Epilepsy in schools in England

Introduction

If you have a child with epilepsy, it is important that you feel confident that they are safe when they are at school. You should know that they are getting the ongoing support, or care they need to manage their epilepsy and keep them well. You should also be confident that if your child has a seizure at school, they will be given the appropriate first aid or emergency medicine.

Responsibilities of schools

From September 2014, new guidance will come into effect, placing a legal requirement on schools in England to support children with medical conditions. The aim is to make sure that all children with medical conditions are properly supported in school, with both their physical and mental health.

The new guidance means that children with epilepsy should have full access to education. They should have the support they need to do as well as they possibly can with their studies. They should also enjoy the same opportunities at school as any other child, which includes PE and school trips.

A school must not deny your child a place because they have epilepsy. They should not send your child home frequently, or prevent them from staying at lunch time, unless there is a very good reason for this. You should not have to give up going to work, just because your child has epilepsy and school is not supporting their needs fully.

School policy for pupils with medical conditions

All schools should have a policy for supporting pupils with medical conditions. The policy should be reviewed regularly and be easily accessible to parents and school staff.
The school policy should set out the procedures they should follow when they are told that a child has epilepsy. The information in the policy should include:

- Who is responsible for making sure there are enough staff trained to help children with medical conditions
- A commitment that all staff who need to know are aware of a child’s medical condition
- Who can provide support for a child with a medical condition, in the case of staff absence
- Information about children with medical conditions for supply teachers
- Risk assessments for school visits, holidays and other school activities inside and outside of the normal timetable
- How individual healthcare plans (IHPs) should be monitored

If your child is starting at a new school, arrangements for their support should be in place in time for the start of the new term. If your child is diagnosed with epilepsy while they are at school, or they move to a new school mid-term, school should try to make arrangements within two weeks.

If your child has not yet had a formal diagnosis of epilepsy, you can still ask the school to make arrangements to support them. They can use information from medical professionals and you, the parent or carer, to make arrangements for the best way to support your child.

**Individual healthcare plans (IHPs)**

If you tell school that your child has epilepsy, they must make sure that there are arrangements in place to support them. They should also make sure that school staff are properly trained to provide this support.

The information about your child’s medical condition and specific needs can be recorded in an individual healthcare plan (IHP). This is a very individual document for each child. It makes it clear what specific support your child needs, when it should be done and who is responsible for making sure that your child gets the support they need.

Not all children with epilepsy will need an IHP. For example, they might only ever have seizures in their sleep, and not have any other effects from their epilepsy. However, if you feel that your child should have an IHP, you should discuss this with the head teacher. They will make the final decision about whether or not your child should have one.

To produce an IHP, the school should work together with you and your child, and a relevant healthcare professional. This could be your child’s epilepsy specialist or epilepsy specialist nurse.

Here is a recommended list of things to discuss when you are developing an IHP for your child.

- Their type of epilepsy
- Their type of seizures
- What happens before, during and after a seizure
• How long their seizures last
• Appropriate first aid
• What the school should do after your child has had a seizure
• How long your child needs to rest following a seizure
• When the school should call for an ambulance
• What the school should do in an emergency
• Triggers for your child’s seizures (if any)
• Any warnings your child has that they may be about to have a seizure (for example a headache or an aura)
• Any medicine they take, and when they need to take it
• Any medicine side-effects that the school needs to be aware of
• Any particular activities that you think may put your child at risk, and what can be done to reduce the risk
• Any adjustments that need to be made to the classroom environment, to support their learning
• Any other provisions the school needs to make, for example extra time in exams
• Any other medical conditions that your child has
• Who the healthcare professionals involved in your child’s care are
• Any behaviour or emotional issues that the school needs to be aware of
• Who else in school needs to know about your child’s epilepsy – class teacher, dinner time assistants and friends

An IHP should be easy to access by anyone who needs the information, but it should also preserve your child’s confidentiality.

IHPs should be reviewed every year, or earlier if your child’s epilepsy or needs change. They should be developed with your child’s best interests in mind and ensure that the school assesses and manages risks to your child’s education, health and social wellbeing.

**Medicines in schools**

**Daily epilepsy medicines**

If your child takes daily epilepsy medicine, you will usually be able to give them their doses outside school hours. The school should only give them medicine during school hours if it would be harmful to their health or school attendance if they didn’t.

If your child does have to be given epilepsy medicine during school hours, the headteacher can ask any member of staff to do this. However, the member of staff can refuse to do so and the headteacher will have to find somebody else who will.

**Emergency medicines**

Your child may have been prescribed emergency medicine, to stop seizures that last a long time or clusters of seizures. Emergency medicines for seizures include buccal midazolam and rectal diazepam.
Buccal midazolam is given to the child through a needle-free syringe, between the cheek and gum. It is absorbed through the cheek cells. Rectal diazepam is given through the child’s back passage.

If your child needs their emergency medicine during school time, it should only be administered by a named person. They should have been trained how to do this by a professional, such as an epilepsy specialist nurse. The people who can administer it will be named in your child’s individual healthcare plan (IHP).

The school should keep a record every time your child is given emergency medicine. This should include what was given, how much, when and who by.

The school should keep emergency medicines stored in a safe and secure place, such as a locked cupboard. They should be very easy to get hold of in an emergency, only by named members of staff. The expiry dates on the medicine should be checked regularly.

**Seizures at school**

If your child has a seizure at school, any member of staff should know what to do to help. This might involve giving first aid or calling for a named person who knows what help your child needs.

If your child has an individual healthcare plan (IHP), this should have detailed information about their seizures and what first aid they need. IHPs should be easily accessible to all members of staff who might be with your child when they have a seizure.

After a seizure, your child might need to go to the school office or medical room to recover. They should not go there alone. School staff must make sure that a suitable person, such as an adult or a responsible pupil goes with them.

**Emergency situations**

**What should happen when there is an emergency?**

The school policy should make it clear what should happen in an emergency situation, for any child with a medical condition.

If your child has epilepsy, an emergency situation at school would be if they:

- Had a single seizure or cluster of seizures that lasts for longer than five minutes, or longer than is usual for them
- Were severely injured as the result of a seizure

All school staff should be able to recognise what is happening and respond quickly. They will need to either:

- Arrange for an ambulance to be called **or**
- Arrange for a named and trained member of staff to give your child emergency medicine **or**
• Arrange for appropriate first aid, if they have been severely injured

If your child needs to go to hospital, staff should stay with them until you arrive at school, or accompany them in an ambulance.

**How will people in school know how to respond to an emergency?**

**School staff**

How a member of staff responds will depend on what the emergency is, and whether your child has an individual healthcare plan (IHP). An IHP should give clear and specific instructions about what to do in an emergency, and who should do it.

Here are some ways that the school can make sure that all staff know what to do in an emergency situation:

- All staff should receive general epilepsy awareness training
- When new members of staff start working at the school, they should receive epilepsy awareness training
- Individual healthcare plans (IHPs) should be easily accessible and familiar to all members of staff who need to refer to them

**Other pupils**

Pupils in school should know to tell a member of staff immediately if your child has a seizure and needs help. The school could give general epilepsy awareness training to the pupils, to make sure they recognise when a child may need help.

**Epilepsy and learning**

For some children, epilepsy can have an effect on how easy or difficult it is for them to learn. There could be many possible reasons for this, including:

- The condition itself
- The cause of the epilepsy
- The effects of seizures
- Side-effects from epilepsy medicines
- Absences from school

**The condition itself**

A recent study of school children with active epilepsy in West Sussex showed that:

- Over half of the children found it more difficult to learn than other people
- Over half of the children had problems with their memory
- Just under half of the children had problems with the speed with which they processed information
- Just under half of the children were not achieving as much as they could at school. The greatest difficulties were in mathematics and understanding their work
Sixty five per cent (65 in 100) parents reported that their child had difficulties with attention and concentration.

It is also known that children with some epilepsy syndromes are more likely to have learning difficulties than others. For example, at least one study showed that children with benign rolandic epilepsy (BECTS) have more problems with reading, writing and maths than children with other types of epilepsy.

**The cause of the epilepsy**

For some children, difficulties with learning can be caused by damage to their brain, which also causes their epilepsy. This damage could have happened before, during, or after their birth.

**The effects of seizures**

Epileptic seizures can disrupt normal brain activity, and this can stop memory from working properly. The confusion that can occur after seizures may also cause memory loss.

Some children have a lot of epileptic activity in their brain, but don’t appear to be having any seizures. This can happen both when the child is sleeping and when awake. If this happens very frequently, it can also affect their memory and how they learn.

Depending on the type of seizures a child has, they may feel very tired or confused after a seizure. They may also have interrupted sleep which will make them tired. Feeling tired or confused can affect how well a child can learn.

**Side-effects from epilepsy medicines**

Some children may have side-effects that affect their learning. These could include drowsiness, dizziness, memory problems, problems concentrating and mood swings.

**Absences from school**

Some children miss parts of their education because they need time off school to go to appointments with the nurses and specialists who manage their conditions. They may also be absent as a result of seizures, recovery after a seizure or injuries from a seizure.

**Epilepsy and behaviour**

For some children, epilepsy can have an effect on their behaviour. There could be many possible reasons for this, including:

- The condition itself
- The cause of the epilepsy
- The effects of seizures
- Side-effects from epilepsy medicines

**The condition itself**

A recent study of school children with active epilepsy in West Sussex showed that:
• Sixty in 100 of the children showed some symptoms of at least one of the following disorders: attention deficit hyperactivity disorder (ADHD), autism spectrum disorder (ASD), developmental co-ordination disorder (DCD), depression or anxiety. Only 20 in 100 of these had been diagnosed with one of these conditions.

The cause of the epilepsy

For some children, behaviour problems can be caused by damage to their brain, which also causes their epilepsy. This damage could have happened before, during, or after their birth.

The effects of seizures

Some children may behave differently in the time before, during and after a seizure. In the hours or even a few days before a seizure, a child’s mood or behaviour may also change. This is called a prodrome.

During a focal seizure, it’s quite usual for a child to appear to be behaving differently. These behaviours may include gagging, lip smacking, running, screaming, crying, and/or laughing. They may not be conscious of what they are doing, but they are in fact having a seizure.

After a seizure, it’s quite usual for a child to be confused, have a headache, feel sleepy or have problems with vision or speech. This can change their behaviour.

Very rarely, a child might have a condition called post-ictal psychosis. This can be very frightening and can change a child’s behaviour. It can cause them to have a strong belief that something unreal is true, or hear or see things that are not there.

Side-effects from epilepsy medicines

Some children may have side-effects that affect their behaviour. These could include hyperactivity, irritability, sleepiness, mood changes, aggression and confusion, problems concentrating and mood swings.

Getting help for your child

If you feel that your child is finding it difficult to learn, or is having problems with their behaviour, they may need extra support. You should discuss these issues with the school, and what kind of support might help, when you are developing an individual healthcare plan (IHP).

School trips and activities

Your child should be allowed to take part in all school trips and activities, including those with overnight stays. They should not be prevented from taking part in any activities, unless a healthcare professional advises that they are dangerous.

When a school trip or activity is being planned, the organisers should do a risk assessment for your child. This will give them the opportunity to look at what extra help your child
might need, because they have epilepsy. They can then decide on what steps they can take, to make sure your child can take part fully and safely. This may involve being flexible and making reasonable adjustments.

You and your child should be involved in the risk assessment. You can help the organisers by sharing as much information as you can about your child’s epilepsy and the support they might need. You can also suggest reasonable adjustments they could make.

The people doing the risk assessment should also get advice from a relevant medical professional, such as an epilepsy specialist or epilepsy specialist nurse.

**Your child’s social and emotional wellbeing at school**

The school should be aware of ways that your child’s epilepsy might have an effect on their social development and emotional wellbeing. For example, your child might:

- Be self-conscious of their epilepsy
- Be frightened that they are going to have a seizure
- Experience anxiety or depression because of their epilepsy
- Be bullied because they have epilepsy
- Have frequent short-term absences from school, due to medical appointments or seizures, causing them to miss some school activities
- Have long-term absences from school because of their epilepsy and need help to get back into their school routine
- Experience side-effects from epilepsy medicine, which could include drowsiness, dizziness, memory problems, problems concentrating and mood swings
- Feel very tired, because they are recovering from a seizure or have had disturbed sleep

The school should make sure that your child receives the support they need to deal with these issues. To help them do this, they should get advice from relevant healthcare professionals. They should also listen to, and value the views of you and your child about how they can do this.

Decisions about how your child can be supported should be recorded in their individual healthcare plan (IHP) if they have one.

**How you can help school**

You have a very important role in helping school to provide your child with the support they need. Here are some ways you can help:

- Keep the school up-to-date with detailed information about your child’s epilepsy and needs, especially if there are any changes in their condition or treatment
- Find a way of communicating important information with the school in a way that works for both of you – some people use a communication book, which you and school staff can record information in on a daily basis
- Go to all the meetings that you are invited to, and try to think beforehand about any information you can provide that will be helpful
• Make sure that the school are easily able to contact you, if there is an emergency
• Make sure that the school has the correct rescue medication (if needed) that is in-date, clearly labelled and in the correct container
• Make sure your child knows who to tell if they get a warning of a seizure

What to do if you are not happy with your child’s care at school

If you are not happy, it is important that you talk to the school as soon as possible.

In the first instance, talk to the members of staff who are directly involved in your child’s care, or the head teacher. It may be that they have not fully understood what your child’s needs are.

If you are still not satisfied, ask the school for a copy of their formal complaints procedure. This might involve explaining your concerns to the school’s board of governors, parent’s council or the local authority.

If you still feel that school has not supported your child properly, you might choose to speak to a solicitor and start legal proceedings. Be aware that this could be very expensive.

Useful organisations

ACE Education
ACE gives advice and information on education issues, including current education law and guidance and covers state funded education for children aged 5-16 years in England only.
The advice line is open Monday to Wednesday 10 till 1pm in term time.
Tel: 0300 0115 142
Website ace-ed.org.uk

Contact a Family
Contact a Family offers advice and networking for families with a disabled child.
Tel: 0808 808 3555
Website: cafamily.org.uk/advice-and-support

Children’s Legal Centre
The Children’s Legal Centre provides legal information and representation on all issues of the law relating to children and young people.
The advice line is open 8am to 8pm Monday to Friday
Tel:0808 802 0008
Website: childrenslegalcentre.com

Network81
Network81 offers advice and support to parents of children with special educational needs.
The helpline is run by volunteers.
Tel: 0845 077 4055
Website: network81.org
BILD
The British Institute of Learning Disabilities provides support and training resources for those working with people with learning disabilities.
Website: bild.org.uk

Department for Education (England)
This offers a wide range of information about educational issues. The website link goes directly to the new guidance on supporting pupils at school with medical conditions.
Website: gov.uk/government/uploads.pdf

Medical conditions at school
A website of resources for schools and school healthcare professionals.
Website: medicalconditionsatschool.org.uk

IASS Network
IASS are an information, advice and support service network. They have a duty to provide information, advice and support to disabled children and young people, and those with special educational needs, and their parents. There should be an IAS Service in every local authority.
Website: iassnetwork.org.uk

IPSEA
The Independent Parental Special Educational Advice service offers free and independent legally based information and advice. They aim to support people to help get the right education for children and young people with all kinds of special educational needs and disabilities. The advice line is run by volunteers.
Tel: 0800 018 4016
Website: www.ipsea.org.uk

NASEN
The National Association for Special Educational Needs promotes the education, training, advancement and development of all those involved in the teaching of children with special and additional support needs.
Website: nasen.org.uk

Young Epilepsy
Young Epilepsy supports young people with epilepsy and associated conditions. They also provide epilepsy related training.
Tel: 01342 831 342
Website: youngepilepsy.org.uk

National Foundation for Educational Research
The NFER aims to improve education and learning, and the lives of learners, by providing independent evidence.
Website: nfer.ac.uk

SEN Magazine
SEN publishes a magazine every two months covering all issues to do with special educational needs and disability.
Website: magazine.co.uk