Epilepsy-related deaths

Help and support for people who have been affected by an epilepsy-related death
During 2013, 1,187 people in the UK with epilepsy died earlier than expected (premature death). Some of these deaths could have been prevented.¹ This information is for you whether you have epilepsy yourself, or you care for someone with epilepsy. It is also for you if someone you know has died from an epilepsy-related death.

Why it’s important to talk about epilepsy-related deaths
Epilepsy Action believes that it is very important for people with epilepsy and their families to be aware of the risks associated with epilepsy. Knowing about the risks can help you to make decisions about your epilepsy treatment and your lifestyle.

If you would like to speak to one of our advisers about epilepsy-related death, please contact the Epilepsy Action Helpline

These are some of the causes for epilepsy-related deaths:

- Sudden unexpected death in epilepsy
- Accidents
- Status epilepticus
- Suicide
- Deaths during pregnancy

Sudden unexpected death in epilepsy (SUDEP)
The definition of SUDEP
If someone with epilepsy dies suddenly and unexpectedly, and no obvious cause of death can be found, it is called sudden unexpected death in epilepsy (SUDEP).

Premature death in people with epilepsy is higher than in the general population, and SUDEP is the most common cause of this.

SUDEP has been shown to be connected with seizures, particularly tonic-clonic (convulsive) seizures. The exact cause is not known and there may be no single explanation. However, it is thought that seizure activity in the brain may sometimes cause changes in the person’s heartbeat or breathing. This could cause the person to stop breathing or their heart to stop beating.

What is my risk of SUDEP?
Like cot deaths, no one can say whether or not a person is in danger of SUDEP. But there is evidence that the risks are different for different groups of people.

- If you have epilepsy, your risk is 1 in 1000
- If you have frequent tonic-clonic seizures, you have an increased risk, particularly if they happen during sleep
- If you are being considered for epilepsy surgery, you are considered to be at increased risk
- If you have a drug or alcohol problem, your risk is higher than someone who doesn’t have these problems
- If you have had a recent epilepsy-related injury or are being treated for depression, you are at increased risk
- If you have absence or myoclonic seizures, you are not known to be at increased risk
- If you have very few seizures, you are at a lower risk, but still at risk

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 to manage your epilepsy:

- Always take your epilepsy medicines exactly as prescribed
- Never stop taking your epilepsy medicines, or make changes to them, without talking to your doctor first
- Make sure you never run out of your epilepsy medicines
- Ask your epilepsy specialist or epilepsy nurse in advance what you should do if you ever forget to take your epilepsy medicines
- 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, which may include surgery
- Try not to sleep on your stomach as recent research suggests that people with epilepsy who sleep on their stomach may be at higher risk of SUDEP

Other possible helpful ideas:

- 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
- Avoid situations which may trigger your seizures. Common triggers include forgotten epilepsy medicines, lack of sleep, stress and too much alcohol
- Consider buying a safety pillow. Safety pillows have small holes. They may help you breathe more easily than a normal pillow if you are lying face down during a seizure. There is no evidence however that safety pillows reduce the risk of SUDEP
• If your seizures happen at night, talk to your family doctor or epilepsy specialist nurse about using a bed alarm. Bed alarms can alert another person if you have a seizure. This will help the person to help you. For example, they can put you in the recovery position or call for an ambulance, if necessary. (Be aware that bed alarms can be very expensive and are not always perfect. They may sometimes miss seizures or go off without a reason. And it’s important to know that there is no proof that bed alarms reduce the risk of SUDEP.)

• Tell people about your epilepsy and let them know how they can help you if you have a tonic-clonic seizure. You may choose to wear identity jewellery or carry some form of epilepsy awareness card to make other people aware of your epilepsy

For information about alarms and manufacturers, you can contact Disabled Living Foundation’s equipment helpline. They provide information about suppliers of specialist equipment to help with everyday living.

If you would like to discuss anything to do with SUDEP, you could speak to an adviser on the Epilepsy Action Helpline, 0808 800 5050 (UK only). You could also contact your family doctor, epilepsy specialist, or epilepsy nurse.

**How someone can help you if you have a tonic-clonic seizure**

If you have seizures that cause you to lose consciousness, you might like to talk to people about what to do to help you recover after a seizure. By being aware of the first aid for tonic-clonic seizures, you can reduce your risk of status epilepticus and SUDEP.

**First aid for tonic-clonic seizures**

The person goes stiff, loses consciousness and then falls to the floor. This is followed by jerking movements. After a minute or two the jerking movements should stop and consciousness should slowly return.

**Do...**

- Protect the person from injury - (remove harmful objects from nearby)
- Cushion their head
- Look for an epilepsy identity card or identity jewellery
- Aid breathing by gently placing the person in the recovery position when the seizure has finished (see pictures)
- Stay with them until recovery is complete
- Be calmly reassuring

**Don’t...**

- Restrain the person’s movements
- Put anything in their mouth
- Try to move them, unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

**Call 999 for an ambulance if...**

You know it is the person’s first seizure or

- The seizure continues for more than five minutes or
- One tonic-clonic seizure follows another without the person regaining
consciousness between seizures or
• The person is injured during the seizure or
• You believe the person needs urgent medical attention

Remember ACTION for tonic-clonic seizures:

<table>
<thead>
<tr>
<th>Assess</th>
<th>Assess the situation – are they in danger of injuring themselves? Remove any nearby objects that could cause injury</th>
</tr>
</thead>
<tbody>
<tr>
<td>Cushion</td>
<td>Cushion their head (with a jumper, for example) to protect them from head injury</td>
</tr>
<tr>
<td>Time</td>
<td>Check the time – if the seizure lasts longer than five minutes you should call an ambulance</td>
</tr>
<tr>
<td>Identity</td>
<td>Look for a medical bracelet or ID card – it may give you information about the person’s seizures and what to do</td>
</tr>
<tr>
<td>Over</td>
<td>Once the seizure is over, put them on their side (in the recovery position). Stay with them and reassure them as they come round</td>
</tr>
<tr>
<td>Never</td>
<td>Never restrain the person, put something in their mouth or try to give them food or drink</td>
</tr>
</tbody>
</table>

If you would like to discuss anything to do with epilepsy-related death, you could speak to an adviser on the Epilepsy Action Helpline, 0808 800 5050 (UK only). You could also contact your family doctor, epilepsy specialist, or epilepsy nurse.

**Status epilepticus**

Many people have seizures that last for less than 5 minutes and stop without any treatment. But some people have seizures that last too long. These are known as status epilepticus and need treating urgently. This is to try and stop them before they cause long-term damage. The sooner the seizure is treated the easier it will be to get it to stop.

By the time a seizure is lasting for 30 minutes or more, it is much more difficult to stop. If a tonic-clonic or cluster of tonic-clonic seizures last longer than 30 minutes, this can cause damage to the brain, or even death.²

Some research suggest that around 16 out of every 100 epilepsy-related deaths are caused by status epilepticus. A study from Northern Ireland suggests that between about 8 and 39

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people out of every 100 who have status epilepticus die. The highest risk is for children and people over the age of 60.

**Reducing the risk of death from status epilepticus**

Around 1 in 20 of all people with epilepsy will have an episode of status epilepticus at some point. These are some possible ways of reducing your risk of status-epilepticus:

- Get the **right treatment and care for your epilepsy** to reduce your risk of seizures
- Don’t reduce or withdraw your epilepsy medicines without advice from your doctor or epilepsy nurse
- Don’t reduce or withdraw any other medicines without advice from your doctor or epilepsy nurse
- Don’t withdraw from drinking alcohol without advice from your doctor or epilepsy nurse if you are dependent on **alcohol**
- Ask your doctor or epilepsy nurse to write a **patient care plan** with you, giving information about how to **treat seizures that last for more than 5 minutes**
- Make other people aware of **how to look after you if you have a tonic-clonic (convulsive) seizure**

**Accidents and how to reduce the risk of epilepsy-related death due to accidents**

Although this information may feel worrying, it’s really important to know about the possible accidents that can lead to an epilepsy-related death. And it’s even more important to know about things you can do to make the risks as low as possible. Injury is a risk you are already likely to know about. But drowning, burning and accidental poisoning are also serious risks. Sometimes these may happen because you are confused during or after a seizure. The best possible way to keep these risks to a minimum is to get the best seizure control possible.

See Epilepsy Action’s information on Getting the **right treatment and care for your epilepsy** to reduce the risk of seizures (and accidents).

None of us can stop all accidents happening. But Epilepsy Action has a range of suggestions that can reduce the risk in different situations:

- Being **safe around the house**
- Taking part safely in **sport and leisure** activities
- **Looking after a young child if you have epilepsy**

**Epilepsy and suicide**

If you have epilepsy there is a higher possibility than the general population that you’ll feel depressed at some point. For some people this can lead to thoughts of suicide. If you’re
feeling depressed it’s really important that you tell someone how you’re feeling. At the end of this section are some places you can try for support.

Some things that may mean you are more likely to feel depressed or suicidal:

- Having an epilepsy medicine that can cause mood swings
- Having temporal lobe epilepsy
- Having difficult to control epilepsy
- Feeling depressed before your epilepsy started
- Having problems with alcohol or drugs

Talking to someone such as your GP, epilepsy specialist nurse or neurologist is the first and most important step in getting some help.

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 0845 790 90 90.

Some useful organisations:

About suicide
NHS Choices website: nhs.uk
Samaritans website: samaritans.org

Depression
Epilepsy Action website: epilepsy.org.uk

Help with alcohol
NHS website: nhs.uk

Help with drugs
NHS website: nhs.uk

Epilepsy medicines and thoughts of suicide
In some countries, the authorities who regulate medicines have described a link between treatment with epilepsy medicines and thoughts of suicide. We don’t know if this increased risk is for people with epilepsy in general, or more likely for people taking certain epilepsy medicines.

Death during pregnancy and up to 6 weeks afterwards (maternal death)
Most women with epilepsy have healthy pregnancies and give birth to healthy babies. However, some women do die during pregnancy or in the first 6 weeks after giving birth.


This affects women who have epilepsy and women who don’t. But the risk is increased slightly if you have epilepsy.\(^5\)

A report published in 2012, *Saving Mothers Lives* investigated the deaths of 14 women with epilepsy who had died during pregnancy in the 3 year period between 2006/2008.\(^6\) The actual cause of death in 11 of the 14 women was classed as Sudden Unexpected Death in Epilepsy (SUDEP). Of the other 3, 1 was from status epilepticus, 1 from a fall and one happened in the bath.\(^7\)

The report recommended that all women of childbearing age who have a medical condition should be offered [pre-conception counselling](#). Pre-conception counselling happens before you get pregnant. For women with epilepsy, it is an appointment with a doctor or nurse who knows about pregnancy and epilepsy. The aim is to make your future pregnancies as healthy as possible.

### Reducing the risk of dying during or shortly after pregnancy

- Try not to get pregnant until after you have had individual advice about any risks to you or your pregnancy. This is known as [pre-conception counselling](#).
- If you are already pregnant, and have not planned to be, don’t stop taking your epilepsy medicine. If you stopped taking it now, it may not make any difference to your baby’s health. But, it could cause you to have more frequent, or severe, seizures. This could cause you to be at risk of status epilepticus or SUDEP.
- If your epilepsy medicine has been changed during your pregnancy, ask for it to be re-assessed following the birth of your baby\(^8\).
- Have your flu jab. This applies to all women, rather than just women with epilepsy. Pregnant women are at increased risk of serious complications and death from flu\(^9\).
- Try to reduce your risk of accidents by considering our [safety information](#) in the [SUDEP Action and the epilepsy deaths register](#).
- If you are feeling depressed or if you have thoughts about harming yourself, speak to your family doctor, midwife, epilepsy specialist or epilepsy specialist nurse straight away. You can also speak with the [Samaritans](#).

### SUDEP Action and the epilepsy deaths register

SUDEP Action is an organisation that:

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• Provides information on sudden unexpected death in epilepsy
• Offers support when someone has died
• Involves people to help make change happen
• Sponsors research and education to prevent future deaths
• Captures data across the UK through the epilepsy deaths register

The epilepsy deaths register
The epilepsy deaths register has the potential to save lives and improve services for people with epilepsy. Researchers, doctors, government and local health and social services urgently need information if they are to:

• Reduce epilepsy-related death
• Decide where best to put funding to improve services for people with epilepsy
• Improve public awareness of epilepsy-related risk, including sudden unexpected death in epilepsy (SUDEP).
• Improve epilepsy advice and treatment plans
• Identify and prioritise new research
• Improve public awareness of epilepsy-related risk, including SUDEP

The epilepsy deaths register is a central reporting system where information about any epilepsy-related death can be registered. If you have been affected by an epilepsy-related death you can contact the register here.

Help and support for people who have been affected by an epilepsy-related death
If someone you know has died from an epilepsy-related death, you are likely to 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:

SUDEP Action
SUDEP Action’s support team can help you to understand:

• The inquest procedure
• The investigations
• What is going on for you emotionally

Tel: 01235 772 852
Email: support@sudep.org
Website: sudep.org

Cruse Bereavement Care
Cruse Bereavement Care will support you after the death of someone close.
Tel: 0844 477 9400
Help is at Hand
The Suicide Bereavement Support Partnership (SBSP) produce 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
SBSP can be contacted through an online form on their website

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 there is anything you would like to say about the information, please contact us at epilepsy.org.uk/feedback

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

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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.

- Visit www.epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- 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 Action Helpline
Freephone 0808 800 5050, text 0753 741 0044, email helpline@epilepsy.org.uk, tweet @epilepsyadvice

Contact details
Epilepsy Action, Gate Way Drive, Yeadon, Leeds LS19 7XY, UK, +44 (0)113 210 8800. A registered charity (No. 234343) and company limited by guarantee (No. 797997) in England.
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