Epilepsy-related deaths and SUDEP

Having epilepsy comes with certain risks. Although it rarely happens, it’s important to know about the risk of dying from epilepsy. On this page we talk about why epilepsy can sometimes be a cause of death. Most important, we talk about ways to reduce your risk.

If someone you know with epilepsy has died, we also have information about where to get support.

How many people die from epilepsy, and why do they die?

Every year in the UK, around 1,000 people die from causes related to epilepsy. Some people die during seizures because of a condition called status epilepticus, or as a result of an accident or drowning. Some people with epilepsy die due to suicide. We talk more about these risks, and how to reduce them, further down this page.

In some cases there’s no clear reason why a person with epilepsy has died. When this happens, it’s called sudden unexpected death in epilepsy (SUDEP).

What causes SUDEP?

Evidence shows that SUDEP is connected with seizures, particularly tonic-clonic seizures. No-one knows the exact cause and there may be no single explanation. However, it is thought that a seizure may sometimes lead to changes in the person’s heart rate or breathing. This could cause the person to stop breathing or their heart to stop beating.

I have epilepsy. Am I at risk of SUDEP?

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SUDEP is rare, affecting around 1 in every 1,000 adults with epilepsy each year. This figure is for people with epilepsy in general. Your individual level of risk will depend on what type of seizures you have and how well-controlled they are. No one can say exactly who will be affected by SUDEP, but research has shown there are some things that can put you at increased risk:

**Tonic-clonic seizures**

The biggest risk factor for SUDEP is having uncontrolled tonic-clonic seizures. The more frequent your seizures, the more you are at risk of SUDEP.

**Sleep seizures**

SUDEP often happens at night. This suggests that you may be at more risk of SUDEP if you have seizures during sleep.

**Not taking epilepsy medicine regularly**

There’s some evidence that people who don’t take their epilepsy medicine regularly, as prescribed by their doctor, have an increased risk of SUDEP.

**What if I don’t have tonic-clonic seizures, am I still at risk?**

If you have other types of seizure, for example focal or myoclonic seizures, your risk of SUDEP is much lower than someone who has frequent tonic-clonic seizures. However, if you take epilepsy medicine to control your seizures, it’s important to keep taking it as prescribed. This is because for some people, not taking their medicine could put them at risk of having tonic-clonic seizures. If you aren’t taking your medicine because it causes side-effects, talk to your epilepsy specialist so the medicine can be adjusted or changed.

**Is my child at risk of SUDEP?**

SUDEP is less common in children than in adults. It’s estimated that each year, for every 4,500 children aged 17 and under with epilepsy, one will die from SUDEP. This figure is for children with epilepsy in general, and some children will be more at risk than others. We

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8. As above

9. As above


11. As above

12. As above
don’t know as much about SUDEP risk in children as we do for adults. However, a recent review of studies into SUDEP in children\textsuperscript{13} suggested that risk factors for children include:

- Having uncontrolled tonic-clonic seizures, especially at night
- Having a type of genetic epilepsy that’s difficult to control
- Having other health problems, especially breathing or heart problems

To find out if your child is likely to be at increased risk of SUDEP, speak to their epilepsy specialist. If the specialist says your child is at increased risk, they should also talk to you about ways to reduce the risk.

**What can I do to reduce my risk of SUDEP?**

The most effective way to reduce your risk of SUDEP is to have as few seizures as possible, especially if you have tonic-clonic seizures.\textsuperscript{14} Having fewer seizures will also reduce your risk of death or injury from status epilepticus or accidents. Here are some suggestions to help you have as few seizures as possible:

- Take your epilepsy medicines every day, exactly as they’ve been prescribed. If you don’t like your medicine or have side-effects, talk to your epilepsy specialist so they can make changes
- Find out in advance what to do if you miss a dose of medicine, or have vomiting or diarrhoea after taking it
- Try to avoid situations which may trigger your seizures. Common triggers include missing a dose of epilepsy medicines, lack of sleep, stress and drinking too much alcohol
- If your seizures are not fully controlled, ask to be referred to an epilepsy specialist for a review of your epilepsy. They may be able to suggest changes to your epilepsy medicines, or other treatment options

**Things to consider if you have seizures in your sleep**

In addition to taking steps to reduce your seizures, there are some extra things you may want to consider if you have seizures in your sleep:

- Living and sleeping arrangements
- Alarms and monitors
- Sleeping on your back
- Safety pillows


Living and sleeping arrangements

There is evidence that having someone in your bedroom, who would be able to help you if you have a seizure, reduces the risk of SUDEP. So this is something to consider when making decisions about your sleeping and living arrangements.

Alarms and monitors

Talk to your epilepsy specialist or epilepsy nurse about using a seizure alarm or monitor. These can alert someone that you are having a seizure in the night, so they can help you, or if necessary call an ambulance. At the moment there is not enough evidence to say if using a seizure alarm or monitor can prevent SUDEP.

Sleeping on your back

Many people who died from SUDEP were found lying on their front. This has led some researchers to say that sleeping on your back may reduce the risk of SUDEP. But other researchers say there’s not enough evidence to prove that sleeping on your back reduces the risk.

Safety pillows

Some people choose to use a safety pillow. They have small holes that may help you breathe more easily if you are lying face down when having a seizure. However, there hasn’t been any research to show if safety pillows reduce the risk of SUDEP.

Other causes of epilepsy-related death

Although it may feel worrying, it’s important to know about all the possible causes of epilepsy-related death. Knowing about the risks means you can take steps to reduce your risk and keep yourself as safe as possible.

Status epilepticus

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Status epilepticus is when a seizure or series of seizures last too long and doesn’t stop on its own. It can happen with any type of seizure, but convulsive (tonic-clonic) status epilepticus is the most dangerous and can sometimes be a cause of death.

Read our information about status epilepticus and how to reduce your risk.

**Accidents, injuries and drowning**

Having seizures, especially if they affect your awareness or leave you feeling confused, can put you at risks of accidents, injuries and drowning. The most effective way to reduce your risk is to do everything you can to reduce the number of seizures you have. But there are also safety measures you can put in place to protect yourself.

Read our safety advice for people with epilepsy to find out more about ways to reduce your risk.

**Suicide**

People with epilepsy are at increased risk of suicide compared to people without epilepsy.\(^{20}\) This may be because people with epilepsy are at increased risk of mental health problems such as depression.\(^{21}\) For some people this can lead to thoughts of suicide. The organisation that regulates medicines in the UK has warned that rarely, epilepsy medicines may be associated with a small increased risk of suicidal thoughts and behaviour.\(^{22}\)

If you are feeling depressed or feeling like you want to die, talking to someone is the first and most important step in getting help. You could talk your GP, epilepsy specialist nurse or epilepsy specialist.

If you don’t want to talk to a medical person, or you need someone to talk to when there is no medical person available, try the Samaritans. They are on the end of the phone 24 hours a day. Their phone number is 116 123.

Rethink Mental Illness has advice for people having suicidal thoughts, including useful contacts and how to get support.

If you are worried about someone who may be having suicidal thoughts, see the Samaritans tips on having a difficult conversation. Rethink Mental Illness also has advice on how to support someone having suicidal thoughts.

**Let us know your thoughts**


Epilepsy Action is working on a project to ensure that people with epilepsy understand the risk of epilepsy-related deaths. Please help us by sharing your views in our survey.

Support when someone with epilepsy has died

If someone you know has died from an epilepsy-related death, you might feel shocked, confused, isolated and not able to take in what has happened. You might have questions that need answering, or you might need to talk about what has happened. These organisations may be able to help you:

**Child Bereavement UK**
Supports families when a baby or child of any age dies or is dying, or when a child is facing bereavement.
Tel: 0800 0288 840
Email: support@childbereavementuk.org
Website: childbereavementuk.org

**Cruse Bereavement Care**
Offers support, advice and information when someone dies.
Tel: 0844 477 9400
Email: helpline@cruse.org.uk
Website: cruse.org.uk

**Help is at Hand**
The Support after Suicide Partnership has produced a document called Help is at Hand, which is an information guide for anyone bereaved by suicide.
Website: supportaftersuicide.org.uk/help-is-at-hand

**SUDEP Action**
Offers support and advice to help you understand the inquest procedure, the investigations, and what is going on for you emotionally.
Tel: 01235 772 852
Email: support@sudep.org
Website: sudep.org

**Winston's Wish**
Supports children and young people after the death of a parent or sibling.
Tel: 08088 020 021
Email: ask@winstonswish.org
Website: winstonswish.org

**The Epilepsy Deaths Register**
If you know someone with epilepsy who has died, you may wish to report their death to the Epilepsy Deaths Register. You don't need to be related to the person who has died, and you can register their death at any time, even if it was years ago.

The Epilepsy Deaths Register provides researchers with anonymised information on epilepsy deaths. Every person who reports an epilepsy-related death helps this research. They bring
knowledge one step closer to finding the answer to SUDEP and other epilepsy-related deaths.

Website: epilepsydeathsregister.org
Tel: 0330 088 1220

Sunflower Tribute funds
A Sunflower Tribute is an online memory page that gives you, your family and friends a place to come together and remember someone special.

Website: epilepsy.org.uk/support-our-work/sunflower-tribute

About this information
This information 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 information, please contact us at epilepsy.org.uk/feedback

To find out why you can trust Epilepsy Action's information, please contact us or visit epilepsy.org.uk/trust

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Your support
We hope you have found this information helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this:

- Call the Epilepsy Action fundraising team on 0113 210 8851
- Donate online at epilepsy.org.uk/donate
- Send a cheque payable to Epilepsy Action to the address below

Did you know you can also become a member of Epilepsy Action from as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.
Epilepsy Helpline
Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

Contact details
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