

## Living With Epilepsy

This leaflet is only a brief introduction to some aspects of living with epilepsy. The organisations listed at the end provide further information, help, and support.

### Practical considerations

#### Medication

For the best chance of controlling seizures you should take medication regularly as prescribed. Try to get into a daily routine. Forgetting an occasional dose is not a problem for some people, but for others would lead to breakthrough seizures.

Some people with epilepsy like to have special tablet dispensers to remind them of times to take medication. Pharmacists are a good source of advice about medication.

#### Driving

By law, people with epilepsy must stop driving. If you have a driving license, you must declare that you have epilepsy to the DVLA (Driver and Vehicle Licensing Authority). They will advise on when it may be possible to resume driving again. This will usually be after a year free of seizures. If you have a HGV or PSV licence, the rules are stricter than for an ordinary licence. The law tries to balance the possible risks to other people with the advantages of driving for an individual.

It is not uncommon for 'driving issue' to be a factor in deciding to risk coming off medication. If you have not had a seizure for two or more years, you may be considering whether to try without medication. However, if you stop medication and a seizure recurs, you will have to stop driving again for at least a further year. For some people this can be a very difficult decision.

Also, the DVLA recommend that if you do come off medication, you should stop driving during the 'weaning off' stage (which can be for several months) and for a further six months afterwards.

#### Work

A few jobs exclude people with epilepsy. However, there are many jobs which are possible. Sometimes the problem of finding employment is due to discrimination by some employers who have wrong beliefs about epilepsy. The Disability Discrimination Act (DDA) means that people with epilepsy should now be protected from this type of discrimination. More information is available from the Disability Rights Commission Helpline on 08457 622 633.

#### School

Most children with epilepsy go to mainstream schools. Many children with epilepsy do not have any other disability, and the seizures are well controlled. Many teachers understand about the correct use of medication and will not be concerned about dealing with a possible seizure. Some children with epilepsy have other disabilities, and may need special schooling.

#### Insurance

Some insurance companies do not take an objective view about epilepsy. You may find premiums unfairly raised. Epilepsy Action has an arrangement with an insurance company to

provide a range of insurance schemes for people with epilepsy. Their address is given at the end.

### **Benefits**

People with epilepsy are entitled to free prescriptions. Other benefits depend on individual circumstances. It may be worth discussing your situation with the Citizens Advice Bureau or the Benefit Enquiry Line on 0800 882200.

### **Sport and leisure**

People with epilepsy can participate in most sports, with informed, qualified supervision and, where appropriate, the relevant safety precautions.

### **Travel**

Make sure you have sufficient medication with you for your travels. Long journeys and 'jet-lag' may make you tired and more prone to a seizure. This should not stop you travelling. However, it may be best that someone on the trip is aware of your situation. There are issues relating to anti-malaria tablets for people with epilepsy. Your pharmacist should be able to advise about this.

### **Contraception**

If you are sexually active and want to avoid becoming pregnant it is important to find a form of contraception that works for you. However some methods of contraception are not suitable to use if you have epilepsy and anti-epileptic drugs may interfere with hormonal methods of contraception. Your doctor will be able to advise you on the suitability of the various contraceptive methods for you. Further information is also available on the Epilepsy Action website.

### **Planning a Pregnancy and Pregnancy**

Most women with epilepsy have healthy pregnancies and give birth to healthy babies. There is a small risk however that having seizures or taking anti-epileptic drugs may affect the health of you and your unborn baby. For this reason you are strongly advised to plan your pregnancy and seek advice from your doctor or epilepsy specialist before becoming pregnant. If you have an unplanned pregnancy do not stop epilepsy medication (which may risk a seizure occurring) but see a doctor as soon as possible.

You should take extra folic acid before becoming pregnant and throughout pregnancy as this can reduce the chance of certain abnormalities occurring.

Further information about epilepsy and pregnancy can be found on the Epilepsy Action website.

### **Preventing seizures**

Some people with epilepsy find that certain 'triggers' make a seizure more likely. These are not the *cause* of epilepsy, but may trigger a seizure on some occasions. Possible triggers include:

- Stress or anxiety.
- Heavy drinking.
- Street drugs.
- Some medicines such as anti-depressants, anti-psychotic medication, and other less commonly used medicines.
- Lack of sleep or tiredness.
- Irregular meals which cause a low blood sugar.

- Flickering lights such as from strobe lighting.
- Menstruation (periods).
- Illnesses which cause fever such as 'flu or other infections.

It may be worth keeping a seizure diary. This may show a pattern which may identify a possible avoidable trigger. Keeping a healthy lifestyle, a well balanced diet, regular meals, and not getting over tired may help you to feel better, and may reduce the chance of seizures occurring.

## Be prepared

Most people with epilepsy have their seizures well controlled by medication. However, it is best to be prepared in case a seizure does occur. Below are some suggestions.

### Tell people

It may be sensible to tell people about your type of epilepsy. It may be possible to give friends, relatives, work colleagues, school teachers, etc, some idea of what will happen if you do have a seizure. They may wish to learn about the recovery position if you have the type of epilepsy that causes unconsciousness. If you have the type of epilepsy where your behaviour may appear to change (complex partial seizures), other people may be more sympathetic and helpful if they understand and are warned about what to expect.

### Medic-alert bracelet

Consider wearing one of these bracelets (or necklets). They give an emergency phone number where details you wish to give about your condition are held. Medic-alert bracelets are often worn by people where emergencies may possibly arise. (For example, people with diabetes, severe allergies, epilepsy, etc). Contact details are given at the end.

### Safety

The aim is to anticipate and avoid potential serious injury if you have a seizure. Below are some suggestions, but common sense will prevail in your own personal situation.

- **Heat.** Do not use open fires. Think about the design of the kitchen. A microwave oven is much safer than a conventional oven, hot plate, or kettle. Cooker guards may be advisable for conventional cookers. Always turn pan handles towards the back of the cooker. Take the plate to the pan, not a hot pan to the plate.
- **Water.** Showers are safer than baths. If you do not live alone, tell someone if you are having a bath, turn off taps before you get in, and leave the door unlocked. Keep bath water shallow. Do not bath a baby alone. When you swim, do it with someone else, and not far away from dry ground.
- **Heights.** Make sure there are sufficient guards or rails in any high situation. Consider a rail at the top of your stairs. It is best not to climb ladders.
- **Electricity.** Use electrical tools with power breakers. Fit modern 'circuit breaker' fuses.
- **Sharp furniture.** Safety corners are available to cover sharp edges. Perhaps consider soft furnishings around the home as much as possible.
- **Glass.** Consider fitting safety glass to any glass in doors or to low windows.

Do not let having epilepsy stop you going out and leading a full and active life. Obviously, not all risks can be eliminated. However, it is best to use common sense and to be 'safety aware'.

## Attitudes

Coming to terms with the diagnosis of epilepsy may be difficult. This may be because of wrong or old ideas about epilepsy. Some parents become over-protective towards children with epilepsy. This is understandable, but may need to be resisted for the child's best interests.

Like a lot of conditions, it is sometimes the attitude towards the condition that may be more disabling than the condition itself. If you find that you are over-anxious or become depressed because of epilepsy, it may be best to have counselling. Ask your doctor for advice about this.

### **Further information**

#### **Epilepsy Action**

New Anstey House, Gateway Drive, Leeds, LS19 7XY  
Helpline: 0808 800 50 50 Web: [www.epilepsy.org.uk](http://www.epilepsy.org.uk)

#### **National Society For Epilepsy**

Chesham Lane, Chalfont St Peter, Gerrards Cross, Bucks, SL9 0RJ  
Helpline: 01494 601 400 Web: [www.epilepsynse.org.uk](http://www.epilepsynse.org.uk)

#### **Epilepsy Scotland**

48 Govan Road, Glasgow, Scotland, G51 1JL  
Helpline: 0808 800 2 200 Web: [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)

#### **MedicAlert Foundation**

1 Bridge Wharf, 156 Caledonian Road, London, N1 9UU  
Freephone: 0800 581 420 or Tel: 020 7833 3034 Web: [www.medicalert.co.uk](http://www.medicalert.co.uk)

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