a diagnosis of epilepsy?

basic medical information
for people with
no medical training

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about the book

A diagnosis of epilepsy can evoke all sorts of emotions ranging from fear through to bewilderment and sheer panic. These emotions are generally the result of a lack of knowledge of the nature of the condition and this booklet is designed to initiate an understanding of basic medical information relating to epilepsy.

Having read the booklet you are advised to delve further and find out as much about your epilepsy as you can, using the facilities offered by the voluntary associations working in the field of epilepsy and from the services offered by Epilepsy Specialist Nurses.

about Mersey Region Epilepsy Association

Mersey Region Epilepsy Association (MREA) is an independent charity providing information and support to people with epilepsy, and their families, across Merseyside and North Cheshire.

It offers non-medical support and information over the telephone via our advice line (0151) 298 2666, or through our range of free leaflets and booklets.

We also offer face-to-face support, either via one of our fieldworkers, who can visit people in their homes - or through our offices at the Neurosupport Centre, Norton Street, Liverpool.

Our services also include a professional speaking service, on all aspects of epilepsy, to professional and public groups, and for those seeking contact with others, we have a network of affiliated groups across the region.
As well as being the most common of all neurological disorders, epilepsy is also the one which is most misunderstood. This booklet is aimed at counteracting a lack of basic medical knowledge about epilepsy and specifically at those people who have it, and more especially at those recently diagnosed.

I would love to be able to cover all the information in this booklet with my patients when they attend my clinics but, unfortunately, time does not allow and I see this excellently produced publication as being the next best thing.

It does not go into any great detail and nor is it intended to. Rather, it is intended as a clear introduction to basic medical facts which offers readers the opportunity to come to a fuller understanding of what is happening to them and of possible treatments they may be offered.

Further help and advice can be obtained from the epilepsy associations listed at the back of the booklet and, in areas where they are available, epilepsy specialist nurses.

David Chadwick OBE
Professor of Neurology
President of Mersey Region Epilepsy Association.
epilepsy - a definition

The medical definition of epilepsy is “repeated seizures of primary cerebral origin.” This means that you have a tendency to have seizures which originate in the brain. It follows that, since the word “repeated” is an integral part of the definition, an isolated seizure does not constitute epilepsy. Some people, for instance, have seizures as a result of an imbalance of sugar levels in the body (diabetes) but this is clearly not epilepsy, since the seizures are not directly linked to brain disorder.

some facts and figures

the incidence of epilepsy

In medical terms, this refers to the number of new diagnoses of a condition occurring in a set population within a given time limit - usually per 100,000 people over a period of one year. Wallace (1998) determined that the incidence of epilepsy is 80 new cases per 100,000 of population are diagnosed each year. Applied to the population of the UK and Ireland this means that every year about 44,000 people are newly diagnosed with epilepsy.

This graph shows that the incidence of epilepsy is highest in early years and especially in the first year of life. It tails off in adolescence and middle age and rises again in old age.
the prevalence of epilepsy
This, in medical terms, describes the number of people in a population who have a particular condition. It is usually expressed in terms of the number of cases in every 1,000 of the population.

In 1995 a sample population of 2,052,922 people in England and Wales showed that the prevalence of treated epilepsy (people who are taking antiepileptic drug treatment) was 5 in every 1,000 people. Applied to the population of the UK & Ireland this means that there are approximately 325,000 people being treated for epilepsy.

Extending these figures to a worldwide population there are many millions of people who are being treated for epilepsy besides those who, for whatever reason, are not receiving treatment.

![Graph showing prevalence of epilepsy by age](image)

**Age in years**
This graph shows that the prevalence of epilepsy is at its highest during later life, rising to a peak towards 70 years of age.

The figures linked to both incidence and prevalence clearly illustrate that, as a person with epilepsy, you are part of a very large group of people.
dispelling some myths and prejudices

- Epilepsy is not selective. It can affect anyone at any time.
- Epilepsy is not contagious. It never has been and it never will be.
- There is no correlation between epilepsy and levels of intelligence. Some people with epilepsy are extremely clever, others are of average ability and there are some who have learning difficulties.
- Epilepsy is not a mental illness. Seizures are merely symptoms of a physical problem within the brain.
- Epilepsy is not necessarily an inherited condition. It is true that it can be genetically inherited but more commonly there is no family history of epilepsy. In the majority of cases inheritance only plays a limited role.
- Epilepsy does not have to be a bar to success. There are many people with epilepsy who enjoy highly successful lives.
- Epilepsy is not always a lifelong condition. Many people who have been free of seizures for three or four years have their medication withdrawn under close medical supervision and remain seizure free for the rest of their lives. Surgery can sometimes be successful in eliminating certain types of epilepsy.
- Seizures do not necessarily cause brain damage. There is no evidence to suggest that short single seizures cause permanent brain damage. Certain types of seizure of long duration (over 30 minutes) can, however, injure the brain.
the brain

Complex as it is, your brain is no different from other organs of your body in so much as it can be subject to malfunction. In order to understand how and why it can malfunction, it is useful to know some basic details of how the brain is constructed.

It is made up of millions of nerve cells, called neurones, and it is the control centre of the nervous system.

**neurones**

The brain consists of a complex of nerve cells called neurones. A neurone has a cell body which receives messages from other neurones via processes called dendrites. Messages leave the cell body via a long process called the axon. The cell body generates electrical impulses which travel along the axon to its end where a chemical called a neurotransmitter is released. The chemical acts on a neighbouring cell dendrite to produce another chemical impulse in that neurone cell body.

Chemical messages can also inhibit neighbouring neurones making them less likely to produce electrical impulses.

A normal neurone fires off impulses at relatively low frequency, whereas ones which are unstable, as in epilepsy, generate in bursts at very high frequency. Seizures happen when many
thousands of these unstable cells produce high frequency discharges. There may be long periods between these bursts when these unstable cells are acting quite normally.

**structures of the brain**

The upper brain is called the cerebrum and is split into two, the right and left hemisphere. These are each divided into four lobes.

At the back of each hemisphere is the occipital lobe which controls vision and at the front is the frontal lobe which controls movement. The right frontal lobe controls movement on the left side of the body and the left frontal lobe controls movement on the right side of the body.

The parietal lobe separates the frontal and the occipital lobes and is responsible for processing sensory information and interacting functions such as reading, as well as being the control centre for artistic and musical appreciation.
The temporal lobes are located on each side of the brain under the frontal and parietal lobe and to the front of the occipital lobe and controls, among other things, language, memory and emotions.

In the centre of the brain is the corpus callosum, a thick bundle of nerves which joins the two hemispheres together.

At the base of the brain is the cerebellum which controls balance and regulated movement.

The lower part of the brain contains the brainstem which controls such functions as breathing, sleep-wake cycles and heartbeat.

The spinal cord, which continues as a continuation of the brainstem, feeds information to and from the body about sensations and movement.
the causes of epilepsy

You will need to know what has caused your epilepsy and indeed your doctor might be able to advise you about this. The vast majority of epilepsies, however, have no known cause and are called idiopathic.

Of known causes, there are two main categories:

a) **brain injury or disease**
   - damage to the brain with or without scarring as a result of (i) injury to the head or (ii) infections of the brain - (encephalitis) or brain linings (meningitis)
   - malformation of the brain
   - degeneration of the brain
   - metabolic (biochemical) disorder as a result of:
     - (i) low blood glucose
     - (ii) low calcium
     - (iii) drugs, particularly alcohol
   - brain tumours
   *(birth injuries rarely cause epilepsy)*

(b) **hereditary factors**
Epilepsy can be inherited but in most people there is no family history of epilepsy. Some types of generalised epilepsies such as absence epilepsy, juvenile myoclonic epilepsy and generalised tonic clonic seizures on awakening (see next section “types of seizure”), have an hereditary component. In the majority of people, however, inheritance only plays a limited role and this is especially true of partial seizures. It is thought that the contributions made by father and mother are of equal importance.
the diagnosis

The first port of call is usually the GP who, if there is a suspicion of epilepsy, refers patients for the expert opinion of a hospital consultant. This specialist is likely to be a consultant neurologist but could be a consultant physician who may have a specialist interest in epilepsy.

If you think back to your first appointment it is likely to have consisted of the specialist taking detailed notes of the events which have been happening, as described by either you or a reliable witness.

The consultant most likely asked you or your companion any or all of the following questions:

- **Was there any warning immediately before the episode?**
- **Can any warning of the episode be described?**
- **Did any member of the family or close associate witness the event?**
- **What happened during the episode?**
- **How long did it last?**
- **What happened after the episode?**
- **How long was it before you felt back to normal?**
- **Was there only one type of episode or was there more than one type?**
- **Has there been any recent illness?**
- **Did you ever suffer any birth or early life illness/injury?**
- **Does anybody else in the family have a history of epilepsy?**
- **Do you have any other medical problems?**
- **Do you take prescribed or illicit drugs or drink alcohol to excess?**

As you read on you will realise why the answers to these questions will have helped the doctor come to an accurate diagnosis and so make sure that the correct treatment is given to suit the type of epilepsy diagnosed.
During the consultation the doctor will have given you a physical examination, testing such things as heart rate, balance, eye control and reflexes.

The diagnosis of epilepsy is usually based on what you and a witness tell the doctor. There is no actual set test for epilepsy. You will probably have an EEG and this may help the doctor decide what type of epilepsy you have. Some people will have a CT or MRI brain scan, either of which may help identify a cause of epilepsy in some people.

At your follow up appointment when you were told that you had epilepsy and that you would be taking medicine as treatment, if you hold a driving licence, the doctor will have advised you to inform the driving licence authority of the diagnosis and to stop driving.

It must be realised that consultants will not have a lot of time to explain all about epilepsy and when you left the consulting room with the diagnosis, no doubt there were many questions you would have liked to have asked. The following information will answer some of those questions but not all of them and maybe not in as much detail as you would want. The answer here lies in using the expertise of an Epilepsy Specialist Nurse. Where appointed these nurses are usually hospital based and help provide continuity of care. They act as a contact point, liaising between specialists and GPs. They can monitor seizure control, adverse effects of medication and advise on issues of day to day living. They also hold significant stocks of literature produced by the voluntary epilepsy associations. A list of associations providing literature direct to people with epilepsy is printed at the back of this booklet.
Types of epilepsy

Seizure types have been classified into two main divisions - generalised seizures and partial seizures. There are also some unclassified seizures which do not fit into any category.

Generalised seizures

In these types of seizure the whole brain is affected by an abnormal electrical disturbance and the person becomes unconscious of surroundings. The following are some examples of generalised seizures.

Tonic-clonic seizures

These used to be known as “grand mal” seizures. The seizure usually starts with a cry and a loss of consciousness with the person falling to the ground. A ‘tonic’ or stiff phase then leads to a ‘clonic’ or twitching phase. Finally there may be confusion, often followed by sleep. In addition to the very obvious convulsive movements, an observer may see the lips turn blue and if the tongue has been bitten blood may trickle from the mouth with frothy saliva. It is possible, but by no means always the case, that the person could be incontinent of urine or in rare cases, doubly incontinent.

Tonic seizures

These seizures are quite dramatic. The muscles stiffen and, if standing up, the person will fall heavily to the floor, often receiving injury to the head. There is no jerking.

Atonic seizures

The muscle tone is lost causing the person to flop and fall to the ground. Sometimes referred to as “drop attacks” or astatic
seizures these can also be quite dramatic. The person falls heavily to the ground and although recovery is swift the result is often head or facial injury.

**clonic seizures**
In these seizures the muscles contract and relax continuously causing the person having the seizure to twitch and jerk repeatedly.

**myoclonic seizures**
“Myo” means muscle and “clonic” means jerk. When myoclonic seizures occur the muscles jerk rather as if the person has had some sort of electric shock.

Seizures usually occur shortly after waking or before retiring to bed when the person is tired. There is a loss of consciousness but it is hardly noticeable because the period is so brief.

**absence seizures (typical)**
These relatively rare seizures are usually confined to children and are sometimes referred to as “petit mal.” They occur suddenly, provoking a brief trance-like state. Affected children stare blankly into space and their failure to respond when they are spoken to often results in them getting told off in school for not paying attention.

**absence seizures (atypical)**
These seizures occur across the whole age range with people who have some form of brain damage. The seizures last longer than simple absence seizures and result in massive jerks or very sudden loss of muscle tone - either of which can cause the person to fall to the ground with some force.
**PARTIAL SEIZURES**

Only one part of the body is affected by these seizures since the activity of the brain is localised. Consciousness may be impaired.

They are subdivided into two types - simple partial seizures and complex partial seizures.

**simple partial seizures**
These seizures are again subdivided into two main categories - focal motor seizures and focal sensory seizures. There is no impairment of consciousness.

**focal motor seizures**
These cause movement of the limbs, head or neck and they originate in the frontal lobes of the brain. If the seizure is in the right frontal lobe then the seizure movement is produced on the left hand side of the body and vice versa. Seizures originating in the frontal lobe can also involve an interruption in speech.

**focal sensory seizures**
These seizures originate in the parietal lobes of the brain, producing physical sensations such as tingling or unnatural warmth. If the seizure is in the right parietal lobe it will produce a tingling or warmth on the left hand side of the body and vice versa.

**complex partial seizures**
These seizures usually originate in the temporal lobes of the brain and are non-convulsive in nature. They differ from simple partial seizures because they produce impaired or altered consciousness. This type of epilepsy is sometimes called temporal lobe epilepsy (TLE).
The seizures often commence with a simple partial seizure (called an aura) in which those experiencing the seizure become disorientated but still aware of what is going on. They may then go on to unknowingly pluck at clothing or smack lips and perhaps wander about aimlessly. Their behaviour is seen to be out of character.

**secondarily generalised seizures**

It is possible for someone who has had a partial seizure to then go straight into a generalised seizure. In these cases, the generalised seizure is known as a *secondarily generalized seizure* and it is usually atonic, tonic, clonic or tonic-clonic.

**status epilepticus**

This phrase is used to describe a situation when a seizure is prolonged or when there is a series of seizures during which the person does not regain consciousness. It is a medical emergency which needs active treatment by a doctor in order to stimulate the brain back to normality.

**treatment of epilepsy using drugs**

Seizures can be controlled using antiepileptic drugs. Doctors will always try to exercise control using a single drug (monotherapy) but occasionally more than one drug is prescribed (polytherapy).

Antiepileptic drugs are identified by two names, the generic (chemical) name and the proprietary (trade) name. Some of the most commonly used drugs are listed in the table on the next page.
### Generic name | Proprietary name
--- | ---
acetazolamide | Diamox®
carbamazepine | Tegretol®
 | Tegretol Retard®
clobazam | Frisium®
clonazepam | Rivotril®
ethosuximide | Emeside®
 | Zarontin®
gabapentin | Neurontin®
lamotrigine | Lamictal®
levetiracetam | Keppra®
phenobarbitone | Luminal®
 | Prominal®
phenytoin | Epanutin®
primidone | Mysoline®
sodium valproate | Epilim®
 | Epilim Chrono®
 | Convulex®
tiagabine | Gabitril®
topiramate | Topamax®
vigabatrin | Sabril®
zonisamide | Zonegran®

Diazepam is the most common drug used to treat status epilepticus. It is manufactured under three names, viz. Valium® Stesolid® and Diazamuls®.

All drugs can have unpleasant side effects and antiepileptic drugs are no exception. You should ask your doctor or pharmacist what the possible side effects of the drug you are taking are so that you can be aware of what to possibly expect. If side effects do become apparent you should contact your doctor so that steps may be taken to overcome any problems.
tolerance to antiepileptic drugs
It is unlikely that you could become so used to taking a particular antiepileptic drug that it would no longer work. In some circumstances, such as in pregnancy or where there is a marked increase in weight, the effectiveness of the drug might be reduced and so the dosage will have to be reviewed.

drug interactions
Antiepileptic drugs can react with other drugs and make them less effective. Your doctor will be aware of these interactions and prescribe medicines for other ailments accordingly.

drug withdrawal
If you remain free of seizures for three or four years you may be invited by your doctor to consider withdrawing from taking antiepileptic drugs. There are pros and cons to be taken into consideration when deciding whether to stay on drugs or withdraw under medical supervision. An obvious risk is to start having seizures again and lose your driving licence or possibly even your job, whilst on the other hand there could be the joy of being both seizure free and medication free.

“illicit drugs”
Because they are sometimes thought of as stress relievers and an opportunity to escape from everyday reality, “street drugs” can be perceived as being helpful in controlling seizures. They are not helpful. In fact, they can be the very cause of seizures.

Indirectly, narcotic drugs (those derived from opium and those manufactured to be chemically similar to opium) can lead, because of an induced forgetfulness, to a failure to take correct doses of antiepileptic medication. Narcotics, when taken in large doses, can directly lead to the brain being deprived of oxygen and can induce seizures.
Stimulants, such as amphetamines, taken in very high doses can cause tonic-clonic seizures, heart attacks and even death.

Cocaine is very dangerous. Seizures induced by taking high doses of the drug have been linked to heart failure and death. The seizures, which can happen within a very short time of the drug being taken, can occur not only in those with a history of epilepsy but in people who have never before had a seizure in their lives.

There is no scientific evidence to support a view that marijuana is in any way effective in controlling seizures.

**Free prescriptions**

Because you have been diagnosed as having epilepsy you are entitled to free medication. In the UK this applies not only to antiepileptic medicines but to any other medicine your doctor may prescribe for other ailments.

**Surgical treatment**

Where epilepsy is difficult to control, surgery may be considered as a possible way forward. It has to be stressed at the outset, however, that not everybody with uncontrolled epilepsy is considered a suitable candidate for surgery. Those who are, are subjected to a series of tests before a final decision is made as to whether the operation could or should go ahead. If you are considered suitable for surgery it is important to realise that it is you who will make the final decision. When actually making the final decision it is absolutely essential to bear in mind that no guarantee about the outcome can be given and that all the risks of major surgery apply.
**triggers**

You should be aware that certain situations can increase your seizure frequency. These are outlined below.

**lack of compliance**
Neglecting to take your medication as and when directed is a recipe for disaster. It is vitally important that you do not attempt to vary dosage or withdraw medication of your own accord. The prescribing of antiepileptic medicine is an exact science and should be left to experts.

**feverish illness**
A rapid rise in body temperature due to some illness can provoke seizures in children.

**tiredness**
It is a well known fact that sleep deprivation can provoke seizures so it is important that you avoid long periods of sleeplessness and that you do try to maintain a regular sleep pattern.

**alcohol**
Excessive drinking leads to an increase in seizure pattern because the effectiveness of antiepileptic drugs can be impaired. There is no evidence to suggest that the occasional social drink is in any way harmful.

**restricted activity and idleness**
Always try to keep your mind busy by following worthwhile pursuits. The regularity of seizures is inclined to increase when the mind is unoccupied.

**emotional stress**
Stress situations encountered in everyday living can provoke seizures. Areas of concern can include such things as a breakdown in personal relationships, financial problems or
difficulties in the workplace. If life starts getting on top of you for any reason, resulting in an increase in the number of seizures, you are strongly advised to seek professional counselling services.

**photosensitivity**

Seizures can be provoked in a small number of people by flickering light. If your seizures are provoked by watching television the following simple precautions can be taken:

- The set should always be viewed in a well lit room, from a distance of at least 2 metres, with a small lamp placed on the set.
- Avoid approaching the set and so use a remote control unit to switch channels. If you do not have a remote control unit, cover one eye as you approach the screen to switch channels or adjust picture controls.

Flashing lights on the dance floor may cause a problem. If this is the case, the only real solution is to avoid clubs which use flashing lights. If you use a visual display unit (VDU) and are photosensitive there are some simple steps to take in order to reduce the effects of light stimulus:

- Sit at a slight angle to the screen.
- After working at the VDU for 15 minutes take a 5 minute break.
- Covering one eye temporarily or permanently does cut down the effect of flicker but can weaken eyesight. Seek advice from an eye specialist before embarking on this type of action.
- Use a special clip-on screen cover to reduce flicker.
some issues for women

pregnancy
If you are planning a pregnancy it is important for you to be aware that 90% of women with epilepsy enjoy normal pregnancies and deliver perfectly health babies. Any possible risk of adversities for the other 10% can be minimised by wise preparation and medical advice.

20% of women with epilepsy experience a decrease in seizures during pregnancy, 50% experience no change in seizure pattern and the remaining 30% experience an increase in seizures.

The increased seizure pattern is very often due to the expectant mother reducing levels of antiepileptic medication for fear that the drugs may harm the developing baby. Since the potential to damage the baby is greater as a result of experiencing a major convulsive seizure than it is from drug side effects it is vitally important that the drugs are taken when and as prescribed.

If you are a sexually active woman of child bearing age you will be advised to take vitamins which contain folic acid and that you should continue taking the preparation for at least the first three months of any pregnancy. The reason for this is that the risk of miscarriage and of foetal malformation (see teratogenesis) is thought to be considerably reduced by taking folic acid.

Because the birth process can be a stressful and traumatic event there is a chance that seizures may occur during this period. It is a wise precaution, therefore, that careful consideration be given to hospital birth rather than home birth.
teratogenesis
This is the production of physical defects in developing babies within the womb. Some antiepileptic drugs can be teratogenic and so you should ask your doctor what, if any, defects can be caused by the drug you are taking. Once you are in possession of the facts you can make informed decisions on how to plan or manage your pregnancy.

breast feeding
If you wish to breast feed your baby, the fact that you are taking antiepileptic drugs should not be a problem since breast milk contains the drugs in very small concentrations.

fertility
There is a small but significant reduction in fertility in both women and men with epilepsy.

contraception
You should be aware that certain antiepileptic drugs can interfere with the effectiveness of some oral contraceptives, causing them to fail with the result of an unwanted pregnancy. If this causes you concern you should seek advice from your doctor who will advise you about appropriate contraception.

hormone replacement therapy
You can be taking HRT and antiepileptic medicine at the same time. Since some antiepileptic drugs can cause a calcium loss the HRT can usefully counteract this loss. HRT can sometimes lead to an increase in seizures but this is not related to interaction with antiepileptic drugs.

menstrual cycle
An increased seizure pattern can be linked to the menstrual cycle. The reasons for this are not fully understood. Seizures associated with the monthly cycle are called peri-menstrual seizures or catamenial seizures.
voluntary associations providing services for people who have epilepsy

Brainwave: The Irish Epilepsy Association
249 Crumlin Road, Dublin 12, Ireland
Tel: 00 353 1 455 7500 Fax: 00 353 1 455 7013
e-mail: info@epilepsy.ie
website: www.epilepsy.ie

Epilepsy Action
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY
Tel: 0808 800 5050 Fax: 0113 391 0300
e-mail: epilepsy@epilepsy.org.uk
website: www.epilepsy.org.uk

Epilepsy Scotland
48 Govan Road, Glasgow G51 1JL
Tel: 0808 800 2200 Fax: 0141 419 1709
e-mail: enquiries@epilepsyscotland.org.uk
website: www.epilepsyscotland.org.uk

Epilepsy Wales
PO Box 4168, Cardiff CF14 0WZ
Tel: 02902 755515
e-mail: epilepsywales@aol.com
website: www.wales-epilepsy.co.uk

Mersey Region Epilepsy Association (MREA)
Neurosupport Centre, Norton Street, Liverpool L3 8LR
Tel: 0151 298 2666 Fax: 0151 298 2333
e-mail: epilepsy@mrea.demon.co.uk
website: www.epilepsymersey.org.uk
**first aid for seizures**

- keep calm
- clear space around the person, moving objects that may be harmful
- reassure others and explain what you are doing
- make the person comfortable by laying him/her down and cushioning the head to prevent facial injury
- loosen tight neckwear - remove spectacles and high heeled shoes, if worn

*When movements have stopped*

- turn the person on their side (first aid recovery position)
- wipe away excess saliva from the mouth, check that dentures or vomit are not blocking the throat

Some people have seizures which put them temporarily out of touch with their surroundings. Behaviour may appear strange to the observer - for example, the person may wander around aimlessly with a glazed expression. During this type of seizure the person should be accompanied and gently led away from any source of danger.

*At the end of the seizure*

- reassure the person if there is confusion and explain what has happened
- check for obvious injury
  - observe and stay with the person until recovery is complete

Assistance may be needed to secure a safe return to routine or to a place of safety. Provide privacy and offer assistance if there has been incontinence.

- **Do not** push anything into the mouth
- **Do not** restrain or restrict movements during the seizure
- **Do not** move unless in danger
- **Never** place anything into the mouth at any stage of a seizure (a bitten tongue will heal - broken teeth will not)
Notes