

# Safety advice for people with epilepsy



# Epilepsy Action – together we can change lives

Together we can help more people gain the knowledge and confidence to live better with epilepsy. We can raise awareness, so that more people understand epilepsy.

Together we can:

- Provide expert information and advice, so everyone affected by epilepsy can get the support they need to live better with epilepsy
- Run local events and support groups, so that fewer people have to face epilepsy alone
- Campaign to help make sure health services and national policies take into account the needs of everyone living with epilepsy

**It's only your support that can make this life-changing work possible.**

**Please donate today.**

You can call the Epilepsy Action fundraising team on 0113 210 8851 or donate online at **[epilepsy.org.uk/donate](https://epilepsy.org.uk/donate)**  
You can also stay up-to-date with all the latest epilepsy news and information by joining Epilepsy Action. Membership starts from just £1 a month - join today by calling 0113 210 8800 or sign up online at **[epilepsy.org.uk/join](https://epilepsy.org.uk/join)**

Thank you.



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## Introduction

This information looks at possible risks in and outside the home if you have epilepsy. It describes how to do a safety check. It covers how you approach risk and how to help yourself feel more confident about going out. Finally it offers some practical tips on staying safe wherever you are.



# Epilepsy and safety: frequently asked questions

## Do I need to think about safety differently from other people?

Epilepsy can come with some risks to safety. However, by putting some safety measures in place, you can lower this risk. There are many activities and situations that carry some sort of risk, even if you don't have epilepsy. But people still do these activities – otherwise no-one would ever cross the road! Like anyone else, you might decide the benefits of doing a particular activity outweigh any risk.

## How could my seizures put me at risk?

If you have epilepsy, your seizures can put you at greater risk of accidents or injuries. During an epileptic seizure, you might fall down, lose consciousness, or have muscle movements that you can't control. All of these can put you at risk of physical injuries such as:

- Bruises
- Burns and scalds
- Cuts
- Drowning
- Fractures
- Head injuries

## Which are the riskiest situations?

- Heights
- Sources of heat or power
- Water

## **Does everyone with epilepsy have the same level of risk?**

Not everyone with epilepsy has the same level of risk. For example, someone who has seizure control may not be at any more risk than a person who doesn't have epilepsy.

But someone who has lots of unpredictable tonic-clonic seizures may be more at risk.

The risk of accidents or injuries depends on:

- What happens during your seizure
- Where you are
- What you are doing
- Who you are with

As well as accidents or injuries, you can also be at risk of sudden unexpected death in epilepsy (SUDEP). Some people seem to be more at risk than others. Epilepsy Action has separate information about this, including ways those risks can be reduced.

## **How do I decide if there's a risk for me?**

A risk for one person with epilepsy may not be a risk for another person. Some people prefer to take some risks. Other people prefer to stay as safe as possible. You'll need to find a balance between your quality of life and staying safe. And then you can make a choice that is right for you.

## What do I do if someone else sees the level of risk differently?

It is likely that different people will see risk differently. This is especially likely with members of your family. It is understandable if they feel anxious for you. But once you're an adult, the choice between quality of life and safety has to be yours. It may help to let them know you're aware of their anxiety. And it would be good to see if, together, you can find a way for them to feel less anxious. This might include agreeing to take a friend with you somewhere, or texting them every so often while you're out, for example. See *safety outside your home* on page 19 for more suggestions.

## How do I do a safety check?

A safety check helps you decide whether something is safe for you personally. And if there are risks, it helps you work out what could be done to make that activity safe enough for you to do. It doesn't need to be complicated. All you need to do is:

- Think about your seizures – what happens, how often they happen, specific triggers
- Keep a seizure diary or download an app to help get any information about patterns or triggers. Knowing about triggers and patterns can offer some useful information about how to make an activity safe for you
- Think about what the risks would be if you had a seizure
- Make a plan to do things that reduce those risks

Here are some questions to help with a safety check.

## **Safety check questions**

### **What is the activity/situation?**

- When and where will the activity happen?
- Will there be other people with you?
- Will there be any potentially dangerous tools or equipment involved?
- How far would you be from help, if you needed it?

### **What is it about your seizures that may put you at risk?**

- What happens when you have a seizure?
- How long do your seizures last?
- How often do you have seizures?
- Do your seizures follow any kind of pattern?
- Do you have any triggers?
- Do you get a warning before a seizure?
- How quickly and well do you recover from a seizure?

### **What can you do to make this activity safer for you?**

- Do you need someone to be with you?
- Do you need any extra equipment?
- Do you need the activity to be changed in any way?
- Do you need any changes to the environment?

### **Do you have to decide not to do the activity?**



# Practical guidance on staying safe

## Funding

Some of the equipment we mention here may be quite expensive for you to be able to put in place by yourself. Or it may just not be practical in your home. For example there may not be enough room. You may be able to get some help with making your home safer from your local authority, if they think that you need it. This would usually involve an assessment by an occupational therapist. You could ask for this through your family doctor, your local social services agency or you could contact an occupational therapist directly. All the details are online.

Website: [nhs.uk/conditions/occupational-therapy](https://nhs.uk/conditions/occupational-therapy)

It's also possible to ask your local social services department for a needs assessment. As well as looking at any changes you may need in the home, this should include other forms of possible support. For parents, it could be someone being with you while you bath your baby.

Website: [nhs.uk/conditions/social-care-and-support-guide](https://nhs.uk/conditions/social-care-and-support-guide)

# Safety around your home

## General safety at home

If you live alone, think about getting a key safe. This is a locked box fitted by your front door. You keep a spare front door key in there. A code is needed to open the safe. Tell selected friends and family the code. This means they'd be able to get into the house if you had had a seizure and they couldn't reach you on the phone, for example. But make sure not to leave your other key in the front door lock. If you do, no-one will be able to unlock the door from the outside.



## Ways to reduce the risk of burns and scalds

- Make sure there are no trailing wires attached to equipment that could cause a fire or burns if pulled over. Cable ties, available from DIY (hardware) stores, can keep wires out of the way
- Use guards on heaters and radiators to stop you from falling directly onto them
- Use a fire guard that is fixed to the wall, so it won't move out of place if you fall on it. Put free-standing heaters in places where they are least likely to be knocked over
- Use a sensor hairdryer that turns itself off when it's put down
- Don't use heated appliances if you are alone – this includes hair dryers, hair straighteners, curling tongs and irons. Or consider using them with a timer, so they could switch off automatically after a certain length of time. This won't necessarily prevent burns but it might help reduce the level of injury
- Switch off heated appliances immediately after use and place them out of reach until they're cool
- Have carpets with high wool content rather than high synthetic content, to reduce the risk of friction burns
- Install smoke detectors, which can be helpful in two ways:
  - They may alert other people if food is burning because you're having a seizure
  - They'll let you know that food is burning if you have memory problems and sometimes forget what you're doing

## Ways to reduce the risk of cuts, bruises, fractures and head injuries

- Avoid having very hard floor surfaces - more cushioned flooring, such as carpets, linoleum, cork and rubber, will provide a softer landing if you fall
- Keep stairs clear of obstructions at all times, to avoid tripping
- Put a soft rug or carpet at the bottom of the stairs, to cushion any falls
- Cover any edges that are sharp or stick out, for example on furniture. Edge and corner guards are available from many different retailers
- Use toughened safety glass or double glazing in windows or doors, or cover ordinary glass with safety film – contact your local glass merchant or DIY (hardware) store for more information
- Make sure that any wide-opening upstairs windows or doors from upper balconies have suitable locks, so you can't fall from them
- Make sure there are no trailing wires that you could trip over. Cable tidies, available from DIY (hardware) stores, can keep wires out of the way
- Where possible, use cordless versions of things like irons and kettles
- For electrical items with long wires, if possible use coiled leads, so you don't trip over them

## **In the bathroom**

If you have seizures, it's important to take extra care when bathing, because there could be a risk of drowning during a seizure. It is much safer for you to have a shower than a bath. We have included information about baths because, for some people, it's just not possible to have a shower.

### **Ways to reduce the risk of drowning**

#### **In the bathroom**

- Ask somebody to stay in the bathroom with you, or to wait outside the door, so they can hear if you have a seizure
- Put 'engaged/vacant' signs on the bathroom door, instead of using locks
- Have a bathroom door that opens outwards, or folds or slides open and closed. Then, if you fall against it during a seizure, you won't block someone from getting in



### In the shower

- Have a shower cubicle with a flat floor rather than a shower tray, so that water can't collect

### In the bath

Showers are much safer than baths, but if having a shower is not possible:

- Keep the water depth in the bath shallow and turn off the taps before you get in. There is still a risk of drowning, even in shallow water, so if possible have someone with you in the bathroom **or**
- Don't put the plug in, but sit in the bath with the water running from the taps or a shower attachment

### Ways to reduce the risk of cuts, bruises, fractures and head injuries

- Make sure that any fittings are as flush to the wall as possible, to reduce the risk of banging against them if you fall
- Have a separate shower cubicle, rather than a shower attachment over the bath
- Use a shower screen made of plastic or safety glass, or a shower curtain
- If the shower is over the bath, cover the taps with protective material, such as a thick towel, to avoid injury if you fall
- If possible, sit down in the shower rather than stand up, to avoid injuries if you fall

### Ways to reduce the risk of scalds

- Make sure that the temperature controls work well and that there's a safety 'cut-off' in the shower

## **In the kitchen**

### **Ways to reduce the risk of burns and scalds**

- Use a microwave rather than a gas or electric cooker
- Use an induction hob that has an inbuilt timer
- Place saucepans on the back burners and with the handles away from the edge of the cooker, so you can't knock them over
- Take plates or dishes to the cooker, rather than carrying hot pans to the table
- Use a toaster instead of a grill to avoid the risk of burning food
- Use kettle tippers and teapot pourers, to avoid the risk of spilling hot liquid



## **In the bedroom**

If you have seizures when you are in bed, here are some suggestions for making your bedroom safer.

### **Ways to reduce the risk of burns and scalds**

- Avoid putting your bed next to a radiator

### **Ways to reduce the risk of cuts, bruises, fractures and head injuries**

- Avoid putting your bed against a wall or next to a radiator, to prevent knocking your limbs
- Put cushions, pillows or a mattress on the floor around the bed, to reduce injuries if you fall out of bed
- Choose a low bed, so there's less distance to fall to the floor
- Keep sharp-edged objects and furniture away from the bed
- Have a pull cord above the bed for your main light, or wall lights behind the bed instead of a bedside table with lamp





## Anti-suffocation pillows

Some people who have sleep seizures use anti-suffocation pillows. These may be safer than ordinary pillows, although we don't have any research to prove this. If you're thinking about buying an anti-suffocation pillow, it's a good idea to discuss this with your epilepsy nurse or epilepsy specialist.

Epilepsy Action has more information about where to buy anti-suffocation pillows

## Lifts

If you have mobility difficulties, you may need to use a stair lift or vertical lift. Neither of these options is risk-free if you have seizures, and there's no perfect solution. To a certain extent, it's a matter of arriving at a compromise between the safest option and what's practical. Some padding between you and the strapping may help to limit bruising if you have a seizure while in the lift.

### Vertical lifts

- Where possible, because they are likely to be small, confined spaces, these should have a padded interior to cushion the blow if you fall

### Stair lifts

- Most stair lifts have simple straps which you should use, as they're not likely to cause injury if you have a seizure
- You may need to wear a full harness to prevent you from falling, but be aware that this could cause injury during a seizure. This may, however, be safer than falling from the stair lift

## In the garden

### Ways to reduce the risk of burns and scalds

- Avoid getting so close to bonfires or barbecues that you could fall on them during a seizure
- If you sometimes wander during a seizure, ask someone to stay with you when you're near a bonfire or barbecue

### Ways to reduce the risk of drowning

- Don't have ponds or pools
- If you do have ponds or pools, make sure they are securely fenced off when you are alone in the garden



## Safety outside your home

Many people with epilepsy worry about having a seizure when out and about. This is a common reason why some people feel safer staying at home.

Our tips for staying safe outside (on page 20) might help you to feel more confident about going out.



## **Some tips for staying safe outside**

- Make careful decisions based on what you learn from each safety check
- Put everything possible in place to minimise risk
- Carry a card or medical identity jewellery which explains that you have epilepsy, what first aid you may or may not need and who to contact
- Consider whether some kind of alarm or tracking device would be useful for you
- If you are feeling anxious about getting out, ask your family doctor if there are any groups which might help you with this
- If you are worried about how your friends or colleagues will react if you have a seizure, share your concerns and check out if they are accurate. If they do have concerns, they may need more information about epilepsy. You could share this yourself or point them to Epilepsy Action resources

## **Epilepsy identification**

You may choose to carry or wear some form of identification, especially if you're out on your own. This could be an ID card or medical identity jewellery.

**Epilepsy Action has more information on ID and medical identity jewellery**

## Alarms for inside and outside the home

There are different types of alarms that can be helpful for some people with epilepsy.

The type of device that could work for you will depend on what you want the alarm to monitor (movement, falling, noise) and who is going to respond to the alarm. Some alarms will only work in the house. Others can send a message to someone at quite a distance, but they're more expensive.

If you don't know someone who could respond to an alarm in the house (for example if you live alone) you may want to consider a telecare service. A telecare service is where the alarm is connected by telephone line to a call centre. The call centre can then contact someone to check on you, or call an ambulance.

### Types of alarms

- Baby intercoms or other listening monitors which can pick up sound
- Video monitors
- Bed alarms or bed sensor mats that can sense different things when someone is asleep, such as unusual sound or movement
- Fall alarms, which can be set off when someone falls to the ground
- Telephone alarms, which can be operated by remote control by someone who needs help
- Smart watches, which can let someone know if you've had a seizure and where you are

For information and advice about alarms and where you can get them, you can contact the Disabled Living Foundation's equipment helpline.

Tel: 0300 999 0004 (calls charged at local rate)

Email: [info@dlf.org.uk](mailto:info@dlf.org.uk)

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

[Epilepsy Action has more information about seizure alarms](#)

## How can I get around safely when I can't drive?

If you don't meet the epilepsy and driving laws you won't be able to drive. For many people this is really hard to come to terms with. And some people also have concerns about staying safe on public transport. If you feel confident using public transport, make sure you plan your journey ahead of time. Also see if there is anything from our general list of staying safe outside the home that would help.

Here are some ways in which people plan their lives when they can't drive:

- Ask for lifts from family, friends and colleagues
- Consider living near a good bus route or railway station
- Plan your journey in advance, so you feel confident about where you are going
- Use a free bus pass and Disabled Person's Railcard
- Use taxis when necessary
- Do shopping online
- Walk, if it's possible
- Cycle, wearing a helmet and avoiding busy roads where possible

## Useful organisations

### **Disabled Living Foundation**

Provides information about equipment for daily living.

Tel: 0300 999 0004

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

### **The Research Institute for Disabled Consumers**

Provides independent information and product reviews for older and disabled consumers.

Tel: 020 7427 2460

Website: [ridc.org.uk](http://ridc.org.uk)

### **Royal College of Occupational Therapists**

Provides information about occupational therapy and has a directory of occupational therapists.

Tel: 020 3141 4600

Website: [rcot.co.uk](http://rcot.co.uk)

### **Dan's fund for burns**

Provides help for people affected by burn injuries.

Tel: 07526 847 699

Website: [dansfundforburns.org](http://dansfundforburns.org)

### **ROSPA (Royal Society for the prevention of accidents)**

Promotes safety and the prevention of accidents at work, at leisure, on the road, in the home and through safety education.

Tel: 0121 248 2000

Website: [rospa.com](http://rospa.com)



## About this publication

This booklet 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 else you would like to say about this booklet, please contact us.

To find out why you can trust Epilepsy Action's information, please contact us or visit [epilepsy.org.uk/trust](https://epilepsy.org.uk/trust)

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Epilepsy Action would like to thank Christine Hanson, advanced clinical nurse specialist in epilepsy, Cardiff, for her contribution to this information.

Christine Hanson has declared no conflict of interest.

## Disclaimer

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

## First aid for tonic-clonic seizures

The person goes stiff, loses consciousness, falls to the floor and begins to jerk or convulse.

### Do...

- Protect the person from injury (remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing the person on their side (in the recovery position) once the jerking has stopped (see picture)
- 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 seizure follows another without the person regaining consciousness between seizures **or**
- The person is seriously injured **or**
- They have trouble breathing after the seizure has stopped

## First aid for focal (partial) seizures

The person is not aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander around.

### **Do...**

- Guide the person away from danger
- Stay with the person until recovery is complete
- Be calmly reassuring
- Explain anything that they may have missed

### **Don't...**

- Restrain the person
- Act in a way that could frighten them, such as making abrupt movements or shouting at them
- Assume the person is aware of what is happening, or what has happened
- 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 seizure follows another without the person regaining awareness between seizures **or**
- The person is seriously injured

Epilepsy Action has information on what to do if someone has a seizure in a wheelchair.

## Epilepsy Action's support services



helpline

Our friendly helpline team offer confidential advice and information to anyone affected by epilepsy:

### **Freephone 0808 800 5050**

Staff are text relay trained and able to offer advice and information in 150 languages, via an interpreting service.

### **Live chat**

Visit [epilepsy.org.uk](https://epilepsy.org.uk) to chat with a member of the helpline team. We usually reply to chat requests within 5 minutes.

### **Email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)**

Send us your question about epilepsy. We aim to reply within 48 hours (on workdays).

To see our opening hours and find out more about the support we offer visit: [epilepsy.org.uk/helpline](https://epilepsy.org.uk/helpline)



talk and support

Our Talk and Support groups offer an opportunity to connect with others affected by epilepsy. You can join a group which meets face-to-face or online.



befriending

Our befriending service links people who are affected by epilepsy to a volunteer befriender. Your befriender can listen if you are going through a difficult time and could also help you take steps towards positive change.

**Continued on page 31**

## Safety advice for people with epilepsy

We would like to know if you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

Yes	No	
		I feel more informed about issues to do with epilepsy
		I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse/other (cross out those that don't apply)
		I have talked to my employer/colleague/teacher/family/other (cross out those that don't apply) and they have improved how well they support me
		I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline or support groups

**Please tell us how you think we can improve this information**

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Please return the completed form to:

**FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action,  
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY**

You can also give us feedback online. Visit [epilepsy.org.uk/feedback](https://epilepsy.org.uk/feedback)

Thank you.

**FREEPOST RTGS-LEYK-XGCK**

**Epilepsy Action**

**New Anstey House**

**Gate Way Drive**

**Yeadon**

**Leeds LS19 7XY**

Registered charity in England and Wales (No. 234343)



**counselling**

Our counselling service is available to adults living in Northern Ireland and Wales who are affected by epilepsy, caring for someone affected by epilepsy, or the parent of someone affected by epilepsy.



**family support  
Northern Ireland**

Our family support services offer support to families and carers of people affected by epilepsy in Northern Ireland and Wales.

**To find out more about the services we offer, including ways to get in touch and how to apply, visit:**  
**[epilepsy.org.uk/support-for-you](http://epilepsy.org.uk/support-for-you).**

## **Information about epilepsy**

Epilepsy Action has a wide range of information on our website about many different aspects of epilepsy. You can also download our information as a factsheet.

**If you would like our information printed in large text, you can order this by contacting the Epilepsy Action Helpline.**

## Epilepsy Action Helpline:

freephone 0808 800 5050

[epilepsy.org.uk](http://epilepsy.org.uk)



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### Environmental statement

All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from well-managed forests.