

Sudden unexpected death in epilepsy (SUDEP)

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Introduction

Epilepsy is a very individual condition that affects everybody in different ways. Many people find that their epilepsy does not get in the way of their everyday life. In fact, up to 70 in every 100 people with epilepsy could have their seizures fully controlled, with the right treatment.

Epilepsy Action believes that it is very important for people with epilepsy and their families to be aware of the risks associated with epilepsy. A small number of people have a risk of sudden death due to their epilepsy.

It is important to remember that the risks of dying because of epilepsy are low. What's more, there are things you can do to make the risks even lower.

Most people who know somebody who has died due to epilepsy say they wished they had known more about the risks before the person died. Therefore, the aim of this fact sheet is to raise awareness of the risk of sudden death associated with epilepsy. It also offers practical advice and suggestions on ways to reduce this risk.

If you would like to discuss any of the information in this fact sheet, you could speak to an adviser on the Epilepsy Helpline, freephone 0808 800 5050. You can also contact your GP, epilepsy specialist, or epilepsy nurse.

Sudden unexpected death in epilepsy (SUDEP)

Most of the time, people with epilepsy recover perfectly well after a seizure. A very small number of people die due to an injury that has happened because of a seizure. In some cases, there's no clear reason why a person with epilepsy has died. If a person with epilepsy dies unexpectedly, and no obvious cause of death can be found, it is called sudden unexpected death in epilepsy (SUDEP). Sometimes, it is called sudden unexplained death in epilepsy.

How often SUDEP happens

In the UK, about 456,000 people have epilepsy. It's estimated that SUDEP causes about 500 deaths each year. Some people with epilepsy have a higher risk of SUDEP than other people with epilepsy.

The causes of SUDEP

SUDEP has been shown to be connected with seizures, but the exact cause is not known. Research suggests that seizure activity in the brain may sometimes cause changes in the person's heartbeat or breathing. Very occasionally this may cause the person to stop breathing and not start again.

Risk factors of SUDEP

There is no way of predicting who will be affected by SUDEP. But the single most important risk factor is uncontrolled generalised tonic-clonic seizures. This is a type of seizure which causes the person to lose consciousness. Their body goes stiff and then starts jerking.

Each person with epilepsy has their own level of risk of SUDEP. It can occur in people who have seizures very often or very infrequently. However, the risk is thought to be higher, the more seizures you have. The risk of SUDEP in people who are seizure-free is very, very low.

Here are some factors which may increase a person's risk of SUDEP.

- Having generalised tonic-clonic seizures
- Not taking anti-epileptic drugs (AEDs) as prescribed
- Having seizures that are not controlled by AEDs
- Having sudden and frequent changes to AEDs
- Being a young adult (in particular male)
- Having sleep seizures
- Having seizures when alone
- Drinking large amounts of alcohol

Ways to reduce the risks of SUDEP if you have epilepsy

Seizure control

The most effective way to reduce the risk of SUDEP is to have as few seizures as possible. If your seizures are not controlled, here are some ways that you can manage your epilepsy, to try and reduce them.

- Always take your anti-epileptic drugs (AEDs) as prescribed.
- Never stop taking your AEDs, or make changes to them, without talking to your doctor first.
- Make sure that you never run out of your AEDs.
- Ask your epilepsy specialist or epilepsy specialist nurse in advance what you should do if you ever forget to take your AEDs at your usual time.
- If your seizures continue, ask to be referred to an epilepsy specialist for a review of your epilepsy. They can suggest changes to your AEDs or other treatment options, which may include surgery or vagus nerve stimulation.

- Keep a diary of your seizures. This can help doctors when they are considering the best treatment for you. It may also help you to see if there is a pattern to your seizures or anything that may trigger your seizures.
- Avoid situations which may trigger your seizures. Common triggers include forgetting to take AEDs, lack of sleep, stress, lack of food and too much alcohol.
- If your epilepsy is very difficult to control, you may be entitled to go to a specialist epilepsy centre for treatment. Contact Epilepsy Action for more information about this.

More information about AED treatment, surgery, vagus nerve stimulation, seizure diaries and triggers are available from Epilepsy Action.

Other ways to reduce risk

- If your seizures happen at night, consider using a bed alarm. Bed alarms can alert another person if you are having a seizure, so they can help you. For example, they can call for an ambulance, if they feel this is necessary. (Be aware that bed alarms are not always perfect. They may sometimes miss seizures or set off without a reason.) Information about bed alarms is available from the Disabled Living Foundation. Tel: 0845 130 9177; website: www.dlf.org.uk
- Tell people about your epilepsy and let them know how they can help you if you have a seizure. You may wish to wear identity jewellery or carry some form of epilepsy awareness card to alert other people to your epilepsy.
- Having seizures when you are alone is a risk factor for SUDEP. You may wish to bear this in mind when you are making plans for where you live and what you do.

More information about safety and epilepsy, identity jewellery and epilepsy awareness cards is available from Epilepsy Action

Ways to reduce the risks of SUDEP for someone who is having a seizure

You may be with someone when they have a seizure which causes them to lose consciousness. Most people recover perfectly well after a seizure, but here are some things you can do to help them recover.

- When the seizure is over, put the person on their side in the recovery position. This can help them to breathe.
- If the person is having difficulty breathing, gently move their limbs. This may encourage breathing to start properly again.
- If the person is still having difficulty breathing, call for an ambulance.

Call for an ambulance if...

- You know it is the person's first seizure
- The seizure continues for more than five minutes
- One seizure follows another without the person regaining consciousness in-between
- The person is injured during the seizure
- The person has difficulty in breathing
- You believe the person needs urgent medical attention.

Further information about SUDEP

Epilepsy Bereaved

Epilepsy Bereaved offers support and information for people affected by SUDEP and other bereavements related to epilepsy. They also promote research into the causes of SUDEP.

Tel: 01235 772 852

Website: www.sudep.org

About this publication

This fact sheet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the fact sheet, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

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