Mersey Region
Epilepsy Association

Adolescents Companion's Guide

Epilepsy in Adolescence - A Companion's Guide

Medical Aspects of Epilepsy

The word epilepsy comes from a Greek word 'Epilamabanien' 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-patent.

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 overemphasized 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:

- Keep calm
- Only move the person if in danger
- Protect and turn the head and body to one side if possible
- Do not try to stop the seizure
- Do not force anything into the mouth
- 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
- 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.

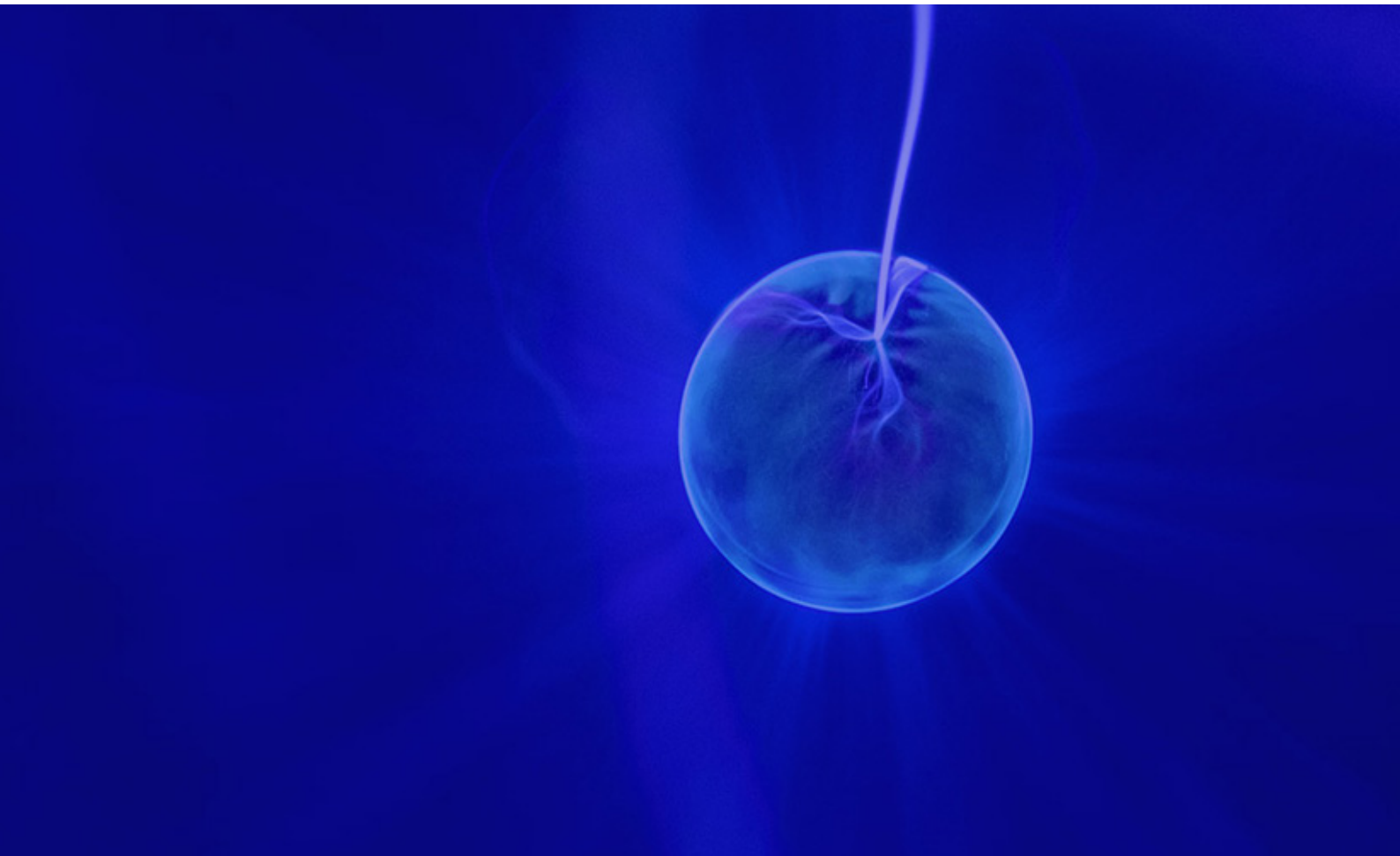
Most people recover fairly rapidly following a seizure but companions should be aware of a condition called 'Status Epilepticus' which is a medical emergency. This is when one seizure follows another without the person regaining consciousness or if a seizure is prolonged. In either case medical help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



Educational Aspects

Mainstream Provision

As a general rule, children in mainstream education transfer to the secondary sector at the age of 11 years.

The transfer to secondary education is a huge step for many children. They are moving into a much larger school, where new relationships with both children and staff have to be established. For the children who have enjoyed a very secure environment within a primary school, where they are known on a first name basis to every member of staff and virtually to all of the rest of the pupils, it is hardly surprising that the transfer to the secondary school, although eagerly awaited, can be quite traumatic.

For those children with epilepsy, special problems can arise at the age of transfer, albeit that most of these can be successfully dealt with. The most important consideration, and a somewhat obvious one, is that of choosing the best school to meet their needs.

Placement options should be considered at least two years before transfer is to take place, i.e. Year 6 of primary school.

A useful first step is to discuss future provision with the primary school headteacher. In areas where designated primary schools 'feed' the local secondary school, relevant information should be readily available.

Further information can be gained personally by visiting a variety of schools to establish if there are any strategies already in place for dealing with pupils who are subject to epileptic seizures. Questions should be asked to establish school policies relating to such areas of staff training in connection with medical conditions of pupils, care and administration of medication if a 'school day' dose is required and special needs provision (particularly if the pupil in question is 'statemented' as a direct result of epilepsy).

Once the concerns relating to the pastoral provision for children with epilepsy have been satisfied, attention should be paid to the overall provision, such as, levels of achievement, extra-curricular activities, parental co-operation and standards of behaviour and discipline.

A study of each school's brochure/website should be made to determine the levels of academic achievement.

Nowadays, schools have to publish the results of public examinations so these can be analysed to determine certain strengths and weaknesses within a school. The brochure/website will also give a clear indication of activities that are offered to pupils over and above the requirements of the National Curriculum.

Visit favoured schools and ask to be shown around during the working day. It is a reasonable request and an appointment will almost certainly be made for such a visit to take place. On such visits it may well be possible to have a quick word with the teacher responsible for the welfare of children transferring from primary education.

Most schools now have 'Open Days/Evenings', where all staff are available for consultation including, in the largest schools, a full-time nurse.

Children with epilepsy should be admitted to schools on the basis that they are normal children who happen to have epilepsy. They should be expected, therefore, to follow the National Curriculum, have access to all, or certainly most of extra-curricular activities and be subject to the same codes of discipline as the rest of the pupils.

It is possible, in exceptional cases, to modify the National Curriculum to meet individual pupil's needs. In the unlikely event of such a step being recommended by a headteacher, the implications are fully explained to parents/guardians.

Because it is virtually impossible to obtain any success in public examinations without a degree of work being done at home, young people are expected, throughout a secondary school career to do homework. Epilepsy is very rarely a reasonable excuse for neglect of homework and should not be offered as one on a regular basis.

Provision is made by examining authorities to cater for the needs of candidates who it is felt have underperformed as a direct result of a medical condition. It is felt that a candidate's performance in an examination has been adversely affected as a result of epilepsy then representations can be made to take such an event into account when consideration is given to the level awarded.

The teacher with the responsibility for examinations will be fully aware of all the regulations and will advise accordingly.

If and when difficulties arise due to any aspect of school life, it is essential that parents are aware of the correct lines of communication which have been set up to resolve them. There is a need to know how the school's pastoral system works. If, for instance, a problem arises as a direct result of epilepsy or it is felt that the problem is causing an increase in seizures, there is almost certainly a teacher with direct responsibility for dealing with and resolving such problems. It is the Headteacher, however, who carries the ultimate responsibility for the progress and welfare of all pupils attending a school and so, if all other channels of communication fail to resolve a difficulty, a direct approach to the Headteacher should be made.

By the time the pupils have reached the stage of concentrating on studying for GCSE's they are also being encouraged to think seriously about life after reaching the school leaving age. The first decision to be made is as to whether they are to stay on at school for further study, transfer to a College of Further Education to meet the same objectives, or leave school and seek employment.

The decision to continue in further education is straightforward in relation to epilepsy. It should make no difference whatsoever. If the desire is there, the facility is available.

The selection of a career is not quite so straightforward for students with epilepsy. It has to be recognised that certain jobs are not available to them and balanced in the knowledge that the number of options available far outweigh those denied to them. Teachers with responsibility for career guidance are in a position to offer advice on the huge number of jobs, which are totally suitable to those with epilepsy.

In addition to careers guidance available within schools, most Local Education Authorities have a Careers Service available to give help and guidance.

At the age of 18+ there is the possible option to continue into Higher Education. Most places available in this sector are allocated on a selection procedure, based on previous examination results. Students with epilepsy should gear their ambitions towards applying for courses where admission will not be restricted because of epilepsy. Once again it has to be stressed that the number of courses available far outweigh those which would be restricted. There are many young people with epilepsy who have university degrees.

Special School Provision

It is more likely that those who attend special schools after the age of 11 years will complete their formal education in those special schools. There is, however, some provision for many of these young people to continue in full-time education until the age of 18 years and their teachers will be in a position to advise as to the levels of that provision.

Notes for teachers

Epilepsy is just one of the many disabilities teachers are likely to come across during a teaching career.

It is likely, however, to be more common than many and will undoubtedly be the most common of all neurological disorders encountered. It is conservatively estimated that over 100,000 children in the UK have some form of epilepsy and so it can be expected that a secondary school of 1,000 pupils will have at least 5 pupils on roll at any one time who have epilepsy and a primary school with 200 children will have at least one.

It is important to be aware at the outset that the pupil should be treated as a normal pupil who happens to have epilepsy. In certain circumstances, however, some special provision has to be made.

It is important that a teacher should be aware of basic first aid procedures for seizures which involve convulsive movement to reduce the possibility of injury. These procedures are relatively simple and straightforward and are clearly described in the section dealing with medical aspects.

Epilepsy is neither a reason nor an excuse for underachievement and no effort should be spared in ensuring that children with epilepsy achieve their full potentials. This means, of course, that the full breadth of the curriculum should be available and that as little compromise as possible is made when determining curriculum content. Many youngsters with epilepsy who are attending mainstream secondary schools are capable of high grades in public examinations and progressing on to further and/or higher education. Using epilepsy as a regular excuse for lack of effort and non-completion of course work and homework should be investigated.

When dealing with pupils who are subject to a sudden transitory loss of consciousness, special consideration has to be made when teaching physical education. It is extremely unwise to allow such children to climb apparatus and lessons can be imaginatively adapted so that they do not feel isolated or incur a loss of self-esteem. Swimming lessons are often unnecessarily barred to children who have epilepsy. Providing that sensible arrangements for effecting a rescue are put into place, there are no valid reasons why children with epilepsy should not learn to swim.

It is likely that young people attending school who have epilepsy will be taking regular medication to control the seizures. It is equally likely that the medication is prescribed to be taken on a twice-daily basis and so the question of a school time dose does not arise. If, however, the situation does arise whereby a school time dose is prescribed, the decision has to be made as to whether teaching staff should take safe custody of the drug and responsibility for its oral administration. This can be a contentious issue for some teachers and needs to be discussed with the Headteacher so that a satisfactory arrangement can be made.

In cases where a child's seizures are prolonged ('Status Epilepticus' – see Medical Aspects) the question of the administration of rectal diazepam is raised. Once again this can be a contentious issue for teachers and should be fully discussed with the Headteacher before a satisfactory care plan is formulated. Teacher trade unions/professional associations will offer appropriate advice on these matters of drug administration.

As well as teachers learning as much about epilepsy as possible it is entirely appropriate that where a class has a pupil with the condition then classmates should also have an understanding of epilepsy. There is a variety of excellent literature available for teaching children about epilepsy. Because epilepsy is so common and so misunderstood it is a suitable subject for inclusion in an in-service training programme and/or PSE programme as part of a health module. The Epilepsy Association will be pleased to accommodate those who would like to incorporate a session on epilepsy into such programmes.

Summary

- Be open about your child's epilepsy.
- Find the school that suits your child's needs best by studying the prospectus and by visiting schools.
- Epilepsy as a single complication is neither a reason nor an excuse for underachievement.
- Children with epilepsy can progress to success in further/higher education.
- Where epilepsy is not well-controlled or is not the only problem special education may be required.
- Some pupils, previously receiving special education, can successfully transfer to mainstream education.
- The full National Curriculum should be available for children with epilepsy.

Adherence

Without being overbearing, every effort should be made to impress upon youngsters who have epilepsy the importance of taking their antiepileptic medication as prescribed. It is not at all unusual for them to forget on the odd occasion and when this does happen it should not be blown up into a major issue.

If, however, there is a suspicion that medication is being missed deliberately, the best way forward is to gently persuade them of the error of their ways. Strangely enough, some degree of non-compliance can be as a result of successful control of the seizures by the very drugs they are failing to take. For some, being seizure free breeds a false sense of security and there is a temptation to test whether it really is the medication that is stopping them from having seizures, by stopping taking the drugs. Unfortunately, this usually leads to complete disillusionment when the almost inevitable seizure occurs. In such cases it is back to the drawing board in gently persuading them to comply with their drug regime.

Sports & Leisure

Young people with epilepsy should be encouraged to pursue a full and active social life, joining in all the usual sporting and social activities.

As adolescents mature their interests lead them to more adventurous pursuits than they enjoyed as young children. Sporting activities become more competitive and varying standards of ability become more apparent. It is vitally important that it is impressed upon them that the only difference between them and their friends is that they are subject to sudden occasional loss of consciousness which, if the seizures are convulsive, can cause them to fall to the ground with muscles jerking out of control. When they are not experiencing a seizure they are as normal as the next person. It follows, therefore, that if the only time that epilepsy is apparent is when a seizure occurs, then during seizure free periods there should be only limited restrictions on the types of sport they can enjoy and participate to high standards.

Whilst being as positive as possible in encouraging participation in sport it has to be recognised that some sports are unsuitable for those with epilepsy. For instance; scuba diving and mountaineering are obviously unsuitable sports for those who are subject without warning to transitory losses of consciousness. Rather than dwell on what cannot be done, far better to concentrate on encouraging participation in the many sports that can be enjoyed fully.

The biggest mistake companions can make is to be overprotective and put a damper on everything. Young people as they mature tend to become more and more self-reliant and attempts to stifle their natural pursuit of fun and enjoyment unnecessarily can cause rebellion, with all its attendant problems.

There are vast numbers of hobbies which can be taken up by young people with epilepsy being diverse as interests in pop music through to classical ballet. They should be encouraged to follow particular interests.

Alcohol

Alcohol taken in moderation can be pleasurable and relatively harmless. It is the abuse of alcohol which causes the trouble.

Virtually all young people are introduced to alcohol before reaching the age where they can legally buy it themselves. It is essential, therefore, that youngsters who have epilepsy are made aware of the particular dangers of excessive use of alcohol in relation to their medical condition. Since epilepsy results from a malfunction of the brain it is fairly obvious that the introduction of a substance that, in any event, affects normal brain function can be a recipe for an increase in seizures. It has to be remembered also that alcohol is not the only foreign substance reaching the brain, there is also the antiepileptic drug which is specifically designed to influence the workings of the brain. Requiring the antiepileptic drug to compete with excess alcohol in the brain is, as a general rule, a recipe for disaster.

Whilst the dangers are obvious, it would be foolish to suggest that outright condemnation of alcohol is the correct way forward. Young people, being what they are, will see prohibition as a direct challenge and, one way or another, will take a drink even if they only defy and prove others wrong. Far better to keep the subject low-key and gently persuade rather than dictate.

In reality, social drinking in moderation will not affect those with epilepsy any more than others who have never had a seizure in their lives. A glass of wine with a meal or a quiet drink with family and friends should do no harm at all.

It is not only important for the young person with epilepsy to be aware of particular problems of alcohol in relation to epilepsy but their friends must have responsible attitudes as well.

Driving

Most young people aspire to the day when, at the age of 17 years, they can apply for a driving licence. It is not difficult to imagine the anger and frustration which sometimes arises when, because of epilepsy, this aspiration is denied.

The fact that some young people have epilepsy does not mean that they will never be able to drive. Once free from seizures for prescribed lengths of time the law does make provision for them to apply for and gain a licence. This fact can be a potent force in ensuring that medication is taken as and when required so as to preserve a seizure free life.

Do not let the situation arise where the youngsters are misinformed as to the legal position. They should be given the facts.

Peer Group Pressure

A lot of pressure not to conform to advice and/or restrictions advocated by adults can be put upon youngsters by their friends and associates. This pressure can tempt those with epilepsy to experiment away from patterns which they have practised for many years and which are aimed to control seizures.

They don't want to be seen as different and so often succumb to suggestions such as neglecting to take tablets and experimenting with alcohol.

Occasionally such peer group pressure can lead to activities which are outside of the law, such as illegal driving of motor vehicles. The temptation to be like the others who have driving licences and drive quite legally is enormous. Unfortunately, giving in to such pressure can lead to disaster. The way forward here is to educate friends about epilepsy by offering a general overview, letting them know and understand why some pursuits are not desirable.

Sexuality

It has to be recognised that nowadays young people are sexually active at an early age. This raises all sorts of issues, not least the whys and wherefores of contraception and in the case of those who have epilepsy, the possible side effects of antiepileptic drugs and the way they affect other medicines such as the oral contraceptive pill.

Some antiepileptic drugs can affect the developing foetus and therefore it is very important that girls receive medical advice before becoming pregnant or as soon as possible when an unplanned pregnancy is suspected.

Parents often find raising such a subject very difficult but nevertheless it should be taken on board if there is cause for concern. Advice on how to deal with such an emotive subject can be obtained from epilepsy specialist nurses.

Summary

- Non-adherence can be a problem and should be approached by gentle persuasion.
- The vast majority of sports and leisure pursuits are available to young people with epilepsy.
- Carefully controlled intake of alcohol should not present a problem.
- There are driving restrictions on those who have epilepsy.
- The law does make provision to allow some people with a history of epilepsy to drive.
- Succumbing to certain peer group pressures can result in an increase in seizures.
- There are some serious issues raised in relation to sexual relations for those who take antiepileptic medication.

Psychological Aspects

Reaction of the Adolescent to Epilepsy

Developing epilepsy in adolescence can also create a number of psycho-social problems in addition to those normally associated with this period of development. Adolescence is a time when young people are considering their own identity, sexuality and independence and epilepsy can severely disrupt this normal development. If epilepsy is diagnosed during adolescence then there may be some denial on the part of the sufferer. Parental overprotection and social restrictions may lead to social isolation which can have a detrimental effect on psychological wellbeing including increased rates of anxiety and depression.

Furthermore, there is some evidence to support the view that adolescents with epilepsy may, because of overprotection, be less socially skilled and subsequently have lower levels of confidence and self-esteem.

Teenagers who believe that they have little or no control over unpleasant circumstances may be more susceptible to psychological problems generally and anxiety and depression in particular. Teenagers with epilepsy (who clearly may feel they have little control over their lives) may develop a significantly poorer sense of control over their lives (mastery) than their friends without epilepsy. Having a poor sense of mastery has been shown to be linked to high levels of anxiety, depression and poor self-esteem. The more people believe that their health is controlled by forces external to them, the more anxious, depressed and ill they may feel.

Gaining Independence

Adolescence is about learning to become independent and living your own life. It is, therefore, important that parents or carers allow the teenager to take more responsibility for the management of their condition.

This can be achieved to a degree by encouraging them to develop a relationship with their own physician and allowing them to ask questions about the management of their epilepsy.

Impact of Epilepsy on Social Functioning

Social withdrawal and isolation is a commonly reported problem for people with epilepsy. Isolation is sometimes caused by fear of having a seizure in public and the possibly hostile reactions of others. The fear of physical injury as a result of a seizure also keeps many people isolated. Some people may be afraid to go out because of the possibility of seizures occurring which might lead to accidents and how they cope with that is to stay at home. For teenagers such fears may lead to restrictions in their social lives which deny them opportunities to develop friendships and engage in normal teenage pursuits like going out with their friends to the cinema or the local night-club.

Leisure activities are an important source for building confidence in both social and work activities. The ability to discuss a hobby or interest is advantageous in situations when meeting another person for the first time.

Helping the Adolescent to understand

Having epilepsy represents only a small part of the affected teenagers' lives. Parents should encourage their teenage child to enjoy many of the activities that other teenagers enjoy, including going out to the cinema, the youth club or the local disco. Generally speaking, there is no reason to restrict their activities.

Parents may be worried about what might happen if their child has a seizure when out with friends. The adolescent should be open with their friends about the risk of seizures and what action to take if such an event occurs when they are out. Unless seizures are poorly controlled and very frequent, the risk of having a seizure may be very small.

Use of Alcohol

Alcohol may sometimes be a problem, particularly if friends drink. Generally speaking, alcohol is safe if consumed in reasonable amounts; this means one or two drinks a night as opposed to six or eight. Parents need to discuss with their teenage children the importance of being sensible with their drinking, sleeping and eating habits and how it might affect the risk of having a seizure.

Forming Personal Relationships

This period of their lives will be critical for forming personal relationships. Some teenagers may find it difficult to form a relationship because they believe that their epilepsy will be a barrier. Anxiety and depression are often a consequence of having epilepsy. If teenagers feel low about themselves it is bound to affect their levels of confidence which will make it even more difficult for them to form relationships.

Some teenagers may well be frightened about having a seizure while they are out on a date. They may also be concerned about having a sexual relationship in case they have a seizure during intercourse, though this is probably very unlikely. These are very delicate problems that need to be handled with sensitivity by parents or carers if a teenager is going to be able to manage them with confidence.

Adherence to Medication

Adherence is a difficult issue for anyone who takes medication. Taking antiepileptic drugs only serves to remind teenagers that they may be different from their friends. Sometimes teenagers may become lazy about taking their medication or deliberately not take it as part of a rebellion against their parents' over-involvement with their epilepsy. It will be important for parents and teenagers to discuss this issue in an honest and open way while recognising each other's concerns. If this is not possible then some advice should be sought from the General Physician who may be able to enlist the help of a counsellor or clinical psychologist who can help the family with their difficulties.

The Role of the Family

The importance of the family in promoting self-esteem and a sense of control in adolescents with epilepsy has been well recognised. Family members, parents in particular, need a way to deal with the feelings of helplessness and loss of control they themselves experience when their offspring begins to have seizures. The way the parents cope influences the teenager's own responses, and in some cases may lead to psychological problems. It is extremely important that parents or carers help teenagers as much as possible to understand their epilepsy and how best to manage it. Epilepsy should be discussed openly and honestly in the family and the parents or carers should be sensitive to ensuring that the teenager does not feel different from others as a result of having epilepsy.

Social withdrawal and isolation may sometimes be the product of parental reactions to a diagnosis of epilepsy, which typically involve over-protectiveness. Such over-protectiveness may lead parents to limit the young person's activities, which in turn may render him or her more socially inept.

Over-protectiveness can lead to a teenager being more dependent on their peers or on their parents. Parents of teenagers with epilepsy, as well as being over-protective, can sometimes have lowered expectations about their potential achievements when compared with their brothers and sisters. Parents' responses to their children's epilepsy can greatly influence their expectations for their teenager and as such, may play a significant role in the under achievement and adjustment problems.

Summary

- Help to ensure that the adolescent with epilepsy does not feel different from their friends or associates.
- Encourage them to develop their independence.
- Allow them to take responsibility for the management of their epilepsy.
- Be sensitive to their concerns about developing relationships with others and help them to develop confidence in themselves.
- Do not be concerned about seeking professional help if it is necessary.
- Help them to understand as much as possible about their epilepsy, particularly the importance of eating and drinking sensibly and sleeping well at night.