Staying safe with epilepsy

Helpline: 0808 800 2200
Text: 07786 209 501
www.epilepsyscotland.org.uk
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### And finally … 30
What is epilepsy?

One person in 130, that’s 40,000 people in Scotland, has epilepsy. It is the most common serious brain (neurological) condition. Anyone can develop epilepsy at any age. It is more common in childhood, teenage years and later life.

**Generally, people with epilepsy have more than one seizure.**

These start in the brain and are caused by disturbances in the brain’s normal activity.

Some people may have one or two seizures during their life. These could be due to a high temperature or an infection. It does not necessarily mean they have epilepsy.

What are the risks?

Up to 70% of people have their seizures controlled by anti-epileptic drugs (AEDs). If your seizures are completely controlled by medication, you can get on with your daily life.

You will also get your driving licence back if you have not had any seizures for 12 months. If you only have seizures while you are asleep the regulations are slightly different. Our ‘Epilepsy and driving’ guide has more information on this. You can also phone our helpline.
Everyone, not just those with epilepsy, faces risks in the home and when out and about. There is a slightly higher risk if you have epilepsy and still have seizures. Ask yourself:

- When do I have seizures?
- How often do I have seizures?
- What type of seizures do I have?
- Do I lose consciousness during my seizures?
- Do I get a warning before a seizure?
- How often do I have seizures?

This will allow you to assess your risk. If your seizures are rare, you only need to take a few extra precautions. If your seizures are not well controlled, you will need to look after yourself a bit more around the house. Have a look at the following chapters. These will give you some hints and tips on how to stay as safe as possible.
Once you are diagnosed with epilepsy, you and your family may be worried about your safety. Your family or friends may try to stop you from doing certain things, such as going out or sports, because they are afraid that you may hurt yourself if you have a seizure.

However, it’s important to keep it all in perspective. Some people for example get warnings or ‘auras’ of a seizure to come. This can allow you to get to a safe place before the seizure starts. A warning can give you time to sit on the floor, so you don’t hurt yourself if you fall.

**Be sensible but don’t let your epilepsy hold you back.**

You can still lead as full and active a life as possible with or without seizures.
Who can assess my risks?

You can do this yourself by using this guide. Look around your home and identify any possible risks. The guide may help you find ways to reduce that risk. You can also phone our helpline and speak to our trained staff.

Occupational therapists can visit you at your home and look at ways to keep you as safe as possible. Your GP can refer you to an occupational therapist. You can also contact your local social work department and ask for a community care assessment. Your social work department will then usually arrange for an occupational therapist to visit. They will look at any support and help you may need. This could be help with meals, respite care, aids and adaptations, allowances and benefits, or home carers and day services.

You can also speak to an epilepsy specialist nurse if you are worried about your safety. They are an excellent source of advice and information. They too can refer you to an occupational therapist.
If you live with someone, make sure they know what to do if you have a seizure.

**It helps to know what to do if:**

- you are unconscious
- you’ve injured yourself and you are bleeding
- you have something stuck in your throat
- you have difficulty breathing or you stop breathing

Read our ‘First aid for seizures’ guide for more information. We can send you a free copy.

If you need emergency medication to stop your seizures, your doctor can prepare a care plan for you. Speak to your doctor or epilepsy specialist nurse about this. In the plan, you can nominate someone you trust to give emergency medication to you. That person will need to be trained first. Epilepsy Scotland can provide this training.

The following sections will give you many suggestions on how you can reduce any risks in your home. There are many special products you can buy, such as epilepsy alarms or shaped plastic pieces that go over sharp corners of furniture.

You should be able to buy these in DIY stores, specialist shops, ironmongers and even some larger supermarkets. Your occupational therapist or epilepsy specialist nurse can tell you where to buy them. The internet is also a useful resource to find out what’s available, who produces and sells it. You can phone our helpline for more details.

If you are worried about the cost of buying these, some charities or charitable trusts may be able to help. Your local social work department may also be able to give you financial support.
If you or your child has sleep seizures, there are alarms that can alert others in your home. This will help to keep you or your child safe during and after a seizure.

There are many different types of alarms. These include bed alarms and fall alarms. They can be connected to an existing community care alarm. They can also dial a telephone number when the alarm is triggered. Some of them can detect movement, sound or moisture in your bed.

If you have sleep seizures, alarms can alert someone who lives with you. This means you are kept safe during and after a seizure.

We have a short factsheet with details of types of alarms and suppliers. Call our helpline for a free copy. Your local social work department may also be able to get an alarm for you.
Bathroom

Having a shower is safer than a bath because the water drains away. This reduces the risk of drowning if you have a seizure while getting washed.

Here are some more tips to stay safe in the shower:

- Your shower should have a flat floor (level access shower). If there is a lip, make sure it’s as low as possible to avoid any water being trapped.
- Sit down when you shower. You can get a specific shower chair fitted.
- If you don’t have a shower, attach a shower fitting to both taps in the bath tub. Sit down in the bath while taking a shower and make sure that the plug is out so that the water can drain away.
- If you use an over-the-bath shower, remove the bath plug or anything that could accidentally block the outflow of water.
- Use a fabric shower curtain or plastic shower screen. This is safer than glass. If it’s glass, check it’s made of safety glass.
- Make sure that the water temperature control is working. Never use very hot water. You can get controls with a safety cut-off to avoid scalding.
- Use a non-slip mat in the shower.
If you are having a bath:

- Keep the depth of water to just a few inches.
- Do not use very hot water.
- Always put the cold water in first.
- Do not get into the bath until the taps have been turned off.
- Do not top up the bath once you are in.

If you have many seizures and they are unpredictable let someone know when you are taking a bath or shower.

Other safety tips for the bathroom:

- Have bathroom fittings which are flush to the wall. If your fittings stick out, cover them with protective material. Or simply wrap a thick towel around them.
- Use plastic containers for toiletries rather than glass.
- An electric shaver is safer than ordinary razors.
- Choose your bathroom flooring carefully. Tiles made of rubber or other soft material, and non-slip flooring are safest.
- If possible hang the bathroom door so that it opens outwards. If you should fall behind the door, it will not become blocked.

Don’t lock the door. To give you privacy, hang an ‘engaged’ notice on the outside door handle. You can also buy special safety locks that can be unlocked from outside the bathroom in an emergency.
Low level beds or a futon reduce the risk of hurting yourself if you fall out of bed during a seizure. Sleeping in the middle of a large bed or placing your bed against one or two walls can also reduce this risk.

It’s also a good idea to keep furniture away from the bedside if your seizures are not controlled.

**Safety pillows**

Soft pillows can be dangerous if you have seizures at night. You could suffocate. Our helpline has details of where you can buy safety pillows. These pillows have small holes. This means if you are face down during and after a seizure you should still be able to breathe.

You can also switch to firm foam pillows as these are safer. Some people prefer to sleep without a pillow at all.

Everybody needs to check their safety before doing DIY. It is safer to do DIY when there is someone else around. If you use power tools, have a look at the Electrical appliances section.

If your seizures are uncontrolled and sudden, don’t use ladders or work at heights. You could seriously injure yourself if you fall off a ladder.
Electrical appliances

**Trailing flexes**
Any electrical appliance with a trailing flex is potentially dangerous. If pulled over during a seizure, the appliance could cause a fire. One way to reduce this risk is by using cable tidies.

**Iron**
If you have a tumble dryer, this will cut down on your ironing. To make ironing safer use a cordless iron which automatically switches off after a set time when you are not using it.

**Kettle**
You can buy cordless kettles which automatically switch off. Some have a hinged lid which locks shut when switched on. This can help prevent accidents. Using a kettle tipper (and teapot pourer) also does away with the need to lift a heavy container full of hot liquid.

**Power tools**
If you use power tools, make sure they are battery operated instead of mains power. This means that there is no power cord to damage if you have a seizure while using it. Some power tools also have a safety cut-out feature. If you have to use mains powered tools, use a circuit breaker on the wall socket. This will protect you against the risk of electrocution.
If you use an electric wheelchair, talk to your doctor or epilepsy specialist nurse.

**In some cases, a manual wheelchair could be safer but this depends on the kind of seizures you have.**

During a complex partial seizure you may be in danger of accidentally pushing a button which could steer you into a busy road.

You are less likely to hurt yourself during a fall if your floors have soft carpeting or cushioned linoleum rather than rough carpeting or tiles. Non-slip flooring may also be helpful.

Carpets with a high wool content are better than those with a high synthetic content. This is because they are less likely to cause friction burns if you fall during a seizure.
Avoid cluttering up your home with too much furniture. Having space to move about or fall down without bumping into furniture can reduce the risk of injury. You can also buy shaped plastic pieces which can be fitted over sharp corners of furniture.

Where possible make sure that any chairs you sit on have armrests. This could stop you from falling to the floor if you have a seizure.
If you like gardening, there are many ways to make your garden safer:

- Cover the ground with lawn or bark chippings. This is safer than concrete or gravel should you have a seizure and fall.

- Go for wooden decking instead of a stone patio.

- Use a petrol lawn mower instead of an electric mower. If you have a seizure, you may accidentally cut through the electric cable. If you use an electric lawn mower, make sure there is a circuit breaker at the plug. Many newer lawn mowers stop automatically when the handle is released. This will make mowing safer.

- If you have a garden pond, consider fencing it in case you fall in during a seizure. It may also help to grow big plants or shrubs around the deeper side of the pond. You will not be able to get too close to the edge of the pond if you wander around during a seizure.

- You can also buy a safety grid that sits just below the surface of the water. If you fall into the pond, the safety grid may hold your weight and could stop you from drowning. Check with the manufacturer such a grid is strong enough to hold your weight and make sure it’s professionally installed. We do not recommend you rely on a safety grid alone.

- If you are thinking about getting a garden pond, think about its position. If it is easily seen, someone might be able to assist you quickly if you need help.
Glass

Consider having safety or toughened panels fitted to glass doors or low windows. If you have a newly built home, it will already have these fitted, as this is a legal requirement. This type of glass is difficult to break. It also holds together if broken.

You can place safety film over glass panels in your home. This should stop the glass splintering if you fall against it during a seizure.

Also check out any mirrors you have in the house to make sure they are made of shatter-proof glass.

Heating

Open fires

If you have an open fire, you need a solid fireguard. Make sure it is securely fixed to a wall or floorboards so you cannot knock it over during a seizure.

Radiators

Radiators that are fixed to the wall or floor are a lot safer than light-weight free-standing heaters. You cannot knock them over if you have a seizure. Fitting a radiator guard can stop you from burning yourself if you fall against a hot radiator. Wrap some insulating material around any hot pipes exposed in your kitchen or bathroom.
Gas or electric cooker

If you have a seizure while using a gas or electric cooker, this could be dangerous. You can get a safety guard for your cooker that is fitted around the front. This can stop you from accidentally touching rings or burners.

Keep pot handles turned in, i.e. away from the cooker edge, so you cannot knock them over during a seizure. Another tip is to use the back rings rather than the front ones.

Using a toaster is safer than grilling toast. Grilling is generally safer than frying or boiling.

Microwave

A microwave oven is safer than a cooker if you have epilepsy. It doesn’t get hot on the outside and it also switches off automatically when the cooking time ends. When you have a seizure, there is no risk of food burning or a fire starting if it is left unattended.

Use microwave proof dishes. They do not get too hot to the touch and you are far less likely to burn yourself.
Carrying hot food and drink

When you serve food or drink, it is safer to take the plate or cup to the saucepan or kettle than vice versa. You can also use a trolley to transfer food and dishes from the oven to the table and back.

A cup with a plastic lid can protect you if you spill a hot drink during a seizure.

Other kitchen safety tips

- A food processor is safer than using a knife.
- Buy unbreakable dishes.
- Wear rubber gloves when you do your washing-up. This will give you some protection against cuts and scalds if you have a seizure.
Out and about

If you have a seizure outside your home, it can help to wear medical identification jewellery such as a bracelet or a necklace. This gives anyone useful information on your epilepsy. It has details of medication you take, how long your seizures normally last and who to contact in an emergency. We can give you contacts for suppliers.

You can also carry an identification card. This can give people important information about your epilepsy, the seizures you have, how to help and who to contact in an emergency. Contact our helpline for a free card.
These are only necessary if you have very frequent seizures which put you at serious risk of a head injury. There are many kinds of protective helmets. If, for example, you tend to fall forward suddenly during a seizure, you would need a helmet with a face guard. Helmets should always be professionally fitted to give the best protection. Our helpline can give you details of suppliers of these special helmets.

If you cycle or ride a horse, we always recommend that you wear a helmet, whether you have epilepsy or not. However, if you have epilepsy, it’s particularly important to protect yourself from a possible head injury should you have a seizure during these activities.

It can be dangerous if you have a seizure while smoking in an armchair or bed. A discarded cigarette during a seizure can start a fire. You can also burn yourself with it during a seizure. Make sure you have a smoke detector fitted at home and check the batteries regularly. It is safer if you smoke outside.

By law, all new furniture has to be made of fire-resistant fabrics. However, if you get second hand furniture, check to see if it is made of fire-resistant fabric. These fabrics will stop any fire from spreading too quickly.
Seizure alert and response dogs

If you are over 16 and have at least 10 major seizures a month, you can apply for a seizure alert and response dog. These dogs are trained to sense when you are about to have a seizure. They can then give you a clear warning signal. This may give you a chance to make sure you are safe. You may want to sit or lie down. Seizure alert and response dogs are also trained to stay with you and help to keep you safe during and after a seizure.

If you are interested in getting such a dog, contact Support Dogs UK on 0114 2617800 or visit their website www.support-dogs.org.uk

Having a seizure alert and response dog can give you more confidence and independence. Once a dog is registered as an Assistance Dog it is allowed to go with you wherever you go. This includes places that are usually restricted to dogs, such as shops and restaurants.
Sport and leisure

Being active is good for us. There is some evidence that being active can reduce the amount of seizures you have.

If your seizures are well controlled, you can enjoy most sports and leisure activities without any restrictions. There are some types of sport, such as scuba diving or boxing which can be dangerous even if your seizures are well controlled. Always check with your doctor or epilepsy specialist nurse first before you take up any sport or leisure activity.

Frequent and unpredictable seizures should not stop you from being active.

A few extra precautions will allow you to enjoy many sports and leisure activities.

Our ‘Epilepsy and leisure’ guide gives you much more information on different kinds of sports and leisure activities. Phone our helpline for a free copy.
Stair gates can prevent you from falling down the stairs during a seizure. Depending on your types of seizures, a gate not only at the top but also at the bottom of your stairs can help. For example, during a complex partial seizure you may try to climb the stairs. A stair gate at the bottom step can stop this.

Always keep your staircase clear. Something soft at the bottom of the stairs such as a rug or carpet can also cushion a fall.

If you have frequent seizures without any warning, stairs can be a major risk. There are however ways you can reduce the risk of serious injury to yourself.

If there are children in your house, it’s important to store your medication safely. It’s best to lock it away so that small children cannot get to it.

Special tablet dispensers can also help you remember whether you’ve taken your medication or not. You can buy these from your local pharmacist. This can stop you from accidentally taking too much of your medication or forgetting to take it at all. In both cases this could trigger a seizure. The website www.tabtime.com also has a good supply of gadgets to help you remember to take your tablets.
Television and computers

A very small number of people with epilepsy (less than five per cent) are photosensitive. This means they have seizures which are triggered by flashing or flickering lights. Watching TV or playing a computer game could possibly trigger a seizure.

However, there are things you can do to reduce the risk:

- LCD or plasma screens are safer. Don’t sit too close. Sit at least three metres away from the TV set.
- Use your remote control to change channels and switch the TV on or off.
- Sit level with, not below the TV screen.
- Watch TV in a well-lit room.
- Don’t watch the screen when you fast-forward or rewind a DVD or video tape.
- Smaller screens (14 inches or smaller) are safer than larger screens.
- If the programme you watch contains flashing or flickering images, cover one eye with one hand. This can help prevent a seizure from starting.
- Programme makers should give you a warning if a programme contains flashing images. If they do, switch off your TV.
- Computer and video games may also contain flashing and flickering images. Have someone check out the game first to make sure it does not contain any images that may trigger a seizure.

We have more information on this in our ‘Photosensitive epilepsy’ guide. Phone us for a free copy.
If you have a baby or small child you need to take extra care.

Not getting enough sleep and worrying about your baby is a source of stress to any new parent. If you have epilepsy, this could increase the risk of seizures.

As a new mother with epilepsy, you also need to watch out for hormone changes and how these may affect your seizure control. Your doctor or epilepsy specialist nurse may want to adjust your epilepsy medication to ensure the seizures do not increase. Our ‘Women’s guide to epilepsy’ can give you more information on this. Phone us for a free copy.

Your health visitor will be able to give you advice on how you can look after your baby as safely as possible.

There are some simple precautions you can take. These will reduce risks to yourself or your baby or young child during and after a seizure:

**Child gates**

If you have a seizure which leaves you unconscious or not fully able to look after your child, you will want to make sure that your child is safe until you recover.

**Fit a child proof gate at the kitchen door and at the bottom and top of stairs.**

Your garden should be completely fenced in. The gate should be sturdy and have a secure lock. If you live in a flat, make sure your front door lock cannot be reached and opened by a small child.
Protecting your child from electric appliances

Use child proof covers for electric sockets. You can buy these from shops which specialise in baby or general safety equipments or most ironmongers. The internet is also a great source.

When you do your ironing or use any other electric equipment, it can be safer to keep a younger child in a playpen during that time. Should you have a seizure and lose consciousness your child will be safe until you recover.

Bathing your child

If you have unpredictable and frequent seizures where you lose consciousness, you should only bath your child when someone else is at home. When you are on your own simply sponge your child in an empty bath, baby bath or on a waterproof sheet on the floor. Only use a small amount of water in a small bowl, and make sure your child cannot reach this.
Carrying your child

If your seizures are frequent and happen without warning, it’s safer not to carry your child in your arms when you are alone. Some parents use a buggy to wheel their baby or toddler around the house.

Breastfeeding your baby

Lack of sleep or disrupted sleep can often trigger seizures in new mothers with epilepsy. If your seizures tend to be triggered through lack of sleep, you can still breastfeed your baby during the day. For night feeds, you can express your breast milk. You can get your partner or someone living with you to bottle feed the baby. This will help you get a good night’s sleep.

Never breastfeed your baby while you are in your own bed. And never have your baby in bed with you while you are asleep.

Mealtimes

Rather than sitting up at a table, it can be safer to sit on the floor to feed your child. Try to have your back to the wall and a large cushion on either side. During a seizure, your child is less likely to be injured as you are already low to the ground and cushioned on either side. If you tend to fall in the same direction, make sure you hold your baby on the opposite side during bottle feeding. As your child grows older you can set a highchair at its lowest height and feed your child as you sit on the floor.

Nappy changing

It’s safest to change your baby’s nappies sitting down on the floor. That way, if you have a seizure, your baby cannot roll far. To avoid falling on your baby during a seizure kneel down at the side of the changing mat.
Childproofing your medication

Make sure your child cannot reach your anti-epileptic drugs or any other medication in your house. Always securely lock it in a cabinet which your child cannot reach.

Pills and tablets are easily mistaken by a small child for sweets. Be extra careful if you carry your pills in a pocket or bag.

Take your medication out of your child’s sight to avoid your child wanting to copy you. You can get pill dispensers with a childproof cap.

Outside the home

When you take your baby out in a pram or buggy you can tie a toddler strap to your wrist and the pram. That way, if you have a seizure, the pram or buggy will not run away if you let go of the handle. The cord should be long enough that you cannot pull the pram over if you fall. Some prams also have brakes which lock when you let go of the handle.

Keep your toddler on a toddler strap tied to your wrist to stop them from wandering off during a seizure. It also helps if your child carries identification. That helps people to return your child safely to you.
We hope this guide has given you many ideas on how to stay safe. It’s usually fear and lack of knowledge that puts up unnecessary barriers. However, with a few sensible precautions, most people with epilepsy live an active, fulfilling and independent life. If you have any more questions please phone our helpline.

Talking to your child about your epilepsy

If your child is slightly older, you can explain more about your epilepsy. You can also get books that are suitable for young children. When you think your child is old enough to understand, you can explain to your child how to help you if you have a seizure. This can be, for example, teaching your child to dial 999.

If you are a single parent, you may want to consider having a community alarm installed. This can alert someone if you have a seizure and need help. Your child, if old enough, can also be taught to use the alarm. Your local social work department or epilepsy specialist nurse can give you more information on this.
**Further information**

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**We also have information leaflets designed for people with learning difficulties. These are:**

| • All about epilepsy                                |
| • Safety and epilepsy                               |
| • Living with epilepsy                              |

Phone us for a free copy.

If you have questions after reading this leaflet, please call our helpline. Our trained staff are available during office hours and until 6pm on Thursdays.

If you would like this leaflet in a different format, large print or language, please call 0808 800 2200.