsysociety.org.uk/helpline)
for opening hours.

Keeping a diary of when your seizures happen will help to show if there is a pattern to your seizures or if certain situations trigger your seizures (like being tired or stressed). It might also be helpful to see how well medication is working to control your seizures.

Visit epilepsysociety.org.uk/seizure-diaries

If you are still having seizures, having a review of your epilepsy and treatment with a neurologist or epilepsy nurse might be helpful. There may be changes to your treatment that would help to reduce the number of seizures you have.

SUDEP and sleep

SUDEP often happens when the person is asleep. If you have seizures during sleep, having a seizure alarm that alerts someone who can help if you have a seizure in bed might be helpful.

Visit epilepsysociety.org.uk/alarms-and-safety-aids

Talk to someone

If you are concerned about SUDEP, you can talk to your neurologist or epilepsy nurse about what any risks mean for you and your situation, and how to lower the risk of SUDEP.

You can also talk to our helpline who offer information and time to talk (see page 1).

Further information

Cruse Bereavement Support

cruse.org.uk

Charity offering bereavement support, information, and campaigning.

SUDEP Action

sudep.org

Charity raising awareness and offering support and counselling around SUDEP.

Epilepsy Society is grateful to Ley Sander MD PhD FRCP Professor of Neurology and Consultant Neurologist, who reviewed this information.

For a printed copy of this information contact our helpline.

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Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

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