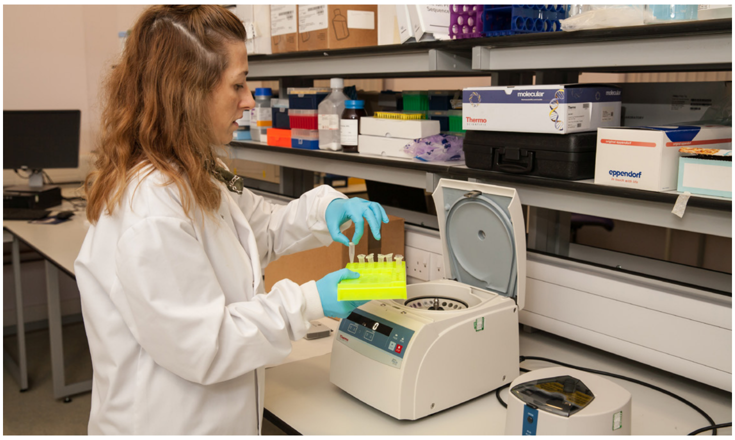
Sudden Unexpected Death in Epilepsy (SUDEP)

About SUDEP



SUDEP is when someone who has epilepsy dies suddenly and no other cause of death can be found.

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 people, although this is rare.

There are over 600,000 people with epilepsy in the UK. Approximately 1 in 1,000 people 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/neuropathology

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/safety-and-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.

The risk factors around SUDEP

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.

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, particularly tonic clonic seizures.
- SUDEP is thought to be more likely in people with frequent seizures, particularly tonic clonic seizures, than in people with infrequent seizures.
- Not taking your anti-seizure medication regularly, as prescribed by your doctor, can trigger seizures which can lead to higher risk of SUDEP.
- SUDEP often happens at night which suggests that you may be at higher risk of SUDEP if you have asleep seizures.
- You may be at higher risk of SUDEP if you live alone.
- The risk of SUDEP is higher in people with a history of alcohol dependency and/or substance misuse disorder.
- Sleeping on your front, in the prone position, may put you at higher risk.

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.

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.

Helpline 01494 601400
Confidential, national call rate.
Information and emotional support.
Visit epilepsysociety.org.uk/helpline for opening hours.

If you have difficulties taking your medication (for example, if you find it difficult to remember to take it), a pill box or drug wallet might be helpful. Find out what to do in advance if you forget to take your ASM, or what to do if you are sick, or have diarrhoea after taking it.
Visit epilepsysociety.org.uk/anti-seizure-medication
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.
Visit epilepsysociety.org.uk/your-appointment-or-review and epilepsysociety.org.uk/care-and-treatment/your-care-plan

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

SUDEP and living alone

If you live alone and have seizures, depending on how your epilepsy affects you, you can contact your local council to ask for a health and social care assessment. If the assessment identifies needs which meet the local authority's criteria, then they have a duty to arrange relevant community care services for you. These services may include adaptations to the home such as a personal alarm. You may need to pay some of the costs.
Visit epilepsysociety.org.uk/about-epilepsy/care-and-treatment/health-and-social-care-assessment-benefits

Talk to someone

If you are concerned about SUDEP, you can talk to your neurologist or epilepsy nurse about your risk as an individual, and how to lower the risk of SUDEP.
You can also talk to our helpline.

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 Dr F J Rugg-Gunn, Consultant Neurologist & Honorary Associate Professor, Clinical Lead, Chalfont Centre for Epilepsy, who reviewed this information.

For a printed copy of this information contact our helpline.

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