Sudden unexpected death in epilepsy (SUDEP)

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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 could feel shocked, confused, isolated and unable to believe what has happened. There may be questions you need answering, to help you to understand. 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
• Understand the investigations
• Understand what is going on for you emotionally

Tel: 01235 772852
Email: support@sudep.org
Website: www.sudep.org

Cruse Bereavement Care
Cruse Bereavement Care will support you after the death of someone close.
Tel: 0844 477 9400
Email: helpline@cruse.org.uk
Website: www.cruse.org.uk

Why it’s important to talk about SUDEP
Epilepsy Action believes that it is very important for people with epilepsy and their families to be aware of the risks associated with epilepsy. This information is about one significant risk, and that is sudden death due to epilepsy.

It is important to remember that the risks of dying because of epilepsy are low. There are also things you can do to make the risks even lower.
Many people who knew somebody who died due to SUDEP have told us they wished they had known more about the risks, before the person died. Therefore, the aim of this information 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.

There have been many studies carried out into SUDEP and research is continuing. However, SUDEP is still not fully understood by medical professionals. In this information, we can only tell you about the current understanding of SUDEP.

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

The definition of SUDEP
If a person with epilepsy dies suddenly and unexpectedly, and no obvious cause of death can be found, it is called sudden unexpected death in epilepsy (SUDEP).\(^1\) Sometimes, it is called sudden unexplained death in epilepsy.

The causes of SUDEP
SUDEP has been shown to be connected with 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.\(^2\)

Risk factors of SUDEP
It is estimated that SUDEP happens to one in every 1,000 people with epilepsy.\(^3\) There is no way of predicting who will be affected by SUDEP. However, some people with epilepsy have a higher risk of SUDEP than others. The single most important risk factor is uncontrolled generalised tonic-clonic seizures.\(^4\) This is a type of seizure that causes the person to lose consciousness. Their body goes stiff and then starts jerking.

SUDEP has occurred in people who had seizures very often, and also in people who did not have them very often. However, the risk is thought to be higher, the more

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seizures you have. The risk of SUDEP if you are seizure-free is very, very low. And, SUDEP is rare in people who are newly diagnosed with epilepsy.

Any of the following things are thought to increase a person’s risk of SUDEP.

- Having uncontrolled generalised tonic-clonic seizures
- Not taking epilepsy medicines as prescribed
- Having seizures that are not controlled by epilepsy medicines
- Having sudden and frequent changes to epilepsy medicines
- 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 epilepsy medicines as prescribed.
- Never stop taking your epilepsy medicines, or make changes to them, without talking to your doctor first.
- Make sure that you never run out of your epilepsy medicines.

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- Ask your epilepsy specialist or epilepsy nurse in advance what you should do if you ever forget to take your epilepsy medicines.
- If your seizures continue, 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.
- 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 triggers your seizures.
- Avoid situations which may trigger your seizures. Common triggers include forgetting to take epilepsy medicines, lack of sleep, stress and too much alcohol.
- If your epilepsy is very difficult to control, ask your specialist if you could be referred to a specialist epilepsy centre for treatment. Contact Epilepsy Action for more information about this.

Epilepsy Action has more information about epilepsy medicines, surgery, seizure diaries and seizure triggers.

**Other ways to reduce risk**
- If your seizures happen at night, consider using a bed alarm, which can alert another person if you have a seizure. This will enable 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 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.)

Information about bed alarms is available from the Disabled Living Foundation:
Tel: 0845 130 9177
Website: dlf.org.uk
- Tell people about your epilepsy and let them know how they can help you if you have a seizure. You may choose to wear identity jewellery or carry some form of epilepsy awareness card to make other people aware of your epilepsy.

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• 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. For example, you may choose to live with other people.

Epilepsy Action has more information about safety and epilepsy, alarms for epilepsy, identity jewellery and epilepsy awareness cards.

**Ways to help someone who is having a seizure**

You may be with someone when they have a seizure which causes them to lose consciousness. Here are some things you can do to help them recover. Your actions may also reduce the risks of SUDEP.

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**Call 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

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Further information about SUDEP and bereavement

SUDEP Action
SUDEP Action 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 772852
Email: support@sudep.org
Website: www.sudep.org

NHS.uk
If you would like more information about dealing with bereavement, go to nhs.uk
http://www.nhs.uk/Livewell/bereavement/Pages/coping-with-bereavement.aspx

About this publication
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

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

Our thanks
Epilepsy Action would like to thank Dr Lina Nashef, consultant neurologist at Kings College Hospital, UK for her contribution to this information. Dr Lina Nashef has no conflict of interest to declare.

Date: Jan 14
Due for review: Jan 2016
Code: F006.04

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 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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