



## Epilepsy Information for schools

### How common is epilepsy?

Epilepsy is the most common serious neurological condition. It affects about one in 279 children under 16. This means that there are about 42,000 children with epilepsy in UK schools. To put it another way, an average sized secondary school will have three to four children with the condition, while an average sized primary school will have one or two children with epilepsy. Over 10 per cent of calls to the Epilepsy Helpline in each year are about issues relating to epilepsy in children.

### What is epilepsy?

Epilepsy is defined as having a tendency to have seizures. A seizure happens when the nerve cells in the brain stop working in harmony. When this happens the brain's messages become temporarily halted or mixed up. A child with epilepsy has recurrent seizures, unless the seizures are controlled by medicine.

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 child is more likely to have seizures than children in general.

### Seizures

A seizure can either affect part of the brain or the whole brain. There are around 40 different types of seizure, some of which are more common in children. Depending on whether a seizure affects the whole or part of the brain it is called either generalised or partial. Generalised seizures affect the whole, or a large part, of the brain and result in a loss of consciousness, which may be very brief, or may last several minutes. Partial seizures only affect part of the brain and only partly affect consciousness.

### The most common types of seizures

#### Tonic-clonic seizures

Children who have tonic-clonic seizures (previously known as grand-mal) 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's important that you stay with them at this point, to make sure they are alright. First aid advice for tonic-clonic seizures can be found on page 11, together with a sample of an epilepsy policy for schools.

#### Absence seizures

During an absence seizure (previously known as petit-mal) the child will briefly lose consciousness, but will not lose muscle tone or collapse. They will appear to be daydreaming or distracted for a few seconds. While these episodes may seem unimportant, they can happen hundreds of times 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.

As the child will lose consciousness during seizures, they are at risk of missing out on vital learning. If a child is having absence seizures during the day, the child's parents may not be aware that their child has epilepsy. Spotting these seizures can help doctors make a diagnosis. There is no first aid needed for absence seizures, but they must not be mistaken for daydreaming or inattentiveness.

### **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 will 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. Complex partial seizures 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.

Although there is no real first aid needed for complex partial seizures, it's important not to restrain the young person unless they are in immediate danger. This is because they may not recognise you and become frightened. However, if the child is walking towards a busy road, you should try to guide them to safety. When the seizure ends the child is likely to be confused, so it is vital to stay with them and reassure them.

For more information about complex partial seizures visit [www.epilepsy.org.uk](http://www.epilepsy.org.uk) or call the Epilepsy Helpline, freephone 0808 800 5050, text 07797 805 390 or email [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

### **Myoclonic seizures**

When a child has a myoclonic seizure the muscles of any part of their body jerks. These jerks are common in one or both arms and can be a single movement or the jerking may continue for a period of time. Myoclonic seizures happen most often in the morning, and teachers need to bear in mind that a child may be tired or lack concentration if they start school after having one of these. There is no first aid needed for myoclonic seizures unless the child has been injured, when usual first aid procedures are used. If the child is 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. Children who have regular atonic seizures may need to wear protective headgear to avoid injuries. There is no first aid needed for atonic seizures, unless the child is injured during the fall.

### **General seizure advice**

Tonic-clonic seizures are the most widely recognised type of epileptic seizure. It's important to note that most children need a rest following this kind of seizure. Depending on how they are feeling, they may be able to return to lessons. However, if they take many hours to recover, they may need to be taken home.

In different seizures, such as absences, there are other issues. For example, symptoms may not be recognised by staff as being seizures. It is extremely important that staff understand and can recognise the lesser known seizures, so that they can provide students with the right support.

## Triggers

A trigger is anything that causes a seizure to occur, in someone who already has a predisposition. There are many different triggers, but some are more relevant to school settings than others. This can include the following situations.

- When a child first starts school, or changes class, they may be excited or anxious. Both of these emotions can trigger seizures.
- When a child or young person is preparing for exams, they may become stressed or not sleep properly. Stress and lack of sleep can be triggers for seizures.
- It's often thought that all people with epilepsy have seizures triggered by flickering light (known as photosensitive epilepsy). This is not the case, as fewer than one in 20 people with epilepsy have photosensitive epilepsy.

Some children with epilepsy may be entitled to extra time or support in exams because their epilepsy affects their ability to function at the same level as their classmates. If a teacher thinks this may be the case, they should speak to the child's parents and, if possible, to a health or psychology service professional. Schools need to apply to the relevant examining body to ask for extra provision. They need to do this as soon as possible.

Guidelines on applying for special adjustments in exams are available from the Joint Council for Qualifications' website: [www.jcq.org.uk](http://www.jcq.org.uk)

## Medicines

The majority of children with epilepsy take anti-epileptic drugs (AEDs) to control their seizures. These drugs are usually taken twice a day, outside of school hours. This means there should be no issues about storing or administering medicines in school time.

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 the child's learning or behaviour, then this should be discussed with their parents.

The only time medicine may be urgently needed 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, emergency medication needs to be administered by a trained member of staff. If this isn't possible an ambulance should be called.

## Emergency medicines

If a child with epilepsy is likely to need emergency medicine to stop a seizure, it is vital that the parents and school staff work together to decide how this should happen. Although it is not a legal requirement for school staff to administer medicines under the Disability Discrimination Act, the school should ensure that a sufficient number of staff are trained to administer emergency medicines. Alternatively other arrangements could be in place such as the school nurse, a paramedic or the child's parents could be contactable to administer the medicine if it is needed. Training can be arranged by the School Health Service, the local authority or through an independent training provider.

For more information visit [www.epilepsy.org.uk](http://www.epilepsy.org.uk) or call the Epilepsy Helpline, freephone 0808 800 5050.

The two main forms of emergency medicines are rectal diazepam and buccal midazolam.

Rectal diazepam has been used for many years. 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. The government's own advice on the use of buccal midazolam states that if the medicine is used in schools then 'instructions for use must come from the prescribing doctor'. These instructions should be written into an individual care plan for each child who may need medication in school time.

The above information may appear daunting for some staff. But despite any fears about 'doing the wrong thing' it is essential for schools to have a clear policy and procedure in place to deal with an emergency situation, and for all staff to be aware of that policy. See section below on legal requirements and responsibilities.

Guidance from the Department for Education and Skills (DfES) on administering emergency medicines states clearly: "In general, the consequences of taking no action are likely to be more serious than those of trying to assist in an emergency."

For more information on emergency medicines, and template forms on storing and administering medicines in schools, see the DfES document *Managing Medicines in Schools and Early Year Settings*. This document can be downloaded at [www.teachernet.gov.uk/medical](http://www.teachernet.gov.uk/medical)

## Why schools need an epilepsy policy

It is essential for schools to have an epilepsy policy. Epilepsy Action believes that all children with epilepsy should be given the same opportunities to achieve their full potential. They should be able to enjoy the same level of participation in school life as their friends and classmates.

The Disability Discrimination Act (DDA) requires schools and education settings to ensure that all children with disabilities (which include epilepsy) are not treated 'less favourably' than their classmates.

To help achieve this, and fulfil legal requirements, every school or education setting should have a school epilepsy policy. Schools can use an epilepsy policy on its own or as part of another policy, for example the school's health and safety policy, its first aid policy or as part of its accessible schools plan.

Some children with epilepsy are prevented from attending school due to prolonged or recurrent absence as a result of their epilepsy. Schools should be prepared to incorporate provision for this in their epilepsy policy. Full guidance on access to education for children with illness or a medical diagnosis can be found in the DfES document Access to Education for Children and Young People with Medical Needs (see further reading). This can be downloaded or ordered from [www.publications.teachernet.gov.uk](http://www.publications.teachernet.gov.uk)

## School Policy Requirements

Schools should use the information below to develop an epilepsy policy. Each school's policy will be different, but every policy should incorporate the following principles.

1. This school recognises that epilepsy is a common condition affecting many children and young people, and welcomes all students with epilepsy.
2. This school believes that every child with epilepsy has a right to participate fully in the curriculum and life of the school, including all outdoor activities and residential trips.
3. This school keeps a record of all the medical details of children with epilepsy and keeps parents updated with any issues it feels may affect the child.
4. This school ensures that all children and staff in the school understand epilepsy and do not discriminate against any children with the condition.
5. This school ensures that all staff fully understands epilepsy and seizure first aid, and that there is at least one member of staff trained to administer emergency medicines in school at all times.
6. This school will work together with children, parents, staff, governors, educational psychologists and health professionals to ensure this policy is successfully implemented and maintained.

## Epilepsy policy for schools

### Implementation

An epilepsy policy should include all of the above points and explain how they are to be implemented. The following is a typical sample policy for a school. The sample forms should help to gather information to implement this policy.

## Example Policy –

### St Egbert's Primary School, Egton, Hatchington

This policy has been written in line with information provided by Epilepsy Action, the Department for Education and Skills (now the Department for Children, Families and Schools), the local authority, the school health service, the governing body, students and parents.

St Egbert's recognises that epilepsy is a common condition affecting children and welcomes all children with epilepsy to the school.

St Egbert's supports children with epilepsy in all aspects of school life and encourages them to achieve their full potential. This will be done by having a policy in place that is developed in conjunction with the local authority and understood by all school staff. This policy ensures all relevant staff receives training about epilepsy and administering emergency medicines. All new staff and supply staff will also receive appropriate training.

#### **What to do when a child with epilepsy joins St Egbert's**

When a child with epilepsy joins St Egbert's, or a current pupil is diagnosed with the condition, the head teacher arranges a meeting with the pupil and the parents to establish how the pupil's epilepsy may affect their school life. This should include the implications for learning, playing and social development, and out of school activities. They will also discuss any special arrangements the pupil may require, for example extra time in exams. With the pupil's and parent's permission, epilepsy will be addressed as a whole-school issue through assemblies and in the teaching of PSHE or citizenship lessons. Children in the same class as the pupil will be introduced to epilepsy in a way that they will understand. This will ensure the child's classmates are not frightened if the child has a seizure in class.

The school nurse or an epilepsy specialist nurse may also attend the meeting to talk through any concerns the family or head teacher may have, such as whether the pupil requires emergency medicine. The following points in particular will be addressed.

#### **Record keeping**

During the meeting the head teacher will agree and complete a record of the pupil's epilepsy and learning and health needs. This document may include issues such as agreeing to administer medicines and any staff training needs. This record will be agreed by the parents, and the health professional, if present, and signed by the parents and head teacher. This form will be kept safe and updated when necessary. Staff will be notified of any changes in the pupil's condition through regular staff briefings. This will make staff aware of any special requirements, such as seating the pupil facing the class teacher to help monitor if the student is having absence seizures and missing part of the lesson.

#### **Medicines**

Following the meeting, an individual healthcare plan (IHP) will be drawn up. It will contain the information highlighted above and identify any medicines or first aid issues of which staff need to be aware. In particular it will state whether the pupil requires emergency medicine, and whether this medicine is rectal diazepam or buccal midazolam. It will also contain the names of staff trained to administer the medicine and how to contact these members of staff. If the pupil requires emergency medicine then the school's policy will also contain details of the correct storage procedures in line with the DfES guidance found in *Managing Medicines in Schools and Early Year Settings*<sup>1</sup>.

#### **First aid**

First aid for the pupil's seizure type will be included on their IHP and all staff (including support staff) will receive basic training on administering first aid. The following procedure giving basic first aid for tonic-clonic seizures will be prominently displayed in

all classrooms.

Stay calm.

If the child is convulsing then put something soft under their head.

Protect the child from injury (remove harmful objects from nearby).

NEVER try and put anything in their mouth or between their teeth.

Try and time how long the seizure lasts – if it lasts longer than usual for that child or continues for more than five minutes then call medical assistance.

When the child finishes their seizure stay with them and reassure them.

Do not try and move the child unless they are in danger.

Do not try and restrain the child.

Do not give them food or drink until they have fully recovered from the seizure.

Aid breathing by gently placing the child in the recovery position once the seizure has finished.

Sometimes a child may become incontinent during their seizure. If this happens, try and put a blanket around them when their seizure is finished to avoid potential embarrassment. First aid procedure for different seizure types can be obtained from the school nurse, the pupil's epilepsy specialist nurse or Epilepsy Action.

### **Learning and behaviour**

St Egbert's recognises that children with epilepsy can have special educational needs because of their condition (*Special Educational Needs Code of Practice*<sup>2</sup>). Following the initial meeting, staff will be asked to ensure the pupil is not falling behind in lessons. If this starts to happen the teacher will initially discuss the situation with the parents. If there is no improvement, then discussions should be held with the school's special educational needs co-ordinator (SENCO) and school nurse. If necessary, an Individual Educational Plan will be created and if the SENCO thinks it appropriate, the child may undergo an assessment by an educational or neuropsychologist to decide what further action may be necessary.

### **School environment**

St Egbert's recognises the importance of having a school environment that supports the needs of children with epilepsy. A medical room is kept available and equipped with a bed in case a pupil needs supervised rest following a seizure.

The above epilepsy policy applies equally within the school and at any outdoor activities organised by the school. This includes activities taking place on the school premises, and residential stays. Any concerns held by the pupil, parent or member of staff will be addressed at a meeting prior to the activity or stay taking place.

### **References**

<sup>1</sup>DfES Managing Medicines in Schools and Early Year Settings Nottingham, 2005

<sup>2</sup>DfES Special Educational Needs Code of Practice Nottingham, 2005

### **Legal requirements and responsibilities**

The following information is taken from the DfES document Managing Medicines in Schools and Early Year Settings. It aims to highlight the importance of having a clear school epilepsy policy and help staff understand their responsibility in ensuring the safety of a child with epilepsy in their school.

The general guidance for ensuring the health and safety of children in schools states that it is the employer's responsibility (under the Health and Safety at Work Act 1974) to make sure schools have a health and safety policy which includes procedures for supporting children with medical needs. It is also the employer's responsibility to make sure that they have taken out Employer's Liability Insurance and that this insurance

provides full cover for school staff acting within full scope of their employment i.e. 'duty of care'. In community and voluntary controlled schools the employer is usually the local authority, while in foundation and voluntary-aided schools, staff are employed by the governing body.

In the day-to-day management of children's medical needs, parents should give schools information about their child's condition, including any relevant details from the child's GP, consultant or epilepsy specialist nurse. Parents are also responsible for supplying any information about the medicine their child needs and providing details of any change to the child's prescription or support required.

There is no legal duty requiring school staff to administer medicine. However, schools should consider this issue as part of their accessibility planning duties. Staff are usually happy to volunteer for training to administer emergency medicines. Some proactive schools require support staff to be trained in administering emergency medicines as part of their role (full roles and responsibilities are detailed in the government document *Managing Medicines in Schools and Early Year Settings*)."  
Epilepsy Action 2009

## Useful contacts

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

New Anstey House, Gate Way Drive, Yeadon. Leeds. LS19 7XY

Tel: 0113 210 8800

Helpline: 0808 800 5050

**Epilepsy Wales** [www.epilepsy-wales.co.uk](http://www.epilepsy-wales.co.uk)

**Epilepsy Scotland** [www.epilepsyscotland.org.uk](http://www.epilepsyscotland.org.uk)

**Department for Education** [www.education.gov.uk](http://www.education.gov.uk)

Castle View House, East Lane, Runcorn. Cheshire. WA7 2GJ

Tel: 0370 000 2288

**Joint Council for Qualifications** [www.jcq.org.uk](http://www.jcq.org.uk)

Veritas House, 125 Finsbury Pavement, London. EC2A 1NQ

Tel: 020 7638 4132

Information taken from:

**Epilepsy Action** (working name of British Epilepsy Association)

New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY

tel. 0113 210 8800 fax 0113 391 0300

**Epilepsy Helpline: freephone** 0808 800 5050 **text** 07797 805 390

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

Form A: Parental questionnaire  
For students with epilepsy

**This questionnaire should be completed by the child's parents and head teacher and, wherever possible, the child**

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

Class/form teacher: \_\_\_\_\_

What type of seizure/s does your child have? (if you know what they are called)

\_\_\_\_\_

How long do they last?

\_\_\_\_\_

\_\_\_\_\_

What first aid is appropriate?

\_\_\_\_\_

\_\_\_\_\_

How long will your child need to rest following a seizure?

\_\_\_\_\_

\_\_\_\_\_

Are there any factors that you have noted might trigger a seizure?

\_\_\_\_\_

\_\_\_\_\_

Does your child have any warning before a seizure occurs?

\_\_\_\_\_

\_\_\_\_\_

What is the name of your child's medicine and how much is each dosage?

\_\_\_\_\_

\_\_\_\_\_

How many times a day does your child take medicine?

\_\_\_\_\_

\_\_\_\_\_

Are there any activities that you feel may require particular precautions?

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Does your child have any other medical conditions?

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Is there any other relevant information you feel the school should be aware of?

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Form B: Parental agreement –  
School or setting to administer medicine

**The school will not give your child medicine unless this form is completed and the school has a policy for staff to administer medicine.**

Name of school: \_\_\_\_\_

Date: \_\_\_\_\_ Class/form: \_\_\_\_\_

Child's name: \_\_\_\_\_

Medical condition or illness: \_\_\_\_\_

Name and strength of medicine: \_\_\_\_\_

Expiry date: \_\_\_\_\_ When to be given: \_\_\_\_\_

Dosage and method of administration: \_\_\_\_\_

Any side effects school needs to know about? \_\_\_\_\_

Procedure to take in an emergency: \_\_\_\_\_

Number of tablets/quantity to be given to school: \_\_\_\_\_

**NOTE: Medicines must be in the original container as dispensed by the pharmacy**

Daytime phone number of parent or adult contact: \_\_\_\_\_

Name and phone number of GP: \_\_\_\_\_

Agreed review date to be initiated by [name of member of staff]: \_\_\_\_\_

The above information is, to the best of my knowledge, accurate at the time of writing and I give consent to school staff administering medicine in accordance with the school policy. I will inform the school immediately, in writing, if there is any change in dosage or frequency of the medicine or if the medicine is stopped.

Parent's signature: \_\_\_\_\_ Print name: \_\_\_\_\_

Date: \_\_\_\_\_

Form C: Staff training record –  
Administration of medicines

Name of school:

Name of staff:

Profession and title:

Type of training received:

Date of training completed:

Training provided by:

I confirm that [name of member of staff] \_\_\_\_\_ has  
received the training detailed above and agrees to carry out any necessary treatment.

I recommend that the training is updated [state how often]

\_\_\_\_\_

Trainer's signature: \_\_\_\_\_ Date: \_\_\_\_\_

I can confirm I have received the training detailed above

Staff signature: \_\_\_\_\_ Date: \_\_\_\_\_

Suggested review date: \_\_\_\_\_

## Form D: Individual Healthcare Plan

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

School: \_\_\_\_\_ Headteacher: \_\_\_\_\_

Parental contact no.: \_\_\_\_\_

Type of seizure/s experienced: \_\_\_\_\_

Symptoms: \_\_\_\_\_

Possible triggers:

Usual procedure following seizure:

Prescribed anti-epileptic medication:

Where medication is stored:

Member of staff responsible for replenishment of medication:

Staff trained to give medication:

i)

ii)

iii)

Member of staff responsible for Home/School liaison:

Emergency procedure if seizure lasts for more than \_\_\_\_\_ minutes.

1. Member of staff to stay with \_\_\_\_\_ to ensure safety.
2. Quietly clear the classroom/area of students if you think this is necessary.
3. Trained member of staff (see above) to give rectal diazepam/buccal midazolam with witness of same sex present (if possible).
4. If needed, telephone 999, ask for Ambulance Service, give name of student, address and phone number of school.
5. Telephone parents.
6. Inform head teacher
7. Stay with \_\_\_\_\_ until ambulance arrives.
8. If parents have not arrived by this time a member of staff will accompany \_\_\_\_\_ to the hospital in the ambulance.
9. Fill in seizure record form for the student file and send copy to parents/GP.

Name: \_\_\_\_\_ Date of birth: \_\_\_\_\_

School: \_\_\_\_\_ Headteacher: \_\_\_\_\_

Parental contact no.: \_\_\_\_\_

**Useful addresses and telephone numbers of professionals involved with:**

<b>Service</b>	<b>Name</b>	<b>Address &amp; Tel No.</b>
Emergency contact		
Epilepsy		
consultant/specialist		
Family GP		
Epilepsy/paediatric/ community support nurse		
Other		

**Parental Consent Form**

I give consent for \_\_\_\_\_ to be given rectal diazepam or buccal midazolam by trained staff in the circumstances described in this document. I will undertake to inform the school of any changes in the nature of his/her seizures or medication.

Signed: \_\_\_\_\_ Date: \_\_\_\_\_

Please print name:

\_\_\_\_\_