

# 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.

Other leaflets in this series include: *'Epilepsy - A General Introduction'*, *'Epilepsy - Partial Seizures'*, *'Epilepsy - Childhood Absence Seizures'*, *'Epilepsy - Could It Be?'*, *'Epilepsy - Treatments'*, *'Epilepsy - Tonic-clonic Seizures'*, *'Epilepsy - Dealing With a Seizure'*, *'Epilepsy - Contraception / Pregnancy Issues'*, *'Epilepsy and Sudden Unexpected Death'*.

## Practical considerations

### Medication

It is important that you take your medication regularly to reduce the risk of having seizures. This is easier if you can 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 have special tablet dispensers to remind them of times to take medication. Pharmacists can advise you further about this and also about your medication.

### Driving

By law, people with newly diagnosed 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 LGV (previously HGV) or PCV (previously 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 the 'driving issue' to be a factor in deciding whether or not to come 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. 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 (for examples, pilots or people working at heights). However, there are many jobs which are possible. Occasionally, 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 Equality and Human Rights Commission - Tel: 0845 604 6610

### 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 then 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 who take anti-epilepsy medication 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 Benefits 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

You should 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. Some antimalaria tablets interfere with anti-epilepsy medication. Your nurse, pharmacist or travel clinic should be able to advise you about this.

## The contraceptive pill

Some medicines used to treat epilepsy interfere with the oral contraceptive pill, and a higher dose pill may be needed for effective contraception. Other contraceptives may not be suitable. Your doctor or nurse will be able to advise you. See separate leaflet called *Epilepsy - Contraception / Pregnancy Issues* for more details.

## Pregnancy

Being pregnant does not usually make epilepsy any better or worse. However, there is a very small chance that the unborn child may be affected by some medicines used to treat epilepsy. Before becoming pregnant it is best to seek advice from a specialist doctor. These small risks can be discussed.

It is recommended that you take extra folic acid (folate) before becoming pregnant and until you are twelve weeks pregnant. This reduces the chance of certain abnormalities occurring.

If you have an unplanned pregnancy, you should not stop epilepsy medication which may risk a seizure occurring. However, you should continue your medication and see your doctor as soon as possible. See separate leaflet called *Epilepsy - Contraception / Pregnancy Issues* for more details.

## 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 may include:

- Stress or anxiety.
- Heavy drinking.
- Street drugs.
- Some medicines such as anti-depressants, anti-psychotic medication.
- 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.

### MedicAlert® 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. MedicAlert® bracelets are often worn by people where emergencies may possibly arise. (For example, people with diabetes, severe allergies, epilepsy, etc).

### 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. 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 advisable to have counselling. You should ask your doctor for advice about this.

## Further information

### Epilepsy Action

New Anstey House, Gateway Drive, Leeds, LS19 7XY  
Helpline: 0808 800 5050 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 2200 Web: [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)

### Epilepsy Wales

PO Box 4168, Cardiff, CF14 0WZ  
Helpline: 08457 413 774 Web: [www.epilepsy-wales.co.uk](http://www.epilepsy-wales.co.uk)

### MedicAlert® Foundation

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

## References

- [Epilepsy](#), Clinical Knowledge Summaries (June 2009)
- [At a Glance Guide to the Current Medical Standards of Fitness to Drive](#), DVLA, Swansea.

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Comprehensive patient resources are available at [www.patient.co.uk](http://www.patient.co.uk)

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