

Keeping safe and avoiding risks



Everyone is different and other people may have different experiences to you. Things that affect them may not be an issue for you.

Visit epilepsysociety.org.uk/epileptic-seizures

Completing a risk assessment can be one way to identify possible risks for an activity and practical ideas to help make an activity safer. You can also ask your local social services for a health and social care assessment (needs assessment) which looks at your safety at home. Your GP or specialist can discuss how your epilepsy could affect your safety.

Visit gov.uk/apply-needs-assessment-social-services or contact your local council.

Alarms and monitors

Some people with epilepsy choose to have an alarm, or monitor, to get help when they have a seizure. This can be helpful if you have seizures at night or if you live alone.

There are different types of alarm for different types of seizures. Some have a button to press if you know that a seizure is going to happen. Others are triggered if you fall with no warning, or shake or jerk during a seizure.

Alarm systems may be available through social services or housing associations as part of a 'needs assessment', and some alarms can be linked to a community alarm service.

Having a key safe outside your front door means others can get in to help you.

Visit epilepsysociety.org.uk/alarms-and-safety-aids and livingmadeeasy.org.uk

Safety aids

Safety helmets help to protect from injury if someone's seizures cause them to fall. Some have face guards to protect your face, if you fall forwards.

Around the house

Some safety issues may not be relevant to you, or you may have your own ideas about what would make situations safer for you. Here are some ideas to help make things safer at home.

Fire safety

If you have a seizure while cooking, smoking or vaping, there is a risk of fire. The UK Fire Service recommends that everyone has a smoke alarm on each level of their home, and that the batteries are checked regularly.

Fire-resistant fabrics and furniture are recommended for everyone but will still catch fire if the heat is intense enough.

Your local fire and rescue service can provide a free fire safety check for your home.

Visit fireservice.co.uk

Floors and furnishings

Some types of hard flooring, such as ceramic tiles, could injure you if you fall on them.

- Anti-slip flooring, linoleum (lino), cushioned flooring, or carpet may reduce the risk of an injury if you fall.
- Cushioning underneath carpets, such as padded underlay, may reduce the risk of injuries further.
- Keeping floors clear of clutter may help.
- Avoiding coarse fabrics may help to reduce the risk of friction burns if you have seizures where you shake or jerk.
- Using protective corners on sharp edges of furniture, or having furniture with rounded edges, may reduce injury if you fall against it.

Keeping safe is important for everyone, whether or not they have epilepsy. If your seizures are controlled by treatment, your safety may not be affected. But if you continue to have seizures, safety may be an issue.

Helpline 0300 102 0024
Confidential, information, and emotional support.
Visit epilepsysociety.org.uk/helpline for opening hours.

Glass

- Try to avoid glass furniture, such as tables, if possible, as it can cause injury if you fall on it and it breaks. Homes built since 1994 in the UK use safety glass for windows to reduce the risk of injuries. Safety glass is designed to be difficult to break or to hold together if it is broken.
- Replacing glass in older buildings with safety glass might be helpful. Safety glass film can prevent glass shattering if it gets broken. It can be fitted onto glass doors and windows, and may be available from some glazing companies and online suppliers.

Heating your home

- Radiator covers may reduce injury and burns if you fall against them during a seizure.
- Using heaters that are secured to the wall or floor means you can't knock them over.
- Open fires and gas fires are best avoided.
- Covering hot pipes can prevent injury if you grip them or fall against them.

Stairs

- Depending on how your seizures affect you, you may want to consider living on one level. Some people may have the option of a toilet, bathroom, or bedroom downstairs, to reduce the need for using the stairs.
- Going up the stairs on your hands and feet, and coming down the stairs on your bottom, may reduce risks of injury if a seizure happens.

Medication

- It is best to keep medication locked away or out of reach.
- The 'message in a bottle' scheme, allows you to keep personal and medical details in a special bottle in your fridge. Bottles are available from GP surgeries, pharmacies, or from the Lions Club.

Visit lionsmessageinabottle.co.uk

Visit epilepsysociety.org.uk/medication

In the kitchen

There may be particular risks in the kitchen because of things that get very hot like cookers and kettles.

Cooking

- Microwave ovens are safer than conventional ovens as they turn off automatically after the cooking time has ended. This means there is less chance of food burning or a fire starting if you leave it unattended. The outside of a microwave may stay cool, so it is less likely than an oven to cause burns if touched.
- Modern air fryers come with safety features such as auto shut-off, overheat protection, and cool-touch exteriors to make cooking safer.
- Turning pan handles to the side can help prevent pans being knocked off the cooker.
- Using rings or burners at the back of the hob can be safer than using those at the front.
- Induction hobs only heat up when a pan is placed onto the hob ring or plate, making them safer than gas hobs.
- Some cookers have an automatic switch-off feature if the hob is accidentally left on or covered by an object such as clothing.
- A cooker guard around the front of the hob means that rings or burners are harder to touch by accident. This may reduce the risk of burns if you lose some awareness during your seizures. However, if you fall during a seizure, a cooker guard could cause injury if you fall onto it, depending on the design.
- Using a low-level grill instead of an eye-level grill can help to reduce the risk of injuring your face if you have a seizure.
- Having a heat resistant work surface means that you may be able to slide heavy pans across it rather than lifting them.
- Using a cooking basket inside a pan means you can lift the basket out after cooking and the hot water drains back into the pan.
- Using a trolley to transfer food from the oven to the table means that you don't have to carry hot or heavy dishes.

Making hot drinks

- Cordless kettles that switch off automatically and have a lid that 'locks' shut can help prevent scalds.
- A kettle tipper (cradle) helps you to pour hot water without lifting the kettle.
- Thermal mugs with lids can help to protect you if you spill a hot drink during a seizure.

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- Drinks can be heated in a microwave. Stirring the drink will prevent any uneven 'hot spots' which could burn your mouth.

Ironing

- Using a tumble dryer may help to reduce the need for ironing.
- Cordless irons that switch off automatically after a set time, and have no cable to trip over, can reduce the risk of burns if you have a seizure while ironing.

In the bathroom

There are a number of things that can be done, or put in place, to make things safer in the bathroom.

Doors, locks, containers, and flooring

- Doors that open outwards can make it easier for other people to get to you if you have a seizure and need help. An alternative is a concertina door, or one that slides sideways.
- Locks that can be opened from the outside, or an "Engaged" sign on the door instead of a lock, allow privacy but means that the door can be opened if you need help.
- Plastic containers for toiletries, rather than glass, may help reduce injuries if you knock them over. Rubber or anti-slip flooring may be safer than tiled floors.
- Floor tiles made of rubber or anti-slip flooring may be safer than tiled floors.

Showers

Having a shower can be safer than having a bath because the water drains away. This significantly reduces the risk of drowning. If you are choosing a new shower or changing your existing one, the following tips may help:

- Walk-in showers give easy access and have fewer hard surfaces to fall against, such as the side of a bath.
- Avoid showers with high-sided bases as the water level can rise if the drain is covered.
- A shower curtain, rather than a screen or door, might make it easier for someone to get to you quickly if you have a seizure. If there is a cubicle door, it is safer if it opens outwards.
- A shower seat may help reduce the risk of injury if you fall during a seizure.
- Soap trays set into the wall (instead of sticking out) and anti-slip shower mats can also help.

Baths

Having a bath carries higher risks than having a shower. If you have no shower, then the following may help to reduce risks:

- Having a bath when there is someone else around means that they can help you if you have a seizure.
- A listening monitor (such as a baby monitor) might make it easier for someone outside the room to hear that you are OK, while still giving you privacy.
- Running a shallow bath and putting cold water in first can help prevent scalds if you have a seizure and fall into the water.
- Fitting thermostatically controlled taps means that the water will not get too hot. A qualified plumber can fit these for you.

Visit livingmadeeasy.org.uk or ridc.org.uk

In the bedroom

If you have seizures while you are asleep there may be a number of things to consider.

Beds

- If there is a risk of you falling out of bed during a seizure, having a low-level bed, or a mattress on the floor, may reduce injuries.
- Sleeping in the middle of a large bed also reduces the risk of falling out of bed during a seizure.
- Padded bed sides may help prevent injuries during a seizure or stop you falling out of bed. However, these should be considered with care as it is possible for your arms or legs to become trapped or injured, depending on the design of the bed sides and how your seizures affect you. The Medicines and Healthcare products Regulatory Agency (MHRA) advises that a risk assessment should be carried out before fitting bed sides, to make sure that they are right for your needs, and that they fit your mattress and bed safely.
- Some people who have seizures during the night may have a bed alarm that detects when they have a seizure.

Safety when sleeping

- Safety pillows have small holes in so that if you are sleeping face down you may be able to breathe more easily. However, there is no evidence that they are safer than ordinary pillows.

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Gardening and DIY

If you have seizures, it may be helpful to think about the type and frequency of your seizures and the potential risks of each job, and whether someone else could do it for you.

Knowing your own abilities may help reduce the risks of accidents or injuries. If you are not sure about doing a job yourself, you may want to talk to a professional such as an electrician, plumber, or gardener.

DIY

For anyone doing DIY it is important to take proper safety measures. If you have seizures, there may be other safety issues to consider.

For example, if you need to do a job at a height using a ladder, it is important to think about the risk of falling if you have a seizure.

Power tools that have a safety cut-out and use batteries, rather than mains power, may be safer, as there is no power cord to damage if you have a seizure while using them. Using a circuit breaker can help protect against the risk of electrocution.

Gardening

- Grass or bark chippings are a softer alternative to concrete or gravel and may reduce the risk of a severe injury if you fall.
- Using artificial grass means there is no need to use a lawn mower.
- Using a petrol lawn mower means there is no chance of cutting through the cable if you have a seizure.
- Some mowers will stop automatically when the handle is released. If you do use an electric mower, a circuit breaker at the plug helps protect against electrocution. Cordless or battery mowers may be safer.

Ponds

- If you have a pond, having it near the house can make it easier for someone to see and help you if you have a seizure and fall in.
- Having a fence around it can provide a safety barrier.
- It may be possible to fit a safety grid that sits just below the surface of the water. This can hold your weight if you fall on it without spoiling the look of the pond.

Seizure alert dogs

Support Dogs UK train dogs to support owners with specific needs. Seizure alert dogs are specially trained to warn their owner before a seizure starts, so they can get help or move to somewhere safe.

Training with a seizure alert dog can be intensive and you need to be having a certain number of seizures to apply. Support Dogs are not able to train your own pet dog.

[Visit supportdogs.org.uk](https://supportdogs.org.uk) or call 0114 261 7800

Needs assessment

Your local council's social services may be able to help by assessing your needs; this includes a risk assessment. Assessments are often carried out by an Occupational Therapist (OT), who will visit you at home to see what help, support, or adaptations you might need because of your epilepsy.

The assessment aims to identify practical ways to reduce risks and make situations safer, to meet your individual needs. You can also ask your GP to refer you.

[Visit epilepsysociety.org.uk/what-help-available](https://epilepsysociety.org.uk/what-help-available)

Out and about

Some people with epilepsy may worry about having a seizure when out and about and they may choose to wear or carry something with them that says they have epilepsy. Epilepsy Society produces a free 'I have epilepsy' card. You can write details about the type of seizures you have, your medication, if you would like someone to be contacted, and how you would like to be helped if you have a seizure.

Other companies provide medical jewellery with your details on, or a phone number where further information can be given. These can be helpful if you are taken to hospital as doctors will be able to get information about your epilepsy and medication.

[Call our helpline for a free ID card or download at epilepsysociety.org.uk/medical-id-cards-and-jewellery](https://epilepsysociety.org.uk/medical-id-cards-and-jewellery)

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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.

Looking at ways of managing risk may help you do things you enjoy and be as independent as possible while still keeping safe.

Making choices about risk

Everyone is different. 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 situation, you might want to include others when making decisions, such as your parents, partner, or carer, and your health or social care professionals.

Activities such as swimming and cycling may be safer if you have someone with you who knows how to help if you have a seizure. 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.

Visit epilepsysociety.org.uk/exercise-and-sport

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-seizure medication (ASM) as prescribed.

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

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 ASM.

As with any medication, ASM 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 ASM. But suddenly stopping ASM can cause seizures to happen again.

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

Visit epilepsysociety.org.uk/medication and epilepsysociety.org.uk/making-most-your-pharmacist

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 you might be able to avoid it so that you have fewer seizures.

Risk assessments

Risk assessments may be useful at work or school, for leisure activities, or for ways to make your home safer. You might want to assess risks for yourself, or it may be appropriate that a carer, employer, occupational therapist, or someone from social services does this with you.

A risk assessment normally includes 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:

- 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?
- What would make the activity safer?

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

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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 they have, and any medication they take.

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

Visit epilepsysociety.org.uk/women-and-girls

Can seizures damage the brain?

Everyone has 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 a person has.

Memory can be affected during or after a seizure 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 find their memory is 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.

Visit epilepsysociety.org.uk/memory

Anti-seizure medication and risk

There are particular risks for women and men taking certain anti-seizure medication (ASM).

Pregnancy

There are specific issues around pregnancy for women with epilepsy. Women with epilepsy who take ASMs during pregnancy can have a higher risk of having a baby with a birth abnormality or developmental problem than women with epilepsy who don't take ASMs.

Different ASMs vary in the risk they pose.

Visit epilepsysociety.org.uk/starting-a-family

It is important not to stop taking any ASMs without speaking to your doctor first.

The MHRA states that sodium valproate should not be prescribed to girls or women under the age of 55, 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 'pre-conception counselling' and focuses on making sure ASM treatment is right, for the mother to get the best seizure control, and for the baby.

Visit epilepsysociety.org.uk/starting-a-family

Risks for men

Due to concerns about the link between sodium valproate and the risk of impaired male fertility, from January 2024 men under the age of 55 should not be started on sodium valproate.

If possible, men who take sodium valproate should change to another ASM unless a specialist decides that there is no other effective treatment or the risks do not apply.

These changes follow a review of safety information relating to sodium valproate.

Visit epilepsysociety.org.uk/sodium-valproate

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 1,000 deaths related to epilepsy per year. Some of these deaths are caused by complications during or after a seizure. Others may be due to accidents, such as falls, 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 stops 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').

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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
- you do not know how long their seizures last.

Visit epilepsysociety.org.uk/first-aid and 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.

Visit epilepsysociety.org.uk/sudep

Mental wellbeing

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 it 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 confidential helpline for support or visit epilepsysociety.org.uk/mental-health-epilepsy or epilepsysociety.org.uk/finding-support

If you are concerned about anything you have read here, 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.



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Epilepsy Society is grateful to Dr F J Rugg-Gunn, Consultant Neurologist & Honorary Associate Professor, Clinical Lead, Chalfont Centre for Epilepsy, who reviewed this information.

For a printed copy of this information contact our helpline.

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