

Managing places and activities that increase risk

◆ When swimming, ask the attendant at the pool to keep an eye out for you, or alternatively, go swimming with someone, rather than going alone.

◆ At home use fireguards, smoke alarms and fire retardant materials and power breakers with electrical tools. In the kitchen using a microwave cooker reduces the risk of burns from direct sources of cooking heat.

◆ At home use a well designed shower or having a shallow bath and fitting a thermostat so the water does not get too hot. If there are others in the house, you can use an occupied notice on the door rather than locking it.

◆ At home if you experience seizures during sleep ask your doctor about your options. There is no data supporting the use of anti-suffocation pillows and there is only limited research on monitors including devices and seizure support dogs, but the benefits and disadvantages can be considered in relation to your particular circumstances.

Responding to Seizures: First Aid

◆ Carrying identification that gives information about the condition, how it affects you and what someone needs to do if you have a seizure. It should also include details of the medication you are taking and any specific allergies.

If you are with someone with epilepsy while they are having a seizure you can do the following to help reduce risk;

◆ Keep calm. Let the seizure run its course and do not do anything to try and stop it. If possible, put something soft under the person's head and move away objects to prevent injury.

◆ After the seizure, lay the person on their side (into the recovery position) and stay until they have recovered for at least 15-20 minutes. Once their breathing and colour is normal it is good to let them sleep until fully recovered.

◆ It is advisable to call an ambulance if the person is injured; the seizure does not stop after a few minutes; a seizure follows closely after another or they are having trouble breathing.

Health professionals can properly inform family and friends about first-aid and additional information is available from epilepsy organisations on specific issues, eg, Status Epilepticus and SUDEP.

Please consult a health professional before embarking on any changes to your medication, treatment and care plan.

Further Information

The following epilepsy organisations produce information about safety and give access to support and advice about ways to reduce risks at home, school or the workplace.

UK wide organisations;

Epilepsy Action
0808 800 5050
www.epilepsy.org.uk

National Society for Epilepsy
01494 601400
www.epilepsysociety.org.uk

National Centre for Young People with Epilepsy
01342 831342
www.ncype.org.uk

National organisations

Brainwave; The Irish Epilepsy Association
Tel: 01 455 7500
www.epilepsy.ie

Epilepsy Scotland
0808 800 2200
www.epilepsyscotland.org.uk

Epilepsy Wales
08457 413 774
www.epilepsy-wales.co.uk

This leaflet was written with epilepsy experts and people with epilepsy and produced by;

Epilepsy Bereaved

Epilepsy Bereaved is committed to preventing SUDEP and other epilepsy deaths through research, awareness and influencing change.

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The Anita Kaufmann Foundation
Educating the public not to fear epilepsy
Visit – www.akfus.org



EPILEPSY

Be Safe

Reduce Risk

Living with epilepsy

Today the outlook for the majority of people with epilepsy (about half a million in the UK) is very good.

If you have recently been told you have epilepsy, there are probably lots of questions that you want to ask about the treatment, or about what's likely to happen in the future.

This leaflet is to help you to talk with your doctor or nurse or epilepsy help-line about questions or worries you may have about the health risks of having epilepsy.

People often want to know whether it is safe to do some things or whether they should do some things differently or not at all, like swimming, using a bath, climbing ladders, going out alone.

There are very few rules which should apply to everyone - it depends on the individual's circumstances.

Risk to people with epilepsy will vary from person to person and depends on their age, the type of epilepsy, the seizure frequency and type/s of seizure; whether the person has a warning or not before the seizure; when and where seizures happen; whether the person has other health problems; and what support is available.

Most of the risks of having epilepsy are related to seizures, so trying to stop them is important. Some of the potential risks that are important include injuries and burns from seizures, water-related accidents, depression, the danger of status epilepticus, and Sudden Unexpected Death in Epilepsy (SUDEP).

There may be some special consideration for women who are pregnant or who have babies or small children, because in some cases seizures in the mother may present a risk to the child.

Most people think it is important to get as complete control of seizures as possible. Up to 70% of people with epilepsy will not have seizures if they are taking the right medication regularly. A few may also become seizure-free after epilepsy surgery. A proportion of people with epilepsy will continue to have difficult to control seizures. You may want to discuss with your medical team the balance you wish to achieve between control of seizures and avoidance of side-effects of medications.

Some risks are avoidable, some are not.

Being aware of Risk

Being aware of the things that increase risk is a first step to managing it. Considerations that will increase risk include:

- ◆ Places where having a seizure is risky e.g. in water; on a ladder
- ◆ Seizures which affect awareness or judgment or involve falling without warning
- ◆ Especially generalised tonic-clonic and complex partial seizures
- ◆ Seizures during sleep

Special Issues

Status Epilepticus and cluster seizures refer to seizures that are prolonged or occur one after another in quick succession. In some seizure types, status, if untreated, can cause brain damage and can be life threatening. It is important that your doctor knows if you have experienced a seizure that is longer than normal. Where appropriate and in discussion with your doctor, early treatment in the community can stop a long seizure or a run of seizures.

It is important to have a plan which informs others what to do in the event of a long seizure or a run of seizures. Your seizure plan may include epilepsy rescue medications which are used to try to stop status epilepticus developing or it may just advise others when to call the emergency services.

Sudden Unexpected Death in Epilepsy (SUDEP) is when a person with a history of epilepsy or seizures dies suddenly and prematurely and no other cause of death is found. SUDEP is uncommon, but may affect at least 500 people with epilepsy in the UK each year. Given the many different types of epilepsy, the risk of SUDEP will vary from low to very low (about 1 in 1000 people with epilepsy or less).

Current research suggests that risk factors include; young adults; generalised tonic-clonic seizures; seizures at night / whilst sleeping; multiple anti-convulsant drugs; abrupt and frequent changes in medication; people whose epilepsy is not well controlled; people not being treated.

Although SUDEP is known to occur in children under 16 (mainly in children with other physical or learning difficulties), it is otherwise rare among that age group. Further information on SUDEP is available from Epilepsy Bereaved.

Understanding and managing your seizures

The most effective way of reducing any of the risks associated with epilepsy is to achieve complete control of seizures.

Good medical diagnosis and treatment are vital and will usually require a referral to a specialist with an interest in epilepsy and then an agreed regular review, with a health professional who has a good knowledge and understanding of your epilepsy.

Making informed choices about epilepsy and wider life issues can be made easier by talking through with the medical team; epilepsy help-line staff or other people with epilepsy. Some local areas have an epilepsy specialist nurse as part of the local team.

The importance of getting your medication right

Anti epileptic drug treatment (AED's) is recognised to be the most effective way to control seizures. For the right drug to be given at the right dose, the medical team will need to have precise information about the number, frequency and type of seizures. If you continue to have seizures ask to be referred again to an epilepsy specialist for a review of your diagnosis and treatment options.

A common reason why some people continue to have seizures is because they do not take their medication as and when prescribed. Sometimes side effects of a particular medication may deter people from taking medication. Epilepsy specialists can provide information on treatment options.

Avoiding triggers for seizures

Seizures are spontaneous and unpredictable but can happen when a person is anxious, stressed, excited, sleep deprived, had too much alcohol (or taken recreational drugs). Seizures can also be triggered by rapid changes in medication or if you forget your tablets. Triggers are very individual and it is best to keep a diary of the seizures and get to know your epilepsy looking out for your own triggers for seizures.

There is also some evidence that being with someone during a seizure may give protection.

"It took my brother's death from epilepsy, then nearly my own from a seizure four years later, to motivate me into learning about the condition"
Simon - has lived with epilepsy for 26 years.