

Sudden Unexpected Death in Epilepsy (SUDEP)

SUDEP is rare in adults, and even rarer in children. To put it in context, anyone living with a long term condition like diabetes or asthma has a slightly higher risk of sudden death, and this is no different with epilepsy.

This factsheet provides an overview of SUDEP, highlights some common risk factors and ways to minimise these risks. It should never replace a chat with your epilepsy specialist nurse or specialist, who can talk to you about risks specific to your own situation.

This information is relevant for anyone affected by epilepsy, or anyone looking after someone affected by epilepsy.

The most important and effective measure you can take to protect yourself or someone you care for is by working closely with your, or your family member's, medical team.

If you have any questions at all, please contact your epilepsy specialist nurse or phone our helpline on 0808 800 2200.

What is SUDEP?

Unfortunately, a small number of people die from epilepsy each year in Scotland.

If there is an obvious cause of death, this is referred to as an epilepsy-related death, not SUDEP. This cause can be an injury resulting from a seizure related accident, drowning or status epilepticus. Status epilepticus means a single seizure which does not stop by itself or a series of seizures without recovery in between.

If, however, there is no obvious cause of death, the term SUDEP is used. SUDEP is often unwitnessed and happens overnight. In some cases, there may be signs that a seizure has happened, but in many cases, no signs of seizure activity can be found.

What causes SUDEP?

SUDEP usually occurs following a suspected seizure but what exactly causes SUDEP and why it occurs is unknown. The most likely explanation is that a seizure interferes with the part of the brain that controls breathing rate and/or the rhythm of the heart.

Research is continuing to help us understand the causes of SUDEP.

Who is at risk of SUDEP?

Generally, the better seizures are controlled, the less risk there is of SUDEP. Other risk factors are a person's age, gender, and type of seizures. So far, research has shown that:

- There is very little risk for anyone with absence seizures or myoclonic seizures only.
- Those who have tonic-clonic or focal seizures with limited awareness are at a slightly higher risk, particularly if seizures are frequent.
- SUDEP rarely happens in children.
- Studies show that children who have epilepsy as well as another condition affecting the brain (such as cerebral palsy or learning disability) have a slightly higher risk of SUDEP, but it is still very low.
- Young people, particularly young men in their late teens and early twenties, are at a slightly higher risk, especially if their seizures are not well controlled.

Other possible risk factors include:

- Having seizures at night or during sleep
- Having seizures when no-one is around to provide first aid
- Not taking AEDs as prescribed

- Abrupt changes in dose or type of AEDs
- Binge drinking or taking recreational drugs
- Infrequent reviews with an epilepsy specialist

Ways to minimise SUDEP risks

Anything that can reduce the number of seizures will usually also reduce the risk of SUDEP:

- Attend regular epilepsy reviews with your specialist. Find out and understand any specific risks associated with your type of seizures.
- Work with your specialist towards better seizure control. If you are no longer under the care of a consultant specialist, ask your GP to refer you back to a consultant who specialises in epilepsy.
- Keep a seizure diary recording type and frequency of seizures. Also record any side effects from your AEDs. All this information will help your specialist review your medication's effectiveness.
- Identify and keep track of possible seizure triggers in a seizure diary. Address or seek help with seizure triggers, such as sleep issues, as this may help improve your seizure control.
- Avoid binge drinking or taking recreational drugs.
- Take your anti-epileptic drugs (AEDs) exactly as prescribed and aim to take them at the same time every day.
- Never make changes to or stop taking your AEDs unless advised and supervised by your specialist or epilepsy specialist nurse. Never skip your medication, even just for one day.
- Set a reminder on your phone or smart speaker to prompt you to take your AEDs on time. Or link taking your AEDs with daily routines like brushing your teeth or breakfast.
- Stay on the same brand or generic version of your AED, if possible. This may reduce the risk of breakthrough seizures as some people can be sensitive to a switch between different makes or generic versions of an AED.

If you are on a branded AED, ask your GP to write the brand name on your repeat prescription. If you are on a generic AED, ask your GP to write the generic name and the name of the manufacturer in brackets on your repeat prescription. That way, your chemist can ensure you get the same make of your AED every time, if at all possible.

- Always put in a request for your repeat prescription in good time to reduce the risk of running out of your AEDs. If you find yourself without your AEDs, phone your GP for an urgent prescription or ask your chemist for an emergency supply of your AED. If this is out of clinic hours, phone NHS 24 on 111 who will be able to direct you to an out of hours service for an emergency prescription.
- If you have seizures while asleep, find out about a seizure alarm. They can alert someone else living with you to a seizure, who can provide first aid to keep you safe, or call for an ambulance if necessary. Our Helpline 0808 800 2200 can provide more information on the different types of alarms and how to get one.

First Aid for seizures

Knowing some simple first aid measures can help keep a person safe during a seizure. There is more extended information on first aid for seizures on our website www.epilepsyscotland.org.uk.

- If a child has a tonic-clonic seizure, turn them onto their side into the recovery position during the jerking (convulsive) phase, if possible. This will keep their airway clear and support breathing.
- If an adult has a tonic-clonic seizure, try turning them onto their side into the recovery position during the convulsive phase although this can often be difficult. If this is not possible, turn them into the recovery position as soon as the convulsions have finished. This simple act of moving the person onto their side can encourage breathing to start again.
- After the seizure has finished, stay with the person until full recovery, which means return to full consciousness and normal breathing.

Calling an ambulance

When you need to call an ambulance usually differs from person to person, and you need to have this conversation with your or your child's medical team. In some cases, a care protocol may be drawn up to specify exactly what needs to be done and when to keep that person safe.

Generally, call an ambulance if:

- the person is injured beyond basic first aid, ie requiring urgent medical attention
- the seizure (not including the recovery period) does not stop after five minutes (or lasts two minutes longer than is normal for that person)
- one seizure follows another without full recovery in between
- the person is having trouble breathing
- liquid, food or vomit may have been inhaled

If you want to find out more about SUDEP, if you are concerned about anything you have read, or if you have been affected by SUDEP, please phone our helpline on 0808 800 2200 or contact SUDEP Action at www.sudep.org.uk.

Our resources are always free. If you would like to support our work please text FACTS to 70085 to donate £3. Texts cost £3 plus one standard rate message.



www.epilepsyscotland.org.uk

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