

# EPILEPSY

## Be Safe Reduce Risk

### **LIVING WITH EPILEPSY**

This leaflet provides information about risks associated with epilepsy and suggests ways to minimise them. Because the types of epilepsy vary so much from person to person, this leaflet is intended as an introduction.

Health care professionals and the epilepsy charities listed on the back of this leaflet can provide more specific information about increasing safety for each individual and can be contacted to discuss concerns about any of the issues raised here.

### **THE OUTLOOK**

Epilepsy is a long-term condition. There are around 450,000 people with epilepsy in the UK. A diagnosis of epilepsy can make the future seem unpredictable and uncertain but today the outlook for the majority is very good.

With modern drug treatments, up to 70% of people diagnosed with epilepsy will not have seizures as long as medication is prescribed and taken correctly. Having access to a specialist; receiving good quality care and support; access to information to help informed decision-making are all important in achieving freedom from seizures.

A few people are also able to benefit from epilepsy surgery which, in some cases, can cure the condition completely.

As with other long term conditions such as asthma and diabetes, having epilepsy can impact on quality of life if seizures are not controlled. It can also carry with it associated health risks.

Epilepsy is common but can raise many issues and questions for someone, particularly when first diagnosed. Making informed choices about epilepsy and wider life issues can be made easier by talking things through with the medical team, epilepsy help-line staff or other people with epilepsy. Some local areas also have an epilepsy specialist nurse as part of the local team.

Potential risks from having seizures are explained in the next section, followed by ways in which risks from seizures can be minimised.

The key point is to assess if and how you may be at risk and to minimise those risks in a way most effective and agreeable to you.

### **POTENTIAL RISKS OF SEIZURES**

Risks 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; and what support is available during the seizure.

People who continue to have seizures are more susceptible to the potential risks of living with epilepsy including:

#### **INJURY**

The potential for injury will obviously depend on the type of seizure being experienced and where seizures happen, particularly if they affect awareness or judgement or if they involve falling without warning. If this is relevant to you, information is available from organisations listed in this leaflet about safe participation in activities, including swimming and other sports.

#### **STATUS EPILEPTICUS**

This is not common and refers 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.

#### **Sudden Unexpected Death in Epilepsy (SUDEP)**

Sudden Unexpected Death in Epilepsy 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 about 500 people with epilepsy in the UK each year. Current research suggests that some people may be more at risk than others and 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; and people whose epilepsy is not well controlled.

Just as there are many different types of epilepsy, the risk of SUDEP will vary from low to very low (about 1 in 1000 people with epilepsy). This is why it is important to understand your own type of epilepsy and how best to manage it.

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

## **PREVENTING SEIZURES TO MINIMISE RISK**

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.

## **THE RIGHT MEDICATION**

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. Whatever the reason, however, the fact remains that while someone continues to have seizures the risk of injury and SUDEP is increased.

## **AVOIDING TRIGGERS FOR SEIZURES**

Seizures are spontaneous and unpredictable but can happen when a person is anxious, stressed, tired, excited, had too much alcohol or had changes to their AEDs.

Triggers are very individual and it is best to keep a diary of the seizures and get to know your epilepsy. Using a diary helps identify some of the triggers for seizures, such as lack of sleep, too much alcohol, and stress, forgetting tablets or other factors. Seizures can also be triggered by rapid changes in medication. Recreational drugs or excess alcohol may also play a part.

## **UNDERSTANDING YOUR EPILEPSY**

To reduce the risks associated with epilepsy and seizures it is important to understand more about your particular type of epilepsy and seizures; the importance of getting the best possible treatment to control all seizures; the best available care, support and information.

## **Improving Safety**

### **Taking care;**

Because seizures are unpredictable and can happen without warning and at any time of day or night, it is important to think about safety.

◆ 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.

◆ Using 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, it might be appropriate to use an occupied notice on the door rather than locking it.

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

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

◆ If you experience seizures during sleep you may wish to discuss your options with your doctor. There is no data supporting the use of anti-suffocation pillows and there is only limited research on monitoring devices, but the benefits and disadvantages can be considered in relation to your particular circumstances.

## **FIRST AID**

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 for 15-20 minutes to check breathing and colour.

◆ 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.**

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

## Further Information

### **Brainwave; The Irish Epilepsy Association**

Tel: 01 455 7500

[www.epilepsy.ie](http://www.epilepsy.ie)

### **Epilepsy Action**

0808 800 5050

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

### **National Society for Epilepsy**

01494 601400

[www.epilepsysociety.org.uk](http://www.epilepsysociety.org.uk)

### **Epilepsy Scotland**

0808 800 2200

[www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)

### **Epilepsy Wales**

08457 413 774

[www.epilepsy-wales.co.uk](http://www.epilepsy-wales.co.uk)

### **National Centre for Young People with Epilepsy**

01342 831342

[www.ncype.org.uk](http://www.ncype.org.uk)

This leaflet was written and produced by

## Epilepsy Bereaved

Epilepsy Bereaved works to prevent SUDEP through research, education and awareness, and by providing support to people affected by SUDEP and other seizure related deaths.

**Office: 01235 772 850**

PO BOX 112, Wantage, Oxfordshire, OX12 8XT

**Bereavement support line: 01235 772 852**

**[www.sudep.org](http://www.sudep.org)**