

Mersey Region Epilepsy Association

Registered Charity Number: 404366



epilepsy in adulthood - a companion's guide

medical aspects of epilepsy

The word epilepsy comes from a Greek word 'epilamabaniēn' which means to seize or attack.

The Greek physician Hippocrates wrote about epilepsy as long ago as 400 BC when he called it the 'Sacred Disease'. Centuries later it became known as 'The Falling Sickness' and today it is almost universally known as 'Epilepsy'.

Over the centuries, knowledge about epilepsy has increased and now seizures are understood to be due to a brain malfunction which causes a sudden alteration in behaviour due to a temporary change in the electrical functioning of the brain.

The passage of time has not produced a cure but huge advances have been made in controlling seizures by use of antiepileptic drugs.

A single seizure does not constitute epilepsy. There must be a history of recurrent seizures before a diagnosis of epilepsy is confirmed.

Seizures can take many forms but most people with epilepsy will tend to have mainly one type. Sometimes however, people have two or more different types of seizure.

Epilepsy can affect anyone at any time, although it often starts in early life. It is often difficult to diagnose as it is not always clear that the episodes people experience are actually epileptic seizures. Sometimes nonepileptic attacks such as fainting or hysterical episodes can be mistaken for epilepsy. These episodes can so closely mimic a true epileptic seizure that they are sometimes referred to as 'pseudoseizures'.

The reason why epilepsy develops is not always obvious and for almost 70% the cause is unidentifiable.

There are two main causes of epilepsy:

- (a) brain injury or disease and
- (b) hereditary susceptibility

The brain damage can occur as a result of injury to the head, infections such as encephalitis or meningitis, malformation of the brain, degeneration of the brain or metabolic (biochemical) disorder as a result of low blood glucose, low calcium level or the effect of drugs, particularly alcohol. One further cause of brain damage is the development of a tumour.

Hereditary factors can be important since epilepsy can be inherited. In the majority of cases, however, inheritance probably only plays a limited role. This is especially true in relation to partial seizures.

More often than not the cause cannot be identified. Epilepsy with no known cause is said to be idiopathic epilepsy.

Many people wrongly believe that there are only two types of seizure - tonic-clonic seizures (incorrectly called Grand Mal) and absence seizures (incorrectly called Petit Mal).

There are, in fact, many types of seizure and an international classification has been developed to differentiate between the different types.

In simple terms there are Generalised Seizures and Partial Seizures. The whole brain is involved in generalised seizure and only part of the brain is involved in partial seizures. Both generalised and partial seizures can be subdivided into various types. More detailed information about seizure types can be obtained from reference books as listed at the back of this booklet.

the diagnosis

The first people to become aware of a problem are almost certain to be parents and they will, in normal circumstances, contact the family doctor for advice.

It is highly likely, and indeed desirable, that a referral will be made to a hospital consultant, who will in turn advise the family doctor on the best course of treatment.

The doctor will want to know as precisely as possible what happened when the episode occurred. The person attending the hospital with adolescents should expect the following line of questioning and be prepared to answer those which they are unable to answer themselves:

- was there any warning immediately before the episode?
- can any warning of the episode be described?
- did any member of the family witness the event? (if so, a video recording of the episode would be extremely helpful in coming to a diagnosis.)
- what happened during the episode?
- how long did it last?
- how did the person feel before the episode?
- was there only one kind of episode or was there more than one?
- have there been any recent symptoms of illness?
- does anyone in the family have epilepsy or suffer from blackouts?

Having completed the documentation, a full medical examination is carried out where such things as heart rate, balance, eye-control and reflexes are checked.

Other tests will be organised which will almost certainly mean a further visit to the hospital. The following routine test is used in investigations for epilepsy.

electroencephalogram (EEG)

The brain works through a network of nerve cells which communicate with each other by electric signals. The EEG detects and records these signals. Up to 20 leads are quite painlessly fixed on to the scalp and the machine amplifies the signals from the surface of the brain and translates them into a pattern traced onto paper (an electroencephalograph). The test takes about 20 minutes and during it the young person will be asked to open and close eyes, breathe rapidly and stare at flashing lights. The EEG helps the doctor to determine the type of epilepsy, if indeed there is any epilepsy at all.

If the EEG is normal and seizures still occur, a further EEG test will be carried out after a period of three days of sleep deprivation. Here, the parents/guardians are asked to keep the youngsters up for two hours each night after their normal bedtime and get them up two hours earlier than they usually get up each morning.

The result of the test will be discussed at a follow-up appointment.

Other tests, sometimes carried out in addition to the EEG, are as follows:

Video EEG Telemetry

The doctor may wish to make observations over a length of time whilst, at the same time, recording an EEG pattern. This is done by linking EEG equipment to a video camera and recorder whereby the traces recorded and the youngster's body activity are combined together on the one recording.

This test is usually carried out in the hospital as an in-patient.

Ambulatory monitoring of EEG

This is portable EEG equipment used to take recordings over a 24-hour period.

Here, a small cassette recorder is carried around the waist and is connected to the scalp by leads. The person will carry on as normal for the 24-hour period, usually at home. At the end of the 24 hours the equipment will be returned to the hospital and the recordings taken will be fed into a computer to produce an EEG pattern.

Computerised Axial Tomography (CT or CAT Scan)

This test is rarely necessary for investigations into epilepsy but occasionally it is required. In essence, the machinery takes X-rays of segments of the brain. The pictures produced are of high quality and clearly indicate any scarring of the brain or an abnormality which might be the cause of the epilepsy.

Magnetic Resonance Imaging (MRI Scan)

Like a CAT Scan, this test is only rarely used for investigating epilepsy in young people. It differs from the CAT Scan in so much as X-rays are not used. The brain's own radio signals are stimulated by a magnetic field and these signals can be mapped out and read by the machine, giving a very clear picture of the inside of the brain. The pictures can be a great help in finding the area of the brain which might be the site of the onset of the seizures.

One problem some people encounter is that they find both the CAT Scanner and the MRI Scanner claustrophobic or noisy. This is usually overcome if a well trusted companion is allowed to be present during the test.

If there is anything about the testing procedures you do not understand, do not hesitate to ask questions of the doctor or any member of the hospital team. Family doctors are also able to help with any explanation required.

When all the tests are completed, doctors will decide whether or not epilepsy is present. If epilepsy is diagnosed the parents/guardians will need to be told:

- the seizure type or types (if there is more than one type)
- the future outlook (e.g. will the epilepsy ever 'go away' or remit?)
- the aims and the duration of the treatment
- the likely and unlikely side effects of antiepileptic drug treatment
- the importance of adherence

Some of this information will be given by hospital consultants and some will be handled by epilepsy specialist nurses, family doctors, psychologists or social workers.

antiepileptic drug treatment

The standard treatment for the control of seizures is antiepileptic drugs. Most people will have to take only one drug but if that fails to control seizures two or more drugs may have to be used in combination with each other.

50 - 70% of people's seizures will be well controlled by medication with minimal side effects. 30 - 35% will have seizures which are resistant to antiepileptic drugs and the management of their epilepsy will be more difficult.

The choice of drug will somewhat depend on the type of epilepsy.

All antiepileptic drugs are used to prevent the onset of seizures and so the importance of taking drugs as prescribed cannot be over emphasised and is dealt with in the section of this booklet dealing with social factors under the heading 'Adherence' and also in the section dealing with psychological factors under the heading 'Adherence to Medication'.

The best sources of information about the drugs, which are prescribed for adolescents with epilepsy, are local pharmacists, epilepsy nurse specialists and family doctors. They are able to give accurate, up-to-date information about all aspects of antiepileptic drugs including possible side effects.

alternative treatments

The indications for using alternative treatments such as acupuncture and aromatherapy have yet to be established in terms of their effectiveness. Despite this they are sometimes used across the age ranges for those with resistant epilepsy.

surgical treatment

Certain people, whose epilepsy is very poorly controlled by drugs, are considered for surgical treatment. This treatment is only available in a few specialist centres and is available only for specially selected hospital patients.

The process of selection is lengthy and complicated involving the skills of consultant paediatric neurologists (or an adult neurologist after the age of 16 years), neurosurgeons and neuropsychologists.

The final decision to progress to surgery lies with the youngster's legal guardians. This is a serious decision and must be given the utmost thought after having listened to the advice of the experts in relation to the risks and benefits.

counselling services

For those who have difficulty in coming to terms with a diagnosis of epilepsy, some specialised clinics provide a counselling service, as do most GP practices.

first aid for seizures

In the event of youngsters being diagnosed as having a convulsive type of epilepsy, it is essential that their companions are fully aware of basic first aid procedures.

These are as follows:

1. Keep calm
2. Only move the person if in danger
3. Protect and turn the head and body to one side if possible
4. Do not try to stop the seizure
5. DO NOT FORCE ANYTHING INTO THE MOUTH
6. Do not call an ambulance unless a seizure lasts more than 5 minutes, or one seizure follows another, or the person has difficulty breathing or is injured
7. Stay with the person and allow him/her to rest after the seizure

It is not unusual for a period of confusion to follow a seizure. If this is the case the youngster should be watched carefully. Gentle reassurance is all that is necessary until full awareness is restored and he/she obviously recognises their surroundings.

Most people recover fairly rapidly following a seizure but companions should be aware of a condition called 'status epilepticus' which is a medical emergency. This is when one seizure follows another without the person regaining consciousness or if a seizure is prolonged. In either case medical help should be sought.

In cases where people are subject to prolonged or continuous seizures some carers are trained to administer a drug which will stop the seizures once they have begun. Outside of a hospital situation one such drug (usually diazepam) is administered rectally.

A training video exists for companions who are likely to administer rectal diazepam. Information on its availability can be obtained from the Epilepsy Associations.

summary

- A single seizure does not constitute epilepsy. The seizures must be recurrent.
- There are many types of seizure.
- Witnesses of seizures play an important role in the diagnosis of epilepsy.
- Diagnostic tests are carried out in hospital.
- Most epilepsy is very well controlled with antiepileptic drugs.
- It is essential to take antiepileptic drugs as and when prescribed.
- For resistant epilepsy surgery may be an option.
- All companions should have knowledge of basic first aid procedures.

Employment

There can be no doubt that jobs are not easily come by in the competitive world in which we live. Furthermore, it very often proves to be the case that it is even more difficult for those who have epilepsy to find employment and so advice and some specialist help is often required.

In seeking employment it is essential that a sense of realism, in relation to suitable work, is applied to the task. It is counter-productive to advise people with epilepsy to apply for jobs for which they are obviously unsuitable. Far better to direct their thoughts towards the huge numbers of jobs in which there are no obvious restrictions for people with epilepsy. For instance, an application for a job as a scaffolder will be doomed to failure whereas one for work as a gardener may meet with success.

One thing which has to be impressed on those with epilepsy is the fact that many people with and despite the condition are holding down highly responsible jobs across the whole spectrum of working life.

Specialist help, provided by the statutory employment services, is available and is well worth pursuing. Attached to all Job Centres are Disablement Employment Advisers (DEAs) who specialise in helping to place people with disability in employment.

In some cases a diagnosis of epilepsy can put a person who is in a secure job at risk of losing that job. The obvious example of this is in the case of a person who earns a living by driving a motor vehicle and loses that job as soon as the licence is withdrawn. In such cases help can be gained from the statutory agencies and other organisations in the voluntary sector.

In seeking work, people with epilepsy need the help and encouragement of those around them, and who are not connected to any statutory or specialist agency, to find suitable work not because they have epilepsy but because they are the best for the job on offer.

When applying for a job it is highly likely that an application form will have to be completed. Equally likely the question "Do you, or have you ever suffered from epilepsy?" will appear on the form. This presents many people with a great dilemma and they may well turn to a companion to seek advice on how to answer the question. Should they be truthful and say "yes" or should they lie and say "no" or should they avoid answering the question and address the matter should they be called for interview?

Being realistic, the chances of getting through the first sift when the truthful answer is given are very much reduced. On the other hand, to get a job as a result of a lie could result in instant dismissal should the truth emerge as a result of a seizure in the workplace. Here lies a real problem and many applicants look for advice on the correct way forward.

In truth, there is no easy answer and applicants have to come to their own balanced decision about which line to follow. Companions can be very useful in talking it through but cannot and should not take the decisions for them.

The better qualified people are the greater chance they have of securing employment and there are many courses available for people to improve their levels of education and qualifications. Companions can be a great help in searching out courses and schemes which could be useful in the jobs market. It sometimes takes a great effort to return to study after years of being away from any formal education and the encouragement of companions could well be the spur needed to 'take the plunge'.

summary

- Most work is suitable for people with epilepsy.
- Unsuitable work has to be clearly recognised.
- The Disablement Employment Advisor (DEA) offers expertise in helping people with epilepsy to find employment.
- A diagnosis of epilepsy by no means precipitates an automatic loss of a job.
- Voluntary agencies are available to maintain present employment and to seek new employment.
- A great dilemma exists in the approach to questions on application forms relating to epilepsy.
- Companions can be helpful in the search for opportunities to seek higher qualification.

educational aspects

Many opportunities are available for people with epilepsy to venture into the fields of further and higher education.

Guidance is needed as to the types of course to be followed and the establishments where suitable courses are provided.

Entry into further education is more readily available now than ever it was. Colleges of Further Education provide courses for people with all levels of ability and disability, ranging from basic skills to academic and vocational qualification. Some specialist colleges provide residential provision for the duration of the course if this should be necessary. Generally speaking, all Colleges of Further Education welcome applications from people who have any sort of special need and a companion can be of great help finding out more about them. The Epilepsy Associations will readily advise on facilities available as will, of course, Local Education Authorities.

Entry into Higher Education is usually by virtue of academic qualification. For instance, entry to a degree course is generally thought of to be via the traditional "A-Level" route. Although this is by far the most usual route, it is by no means the only one. Provision is made in all institutes of higher education to provide facilities for mature people who may not have any formal entry qualification but who are able to clearly demonstrate that they could cope with the rigours of high levels of study. The general criteria for entry will not be whether or not applicants have epilepsy (or indeed any other medical conditions) but whether they have the academic ability to cope with the levels of study and the application required to complete the course successfully. Whilst looking at the scope of provision companions should highlight the wonderful opportunities provided by the Open University.

For those who find themselves at a loss for the future because of the restrictions placed on them by a diagnosis of epilepsy the encouragement of others, in relation to the pursuit of educational opportunity, is invaluable. They should be constantly reminded that it is never too late to learn and that there is opportunity available regardless of having epilepsy.

summary

- Further and Higher Education are readily available to those with epilepsy.
- Colleges of Further Education cater for all levels of ability and disability.
- Formal academic qualification is not the only entry route to Higher Education.
- Guidance should be given to select the best course to suit individual needs.
- Open University provides tremendous scope for extended study.
- Companions' interest and encouragement is invaluable in gaining success.

social aspects

statutory benefits

Here is a list of some of benefits designed to help those with disability including those with epilepsy

Attendance Allowance; Carer's Allowance; Carer's Credit; Disability Living Allowance; Disability Premiums (Income Support) Disabled facilities Grants; Disabled Student's Allowance; Employment and Support Allowance; Incapacity Benefit; Income Support; Independent Living Fund; Personal Independence Payment. Personal Relationships

at work

Workmates can be a great help to those who have epilepsy in several ways.

Their attitudes towards the condition are all important in its level of acceptance in the workplace. The informed workmate can do much to overcome fear and prejudice by bringing others to a better understanding of the condition and so dispel the myths and misunderstandings that unfortunately do tend to prevail even in our modern culture.

Once people are aware of the condition in a workmate it can be discussed openly and in positive terms.

It is far better for everybody to know what to do if and/or when seizures occur than to leave the onus on one person.

The aim should always be to continue in gainful employment regardless of a diagnosis of epilepsy. Working companions, especially those who are employers, should make every effort to ensure that this is possible.

at home

Family members of those who have epilepsy have important roles to play in the management of the condition. They should try to make every effort to learn as much about epilepsy as possible so as to become aware of possible causes and of varying treatments.

In the case of adult onset of epilepsy every effort should be made to continue family life in the same manner as before the epilepsy ever appeared on the scene. This may not always be easy. For instance, if it is the driver of the family car who contracts epilepsy life styles are going to change for everybody in the household. In such cases alternative plans, at least for one year, have to be made to cover for the loss of the car.

Family members have to be careful not to over compensate for changes in lifestyle and become overprotective. It is very easy to try and cover every contingency for the possible onset of a seizure but it is simply not possible. Life must go on as normally as possible and hurdles crossed as they present themselves in daily life.

at play

There are so many leisure activities available for people who have epilepsy that it would be impossible to list them all.

There are, however, some pastimes which are unsuitable for those with epilepsy and, regretfully, these have to be avoided even if they were a major hobby before the onset of epilepsy. Activities which are unsuitable include mountaineering, deep sea diving and activities involving the use of firearms or other weaponry. In such cases companions can be of great assistance in helping to make the necessary adjustments to compensate for the loss of the activity.

driving

For many people, particularly those who earn their livings by driving, one of the most serious social complications of a diagnosis of epilepsy is the withdrawal of the driving licence. The rules regarding driving are quite specific.

The Driving regulations relating to epilepsy are laid out as follows:-

GROUP 1 (CAR + MOTORCYCLE) DRIVING ENTITLEMENT

1. A person who suffers from epilepsy may qualify for a Group 1 driving licence if he or she has been free from any epileptic attack for one year. An epileptic attack includes a minor one as well as such signs as limb jerking, auras or absences and need not necessarily involve loss of consciousness.
2. A person who has suffered an epileptic attack whilst asleep must also refrain from driving for one year from the date of the attack, unless they have had an attack whilst asleep more than three years ago and have not had any awake attacks since that asleep attack.
3. A person may qualify for a Group 1 driving licence provided that he or she has established, over a period of 12 months (beginning on the date of a sleep attack), a history or pattern of attacks which have only ever occurred whilst asleep.
4. Seizures occurring without any influence on the level of consciousness or causing any functional impairment in those with no history of any other type of seizure may continue to be licensed despite ongoing attacks once the pattern has been established for 1 year.

In all above cases the applicant or licence holder suffering from epilepsy must not be regarded as likely to be a source of danger to the public as a driver. If whilst holding a driving licence a driver suffers from any epileptic attack then driving must cease immediately (unless 3 or 4 can be met) and the DVLA must be notified. If a licence is issued under 3 or 4 and a different type of seizure occurs then the concession is lost and driving must cease and the DVLA notified.

Isolated Seizure

A person who has suffered from a single unprovoked epileptic seizure (isolated fit) will qualify for a driving licence if he or she has been free from further attacks for a six month period, provided there are no further clinical factors or investigations that may suggest an unacceptably high risk of a further seizure occurring in which case it shall be 12 months of driving.

Withdrawal

If a seizure occurs as a result of a physician-directed change OF/or reduction of anti epileptic medication the epilepsy regulations state that a licence is revoked FOR 12 MONTHS AS PER THE EPILEPSY REGULATIONS but reapplication can be accepted EARLIER once treatment has been reinstated for six months and as long as there have been no further seizures in the 6 months period after recommencing.

GROUP 2 (lorry and bus) DRIVING ENTITLEMENT

Epilepsy

Drivers of these vehicles must satisfy all of the following conditions:-

- Hold a full ordinary driving licence
- Have been free of epileptic attacks for the last ten years
- Have not taken any anti-epileptic medication during this ten year period
- Do not have a continuing liability to epileptic seizures

Isolated Seizure

Drivers of these vehicles must satisfy all of the following conditions:-

- Hold a full ordinary driving licence
- Have been free of epileptic attacks for the last five years
- Have not taken any anti-epileptic medication during this five year period
- Have undergone a recent assessment by a Neurologist
- Have satisfactory results from investigations

Finally do be aware that a diagnosis of epilepsy does not mean a lifetime ban from driving a motor vehicle. Successful control of seizures can result in a licence being restored after a period of 12 months or in the case of an isolated seizure or withdrawal seizures a minimum of six months.

free travel

In some parts of the country local authorities provide free transport to adults who have epilepsy. To qualify for such concessionary travel, medical evidence of inability to drive, by virtue of epilepsy, must be provided.

By way of example, the system operates in Merseyside where those receiving the concession are provided with a pass which enables them to use bus, rail and ferry services across the area without charge.

summary

- Statutory Benefits are available for some people who have epilepsy
- Helping to developing personal relationships at work, in the home and in leisure pursuits is an important part of social integration
- It is important to know the law in relation to driving regulations applying to people with epilepsy
- In some areas concessionary travel is available for those with epilepsy

psychological aspects

Adults who have epilepsy are prone to suffer significant psychological problems in comparison with those who do not have the condition. These include high levels of anxiety and depression, poor self-esteem, a lower sense of control and feelings of stigmatization. For those, however, with well controlled epilepsy, the picture may be much brighter. For this group epilepsy does not appear to profoundly diminish their ability to enjoy their lives to the full.

anxiety

Anxiety has, for a number of years, been cited as a common, if not the most common consequence of the unpredictable nature of some epilepsies in adults. Although many adults with epilepsy are fearful of their seizures, only a relatively small number develop a true phobic anxiety resulting in social isolation. Many experience anxiety as a result of the diagnosis of epilepsy.

Anxiety may also occur as an integral part of each stage of a seizure. Some adults will have attacks that are associated with or precipitated by anxiety.

The link between epilepsy and anxiety may be understood in terms of a number of potential sources; first, the fear of having a seizure and the belief that seizures may lead to death; second, the stigmatising condition of epilepsy may result in higher levels of anxiety and depression.

There is clear evidence of a relationship between level of seizure activity and psychological functioning with individuals with frequent seizures having significantly higher rates of anxiety and depression than those with infrequent or no seizures. Finally, some people experience anxiety as a result of their determination to conceal their condition.

depression

Depression is more common among people with epilepsy than those who do not have the condition. Evidence exists that 10% - 15% of adults with epilepsy will be clinically depressed but what causes the depression is unclear. It can be associated with changes in the body's chemical functioning or as a reaction to living with a stigmatising disorder. It is certainly more common in people with multiple seizure types and frequent seizures. In some adults with resistant epilepsy what might be important is not how many seizures they are having but how severe they are.

Depression can be self-reinforcing and is associated with a loss of confidence, low self-esteem and agoraphobia. In addition, the effects of antiepileptic drugs may impair learning and therefore interfere with normal coping responses to stress, including depression. For many adults developing seizures, there are important social consequences of coming to be labelled "epileptic" - for example, in relation their ability to function in the role of an employee or a family supporter. Understanding this is important for determining how we address the problem of depression in people with epilepsy.

aggression

Historically, aggression has been associated with epilepsy, yet there is very little evidence to believe that people with epilepsy are purposefully aggressive during their seizures. Where violence has been witnessed during a seizure in adults with epilepsy it has usually been as a response to constraint by others during the final stage of a seizure. There is little evidence to suggest that epilepsy is more common in violent or aggressive people or that violence or aggression is more common in people with epilepsy.

self-esteem

Low self-esteem is significantly lower in people with epilepsy than in those who do not have the condition. Why should this be so? The answer lies in the way people feel about themselves and the way they think that others may perceive them because of epilepsy. Just having epilepsy may well make people feel less good about themselves, even if they are not having seizures or only having a few seizures. Many adults with epilepsy believe that their self-esteem would be improved if they did not have epilepsy. Low self-esteem in those with epilepsy may have a number of potential sources, including family over-protection, perceived stigma and dissatisfaction due to a failure to fulfil expectations.

loss of control

Epilepsy is a condition characterised by loss of control. For a significant number of people with epilepsy seizures may occur anywhere, at any time, with little or no warning. The threat of a sudden and unpredictable loss of control (and consciousness) has been thought to be an essential part of epilepsy. The unpredictability of seizures may lead the person with epilepsy to believe that they have little real control over many important and basic events in their lives, perceiving events to be attributable more to the effect of luck, chance or fate. Such beliefs may make some individuals more susceptible to anxiety or depression. A number of factors including parental behaviour, the severity and frequency of seizures and the perceptions of themselves and their condition play an important role in understanding why many people with epilepsy have a high external locus of control.

summary

- High levels of Anxiety can be associated with those who have epilepsy.
- Between 10 - 20% of adults who have epilepsy will be clinically depressed.
- It is very often the case that people with epilepsy are subject to low self-esteem.
- People with epilepsy often greatly fear the sudden loss of control associated with seizures.

recommendations

- If the epilepsy is long-standing and the psychological problems have been in existence for some considerable time, professional help should be sought. Help can be obtained from a clinical psychologist or a qualified counsellor. Contact can be made through the family doctor, a hospital doctor
- It is important to ensure that those with epilepsy and their families are encouraged to discover for themselves much of the necessary information they require to make sense of their condition and of its management
- It is important for family members and companions to find out as much about epilepsy as they can.
- Use of psychological treatments that can sometimes help with psychological problems associated with epilepsy should be explored, including psychotherapy, counselling and relaxation training.

Brainwave
The Irish Epilepsy Association
249 Crumlin Road
Dublin
Tel: Dublin 4557500
Fax: Dublin 4557013
(From the UK prefix the numbers given with 00 353 1)

British Epilepsy Association
Anstey House
40 Hanover Square
Leeds LS3 1BE
Tel: 0808 309030 (Freephone Helpline)
Fax: 0113 2428804
e-mail: epilepsy@bea.org.uk

As from August 1999 the new address will be
New Anstey House
Gateway Drive
Yeadon
Leeds
LS19 7XY

Epilepsy Association of Scotland
48 Govan Road
Glasgow G51 1JL
Tel: 0141 427 4911
Fax: 0141 427 7414

Mersey Region Epilepsy Association
The Glaxo Neurological Centre
Norton Street
Liverpool L3 8LR
Tel: 0151 298 2666
Fax: 0151 298 2333

The National Society for Epilepsy
Chalfont Centre for Epilepsy
Chalfont St Peter
Gerrards Cross
Buckinghamshire SL9 0RJ
Tel: 01494 601400 (Helpline)
Fax: 01494 871927

Epilepsy Wales
15 Chester Street
St. Asaph
Denbighshire
LL17 0RE
Tel: 01745 58444
0345 413774 (Helpline)

International Bureau for Epilepsy
PO Box 21
2100 AA Heemstede
Netherlands

Telephone from UK: 00 31 23 529 10 19

Fax from UK: 00 31 23 547 01 19

Disability Alliance ERA
Universal House
88-94 Wentworth Street
London E1 7SA

“Opportunities for People with Disabilities”

Bank Buildings
Princes Street
London EC2R 8EU
Tel: 0171 726 4961

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