

Safety advice for people with epilepsy



epilepsy

Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work...

- We provide information to anyone with an interest in epilepsy.
- We improve the understanding of epilepsy in schools and raise educational standards.
- We work to give people with epilepsy a fair chance of finding and keeping a job.
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations.
- We promote equality of access to quality care.

Epilepsy Action has local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Join us...

You can help us in our vital work by becoming a member. All members receive our magazine *Epilepsy Today*, free cover under our unique personal accident insurance scheme and access to our services and conferences.

“ Our vision is to live in a society where everyone understands epilepsy and where attitudes towards the condition are based on fact not fiction ”

Epilepsy Action, vision statement

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Introduction

Like many people with epilepsy and their families, you may have concerns about safety in relation to seizures. In this booklet we look at some aspects of everyday life, where there could be a risk of injury during a seizure. We also make suggestions on how to reduce risk.

It's important to remember that our safety suggestions are not right for everyone. So some things may not be relevant – or necessary – for you. For example, if you are seizure free, you may only need to take the same precautions as someone without epilepsy. If you get a useful warning of your seizures, you may be able to reduce risk of injury by stopping what you're doing. If you have fairly frequent seizures without warning, however, you may need to take extra care.

Acknowledgements

Epilepsy Action would like to thank Pam Mantri, epilepsy nurse specialist (Sapphire Nurse), County Durham PCT for checking *Safety advice for people with epilepsy*, and for her invaluable comments and suggestions for improvement. Thanks also go to Alison Holmes, Sapphire epilepsy specialist nurse, Derby City PCT for her comments on *Safety advice for people with epilepsy*.

Safety assessments

If you have unpredictable seizures you could be at risk of injuring yourself at home. To be as sure as possible that you are doing everything you can to reduce risk, you could ask your local Social Services to arrange for an occupational therapist (OT) assessment of your home. You could also discuss safety with your epilepsy specialist nurse. If you have learning disabilities, you could ask your learning disabilities nurse to do a formal risk assessment.

Bathing

If you have seizures, you will need to do everything you can to reduce the risk of drowning during bathing. One way of doing this is to have someone in the bathroom with you or just outside. You will, however, want to balance this against your need for privacy.

A shower is considered to be safer than a bath for people with epilepsy. However, neither is entirely risk free.

Showers

A shower should ideally be in a separate cubicle, rather than over the bath. If possible, the cubicle should have a flat floor, instead of a shower tray. This is because water could collect in a shower tray, increasing the risk of drowning. The shower screen should be made of plastic or safety glass. A shower curtain is an alternative.

You may also need to look at your bathroom fittings. These need to be as flush to the wall as possible. This will reduce the risk of injury, if you have a seizure and fall. If fittings stick out, or if you use a shower over a bath, you could cover the fittings with protective material. Even a thick towel can be effective in reducing the risk of injury if you fall. It is important that the temperature control works well. It should have a safety 'cut-off', in order to avoid scalding yourself. Taking a shower while sitting, if this is possible, will reduce the risks of injury if you have a seizure.

Baths

If you use a bath, it's best to keep the water depth shallow to reduce the risk of drowning. However, this will not remove the risk entirely. The taps should be turned off before you get into the bath. Some people prefer to wash with running water, without putting in the plug. If you decide to do this, you could use a shower attachment. This way the water can be mixed to a comfortable temperature. However, shower attachments don't have a safety 'cut-off', so can't prevent scalding if the water temperature changes.

Bathroom doors

You could use an 'engaged/vacant' sign to protect your privacy, instead of locking the bathroom door. If possible, the door should be hinged so that it opens outwards. This way, if you have a seizure and fall against the door, you won't block someone getting into the bathroom if you need help. If it's not possible for the door to open outwards, you could consider having a 'concertina' door (where it folds open and closed).

Kitchen safety

It's safer to use a microwave oven than a gas or electric cooker. If you use a cooker, turn saucepan handles away from the edge so you are less likely to knock the saucepan over. It will reduce the risk of scalding if you take plates or dishes to the cooker, rather than carrying hot pans to the table. Using a toaster can avoid the danger of leaving a grill on. Kettle tippers



and teapot pourers are available to avoid lifting containers of hot liquid, although these will not remove the risk completely.

There may be other safety aids that could be helpful. Contact the Disabled Living Foundation for further details (see page 15). A limited range is also available from some shops, such as DIY stores. Some of these safety aids may be mainly intended for child safety, but could still be useful.

If you have memory problems, you could forget you've turned on the grill or cooker. You might, therefore, decide to get a smoke detector. The smoke alarm will sound when smoke hits the sensor, for example from burning food.



Ironing

If you have unpredictable seizures, you may decide not to iron when alone in the house.

Electric flexes

It is wise to avoid having trailing flexes. This is particularly important where they are attached to appliances which could cause a fire, or burns, if pulled over. You can use cable tidies, available from DIY stores, to make sure that flexes are kept out of the way. You could also consider using a cordless kettle and iron.

Heating

If you have free-standing heaters, try to place them where they are least likely to be knocked over during a seizure. Some modern electric heaters have a safety cut-off if they are knocked over. However, you will still need to think about having guards on your heaters or radiators to minimise



the risk of being burned if you fell against them. If you have an open fire be sure to use a substantial fixed fire guard.

Flooring

If at all possible, avoid having very hard floor surfaces as they can increase the risk of injury during a seizure. Different types of flooring are available which will provide a softer landing if you should fall. Examples are vinyl cushion, linoleum, cork and rubber. Carpets with a high wool content are less likely to cause friction burns during a seizure than those with a high synthetic content.

Stairs

If you have frequent and unpredictable seizures, stairs can be a major hazard. Even so, it is possible to reduce the risks. For example, keep your staircase clear of obstructions at all times. And consider having a soft rug or carpet at the bottom of the stairs. This will help to cushion any falls.



Image courtesy of www.istockphoto.com/Andrew_Howe

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 also have seizures.

Vertical lifts

If you use a vertical lift, it should, if possible, have a padded interior to reduce the risk of injury if you have a seizure.

Stair lifts

Most stair lifts have simple lap straps. These are unlikely to cause injury if you have a seizure. Some people may need the added protection of a full harness, to prevent them falling. Where this is the case, it's important to be aware that the harness could cause injury during a seizure.

There is no perfect solution where stairs or lifts are concerned. To a certain extent, it is a matter of arriving at a compromise between the safest option and what is practical in your home.

Electric wheelchairs

If your seizures are not controlled and you want to use an electric wheelchair, you will need to think about safety. You could discuss this with your doctor. They would consider what dangers there might be for you, if you had a seizure while using an electric wheelchair. They would also consider the type of seizures you have and if you have a warning of your seizures.

Glass doors and windows

Falling against glass doors or windows could cause serious injury. You can reduce the risk by using toughened safety glass, or by covering ordinary glass with safety film. Contact your local glass merchant or DIY store for more information and advice. You may also want to make sure that any wide-opening upstairs windows, or doors from upper balconies, have suitable locks in place so that you can't fall from them.

Sharp edges

You may want to cover sharp edges, or any that stick out, for example on furniture. You could use padding, such as pieces of foam rubber that come in sheets, or tubes that are designed for lagging pipes. A DIY store may stock other options. When buying new furniture, you could consider making sure these have rounded edges or corners.

Protective headgear

If you have frequent, unpredictable seizures, which might cause injury to your head or your face, you may wish to consider wearing a protective helmet. Your hospital consultant can prescribe one if they feel it is appropriate. You can also buy these privately.

Alarms

Some people are worried about having seizures when they are alone. There are different types of alarms that can alert other people that you may need help.

- Baby intercoms can pick up sound.
- Bed alarms can sense different things when someone's asleep, such as unusual sound, movement or dribble.
- Fall alarms can be used when someone has fallen to the ground.
- Telephone alarms, operated by remote control, can be used to call someone for help.

Before investing in any of these alarms, you need to consider whether they are necessary and if they would be effective for you. For example, there would need to be somebody else available to hear a fall alarm. Baby intercoms only pick up noise, not movement. Generally, you would need to have a warning of a seizure for a telephone alarm to be useful. However, a telephone alarm can be used when the seizure is over to call for help if you need to.

Beds

If your seizures involve convulsions or jerking movements, try to avoid placing your bed against a wall or next to a radiator. This can prevent you knocking your limbs on the wall, or burning yourself.

Placing protective cushions or a mattress around the bed can help to reduce any injury caused by falling out of bed. The lower the bed, the less



distance there is to fall. This will reduce the risk of injury. It is also a good idea to keep sharp-edged objects, and furniture such as bedside tables, away from the bed, to prevent injury.

Parents with epilepsy caring for young children

If you are a parent with epilepsy you may worry about your children's safety, if you have a seizure. Besides following general safety measures for all parents of young children, there may be other ways to reduce the risk of injury and accidents. These include, for example, fitting a safety brake to the pram, and special ways of feeding, bathing and looking after your baby or young child. Child reins, harnesses and wrist straps can keep your child close to you when you are out and about. If you fall during a seizure you may pull your child over. However, this is safer than allowing your child to wander off unsupervised.

More information is available from Epilepsy Action.



Sport and leisure

Most sport and leisure activities are possible for people with epilepsy, as long as common sense precautions are taken, where relevant. Sports on or near water, or at heights, may need extra safety measures or supervision.

More information is available from Epilepsy Action.

Carrying identification

You may feel reassured by carrying or wearing some form of identification, particularly if you are out on your own. Epilepsy awareness cards, or medical identity jewellery, are available.

More information is available from Epilepsy Action.



Additional precautions

If you have frequent seizures you may feel the need to take additional precautions. Information on daily living aids can be obtained from: Disabled Living Foundation, 380-384 Harrow Road, London, W9 2HU. Helpline number: 0845 130 9177; www.dlf.org.uk; email: info@dlf.org.uk

A fact sheet listing suppliers of alarms, medical ID jewellery/cards, medication aids and protective headgear is available from Epilepsy Action.

Epilepsy Services, Epilepsy Action

October 2009

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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.

Further information

If you have any questions about epilepsy, please contact the Epilepsy Helpline, freephone 0808 800 5050, email helpline@epilepsy.org.uk, text 07797 805 390 or visit our website www.epilepsy.org.uk

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Please contact the Epilepsy Helpline to request your free information catalogue.

Information is available in the following formats: booklets, fact sheets, posters, books, videos, DVDs and CDs.

Information is also available in Braille and large text.

Epilepsy Action's support services

Local meetings: around 100 local branches offer support across England, Northern Ireland and Wales.

Volunteers: these are local people (usually with epilepsy or with a family member who has epilepsy) who have been specially trained by Epilepsy Action to give advice on a one-to-one basis. They can also give presentations about epilepsy to groups of people.

forum4e: our online community provides an opportunity to contact other people with epilepsy from all over the world, in a safe and secure website: www.forum4e.com (For ages 16 years and over.)

Live online advice: from time to time we run regular advice forums, where trained advisers answer your epilepsy questions live on our website. For more details, visit www.epilepsy.org.uk/liveadvice

If you would like more information about any of these services, please contact the Epilepsy Helpline or visit our website.

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Registered charity in England (No. 234343)

How to contact us

Telephone the Epilepsy Helpline freephone **0808 800 5050**

Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm

Our helpline staff are Typetalk trained

Write to us free of charge at **FREEPOST LS0995, Leeds, LS19 7YY**

Email us at **helpline@epilepsy.org.uk** or visit our website:

www.epilepsy.org.uk

Text your enquiry to **07797 805 390**

About the Epilepsy Helpline

The helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people's cases on their behalf.

Our staff are trained advisers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative, about our services.

To ensure the quality of our services we may monitor calls to the helpline.

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Epilepsy Helpline:

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Epilepsy Action is the working name of British Epilepsy Association

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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 sustainable forests.