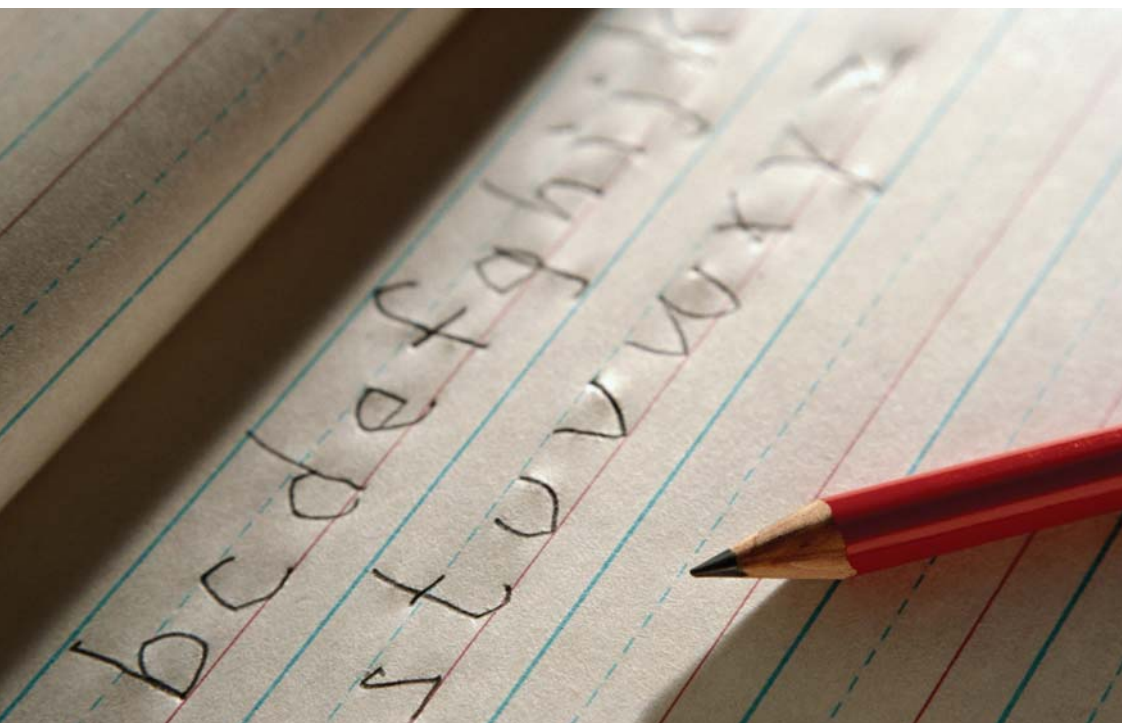


Epilepsy and education – information for parents



epilepsy

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

Our work...

- We provide information to anyone with an interest in epilepsy.
- We improve the understanding of epilepsy in schools and raise educational standards.
- We work to give people with epilepsy a fair chance of finding and keeping a job.
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations.
- We promote equality of access to quality care.

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

Join us...

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

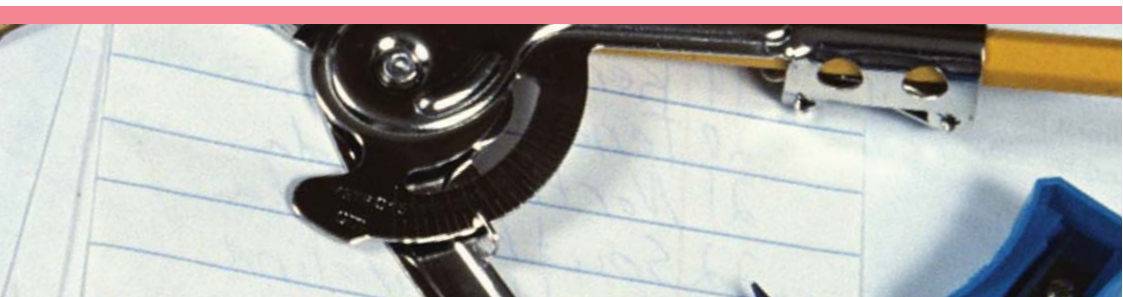


Contents

Introduction	4
What is epilepsy?	5
Seizures	6
Triggers	9
Photosensitive epilepsy	11
Medicines	15
Learning and behaviour	18
The Disability Discrimination Act	21
School trips	22
Sport and leisure activities	24
Further/higher education	27
Further information	28

“We want to live in a society where everyone understands epilepsy and where attitudes towards people with epilepsy are based on fact and not fiction”

Epilepsy Action, vision statement





Introduction

Epilepsy is a complex condition and as a parent of a child with epilepsy you are likely to have many questions. In this booklet we have not tried to answer every question or to cover every aspect of epilepsy and education. We aim to tell parents and carers about epilepsy and to suggest ways in which children with epilepsy can participate fully in school life and achieve their potential. More information about specific educational issues can be found on our website: www.epilepsy.org.uk or from the Epilepsy Helpline, freephone 0808 800 5050.

What is epilepsy?

Epilepsy is defined as having a tendency to have seizures. An epileptic seizure happens when normal electrical activity in the brain is suddenly disrupted. An epileptic seizure can take a number of different forms - it can cause changes in a person's body or movements, awareness, behaviour, emotions or senses (such as taste, smell, vision or hearing). Usually a seizure lasts for only a few seconds or minutes and then the brain activity returns to normal.

What causes epilepsy?

Some children have epilepsy as a result of damage to the brain. This may have been due to injury before, during or after birth and is known as symptomatic epilepsy. For other children there is no known or identifiable cause. They have an inherited tendency to have epilepsy. This is known as idiopathic epilepsy and is thought to be related to a low seizure threshold. Everyone has a seizure threshold; having a low seizure threshold means that a person is more likely to have seizures than people in general.

Some people develop epilepsy in childhood and about a third of children will have outgrown their epilepsy by the time they become adults. Some young people develop epilepsy during their teenage years. Depending on the type of epilepsy they develop, these young people may or may not grow out of their epilepsy by the time they become adults.

How common is epilepsy in school children?

In the United Kingdom it affects around 60,000 children of primary and secondary school age.

Seizures

A seizure may affect either part or the whole of the brain. There are around 40 different types of seizures, some of which are more common in childhood. Some seizures affect both halves of the brain and lead to loss of consciousness, though this may be very brief. These are called generalised seizures. Some seizures affect only a small part of the brain. These are called partial seizures and, although they may change a child's consciousness level, the child does not become unconscious. Some children will have partial seizures which develop into generalised seizures. These are known as secondary generalised seizures.

Tonic-clonic seizures

Children who have tonic-clonic seizures (sometimes known as grand-mal seizures) lose consciousness and fall to the ground. Their body goes stiff and their limbs jerk. When their seizure is over their consciousness returns, but they may be very confused and tired. It is important that you stay with them at this point to make sure they are all right. First aid information for seizures is given later in this booklet.

Absence seizures

If a child has absence seizures (sometimes known as petit-mal) they will briefly, lose consciousness, but will not lose muscle tone or collapse. They may appear to be daydreaming or distracted for a few seconds. While these episodes may seem unimportant, they can happen hundreds of times in a day. This can cause the child to become confused about what is happening around them.

Absence seizures are most common in children between the ages of six and 12 years old. This is an important time for learning. It is important



that these seizures are recognised and treated so that the child doesn't become confused, struggle at school or lose their confidence.

Complex partial seizures

This type of seizure can be difficult to recognise. The child's consciousness level will be affected to some extent and they may not be fully in touch with what is happening around them. During the seizure they may do things repeatedly, such as swallowing, scratching or looking for something. These seizures can be short or may last several minutes. They can be misinterpreted as bad behaviour. In fact, the child will not know what has happened and will not remember what they were doing before the seizure started.

There is no real first aid needed for complex partial seizures, but it is important not to restrain the child unless they are in immediate danger. This is because they may not recognise what you are trying to do and become frightened. However, depending on the circumstances, for example if they were walking into a busy road, you would need to decide how to prevent the child from having an accident. More information about complex partial seizures can be found on our website: www.epilepsy.org.uk or from the Epilepsy Helpline, freephone 0808 800 5050.



Myoclonic seizures

When a child has a myoclonic seizure the muscles of any part of the body jerk, typically one or both arms. It may be a single jerk or the jerking may continue over a period of time.

There is no real first aid for the seizure itself. First aid may be needed if the child is injured. For example, if the child had a jerk involving the arm when holding a hot drink, they may be scalded. Normal first aid would be used to deal with this. If the child was distressed by the seizure, they may need comforting and generally reassuring.

Atonic seizures

Atonic seizures cause a child to lose muscle tone. When this happens the child falls to the ground without warning. This can result in injuries to the face and head. If the child has this type of seizure they may need to wear a helmet to reduce the risk of injury. There is no first aid needed for atonic seizures, unless an injury happens during the fall.

Triggers

If your child is old enough, they may be able to identify factors that make their seizures more likely. These are known as triggers and the following are some of the most common:

- tiredness
- lack of sleep
- lack of food
- stress
- photosensitivity

Tiredness

If you know that your child is more likely to have seizures when they are very tired, it may be possible to look at ways that they can have restful periods during the day. How this is done will depend on their age and their need for sleep. With careful planning of school and leisure activities you may be able to reduce their risk of seizures. If your child has sleep seizures, they may be more tired than usual some mornings. It may be possible for them to start school later than usual on the days they have had a seizure. Talking to their teachers about this may reduce the number of days when they cannot go to school at all.

Lack of sleep

Some children find it difficult to get to sleep or simply do not want to go to bed. Other children struggle to fit in homework and coursework and have very late nights. Lack of sleep can trigger seizures. How much sleep a child needs will be very individual to them. If lack of sleep is a problem for your child, you may need to negotiate a regular sleep pattern with them.



Low blood sugar levels

Some children and young people do not enjoy eating breakfast and you may find that their seizures occur mid or late morning. If you cannot persuade them that having breakfast might reduce the risk of having seizures, you might want to encourage them to have small healthy snacks or fruit drinks at break times. This may prevent their blood sugar levels falling and triggering a seizure. Again, some people may experience seizures in the late afternoon. It may be possible to avoid these by having something to eat straight after school.

Stress

While it is normal for adults and children to experience stressful situations, stress can trigger seizures in some people. Excitement may be a form of stress for some children. Anxiety about doing something different or worrying about school work can be another form of stress. If you recognise stress as being a trigger for your child, it may be worth speaking with school staff to see if this can be limited as much as possible. However, it will never be possible, or realistic, to remove stress completely from a child's life, so they could find learning relaxation or stress management techniques helpful.

Photosensitive epilepsy

Photosensitive epilepsy is the name given to epilepsy in which all, or almost all, seizures are provoked by flashing or flickering light, or some shapes or patterns. Both natural and artificial light may trigger seizures. Various types of seizure may be triggered by flickering light.

Many people think that everybody with epilepsy is photosensitive, but in fact only five in every hundred people with epilepsy are. Photosensitive epilepsy usually begins before the age of 20 years. It is most common between the ages of seven and 19. Photosensitivity tends to affect girls more than boys. There is also evidence that photosensitive epilepsy can be passed on through the genes.

Diagnosing photosensitive epilepsy

A common investigation that is carried out to help diagnose epilepsy is an electroencephalogram, or EEG. The EEG records brainwave patterns from the continuous tiny electrical signals coming from the brain. During one part of the EEG, your child will be asked to look at flashing lights, to see if this triggers epileptic activity in their brain. If it does, then this may indicate that your child has photosensitive epilepsy.

If your child has been diagnosed with photosensitive epilepsy, you may find the following information of interest.

Hertz

The word hertz (Hz) refers to how often something happens in a given time. In photosensitive epilepsy, hertz (Hz) refers to the number of flashes or flickers each second. When talking about televisions or computer screens, hertz refers to the rate the scanning lines 'refresh' themselves.

Most children with photosensitive epilepsy are sensitive to 16-25Hz, although some children may be sensitive to rates as low as 3Hz and as high as 60Hz.



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Television

Watching television is a common trigger for photosensitive seizures. The nearer you are to the screen the more likely it is to trigger a seizure. This is because a larger area of your eye's retina is stimulated by the flicker of the picture, increasing the risk of a seizure. If you sit close to the screen you can see the 25Hz flicker of the lines as well as the 50Hz mains flicker on the screen as a whole. It is common for children with photosensitive epilepsy to be sensitive to 25Hz, so it makes sense to sit well back from the television to minimise the risk of seizures.

The pictures shown on the screen can also make seizures more likely to happen. For example, if there is a particular combination of colour and flicker, or where there are many press photographers using flash photography all at the same time.

100 Hz televisions

100 Hz televisions are unlikely to trigger seizures in children with photosensitive epilepsy.

Plasma or liquid crystal display (LCD) televisions

Plasma and LCD screens do not use the scanning lines of other televisions and are therefore less likely to trigger seizures. However, plasma screens tend to be brighter, with high contrast. This could make seizures more likely for some children with photosensitive epilepsy. If you are choosing between these types of screens, and your child has photosensitive epilepsy, the current advice is to buy an LCD.

Precautions when watching television

- Watch the television in a well-lit room.
- Have a small, lit lamp on top of, or close to the television.
- Don't sit too close to the television. Watch from a distance of at least 2.5 metres (8 feet).
- Use the remote control wherever possible – from a safe distance - to adjust the television or to change channels.
- If you have to go near the television, cover one of your eyes with the palm of your hand. This will cut down the number of brain cells that are stimulated by any flicker on the screen.

Computer monitors

Many people think that children with photosensitive epilepsy are not able to use computers, because they will trigger a seizure. Although some images being displayed on the screen could be a problem, using a computer in itself is extremely unlikely to trigger a seizure.

Cathode ray tube (CRT)

These are the traditional, large monitors. CRTs have scan frequencies of 70 Hz and above. As most children with photosensitive epilepsy are sensitive to 16-25 Hz, CRTs, provided they are not faulty, are unlikely to trigger seizures.



Liquid crystal display (LCD) – also known as thin film transistor (TFT)

These thin, flat, screens are flicker free. This means they are unlikely to trigger seizures.

Risk from material displayed on computer monitors

If the material contains flashing, flickering or repetitive patterns, it will carry the same risk whether it is viewed on a CRT monitor or an LCD monitor. Images displayed on LCDs are sharper and brighter than on CRTs. Some people are sensitive to patterns with a high contrast. Where these appear on an LCD screen, the brightness and sharpness of the screen may increase the risk to children with photosensitive epilepsy of having a seizure.

Anti-glare screens

Anti-glare screens can be of help in reducing glare. However, they do not reduce the flicker rate and are therefore of no specific benefit to children with photosensitive epilepsy.

Interactive whiteboards

Interactive whiteboards are commonly used in schools. We are not aware of interactive whiteboards causing any problems for children with photosensitive epilepsy, so long as any images being shown on the whiteboard are within the frequency and flicker rates that are unlikely to be a problem for people with photosensitive epilepsy. If your child has photosensitive epilepsy, you may wish to discuss this with their teachers.

Medicines

The majority of children with epilepsy take medicine to control their seizures. This medicine is usually taken twice each day, outside of school hours. This means it does not raise any issues about storage or administration for school staff. Some children need medicine three times daily but even then it is usually taken before school, after school and before going to sleep.

The only time medicine may be urgently required by a child with epilepsy is when their seizures fail to stop after the usual time or the child goes into 'status epilepticus'. Status epilepticus is defined as a prolonged seizure or a series of seizures without regaining consciousness in between. This is a medical emergency and is potentially life threatening.



If this happens, an emergency sedative needs to be administered by a trained member of staff. The sedative is often the drug diazepam, which is administered through the child's bottom, although many children needing emergency medicine are now being prescribed a drug called midazolam that is administered through the mouth (see the section on emergency medicine below for more information).

Certain types of medicines taken for epilepsy can have an effect on a child's learning or behaviour. It is important staff are aware of this. If a teacher notices a change in your child's learning or behaviour they should talk to you about this.

Emergency medicines

If your child is likely to need emergency medicines then it is vital that you tell the school. Although it is not a legal requirement for school staff to give medicines, the school should make sure that a number of staff are trained to give emergency medicines. This training can be arranged by the School Health Service, the local authority or through an independent training provider.

The two main forms of emergency medicines are rectal diazepam and buccal midazolam. Rectal diazepam has been in use for many years but there are some issues around schools using this, as it is administered through the child's bottom.

Buccal midazolam is currently unlicensed for treating epilepsy in children. However, many consultants and some epilepsy specialist nurses prescribe this drug as it is easier to use and less invasive than rectal diazepam.



If your child may need to have emergency medication administered, their epilepsy specialist will be able to discuss the advantages and disadvantages of the different treatments with you

The government's own advice on the use of buccal midazolam states that if the medicine is used then "instructions for use must come from the prescribing doctor". This means that if it is prescribed for your child, their doctor must provide an individual care plan for them. A sample of an individual care plan for administering emergency medication is available from Epilepsy Action.

It is likely that the school will also need written agreement to administer medication for your child. This agreement will show who has been trained to administer the emergency medication and in what circumstances.

Epilepsy Action has a form for this. It is called Parental agreement for school or setting to administer medicine. This is in the Epilepsy policy for schools booklet and is available through the website: www.epilepsy.org.uk or from the Epilepsy Helpline, freephone 0808 800 5050.

Learning and behaviour

Many children with epilepsy will go through their school lives with few problems related to their epilepsy. However, some children will have specific learning difficulties or behavioural problems. These may be related to the following:

- How severe the epilepsy is.
- How often they are having seizures.
- Whether the child has any damage to the brain.
- The part of the brain where the epileptic activity is. For instance, if there is epileptic activity in the memory part of the brain, then the child may have specific learning difficulties.
- The type of seizure. As we have seen earlier, in a complex partial seizure a child or young person may do unusual things. This may be considered naughty behaviour by someone who is not familiar with the child's epilepsy.





- How the child is reacting to other things in their life. Children are individuals and respond to people and situations in different ways. How a child deals with family, school and epilepsy related issues may influence their school work or behaviour.
- The child is having sub-clinical seizure activity. This is when there is continuous epileptic activity taking place in the brain, without any obvious outward signs of a seizure. When this type of activity is taking place a child may appear sleepy, confused or irritable.
- If the child is having prolonged partial seizures. This may make them appear confused and act in an unusual way.
- Some anti-epileptic drugs (AEDs). These may cause drowsiness or sleepiness or lack of energy. In a child, this may be seen as a general slowness and lack of enthusiasm.



Any child who has learning or behaviour problems needs to have these problems identified and steps taken to minimise them. If you suspect your child needs help in this way, speak with the school, who can arrange to assess your child's needs. Alternatively you could ask their epilepsy specialist for advice or to refer them to the clinical psychological services.

Another source of support is the educational psychology service. They will be able to offer advice and support to the school staff about your child's learning needs or behaviour. Each school has a named educational psychologist who is responsible for their pupils. You can ask for a referral through the school or through your local authority.

Check our website www.epilepsy.org.uk for more information about these issues.

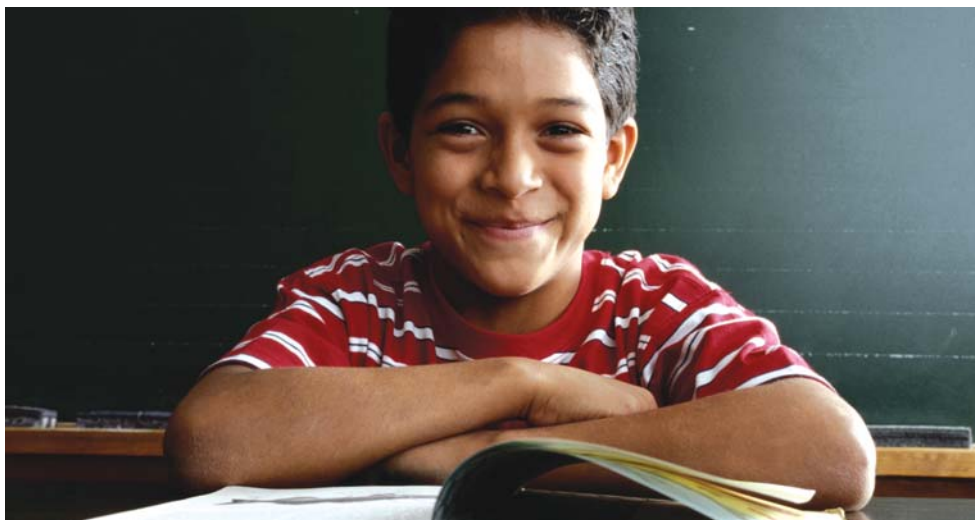
Some young people with epilepsy may be entitled to extra time in external exams. This would be a reasonable adjustment under the Disability Discrimination Act (DDA – see across). It is important for parents to be aware of this and to make sure that school staff know and apply in good time to the relevant exam boards. An epilepsy specialist or healthcare professional may be able to give some advice and support on whether extra time is needed.

The Disability Discrimination Act

The Disability Discrimination Act (DDA) is a law that makes it illegal to discriminate against disabled people in many areas of life, including education.

Children with epilepsy are covered by this act. As well as making sure that they are not discriminated against, the act states that 'reasonable adjustment' may be needed to make sure that they can take part in school related activities. These activities may be recreational or educational.

At school, reasonable adjustment may mean sitting a visually or hearing impaired child at the front of the class where they can most easily see the teacher. For a child with absence seizures or seizures where their concentration is impaired, this may mean providing written notes at the end of the lesson, so they can make sure they haven't missed anything. It may mean providing a child with photosensitive epilepsy with an LCD computer.





School trips

Many schools arrange educational day or residential trips for their pupils. These are an important learning tool for all children, teaching them independence and social skills. Children with epilepsy need to take part in these experiences if they are to grow into fully rounded individuals.

Having epilepsy is not a reason to deny a child these opportunities, although there are extra considerations.

If it is possible that your child may need emergency medication while on the trip, it is likely that the school will need written agreement to administer this medication. This agreement will show who in the party is trained to administer the medication and in what circumstances. Epilepsy Action has a form for this. It is called Parental agreement for school or setting to administer medicine. This is in the Epilepsy policy for schools booklet and is available through the website: www.epilepsy.prg.uk or from the Epilepsy Helpline, freephone 0808 800 5050.

The organisers should consider taking an emergency pack containing items such as a mobile phone and something light to cover the person to maintain their dignity during delivery of the emergency medication. Contact numbers and the address of the local hospital would also be useful.

If your child's daily medication will be needed on the trip, a safe storage place should be identified and, if necessary, an adult to make sure that it is taken correctly.

It is perfectly normal to feel apprehensive about letting your child go on trips away from home. You will need to work with your child and school staff to make sure they are fully prepared for the trip and that sensible precautions are taken, without restricting their activities more than necessary.



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Sports and leisure activities

There are many different types of sports and leisure activities. Due to misunderstandings about epilepsy, we hear of many children not being allowed to take part, either at school or in their own time. This is a mistake because children need to have as healthy a lifestyle as possible. With some forward planning and sensible precautions, most activities should be safe.

Precautions will depend on the child's seizure type and frequency, whether they have a useful warning of when a seizure is going to happen, their age and general level of fitness and ability. The following are some of the most commonly available sports and leisure activities.

Swimming

Swimming is often a very sociable activity, as well as a life-saving skill. It is an activity that is just as likely to be enjoyed in a school setting as at home. As it is impossible to be certain that a child will not have a seizure while swimming, it is important to be aware of the risks involved. The following guidelines should be followed.

- Never let your child swim alone, or take any unnecessary risks.
- Always advise the pool supervisor or life-guard about the child's epilepsy.
- If there is no qualified life-guard present, make sure your child stays in shallow water and that their companion knows what to do and is strong enough to help them should a seizure occur.
- Swimming in the sea, lakes or in very cold water such as reservoirs is dangerous and should be avoided.
- Don't allow your child to swim if they are unwell.
- Avoid overcrowded situations, which may make it difficult for others to notice your child having a seizure.

More information about epilepsy and swimming is available on our website: www.epilepsy.org.uk or from the Epilepsy Helpline, freephone 0800 800 5050.





Contact sports

Many young people enjoy team games such as football, rugby and hockey. There is no reason why young people with epilepsy should avoid these sports, as long as normal safeguards are followed. These safeguards include adequate head protection as recommended by the official sporting body. The only caution to taking part in these games would be if your child's epilepsy is the result of a head injury. In this case it would be wise to seek advice from their doctor.

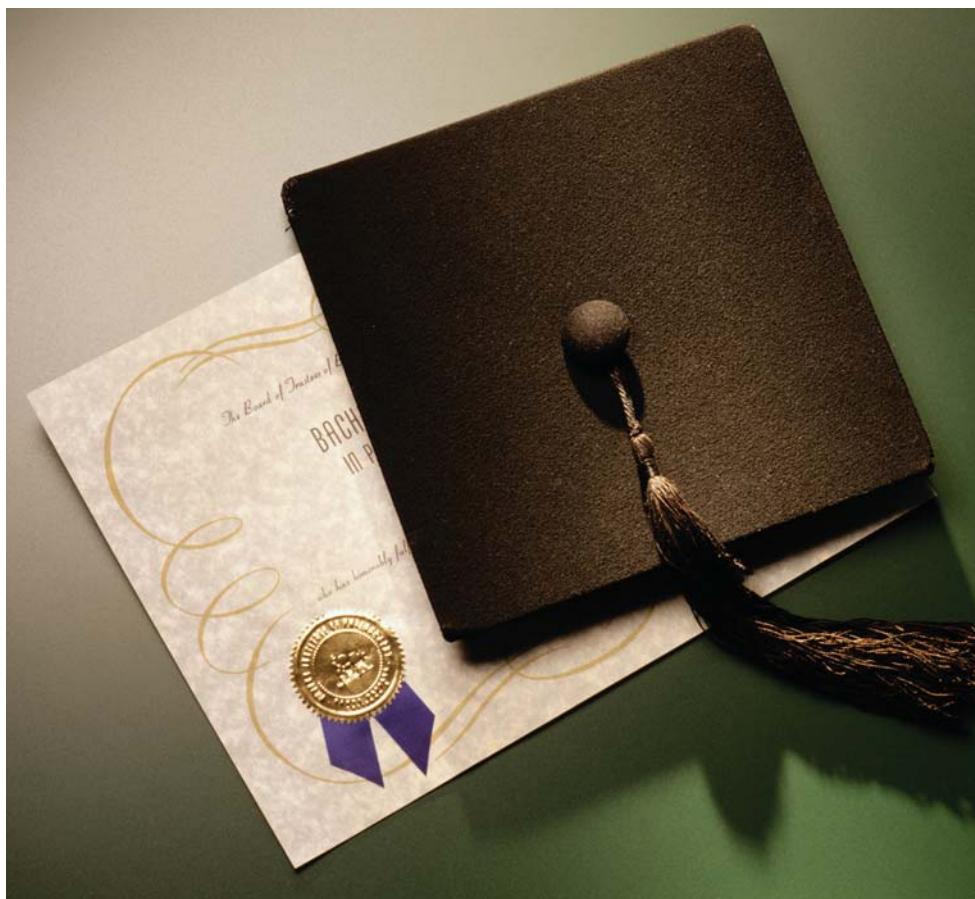
Theme parks

Schools often take young people to theme parks during the summer months and the Epilepsy Helpline has many enquiries about safety on rides. If your child has frequent and/or severe seizures it would be useful to seek advice from their doctor. Otherwise, so long as general safety precautions are in place, rides do not have to be avoided. If your child has photosensitive epilepsy they may need to avoid attractions with flashing or flickering lights.

Comprehensive information about other sports and leisure activities is available from our website: www.epilepsy.org.uk or from the Epilepsy Helpline, freephone 0800 800 5050.

Further/higher education

Many young people progress from secondary school to a college of further education and university. Studying for a higher diploma, honours degree or similar will give more career opportunities. When a young person reaches this stage they can find lots of information on our website: www.epilepsy.org.uk or from Skill: National Bureau for Students with Disabilities: www.skill.org.uk, Telephone: 0800 328 5050.



Further information

We hope that you have found this booklet helpful. If you have any more questions about employment and epilepsy, you may wish to speak to an adviser on the Epilepsy Helpline.

Tel: freephone 0808 800 5050

Email: helpline@epilepsy.org.uk

Further information on many aspects of epilepsy, including a booklet for employers of people with epilepsy, is available from Epilepsy Action. Please write to us or contact the Epilepsy Helpline to ask for your free information catalogue.

Kathy Bairstow
Epilepsy Services
August 2007

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

Epilepsy and education – information for parents

Please complete this form to tell us what you think of this publication.

How useful have you found this publication?

☐ Very

☐ Fairly

☐ Quite

☐ Not at all

Is the language clear and easy to understand?

☐ Very

☐ Fairly

☐ Quite

☐ Not at all

Does this publication cover all you want to know about the topic?

☐ Completely

☐ Almost

☐ Not at all

What do you think of the design and general layout of this publication?

☐ Excellent

☐ Good

☐ Fairly Good

☐ Poor

Please let us have your comments:

Date: _____

Please return the completed form to:

Epilepsy Services, Epilepsy Action, FREEPOST LS0995, Leeds LS19 7YY.

“We want to live in a society where everyone understands epilepsy and where attitudes towards people with epilepsy are based on fact and not fiction”

How to contact us

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

Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm

Our Helpline staff are Typetalk trained

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

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

email us at **helpline@epilepsy.org.uk** or visit our website:

www.epilepsy.org.uk

About the Epilepsy Helpline

In partnership with the organisation Language Line, the Helpline is able to offer advice and information in 150 languages.

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

Our staff are trained Advice and Information Officers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative about our services.

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

The logo for Epilepsy Action, featuring the word "epilepsy" in white lowercase letters on a blue rectangular background, followed by the word "action" in pink lowercase letters on a pink rectangular background.

Epilepsy Helpline freephone: 0808 800 5050
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