

Directorate of Neurosciences

Epilepsy – What you need to know

Introduction

This booklet aims to give an idea of what epilepsy is and how it may affect you. You will find details of where to get more information at the end of this booklet.

What is epilepsy?

Epilepsy is a tendency to have recurrent (more than one) seizures.

It can happen to anyone at any age. It is a common condition – more than one in every 200 people in the United Kingdom will have epilepsy at some stage in their life.

Epilepsy has many causes. Investigation is often needed to find out why someone has developed epilepsy and to decide what treatment should help.

Most people's epilepsy will be controlled by taking regular anti-epileptic medication.

What are the investigations for epilepsy?

The doctor may arrange some tests. These could include:

- **Electroencephalogram (EEG)** – this measures the electrical activity of the brain and may help when deciding the type of epilepsy someone has.
- **Computerised Tomography scan (CT) or Magnetic Resonance Imaging (MRI)** – which may identify an abnormality in the brain.

How would anyone know that I have epilepsy if they needed to?

Some people wear special jewellery or carry a card with details of their epilepsy. You can get a card from either of the charities below.

Various companies make jewellery with room for your details. For example:

Medic alert: tel: 0800 581 420
www.medicalert.org.uk

SOS talisman: www.sostalisman.co.uk

What is a seizure?

A seizure is a sudden disturbance of electrical activity within the brain. This may only affect one area of the brain (a partial seizure) or the whole of the brain (a generalised seizure).

Most people experiencing a partial seizure may not lose awareness. They may only notice minor symptoms such as a strange smell or a 'rising feeling' in their stomach.

Anyone watching them may notice that they look 'vacant' and they may be a little muddled for a short time.

Most people experiencing a generalised seizure will be unaware, but this may only be for moments (an 'absence') or may be a longer seizure with unconsciousness and jerking. This used to be known as a 'grand mal' fit.

What is the right first aid for seizures?

Partial seizures

Someone having a partial seizure may appear confused or may be acting a little strangely. You should:

- Approach them calmly
- Do not shout at them
- Gently guide them away from any danger
- Stay with them until they are fully recovered

Generalised seizures

When someone has a generalised seizure they will be unconscious. You should:

- Lie them down if you can – this is the safest position
- Don't move them unless they are in danger
- If possible, move anything from around them that they may injure themselves on
- Protect their head but don't restrict their movements
- Don't put anything in their mouths

After the seizure

- Turn them onto their side (see diagram)
- They may be drowsy following a seizure and may well want to rest. They may also be confused. Do not worry, this can happen after a seizure and will wear off. If possible, stay with them until they are fully recovered
- Call an ambulance if the seizure lasts for more than five minutes, if they have injured themselves or if they have a series of seizures without recovering in between.



What about taking medication?

Your doctor may prescribe tablets to try to control your seizures. It can take time for the seizures to be controlled but most people notice an improvement after starting medication.

You may feel some side-effects from your tablets but, with adjustments, these can often be overcome. Your doctor or nurse will discuss possible side-effects with you before you start the tablets.

If you are having problems with your tablets, do not stop taking them but talk to your doctor or nurse.

If you take tablets, you **must** take them regularly and not miss doses or you may have a seizure

If you have epilepsy you can get free prescriptions. You will need to fill in a Medical Exemption Certificate application form FP92A. You can get a form from your own GP surgery or pharmacy.

Can I still use a computer and watch television?

Many people think that if you have any type of epilepsy you cannot use a computer etc. This is not true.

Only a very small number of people with epilepsy are photosensitive (have seizures triggered by lights) and they need to be more careful when using a computer, watching television etc.

Your doctor will tell you whether you are photosensitive or not.

How can I help myself?

In some people, lack of sleep and excess alcohol can increase the number of their seizures. It is important for you to look after your general health by eating a balanced diet, having regular periods of sleep and exercise, and avoiding drinking too much alcohol.

What about exercise?

You should try to lead as normal a life as possible, including exercise, but ask your doctor or nurse for advice if you are unsure.

By assessing potential risks sensibly, you can judge whether you can take part in any sport safely. For example, if you go swimming, you should take someone with you who knows about your epilepsy, or tell the lifeguard (who will keep an eye on you). It is generally not safe to swim in the sea.

If you are a member of a club or sports team make sure that there is always someone around who knows that you have epilepsy.

Telling people may be difficult but it can make it safer for you and them and may help them to understand epilepsy better.

What about work?

There are some jobs that you cannot do, due to the type of work involved. These include the armed forces, emergency services, the police and airline pilot.

Jobs which would put you or the people around you, at risk should also be avoided, for example, working at heights, underground or underwater.

When applying for a job you must disclose your diagnosis on the health questionnaire or at interview. If you are already working you did not have to tell your employer that you have epilepsy, providing that, if you had a seizure, it would not be dangerous for you or the people around you. However, it is strongly recommended that you do so.

You can get more information and support from the Disability Employment Advisor at your local Job Centre – this service is confidential and you can make an appointment yourself.

How do I stay safe at home?

Someone with epilepsy needs to take sensible precautions within their home to help avoid injury during a seizure.

You could try walking around your home and thinking 'what would happen if I had a seizure here and now and how can I reduce the risks'.

Tips:

- Avoid using locks on doors and (if possible) have the doors opening outwards so that they cannot be blocked from inside the room during a seizure
- Your kitchen is particularly dangerous. Don't use a 'chip pan', put all pans on the back rings of the cooker and use a cooker guard. Carry plates/cups to the cooker rather than hot pans/kettles to the table.
- It is generally safer to shower rather than take a bath
- If using a bath, run the cold water in first. Turn off all taps before you get into the bath and keep the water fairly shallow.
- Tell someone that you are going into the bath or shower and leave the door unlocked.
- It is safer to iron when someone is with you.

What about starting a family?

Contraception

Certain types of contraceptive pill are affected by some of the anti-epileptic medications making the pill less effective.

Tell your doctor if you are on or thinking about starting the contraceptive pill. They will try to give you medication that does not affect the pill, a higher dose of the pill or a contraceptive (e.g. condoms) that is not affected by your medication.

Periods

Some women notice that their periods are irregular or that they have more seizures when their periods are due. If this happens to you, mention this to your doctor. It may be possible to treat this with changes to your medication.

Pregnancy

Most women with epilepsy have normal pregnancies and healthy babies. It is, however, wise to let your doctor know if you plan to have a baby so that you can be advised about some sensible precautions you can take to ensure you and your baby remain well.

Do not stop your medication suddenly if you find out you are pregnant. This can cause seizures that may be difficult to control.

Can I drive?

If you have a driving licence (full or provisional) you **must** inform the Driver Vehicle Licensing Authority (DVLA) immediately you have **any** form of seizure – this includes ‘warnings’ (auras) and myoclonus (jerks).

Do not drive until they tell you that you can. A **class one** licence (car/bike) will probably be issued/reissued after a period of one year without any seizures.

- **If you drive following a seizure you are breaking the law and your insurance is invalid**
- **You are responsible for informing the DVLA about your epilepsy.** This is not the responsibility of your doctor.

If you have **only** had seizures in your sleep, for three years, you can apply for a licence. It would be renewed every three years.

If you have a **class two** licence (heavy goods, public transport etc) the regulations are much stricter – please speak to your doctor, nurse or the DVLA about this.

When you are ready to get your licence back, you may find that your insurance premium is more expensive. It is worth ‘shopping around’ for cheaper quotes.

Without my car, how do I get to work?

Talk with your nurse/local Job centre about **Access to Work** benefit. This may help you get to or do your job.

It won’t unfortunately, help you to get your shopping, take the children to school, visit friends or go on holiday.

So ...

How do I get around now?

The Concessionary Bus Travel Act 2007 gives free travel in England for people who are eligible for a bus pass. If you have epilepsy you would be eligible if;

- You were refused a driving licence if you applied for one
- You have been awarded the higher rate mobility component of Disability Living Allowance (DLA) for at least one year
- You are a blue badge holder

You can get a disabled person’s rail card that will give you discounts on rail travel. You will need a letter from your GP.

Once your seizures are under control it is OK to cycle but it is worth taking basic precautions

- Always wear a helmet
- Avoid busy roads and use cycle tracks where available

- Make sure that anyone with you knows what to do if you have a seizure

When you are travelling alone, whether it is by bus, train, cycle or just walking, it is worth considering taking a mobile phone with you so that you could contact – or be contacted by family/friends if needed.

When travelling abroad, always take your medication and a spare supply and carry details of your epilepsy with you.

If you are travelling abroad, check with your practice nurse about any travel vaccinations etc you may need in plenty of time. Some of them may interact with some anti-epileptic medications. The nurse may need to check what you need.

If your travel involves crossing different time zones, try to take your medication at roughly your usual time, regardless of the actual time in the country you are visiting. Keep your medication/extra supply etc in your hand luggage.

Where can I get more information?

There are two national charities for epilepsy in England:

Epilepsy Action:

Anstey House
40 Hanover Square
Leeds, LS3 1BE
Freephone helpline 0808 800 50 50
<http://www.epilepsy.org.uk>

Epilepsy Society (The National society for Epilepsy)

Chalfont St Peters, Gerrard's Cross
Bucks, SL9 0RJ
Local rate helpline: 01494 601 400
<http://www.epilepsysociety.org.uk>

You could also speak with your GP/doctor/specialist nurse or practice nurse or contact;

Penny Burt Epilepsy Specialist Nurse at RVI:

0191 2823995, (Mon-Fri, 9am-5pm)

Every effort has been made to ensure that the information in this leaflet is correct. It is, however, only intended as a guide and everyone's care may be different

Your doctor/nurse will advise you on your own personal treatment.

Information produced by Epilepsy Specialist Nurse, July 2004

Reviewed: April 2011

Next Review: April 2014