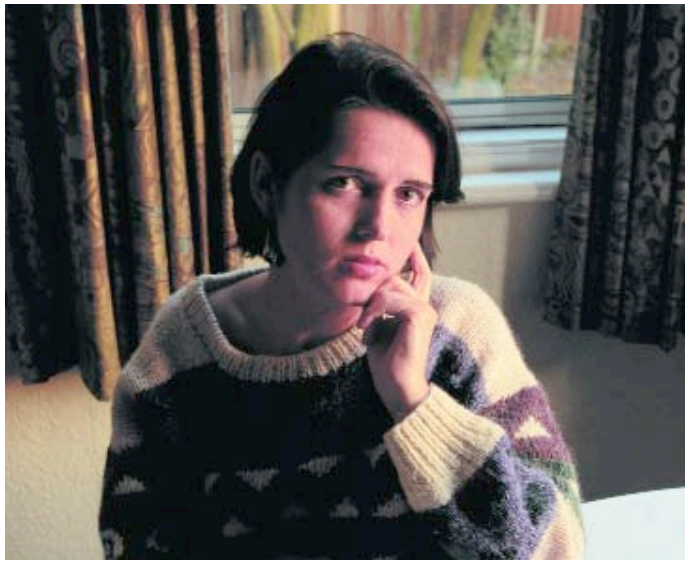




**epilepsy** *action*

# **Epilepsy & Everyone**



## Introduction

In the time it takes you to read to the end of this page someone in this country will experience an epileptic fit, or seizure. In fact one in 133 people in the UK - that's around 440,000 - has epilepsy making it the most common serious neurological condition. (Neurological means to do with the nervous system.)

In the past epilepsy was very much misunderstood, but thankfully attitudes are changing. People are talking more openly about living with epilepsy, both as a medical condition and as it relates to everyday life. This is very welcome because only through wide discussion can the needs of people with epilepsy be acknowledged and provided for.

This booklet is intended to provide an introduction to the medical and social issues which people with epilepsy have to be aware of and deal with. Some of the information is very general, relating to issues affecting everyone with epilepsy. Other information looks specifically at different seizure types or epilepsy at particular life stages.

*Epilepsy & Everyone* will arm you with the facts about epilepsy so that - whether you have it yourself, care for someone with it or just have an interest in epilepsy - you will feel more confident in your understanding of the condition.

# Contents

What is epilepsy?	4
Who has epilepsy?	5
Different seizure types	6
Possible causes of seizures - the triggers	7
Medical aspects of epilepsy	9
At the hospital	12
Side effects of medication	16
Other forms of treatment	18
Dealing with a seizure	22
Living with epilepsy	24
Epilepsy in later life	30

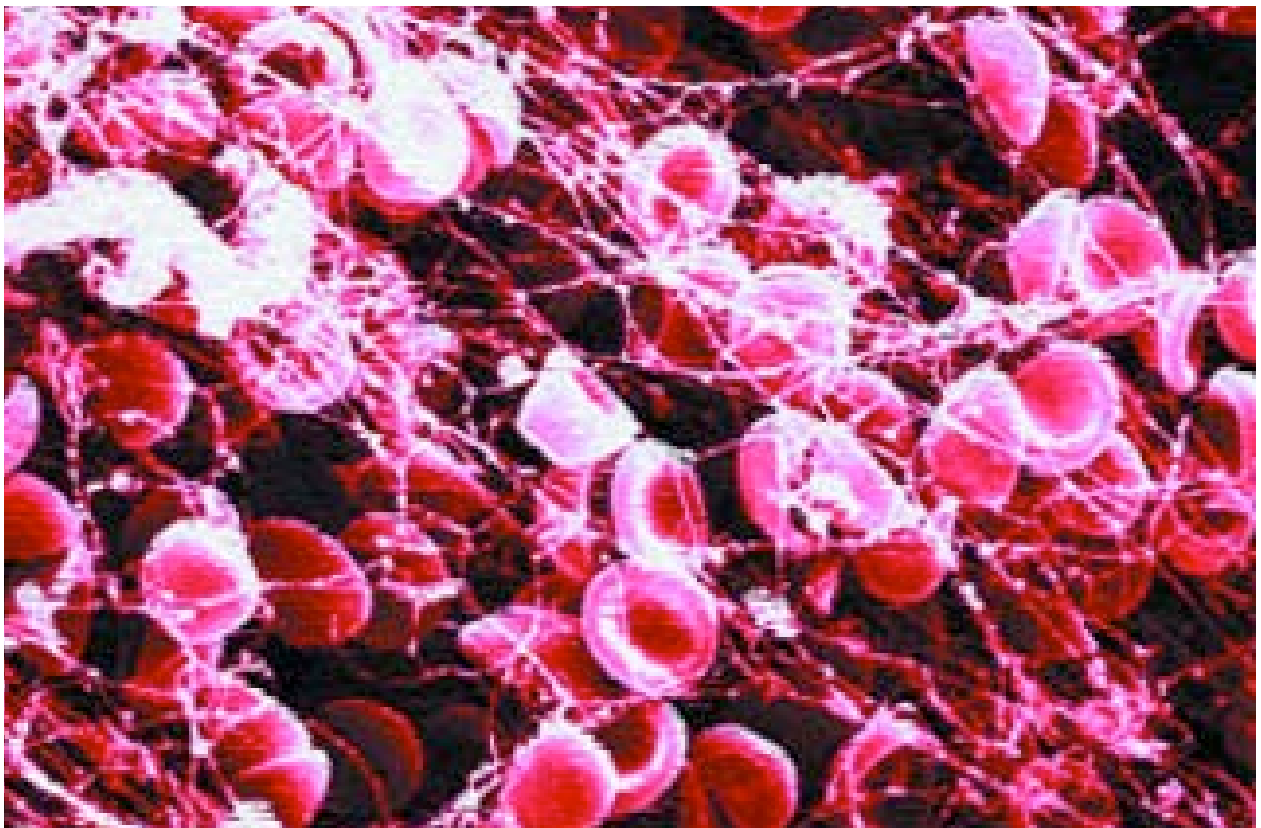


## What is Epilepsy?

Epilepsy is defined as a tendency to have recurrent seizures. A complex and sensitive organ, the brain is carefully protected inside the bony skull and it regulates and controls everything we do. To fulfil its many functions the brain's nerve cells (neurons) must work in smooth harmony. Sometimes, however, an upset in the brain's electrical activity can cause a brief disruption within the nerve cells and the result is an epileptic seizure.

What a person experiences during a seizure will depend on where in the brain the epileptic activity begins and how widely and rapidly it spreads. During a seizure some people may black out, while others experience a number of unusual sensations or movements. Seizures generally last only a few seconds or a few minutes, after which the brain cells return to normal.

Epilepsy is commonly thought of as a single condition. In fact there are many different kinds of epilepsy and over forty different seizure types. Each person will experience epilepsy in a way that is unique to them.



# Who has epilepsy?

Epilepsy can affect anyone, at any age and from any walk of life. Boys and men tend to be slightly more prone to develop it than girls and women - though no one really knows why. Many people develop epilepsy during childhood and people over the age of 60<sup>(1)</sup> are also more likely to develop the condition.

Sometimes the reason epilepsy develops is obvious: brain damage caused by a difficult birth; a severe blow to the head; a stroke which starves the brain of oxygen; or an infection of the brain such as meningitis. Very occasionally the cause is a brain tumour. Epilepsy with a known cause is called 'symptomatic' epilepsy. For most people - six out of ten, in fact - there is no known cause and this is called 'idiopathic' epilepsy.



In some instances the tendency to have seizures runs in the family. It is not necessarily epilepsy itself which is inherited but a low trigger point or 'seizure threshold'. This leads the brain cells to change their behaviour in circumstances which wouldn't cause a seizure in other people with a higher seizure threshold.

More knowledge is being gained all the time and it is becoming apparent that some types of epilepsy, such as juvenile myoclonic epilepsy<sup>(2)</sup>, can be inherited. There are also some syndromes, such as tuberous sclerosis, which have epilepsy as one of the symptoms - these syndromes can be inherited.

[Further information on types of epilepsy is available from Epilepsy Action.](#)



## Different types of seizure

Seizures can be divided into two main categories: generalised and partial.

Generalised seizures involve most or the whole of the brain. Partial seizures involve just part of the brain and can be either 'simple', when consciousness is not affected, or 'complex', when consciousness is affected to some extent. Whether simple or complex, the epileptic activity may stay in one spot or may spread to the rest of the brain.



A number of people with epilepsy experience seizures during sleep. These can be generalised or partial.

What you experience when you are having a seizure or what you can see when witnessing a seizure will depend on where in the brain the epileptic activity begins and how widely and rapidly it spreads (see pages 20-21).

In recent years the medical names given to various types of seizure have changed so you may hear one seizure referred to by different terms. Tonic-clonic seizures used to be called 'grand mal', for instance, and this term is sometimes still used.

# Possible causes of seizures - the triggers

Most seizures happen completely out of the blue. However some of us can pinpoint certain factors which set them off. These are known as 'triggers'. They do not cause epilepsy, but they can cause a seizure. Some of the more common triggers include:

## Stress

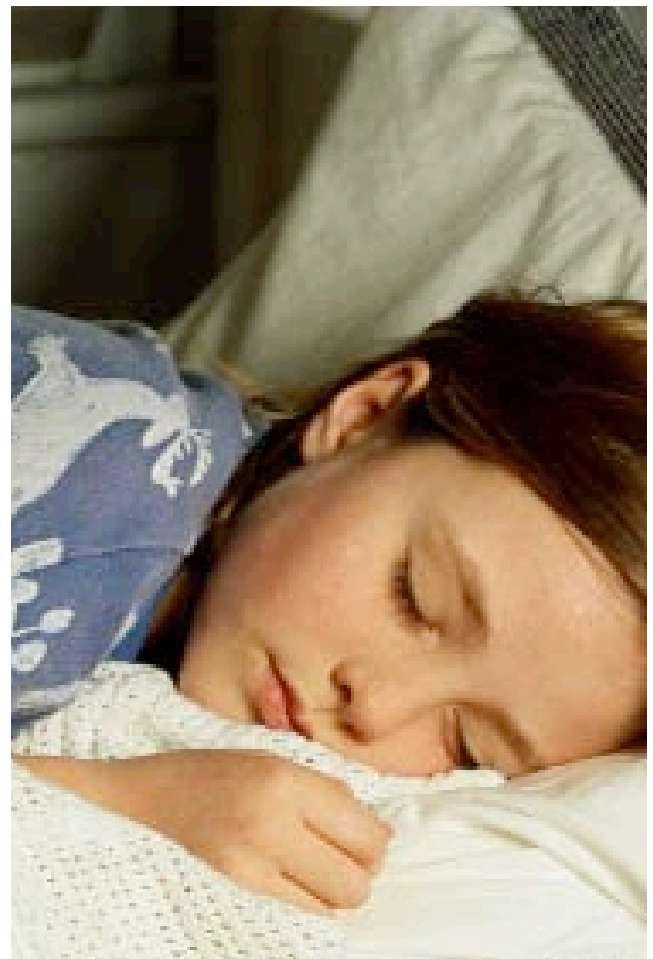
Some people experience more seizures during or after periods of anxiety, stress or excitement. Some stress is part of everyday life so finding ways to manage or cope with it, for example by using relaxation techniques, can be useful.

## Photosensitivity

Many people believe that watching TV or playing video games can trigger a seizure. This is true in a few people who are photosensitive (sensitive to flickering light), though it is far less common than most people imagine. In fact only five per cent of people with epilepsy are affected.

## Late nights and lack of sleep

Too many late nights or going without sleep can trigger seizures. For most people the odd late night should not be a problem, but where it is a problem, trying to establish regular sleep patterns is worth considering. Travelling across time zones may need special management and shift working may not always be the best option.



## Diet

Skipping meals and an unbalanced diet can lead to low blood sugar levels which may also be a trigger. 'Crash' or extreme slimming diets are usually not recommended for people with epilepsy as they could make seizures more likely. There is no evidence to suggest that specific foods can bring on seizures.

## Alcohol

Generally speaking, drinking in moderation should not be a problem for most people with epilepsy but excess alcohol can trigger a seizure - even in people without epilepsy.

[Epilepsy Action produces information on photosensitive epilepsy, women and alcohol & recreational drugs.](#)





# Possible causes of seizures - other factors

## Illness

When a person with epilepsy is unwell for any reason, seizures can be more likely.

## Hormones

Epilepsy can start or go away at any time of hormonal change. This could be puberty, in both sexes, or for women, during pregnancy or at the menopause. It is not clear why this should be. Some women report that their seizures are linked to their menstrual cycle and there are treatments available in this instance.

# Medical aspects of epilepsy

## Getting a diagnosis

There is no one test which can prove or disprove epilepsy and there are many other possible reasons for loss of consciousness. Since epilepsy is the tendency to have recurrent seizures and about one in 20 people has a single epileptic seizure at some time in their life, some doctors prefer to 'wait and see' after a single attack.

Providing the doctor with all the information available about the seizure(s) will be useful. As most people don't recall what happens during their seizures it may be helpful to take someone along who has witnessed one.



## Questions the doctor may ask...

### ...The person who had the seizure

- How did you feel before you had the seizure for example hot, cold, hungry, tired?
- Did you experience any unusual symptoms beforehand for example nausea, dizziness, chest pain? (This is to help rule out medical conditions that could be confused with epilepsy such as heart problems, migraine, panic attacks or fainting.)
- Had you drunk any alcohol or taken any drugs of any kind?
- Did you have any warning beforehand? If so what?
- Do you remember anything about the seizure? If not, what happened when you came round?
- Did you fall over and/or injure yourself?
- Were there any symptoms after the attack for example numbness or weakness?
- Is there any other information which could help in making a diagnosis for example have you had a head injury or previous seizures?



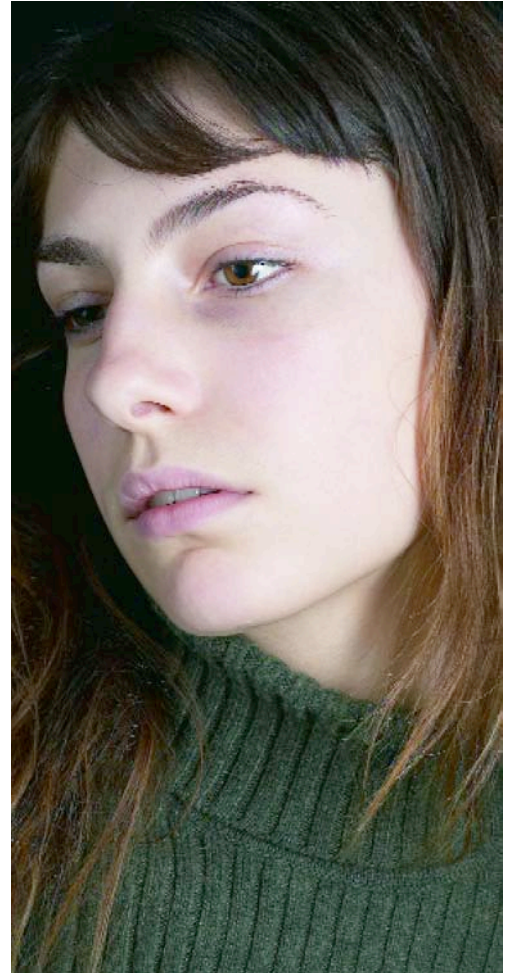
## ...The eye witness

- What was X doing when the seizure(s) started?
- What exactly happened when X had the seizure(s)?
- How long did the seizure(s) last?
- Was there a period of confusion afterwards?

## Questions to ask the doctor...

As a person with epilepsy, or their carer, you have a right to up-to-date information about diagnosis, treatment and the outlook for the future. Here are some questions you might want to ask. Many of us forget what we want to say the minute we step into the doctor's surgery, so it may help to write it down.

- What sort of epilepsy do you think I have?
- Why do you think I have developed it now?
- Will I always have it?
- What tests are you recommending and what are you looking for?
- How will you treat my epilepsy?
- Why do I need medication?
- Is there anything I can't or shouldn't do?
- What can I do to help prevent seizures?
- Where can I get more information about epilepsy?
- Will the medication interact with any other drugs I am taking? **Note for women:** Women taking the contraceptive pill should be aware that some anti-epileptic drugs speed



up the way the liver breaks down the Pill, which may reduce its effectiveness. This issue should be discussed with your doctor.

## At the hospital - tests for epilepsy

If the GP suspects epilepsy they should refer you to a specialist in epilepsy, usually a neurologist. The specialist may arrange a number of tests to help decide whether you have epilepsy and, if so, identify what type it is. Although such tests are not always conclusive, together with your symptoms, they can help to give a fairly clear idea of whether epilepsy is likely. The following are some of the more usual tests.

### Blood tests

The doctor will usually take a blood sample to check your overall health and to look for any other condition that could be responsible for your seizures.

### EEG (electroencephalogram)

The EEG is a harmless investigation which tells the doctor about the electrical activity of the brain.

### CT scan (Computerised Tomography)

This scan is a type of x-ray which looks for any areas of damage to the brain that could account for the seizures.

### MRI scan (Magnetic Resonance Imaging)

The MRI provides a high-quality image of the brain using radio waves and a magnetic field.



## Other Tests

Other scans, available in a number of cases, are DTI (Diffusion Tensor Imaging), PET (Positron Emission Tomography) and SPECT (Single Photon Emission Computerised Tomography).

[More detailed information on all the tests for epilepsy is available from Epilepsy Action.](#)

## What's on offer - medical treatment for epilepsy

The standard medical treatment for epilepsy is in the form of anti-epileptic drugs (also known as anticonvulsants). Other treatments for epilepsy are discussed briefly at the end of this section.

There is a wide range of effective anti-epileptic drugs (AEDs). Most are available in a choice of formulations, such as tablets or capsules or liquid or syrup. Taking the medication on a daily basis, as prescribed by the doctor, helps most people to get on with their lives without epilepsy getting in the way too much. For four out of five people's seizures can be controlled by taking the right drug.



## Which drug?

Once you've been diagnosed as having epilepsy the doctor will try to find the drug that best controls your type/s of seizure, aiming for the lowest effective dose.

Most doctors prefer to prescribe just one drug at a time. This is known as monotherapy. If monotherapy doesn't control your seizures you may need to take more than one type of AED. On the whole doctors try to avoid prescribing more than two different drugs at a time.

It is important to take the right dose at the right time, as prescribed by the doctor, otherwise it can be hard to achieve the best level of seizure control.

## Free prescriptions

If you have epilepsy and require medication you don't have to pay prescription charges. Epilepsy Action can provide details of how to arrange this.

## Epilepsy Nurses

Once your treatment plan has been worked out you'll be referred back to your GP. Some areas have an epilepsy specialist nurse who acts as a 'link' between the specialist and the GP. Some of these nurses are called Sapphire Nurses and are part of an Epilepsy Action initiative to improve epilepsy services. The nurse can also answer any questions you may have and help explain the effects of epilepsy to employers, teachers and so on.



## Working as a team

As a patient in the modern NHS you will expect to work with your doctors in choosing your treatment. In addition to following carefully any treatment plan, success also relies on being aware of your own body and the effect any AEDs have upon you. It is vital to report any side effects, so the doctor can make the right decision about your treatment.

It can take time for the amount of drug in the blood to reach the right levels or it may be necessary to try a different drug if the first does not suit you for any reason. Make sure you understand exactly how you are supposed to take your AEDs and what to do if you miss a dose. Don't be afraid to ask your doctor or epilepsy specialist nurse if any aspect isn't clear.

You should always tell any doctors, dentists and other health practitioners who are treating you that you have epilepsy and take medication.



## Keeping an eye on your progress

The doctor will introduce the drug they have selected for you gradually until the best control of your seizures is achieved. During this time you'll have regular check-ups and the doctor may take blood samples to check on the levels of the drug in your blood.<sup>(4)</sup> Some trial and error may be involved before the right treatment is found. After that initial period you will still need to visit your GP or hospital but not as frequently.

Once you become settled on medical treatment consult the doctor if:

- You suddenly start experiencing more seizures than usual
- You can't take your medicine for any reason e.g. a stomach upset
- If you start having symptoms which may be due to side effects from your AEDs
- Other aspects of your health change

- You are thinking about starting a family
- You find you are pregnant

## Side effects

All medicines have potential side effects as well as benefits. Balancing the two can be a fine art. Some people are lucky and don't experience any side effects. Even when they do happen they may be fairly minor, often occurring at the start of treatment and settling down after a few weeks. Although there are more potentially serious side effects, these are rare.

The most common side effect is sleepiness. Luckily this often passes as your body adjusts to the drug. Sometimes the drugs may make you feel unsteady and 'woozy'; this is usually, but not always, a sign that the dose is too high and needs to be altered. Some people are allergic to certain drugs and develop a skin rash or other symptoms. In this case the doctor may take them off the drug and try them on something else.

More troublesome side effects can occur when certain anti-epileptic drugs are taken for a long time. They can include poor memory and concentration, irritability, overactivity (in children), swollen gums, and acne. These side effects most commonly occur with the older AEDs, such as phenytoin, phenobarbitone and ethosuximide.



### If you experience side effects

If side effects are causing concern or discomfort you should discuss them with your GP. Never just stop taking a drug without medical advice as you could have a seizure.

The range of drugs available means that if you do suffer unacceptable effects with one drug the doctor can usually switch you to another that may suit you better. Occasionally people can be faced with a choice between having no seizures but some side-effects, or



having side effects but no seizures. If this is the case for you, remember it is your decision. Do discuss it with the doctor, however, so you can be sure you're aware of all the options.

## Interactions

Some over-the-counter medicines, such as cold cures, antacids and some preparations used to treat hayfever, interact with epilepsy or anti-epileptic drugs. Consult the pharmacist, or your doctor, when buying non-prescription medicines.

## Keeping a diary

One way you can help yourself and your doctor is to keep a written record of your seizures. This could include the date when you had a seizure, how severe it was, and any other details of that time such as having a late night, or your period if you are a woman. A seizure diary is a convenient way to do this.

Special diaries designed for this purpose are available from Epilepsy Action.



## Stopping treatment

Some people with epilepsy will need to take anti-epileptic drugs for life. Others may be able to stop taking drugs after a period without seizures, usually at least two years. Treatment will generally be reduced very gradually.

**Stopping your medication suddenly could cause uncontrolled seizures, so it is vital to do it with your doctor's guidance.**

## Other forms of Treatment

### The surgical option

Brain surgery for epilepsy has been around for many years. Where all attempts at controlling seizures with medication have failed, this may be an option, although not everyone's epilepsy is suitable for surgery.

Naturally certain risks are involved, but the majority of people who have had surgery for their epilepsy have a positive outcome. If you think surgery could be an option for you, you should discuss this with your GP or specialist.

In the past only a small number of people were considered for surgery, but now more people with uncontrolled epilepsy are being offered this option. There are still only a few specialist centres where epilepsy surgery is carried out, so you may experience a long wait. However if you are fortunate in having this option an operation could completely control your seizures or substantially improve them.



### Vagus Nerve Stimulation

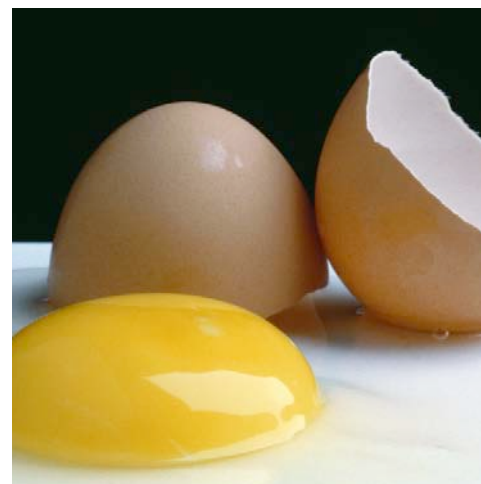
Another form of treatment involving surgery is the Vagal Nerve Stimulator. This involves implanting the stimulator - a small disc - into a space, usually near the collar bone, and connecting it to the vagus nerve in the neck. This treatment is another option for people who have not found an anti-epileptic drug to control their seizures.



## The ketogenic diet

This is a high fat diet occasionally used to treat very severe childhood epilepsies which conventional medication cannot control. This diet should only be attempted under medical supervision.

Further information on the treatment of epilepsy is available from [Epilepsy Action](#).



## Could complementary treatments help me?

Some people with epilepsy report that natural or complementary treatments have helped to improve their condition. Such treatments aren't usually subject to the same strict trials that medical treatments have to undergo. For this reason conventional doctors tend to be wary of recommending them. However there is increasing evidence that, used alongside medical treatments, some therapies can help improve the quality of life for people with long-term conditions like epilepsy. These days some GPs and hospital doctors are becoming more open to such therapies. A few even offer them in conjunction with more conventional treatments in their clinics.

The most promising types of complementary therapy for epilepsy seem to be those that act to relieve stress and promote relaxation, such as yoga, hypnotherapy, reflexology (foot massage) and aromatherapy (the use of scented oils).

It is important to note that complementary therapies are not without their risks. For example, entering states of very deep relaxation (as in some types of yoga or meditation) can trigger seizures.

Certain aromatherapy oils should not be used because they may trigger seizures in some people. Herbal treatment could also be risky as it could interfere with drug treatment.

continued on page 22

## Generalised & Partial Seizures

<b>Tonic-clonic seizures</b>	This is the most common sort of generalised seizure. It is also the one most of us think of when we imagine someone having an 'epileptic fit'. Tonic-clonic seizures used to be known as 'grand mal' and some people still use this name. Some people experience only the stiff 'tonic' phase or the jerking 'clonic' phase.
<b>Absence seizures</b>	This type of generalised seizure is literally an absence - a momentary lapse in awareness. It used to be known as 'petit mal' and you may still hear this name. Absence seizures are rare in adulthood. Girls experience them more than boys.
<b>Other generalised seizures</b>	There are other less common types of generalised seizures. These include atonic and myoclonic seizures.
<b>Simple partial seizures</b>	In this type of seizure the disturbance stays in just part of the brain so you remain fully conscious. Different regions of the brain are associated with different mental and bodily functions. So in a simple partial seizure your experience will depend on which region of the brain is affected.
<b>Complex partial seizures</b>	Those of us who have this common form of partial seizure - sometimes referred to as temporal lobe epilepsy or psychomotor seizures - are not aware of our surroundings or of what we are doing.

Further details are provided in our publication *Seizures Explained*



## What might happen

The muscles contract, forcing the air out of the lungs, the body stiffens and then jerks uncontrollably. Because of the muscles contracting you may seem to let out a cry as you fall down unconscious. For the same reason you may bite your tongue, be unable to swallow saliva normally or be incontinent. Your breathing may be irregular, your face may look very pale with a bluish tinge around the lips due to lack of oxygen. After a few minutes the jerking movements slow down and then stop.

A period of drowsiness, confusion, headache and sleep often follows. When you come round you can't remember what has happened. Recovery times vary.

You stop what you are doing, stare, blink or look vague for a few seconds before carrying on with what you were doing. An onlooker may simply think you are daydreaming or may not even notice, although you may experience many absences a day.

In atonic seizures ('drop attacks') the muscles suddenly lose their tone causing you to fall heavily to the ground. In myoclonic seizures, you have brief forceful jerks, similar to those many of us experience as we drop off to sleep.

Jerking or twitching, numbness, pins and needles, sweating, dizziness, nausea, disturbances of perception and memory, disruptions to hearing, vision, smell or taste, things seeming larger or smaller, or feeling that you've been somewhere before ('deja vu') are examples of what you may feel, but there are many others. Simple partial seizures may last for several seconds or minutes.

Simple partial seizures can progress to complex partial seizures or to a generalised seizure. When this happens these early symptoms can serve as a warning and are known as an aura.

You may appear to behave strangely; for example you may pluck at your clothes, fumble with buttons, smack your lips, swallow repeatedly, or stagger around. Such actions are known as automatisms. From time to time they take more unusual forms - for instance some people may undress or behave affectionately to complete strangers.

Complementary therapies are not intended to replace medical treatment. Always consult a qualified practitioner, and never stop taking prescribed medicine without consulting your doctor.

For more information on complementary treatments for epilepsy contact Epilepsy Action.

## Dealing with a seizure

Knowing what to do in the event of witnessing a seizure makes everybody feel more confident. Some people choose to carry a special card - available from Epilepsy Action - or wear a tag, or bracelet detailing their condition and what to do if a seizure occurs.

For further information on organisations that supply identity jewellery contact Epilepsy Action.

### Do...

- Stay calm
- Loosen any tight clothing around the neck
- Protect the person from injury (remove sharp or hard objects from nearby; or guide them away from danger if they are having a complex partial seizure)
- Cushion their head if they fall down
- Once the seizure has finished aid breathing by gently placing the person on their side if they have fallen (the pictures above show the recovery position)



- Stay with a person who has had a tonic-clonic seizure until they come round and are fully recovered
- Be quietly reassuring

## Don't...

- Try to restrain the person having the seizure
- Put anything in the person's mouth or force anything between their teeth
- Try to move them unless they are in danger
- Give the person anything to drink until they are fully recovered

## Call an ambulance if:

- it is the person's first seizure
- a tonic-clonic seizure carries on for more than five minutes
- one tonic-clonic seizure follows another without the person regaining consciousness between seizures
- the person is badly injured during a seizure or may have inhaled water e.g. in the bath or swimming pool



## Status epilepticus

This is a term used to describe a prolonged seizure (usually defined as lasting for 30 minutes or longer) or a series of seizures that happen without any recovery in between. A person experiencing status epilepticus needs urgent medical treatment to stop the seizures.

## Living with epilepsy

Learning you have epilepsy can come as a shock. It can affect both the way you feel about yourself and the way others see you.

It is a sad fact that epilepsy still carries a stigma. Faced with this it is easy to see why some people choose to hide the fact they have epilepsy. Each person has to decide for themselves who to tell and what to tell them. However it is only by everyone being open about epilepsy that we can help banish misconceptions about the condition.

### Coming to terms with epilepsy

It can take time to accept a diagnosis of epilepsy. Talking to people such as a nurse or counsellor at the epilepsy clinic or Epilepsy Action's Epilepsy Helpline staff can be helpful.

Remember that most people with epilepsy can - and do - lead full and active lives. Learning what does and doesn't trigger your seizures, remembering to take your medication and adapting your lifestyle to minimise the risk of triggering seizures is all part of managing your own condition.

People with epilepsy are individuals - they have their own size, shape, personality, skills, talents and ambitions in life. They also happen to have epilepsy. Thinking of yourself as 'an epileptic' means putting your epilepsy before every other aspect of yourself a person. This is why Epilepsy Action promotes the term 'person with epilepsy'.





## Memory

It is probably true to say that more people with epilepsy experience problems with their memory than people in general. Although further research is needed into why this is the case, possible explanations are that it is due to the cause of the epilepsy (such as damage to the brain) or the epilepsy itself. It is also thought that some anti-epileptic medication can affect memory.

## Depression

Depression is a common experience for many people but it tends to be more common in people with epilepsy. It may be related to the physical cause of the epilepsy. It may occur as a result of needing to come to terms with having epilepsy. Occasionally, it can be a side effect of anti-epileptic medication. Depression can also be directly related to seizure activity, occurring before, during and after a seizure. Sometimes, of course, depression is not connected with the epilepsy at all. Whatever the cause of depression, help is available through the GP.

[Further information on memory and depression is available from Epilepsy Action.](#)



## Everyday life

No-one's life can ever be entirely risk free. Be sensible about what you do - but don't let epilepsy rule your existence. If you are responsible for someone with epilepsy, try to avoid the temptation to be over-protective.

### In general

- Avoid the things that trigger your seizures if you can; but don't become obsessed by this
- Don't let epilepsy stop you seeking out new experiences
- Keep stress to a minimum; but bear in mind you can't avoid it altogether
- Learn to pace yourself
- Eat regular meals and a healthy diet
- Take regular exercise and participate in the sports you like - taking sensible precautions
- Stick to a regular bedtime (as far as is possible) and try to avoid getting overtired
- Make sure you have a sufficient supply of your drugs (at all times)
- Have a plan for dealing with seizures (if you live alone it may help to arrange a back-up system with a friend or neighbour)



# Safety first

Epilepsy or not, most accidents take place in the home. The following tips will help make your surroundings as safe as possible to avoid needless injury. Which tips you follow will depend on how active your epilepsy is. You may also be able to receive some help with costs. Contact your local Social Services for information.

## In the kitchen

- Consider using a microwave (it is safer than an ordinary cooker if you have a seizure)
- With a conventional hob use a cooker guard; use the back burners; turn saucepan handles towards the back of the cooker to make them less easy to knock over
- Carry plates to the pan
- Consider using a cordless kettle and cordless iron



## In the living room

- Avoid open fires; if you have one use a secured fireguard
- Radiators can get very hot - guards are available
- Avoid trailing wires and flexes
- If possible, choose a soft carpet
- Fit safety glass in windows and doors

## In the bedroom

- Choose a wide, low-level bed
- If possible, choose a soft carpet





## In the bathroom



- If you don't live alone tell a family member or housemate before you have a bath or shower so that they can keep a close eye on you
- Showers are generally safer than baths but make sure the temperature control is working efficiently
- Don't have the water too hot
- When taking a bath turn off the taps before you get in; keep the water shallow
- Fit a door that opens outwards so it will not be blocked if you fall behind it
- Do not lock the door - an 'engaged' sign or similar will tell people the bathroom is in use

## In the garden

- Use a power-breaker with electric tools or gadgets
- Plan your garden with care - grass is better than paving

## Out and about

- If seizures are likely, consider carrying an identity card or wearing identity jewellery

# Practicalities

## Leisure activities

Very few leisure activities are 'out of bounds' to people with epilepsy. With suitable safety precautions and some common sense it is possible to participate in most things.



## Driving

If you experience a seizure you must not drive by law until you have been seizure-free for 12 months or have experienced seizures during sleep for a period of three years or more. This can be difficult to adapt to, but if you continue to drive neither your licence nor your insurance, including third party, will be valid. You need to inform the DVLA (Driver and Vehicle Licensing Authority) or the DVLNI if you live in Northern Ireland as soon as you can.



## Working

Most people with epilepsy manage to work successfully in a whole range of jobs. Only a handful of jobs are actually barred by law to people with epilepsy. The Disability Discrimination Act covers people with epilepsy and, in principle, makes it illegal to discriminate against someone merely because they have epilepsy.



## Insurance

It can sometimes be hard to find an insurance company willing to insure people with epilepsy because it is often thought that they are too risky a prospect. It pays to check the small print whenever you take out any insurance so you don't find you aren't insured because of an exclusion clause for people with epilepsy. The Disability Discrimination Act covers Insurance, but there are special rules that enable Insurers to discriminate in some circumstances. Epilepsy Action can suggest companies who can provide car, travel and other insurance cover. Epilepsy Action also has its own personal accident insurance scheme for its Members.

## Benefits

If your epilepsy is poorly controlled you may be able to claim certain social security benefits. There are also special concessions for rail and bus travel. And, of course, if you are unemployed or are on a low income you are entitled to all the usual benefits. Further details can be obtained from your local Benefits Agency, welfare rights worker at the social services department or your local Citizens Advice Bureau.

For more information about any of these topics contact Epilepsy Action's freephone Helpline on 0808 800 5050.

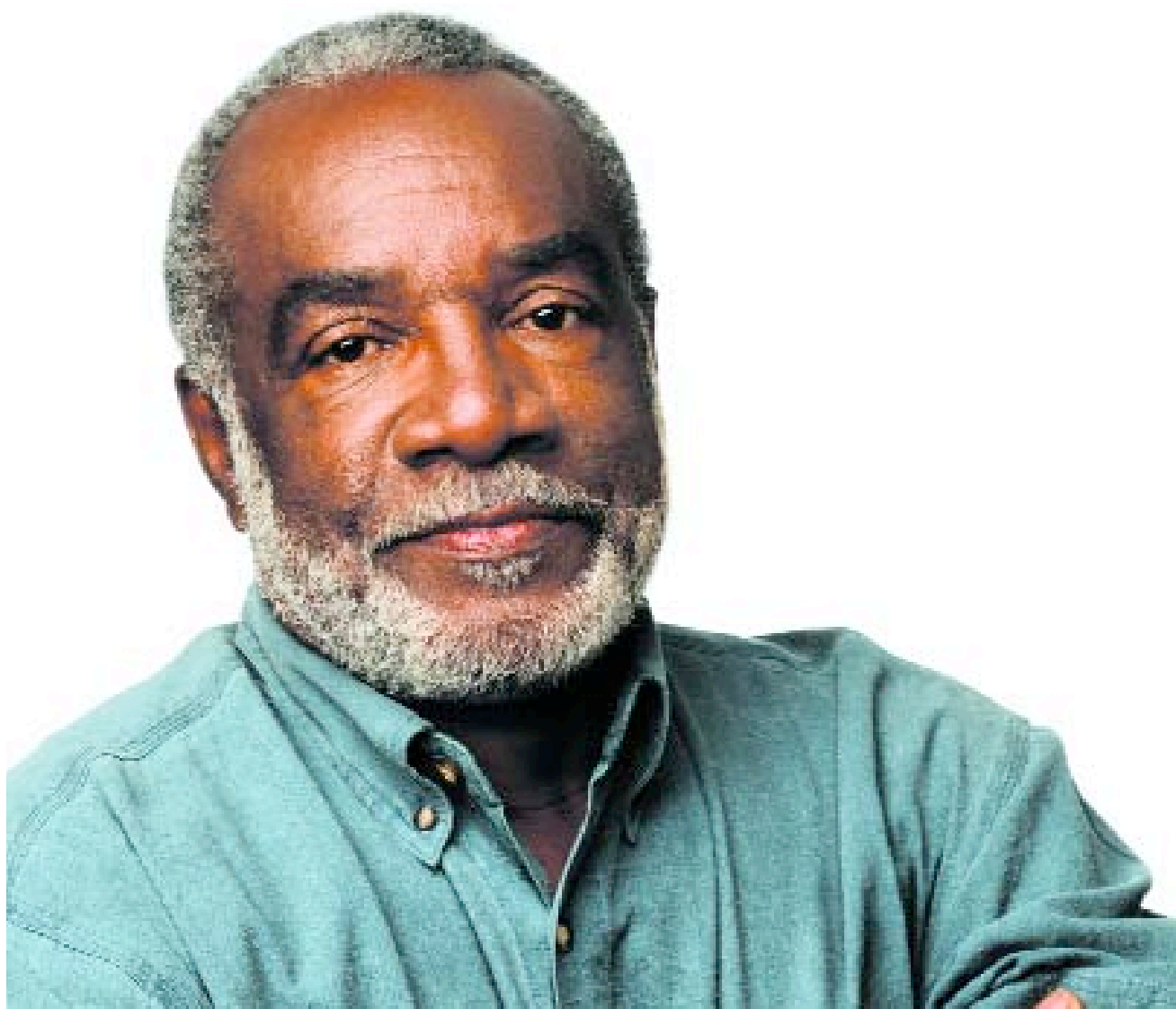


## Epilepsy in later life

Doctors used to dismiss epilepsy in older people in the mistaken belief that it was rare. Today that thinking is changing as it is recognised that there is a sharp rise in the number of people experiencing seizures over the age of 60. Most of the topics already covered in this booklet apply to people with epilepsy regardless of age. However, this section looks at some issues which particularly affect people over 60.

It may be that you have had epilepsy for a long time and be well adjusted to living with the condition. If you have developed epilepsy in later life for the first time the diagnosis can come as a complete shock. Having a seizure can be unpleasant at any age, but when you are older the immediate effects, such as muscle aches, confusion and generally feeling unwell, can last longer than in someone younger. Falls may also result in more injuries because older bones tend to be more brittle. This in turn, can affect your confidence and independence.

A seizure can also bring back memories of the days when epilepsy carried a greater stigma, was poorly controlled and often associated with loss of mental function. It is reassuring to know that, in the modern world, epilepsy can usually be effectively controlled.



## Why now?

Epilepsy can happen to anyone at any age, but some aspects of the ageing process can make people more prone to develop it in later life. Hardening and narrowing of the blood vessels in the brain (cerebrovascular disease) is a common cause as people get older. Strokes - interruption of the brain's blood supply or leakage of blood through the vessel walls - are another. Other medical problems may play a part too. There are also a number of older people in whom no definite cause can be identified.

## Special considerations

There are various special factors that need to be taken into account with regard to epilepsy when you are older.

Drugs often produce more side effects as people get older because their bodies take longer to process them. As we have seen, most doctors today prefer to control epilepsy using just one drug rather than several. Taking several drugs increases the risk of side-effects such as drowsiness. It can also be confusing if you have to take drugs for other medical problems. For this reason the doctor will try to keep treatment as simple as possible. If you feel you are experiencing side effects from your medication, do talk to your doctor. This will give them the opportunity to make adjustments if appropriate.



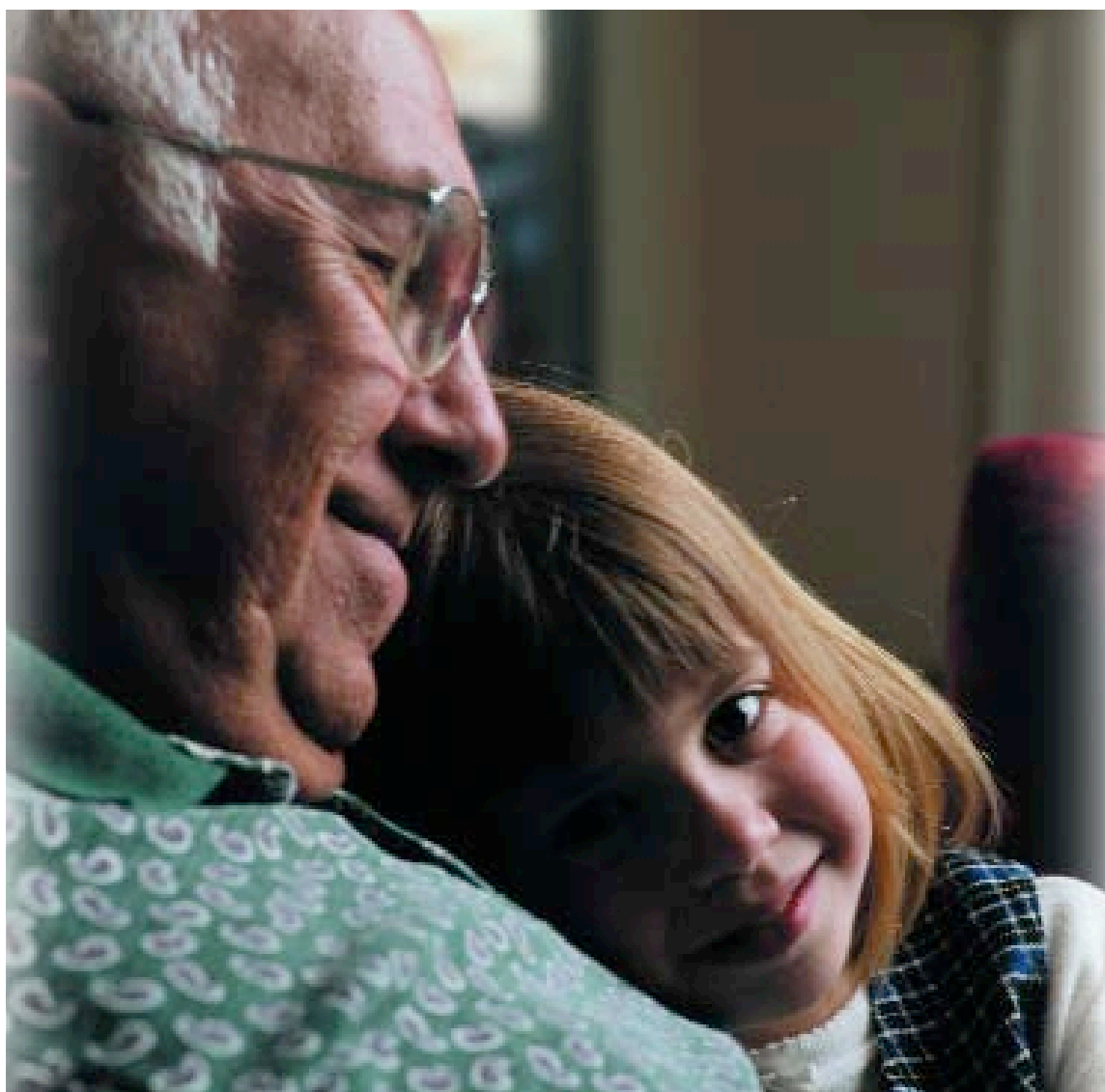
Note: Special dispensers designed to remind you when to take your tablets are available from the chemist. Epilepsy Action or your local pharmacy can give you more information.

## Staying independent

The impact of seizures can include negative effects on the attitudes of those around you such as friends, relatives and carers. If you are a grandparent, this may mean you are no

longer encouraged to look after your grandchildren. Or well-meaning adult children may become over-protective so that you feel you are losing your independence. This kind of reaction is understandable but people who develop epilepsy are still people first and foremost and should be allowed as much independence as possible.

Independence means different things to different people. It may mean living alone or living in shared or sheltered accommodation, with support services to hand. Whichever you choose, support can be obtained from your local social services department. They are able to carry out an assessment of your needs and, if necessary, provide support in the home as well as making adaptations to make life more manageable. The doctor and district nurse, as well as local voluntary services, can also be called on for help and advice.



The loss of a driving licence can be particularly hard, particularly if you have mobility problems. Some local authorities have special transport for older people and there are also voluntary organisations who can provide volunteer drivers. Information about this kind of service is available from your local Citizens Advice Bureau.

Further information on all aspects of epilepsy is available from Epilepsy Action.

If after reading this you have more questions, please consult your doctor or nurse. You can also call Epilepsy Action's freephone Epilepsy Helpline on

**0808 800 5050**

**or**

**visit our website**

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





## References

- (1) Tallis, R (1995) Epilepsy in Elderly People, Martin Dunitz Ltd, London, p8.
- (2) Freeman, J M et al (1997) Seizures and Epilepsy in Childhood - A Guide for Parents, The Johns Hopkins Press Ltd, London, p296.
- (3) Chadwick, D (1997) The Encyclopaedia of Epilepsy, Roby Education Ltd, UK, pp11-12.
- (4) Freeman, J M et al, as above, p127.

Epilepsy Services  
Epilepsy Action  
August 2003



Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

## Join us in Epilepsy Action by becoming a member of British Epilepsy Association

### **Member benefits include:**

- q A Membership Pack containing information about epilepsy and our services and activities
- q The quarterly magazine *Epilepsy Today* with the latest news - free of charge
- q Ready access to our professional staff
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- q Access to our exclusive motor, holiday and other insurance schemes
- q Invitations to our conferences at special Member rates
- q Access to 100 local branches nationwide
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Today in the UK there are 440,000 people with epilepsy

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# Epilepsy Services

## How to contact us:

Telephone the freephone Epilepsy Helpline **0808 800 5050**

Monday to Thursday 9.00 am to 4.30 pm

Friday 9.00 am to 4.00 pm

Our Helpline staff are Typetalk trained

Fax your enquiry to us free of charge on **0808 800 5555**

Write to us free of charge at  
**FREEPOST LS0995, Leeds, LS19 7YY**

Email us at the following address  
[helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

Information on a number of epilepsy related subjects is available from us in the following formats:  
leaflets, factsheets, books, videos, CD-Rom and audiotape.  
Information is also available in Braille, Moon and large text.

In partnership with the organisation Language Line, the Helpline is able to offer advice and information in over 120 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell you what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people's cases on their behalf.

***To ensure the quality of our services we may monitor calls to the helpline.***



Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work includes:

- providing information to anyone with an interest in epilepsy
- improving the understanding of epilepsy in schools and raising educational standards
- working to give people with epilepsy a fair chance of finding and keeping a job
- raising standards of care through contact with doctors, nurses, social workers, government and other organisations
- promoting equality of access to quality care

Epilepsy Action has a network of local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Join us...

You can help us in our vital work by becoming a member. All members receive our magazine *Epilepsy Today*, free cover under our unique personal accident insurance scheme and access to our services and conferences.

## **Getting more information**

Call our Freephone Helpline on 0808 800 5050

Freefax 0808 800 5555

Email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

Epilepsy Action

New Anstey House, Gate Way Drive

Yeadon, Leeds LS19 7XY

Tel: 0113 210 8800 Fax: 0113 391 0300

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

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