

**epilepsy  
society**

# **risk**

Does my epilepsy put me at risk?



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This symbol means further information is available.

You can find any further updates at  
[epilepsysociety.org.uk/risks-epilepsy](https://epilepsysociety.org.uk/risks-epilepsy)

Call us for a large print version

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## helpline

**01494 601 400**

Confidential, national call rate.

Information and emotional support.

# does my epilepsy put me at risk?

In all areas of our lives we take risks, but some risks we worry about more than others. Risk is the chance of something happening such as loss or injury, and so risk is often about uncertainty. Sometimes, taking a risk can mean trying something new and challenging yourself in a positive way. But it can also mean the chance of injury, danger, or damage to your health.

Epilepsy varies greatly from person to person, so risks due to epilepsy may depend on:

- whether you currently have seizures;
- the number and type of seizures you have;
- how your seizures affect you; and
- whether you have other medical conditions, such as heart or breathing problems.

Possible risks to your health and safety can be difficult or frightening to think about. But looking at risks can also be positive if this helps you to find ways of reducing risk or making activities safer. It may also make you feel more in control and help you to work out what risks are relevant to your situation, so that you can see what is important *for you*.

People may also face specific risks because of their epilepsy, such as the risk of accident or injury. Looking at ways of managing risk may help you do the things you enjoy and be as independent as possible while still keeping safe (see page 5).

## **making choices about risk**

Everyone is different. You may find it helpful to look at your own situation to see what you think the risks are to you because of your seizures. Being involved in making decisions about things that affect you may help you to feel more in control of your epilepsy and confident about making decisions in the future.

Depending on your age and situation, you might want to include other people when making decisions, such as your parents, partner, or carer, and your social care or healthcare professionals.

## **getting good seizure control**

Often the best way to reduce risks due to epilepsy is to stop seizures happening, or reduce the number of seizures as much as possible. For most people, this is by taking anti-epileptic drugs (AEDs) as prescribed.

To work best, AEDs need to be taken every day. Using a pill box or drug wallet can help you to remember when to take your medication.

Some medication affects how other medications work, which can affect seizures. It is a good idea to check with your doctor or pharmacist before taking other medications alongside your AEDs.

As with any medication, AEDs can have side effects. Possible side effects include tiredness, confusion, and changes in mood.

For some people these side effects mean that they don't want to continue taking their AEDs. But suddenly stopping AEDs can cause seizures to happen again.

If you continue to have seizures even with AEDs, or you are having side effects, you can talk to your doctor, pharmacist, or neurologist about it. There may be other AEDs or doses you can try or other types of treatment may be an option.



**See our factsheet *making the most of your pharmacist and our booklet medication for epilepsy.***

Some people have triggers for their seizures: situations that bring on a seizure such as stress or tiredness. If you know you have a trigger for your seizures you might be able to avoid the trigger so that you have fewer seizures.

## staying safe

It is often worth remembering that some activities have risks whether you have epilepsy or not.

Making an activity or environment safer will often depend on how your seizures affect you, and what the activity or environment is.

For example, at home, safety measures might include looking at risks around cooking, fire safety, and bathing. Other activities such as cycling or swimming may be safer if you have someone with you who knows how to help if you have a seizure.



**See our leaflets *safety and leisure*.**

Telling people how your seizures affect you may mean they feel more confident helping you to keep safe, and know what to do if you have a seizure. Some people carry an ID card that says that they have epilepsy and how to help during a seizure. There are also companies that make medical jewellery.



**Call our helpline for a free 'I have epilepsy' ID card, or, for more information on medical jewellery, visit [livingmadeeasy.org.uk](http://livingmadeeasy.org.uk)**

## **safety aids and equipment**

### **Seizure alarms and monitors**

Some people choose to have an alarm, which is set off when they have a seizure, to get help. This can be helpful if you have seizures during the night or if you live alone. There are different types of alarm for different types of seizure. Some are set off when someone falls in a seizure, or has a tonic clonic seizure in bed, and others can be set off by the person themselves if they feel a seizure coming on.

### **Safety pillows and helmets**

Some people who have seizures during the night use safety, or 'anti-suffocation', pillows. These pillows have small holes in them so that, if someone is lying face down during a seizure, they may be able to breathe more easily. However, there is no evidence that they are safer than ordinary pillows.

Safety helmets help to protect someone from injury if their seizures cause them to fall suddenly. Some helmets have face guards to protect the face if the person falls forwards.



**Call our helpline for more information.**

## risk assessments

Risk assessments may be useful at work or school, for leisure activities, or for ways to make the home safer. You might want to do a risk assessment yourself, or it may be appropriate that a carer, an employer, an occupational health worker, or someone from social services does this with you.

A risk assessment would normally include looking at whether you have seizures or not, how your seizures affect you, and what the environment or activity is.

A risk assessment might include the following:

- What is the activity?
- What are the risks to safety for *anyone* doing this activity?
- What is it about your epilepsy that may put you, or other people, at risk (depending on the type of seizure you have)?
- What would make the activity safer?

Risk assessments can help to identify practical ideas for reducing risk to make situations safer.



**Visit [epilepsysociety.org.uk/risk-assessment](https://www.epilepsysociety.org.uk/risk-assessment)**

## women and risk

Some issues around risk are specific to girls and women with epilepsy. This depends on their age, the type and number of seizures, and any medication they are on.

Hormone levels change during puberty, periods, pregnancy, and through the menopause. For some girls and women, there is a link between hormones and when they have seizures. This means that they may be more likely to have seizures, and be at greater risk of injury because of seizures, at these times.

There are specific issues around pregnancy for women with epilepsy. Women with epilepsy who take AEDs during pregnancy can have a slightly higher risk of having a baby with a birth abnormality or developmental problem than women with epilepsy who don't take AEDs. Different AEDs vary in the risk they pose.

However, it is important not to stop taking any AEDs without speaking to your doctor first.

The Medicines and Healthcare products Regulatory Agency (MHRA) states that sodium valproate should not be prescribed to girls or women who are pregnant, or who may become pregnant in future, **unless** it is the only effective drug for them and they are on a pregnancy prevention programme.

This risk needs to be balanced with the risk of injury to the mother and baby if seizures are not controlled with medication. In rare cases, risks of uncontrolled seizures can mean very





serious injury, or even death. Because these issues are often complicated and specific to each woman, it is important that women talk to their epilepsy specialist *before* becoming pregnant.

This is called 'preconception counselling' and focuses on making sure AED treatment is right, for the mother to get the best seizure control, and for the baby.



**See our leaflets *women and pregnancy and parenting and medication for epilepsy.***

## can seizures damage the brain?

Everyone has some brain cell loss as they get older. Whether seizures cause any extra loss of brain cells is not clear. This may depend on the type and length of seizure that the person has.

Memory can be affected during or after a seizure. This can be because brain cells in parts of the brain responsible for memory can be sensitive to the effect of seizures. How long it takes to recover can vary from one person to another, and even after fully recovering from a seizure some people's memory might be permanently affected.

If you are worried about this, you might like to talk to your neurologist or doctor about how your epilepsy might affect you.



**See our leaflet *memory.***

## how serious can risks be?

As with many other medical conditions, for some people there is a risk of dying due to their epilepsy. In the UK there are around 1,200 deaths related to epilepsy per year. Some of these deaths are caused by complications during or after a seizure. Other deaths may be due to accidents, such as falls or drowning, suicide, or they may be linked to another condition that a person may have alongside their epilepsy.

### **What is status epilepticus?**

Usually a seizure will stop by itself. Sometimes this does not happen and a seizure is very long or one seizure happens after another without the person recovering in between. If this carries on for five minutes or more, it is called status epilepticus (or 'status').

If status happens in a tonic clonic seizure (where people fall down and shake) this is a medical emergency and an ambulance needs to be called immediately. Emergency medication may need to be given to stop the seizure. If a tonic clonic seizure goes on for 30 minutes or more, this could cause lasting damage to the brain, or even death.

### **An ambulance should be called if:**

- it is the person's first seizure;
- they have injured themselves badly;
- they have trouble breathing after the seizure;
- one seizure immediately follows another with no recovery in between;
- the seizure lasts **two minutes longer than is usual** for them; or
- the seizure lasts for **more than five minutes**.



See our leaflet *first aid* and our factsheet *the recovery position* or visit [epilepsysociety.org.uk/recovery-position](http://epilepsysociety.org.uk/recovery-position).

### **What is SUDEP?**

On rare occasions people die suddenly for no clear reason. When this happens to someone with epilepsy it may be called sudden unexpected death in epilepsy (or 'SUDEP').

SUDEP is when a person with epilepsy dies suddenly and where no other cause of death is found. It may be that they died during or after a seizure. Because SUDEP often happens when the person is asleep and is not witnessed, it is hard to be sure why it happens. It may be that during a seizure the person's breathing or heartbeat have been affected.

In the UK around 600 people die from SUDEP each year. This is 1 in 1000 people with epilepsy, so SUDEP is relatively rare.

But these figures do not show the *risk* of SUDEP for *an individual* because everyone's individual level of risk may depend on their epilepsy, lifestyle, any conditions they have alongside epilepsy, and other factors, such as their age and sex.

Research shows that SUDEP is related to seizures. So a key way to reduce the risk is to try to get the best seizure control possible, in particular for tonic clonic seizures.

Things that can help reduce risks of SUDEP include:

- taking your AEDs as prescribed;
- avoiding sudden changes to your AEDs;
- having good seizure control especially at night, and using a seizure alarm if you have seizures at night (see page 6); and
- having regular reviews with your doctor or specialist to monitor your epilepsy and your general health.

Your specialist can discuss with you your individual epilepsy, and whether these risks apply to you.

## quality of life

Many people with epilepsy enjoy a full and active life. But for some, epilepsy may affect their health and quality of life more than just because of having seizures: their epilepsy may come alongside anxiety, stress, or depression.

Not everyone with epilepsy has anxiety or depression, but they are the most commonly reported mental health problems in people with epilepsy. Epilepsy can make anxiety or depression worse due to not knowing when seizures will happen, concerns about side effects of medication, or feeling isolated. Everyone is different in how they cope with anxiety or depression, but this may increase the risk of long-term problems or even suicide.

If you feel that your epilepsy affects your wellbeing or quality of life, you may be able to get support through your GP, a counsellor, an epilepsy specialist nurse, or a helpline.



**Contact our helpline for support (see back page for details), see our booklet *the bigger picture* and our factsheet *finding support*.**

If you would like to contact other people who have epilepsy there are some support groups in the UK.



**Contact our helpline for details of support groups.**

Self management UK runs free courses in the UK for anyone living with a long-term condition. The courses cover quality of life issues such as wellbeing, self-esteem, depression and anxiety.



**Call 0333 445 840**

**or visit [selfmanagementuk.org](https://selfmanagementuk.org)**

## who can I talk to?

If you are concerned about anything you have read in this leaflet, it is worth remembering that not all of these risks may apply to you. Risks depend on the type and number of seizures you have, and how they affect you.

There may also be things you can do to help reduce your risks. You could also talk to your doctor or specialist about any concerns.

If you would like to talk to someone in confidence about what you have read, you can call our helpline (see back page).



## further information

### **Epilepsy Society information**

The Bigger Picture – epilepsy and mood

Finding support

First aid

‘I have epilepsy’ ID card

Leisure

Making the most of your pharmacist

Medication for epilepsy

Memory  
Pregnancy and parenting  
The recovery position  
Risk assessment  
Safety  
Seizures  
Women

## other organisations

Disabled Living Foundation

Helpline 0300 999 0004

**[livingmadeeasy.org.uk](http://livingmadeeasy.org.uk)**

UK charity providing information and advice on alarms, safety and living and medication aids and suppliers.

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.



**epilepsysociety.org.uk**

A full life for everyone affected by epilepsy.

## **research**

Pioneering medical research.

## **treatment and care**

Individualised medical and care services.

## **information**

Website, leaflets, factsheets.

## **education**

Training for individuals and professionals.

## **connect with us**



Volunteer, become a member, fundraise.

## **helpline** 01494 601 400

Confidential, national call rate.

Information and emotional support.

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