Sudden Unexpected Death in Epilepsy (SUDEP)

Anyone living with a long term condition like diabetes or asthma has a slightly higher risk of sudden death. This also applies to epilepsy. SUDEP (Sudden Unexpected Death in Epilepsy) is a known risk to people with epilepsy.

Epilepsy is a long term condition and the outlook for most people is very good. With a clear understanding of epilepsy and good management of seizures, the risk of SUDEP can be minimised. It is important to remember that SUDEP is uncommon.

This factsheet will explain about SUDEP. It will also explain how to assess any risks and suggest ways to reduce these risks to keep safe.

What is SUDEP?

If a person with epilepsy dies suddenly and no clear cause of death is found, the term SUDEP is used.

In Scotland, a small number of people die from epilepsy each year. This can occur due to accidents resulting from a seizure, and due to status epilepticus. Status epilepticus happens when a person has either a number of seizures without recovering between each one, or a single seizure which does not stop by itself. It requires emergency medication and/or other medical interventions to stop the seizure(s).

SUDEP makes up about half of all epilepsy-related deaths (Epilepsy prevalence, incidence and other statistics, Joint Epilepsy Council 2011)
What causes SUDEP?

SUDEP usually occurs following a 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?

The risk of SUDEP is generally very low, but for a small number of people the risk may be slightly higher. This will depend on many factors, such as age, gender, frequency and type of seizures. Generally, the better seizures are controlled, the less risk there is of SUDEP. So far, research has shown that:

- People with some types of seizures, such as those with absence seizures only, are not considered to be at risk.
- Those with tonic-clonic or complex partial seizures are at a slightly higher risk, particularly if seizures are not well controlled.
- 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 males in their late teens and early twenties, are considered to be at a slightly higher risk, especially if their seizures are not well controlled.

Other possible risk factors include:

- Having seizures during sleep
- Having seizures when no-one is around to help
- Not taking anti-epileptic drugs as prescribed
- Abrupt changes in dose or type of anti-epileptic drugs
- Binge drinking or taking recreational drugs

Ways to minimise risks

- Ask your doctor or epilepsy specialist nurse what type of epilepsy you have and check for any specific risks associated with it.

- If you are not seizure-free ask your GP to refer you back to a consultant who specialises in epilepsy. Talk to your consultant or epilepsy specialist nurse about any concerns you have about SUDEP. They can usually put your mind at rest and explain your specific risks.

- Keep a seizure diary recording how many and what kind of seizures you have. If you have any side effects from your medication, write this down as well. This will help your consultant prescribe the best possible anti-epileptic drug and dose for you.

- Some people find their seizures are triggered by certain things or events. Keep track of these possible triggers by recording them in a diary. Try to avoid these if possible, as this may help improve seizure control. It is important to remember that not everyone has identifiable seizure triggers and seizures may happen anyway.

- Take your anti-epileptic drugs (AEDs) exactly as prescribed and aim to take them at the same time every day. Using a pill box can help remind you to take your medication. Regular doses will keep the level of your AED high enough to help control seizures. Never make changes to or stop taking your AEDs without discussing it with your doctor or epilepsy specialist nurse first.

- Ask your GP to write the brand name of your anti-epileptic drug on the prescription, not the generic name. This will ensure you get the same make of drug every time. Some people may have a seizure if switched to a different make or generic version of a drug.
- Make sure you always have enough of your anti-epileptic drugs. If you run out of your medication at the weekend, you can phone NHS 24 08454 24 24 24. A chemist may also be able to give you emergency cover if you have a copy of your usual prescription or an empty box or bottle of your medicine which is labelled.

- Seizure alarms may help if you have seizures while you are asleep. Our Helpline 0808 800 2200 can provide more information on the different types of alarms and how to get one.

- Get enough sleep. Lack of or disrupted sleep can sometimes trigger seizures.

- Avoid binge drinking and recreational drugs.

**First Aid for seizures**

Knowing some simple first aid measures can reduce the risks.

- If a child has a seizure, turn them onto their side into the recovery position during the jerking (convulsive) phase, if possible. This will keep their airway clear.

- If an adult has a seizure, turn them onto their side (into the recovery position) when the seizure has finished. If breathing has stopped, the simple act of moving the person could encourage breathing to restart again.

- Stay with the person after the seizure has finished and ensure that their breathing is regular and their colour is back to normal.

- Never put anything in a person’s mouth or between their teeth.

**Calling an ambulance**

A consultant or epilepsy specialist nurse may already have drawn up a care plan which would specify when to call an ambulance. Other reasons to call an ambulance include if:

- the person is injured requiring urgent medical attention
- the seizure (not including the recovery period) does not stop after 5 minutes (or lasts 2 minutes longer than is normal for that person)
- one seizure follows another without recovery in between
- the person is having trouble breathing
- liquid may have been inhaled
- you feel you need medical support

An epilepsy specialist nurse (ESN) or Epilepsy Scotland can provide further training on how to deal with a seizure.

There is more information about SUDEP at [www.sudep.org.uk](http://www.sudep.org.uk), email [information@epilepsybereaved.org.uk](mailto:information@epilepsybereaved.org.uk) or phone 01235 772 850.