

**epilepsy
society**

children

A guide for parents and teachers



epilepsy society

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When you see this symbol, it means further information is available.

Call us for a large print version

Epilepsy Society is grateful to Christine Morley, Paediatric Epilepsy Specialist Nurse, for her guidance on this leaflet.

helpline

01494 601 400

Monday to Friday 10am to 4pm
(national call rate)

what is epilepsy?

Epilepsy is a neurological condition (affecting the brain and nervous system) where a person has a tendency to have seizures that start in the brain.

The brain is made up of millions of nerve cells that use electrical signals to control the body's functions, senses and thoughts. If the signals are disrupted, the person may have an epileptic seizure (sometimes called a 'fit' or 'attack').

Epilepsy in childhood

In the UK, there are an estimated 60,000 children under 18 with epilepsy. Epilepsy can start at any age including childhood.

If your child develops epilepsy you may have questions or concerns. This leaflet aims to answer some of these questions and gives a brief introduction to how epilepsy can affect children. It also includes specific information about education for parents and teachers.

Not all seizures are epileptic. Other conditions that can look like epilepsy include fainting (syncope) due to a drop in blood pressure, and febrile convulsions due to a sudden rise in body temperature when a young child is ill. These are not epileptic seizures because they are not caused by disrupted brain activity.



See our leaflet *what is epilepsy?*

What happens during a seizure?

There are many different types of epileptic seizure. The type of seizure a child has depends on which area of their brain is affected.

There are two main types of seizure: focal seizures (sometimes called partial seizures) and generalised seizures. Focal seizures affect only one side of the brain and generalised seizures affect both sides of the brain.

Generally, adults and children have the same types of seizure, although some may be more common in childhood than adulthood.

Different seizures include jerking of the body (convulsions); repetitive movements; or unusual sensations, such as a strange taste or smell, or a rising feeling in the stomach. In some types of seizure, a child may be aware of what is happening. In other types, a child will be unconscious and have no memory of the seizure afterwards.

Some seizures are more common in childhood. For example, absence seizures which can be very brief and are often mistaken for 'daydreaming' or not paying attention.

Some children may have seizures when they are sleeping (sometimes called 'asleep' or 'nocturnal' seizures). Seizures during sleep can affect sleep patterns and may leave a child feeling tired and confused the next day.



Seizure types are explained in more detail in our *seizures* leaflet.

why does my child have epilepsy?

Some children develop epilepsy as a result of their brain being injured in some way. This could be due to a severe head injury; difficulties at birth; or an infection which affects the brain such as meningitis.

Epilepsy with a known structural cause like this is called symptomatic epilepsy.

For some children, their epilepsy has a genetic cause. This may be inherited from one or both parents, or it may be a change that happened in the child's genes (before they were born). Epilepsy with a likely genetic cause is called idiopathic epilepsy.

Everyone has a level of resistance to seizures, called a seizure threshold. This is included in the genes passed from parent to child. A child with a low seizure threshold may start having seizures for no obvious reason. However, having a low seizure threshold doesn't always mean that seizures will start. Other children in the family may have a similar seizure threshold but may not develop epilepsy.

how is epilepsy diagnosed?

A diagnosis of epilepsy may be considered if your child has had more than one seizure. The GP will usually refer them to a paediatrician (a doctor who specialises in treating children).

You (and your child if they can) may be asked to describe in detail what happened before, during and after the seizure.

Having a video recording of the seizure can help the paediatrician to understand what is happening.

The paediatrician may also suggest a few tests to help with the diagnosis. The tests alone cannot confirm or rule out epilepsy, but they can give extra information to help find out why your child is having seizures.



See our leaflet *diagnosis*.

what is a childhood epilepsy syndrome?

If your child is diagnosed with a childhood epilepsy syndrome, this means their epilepsy has specific characteristics. These can include the type of seizure or seizures they have; the age when the seizures started; and the specific results of an electroencephalogram (EEG).

An EEG test is painless, and it records the electrical activity of the brain.

Syndromes follow a particular pattern, which means the paediatrician may be able to predict how your child's condition will progress.

Syndromes can vary greatly. Some are called 'benign' which means they will have a good outcome, and usually go away once the child reaches a certain age.

Other syndromes are severe and difficult to treat. Some may include other disabilities and may affect a child's development.



See our factsheet *childhood epilepsy syndromes*.

treatment for children

Your child's GP is normally responsible for their general medical care. They may be referred to a paediatrician or paediatric neurologist (a children's doctor who specialises in the brain and nervous system). An epilepsy specialist nurse may also be involved in their care.

Young people usually start to see a specialist in adult services (a neurologist) from around 16 years old.

Anti-epileptic drugs

Most people with epilepsy take anti-epileptic drugs (AEDs) to control their seizures. The paediatrician can discuss with you whether AEDs are the best option for your child.

Although AEDs aim to stop seizures from happening, they do not stop seizures *while* they are happening, and they do not cure epilepsy.

Most children stop having seizures once they are on AEDs that suit them. Like all drugs, AEDs can cause side effects for some children. Some side effects go away as the body gets used to the medication, or if the dose is adjusted.

If you are concerned about your child taking AEDs you can talk to their paediatrician, epilepsy nurse, GP or pharmacist. Changing or stopping your child's medication without first talking to the doctor can cause seizures to start again or make seizures worse.

Although AEDs work well for many children, this doesn't happen for every child. If AEDs don't help your child, their doctor may consider other ways to treat their epilepsy.



See our leaflets *medication for children, or medication for adults for children aged 13 and over.*

Ketogenic diet

For some children who still have seizures even though they have tried AEDs, the ketogenic diet may help to reduce the number or severity of their seizures. The diet is a medical treatment, often started alongside AEDs, and is supervised by trained medical specialists and dietitians.



See our factsheet *ketogenic diet.*

will epilepsy affect my child's life?

Triggers for seizures

Some children's seizures happen in response to triggers such as stress, excitement, boredom, missed medication or lack of sleep. You might find it helpful to keep a diary of their seizures

to see if there are any patterns to when seizures happen. If you can recognise triggers, avoiding them as far as possible may help reduce the number of seizures your child has.

Getting enough sleep, and well-balanced meals, will help keep your child healthy and may help to reduce their seizures.



Contact us for a *seizure diary*.

Immunisation (vaccination)

Some parents are nervous about immunisation, whether or not their child has epilepsy. The Department of Health recommends that every child is immunised against infectious diseases. This includes children who have epilepsy. If you are concerned about immunisations your child's GP or paediatrician can give you more information.

Behaviour

For some children, having epilepsy and taking AEDs will not affect their behaviour. However, some people notice a change in their child's mood or behaviour, such as becoming irritable or withdrawn. Having epilepsy does not change someone's character, but some children may be responding to how they feel about having epilepsy, and how it affects them. They may also want to be treated the same as their siblings or friends, and to feel that epilepsy isn't holding them back.

Encouraging your child to talk about epilepsy may help them feel better.

Behaviour changes and problems can happen for all children regardless of having epilepsy and for many, may just be part of growing up. In a few children, irritable or hyperactive behaviour may be a side effect of AEDs. If you have concerns about changes in your child's behaviour, you may want to talk to their doctor or epilepsy specialist nurse.

Leisure activities

Most children with epilepsy can take part in the same activities as other children. Simple measures can help make activities such as swimming and cycling safer. For example, making sure there is someone with your child who knows how to help if a seizure happens.



See our leaflets *leisure and safety*.

can epilepsy change as children get older?

Seizures may change over time, either in type or frequency. Some children outgrow their epilepsy by their mid to late teens. This is called 'spontaneous remission'. If they are taking AEDs and have been seizure-free for over two years, their doctor may suggest slowly stopping medication.



Adolescence

Adolescence is a time when many young people become more independent, and will want to make their own choices about their lives. Finding out what affects their epilepsy can be part of making informed choices. Late nights, emotional stress, and trying alcohol or recreational drugs can be typical parts of teenage life. However, all these can make seizures more likely to happen.

Some young people find epilepsy difficult to live with, especially if they have frequent seizures or side effects from their medication. They may decide to stop seeing their doctor or to stop taking their medication. Talking to someone they feel comfortable with can help them to feel supported and encourage them to take control in making decisions about their epilepsy.



See our guide *your epilepsy – now and next*.



Visit www.youthhealthtalk.org where young people talk about their epilepsy.

how might my child feel?

Having epilepsy can affect a child in different ways. Depending on their age and the type of seizures your child has, the impact may vary.

For some children a diagnosis of epilepsy will not affect their day to day lives.

For others it may be frightening or difficult to understand. They may feel embarrassed, isolated or different in front of their peers. Talking to your child about their concerns may help them to feel more positive.

Most children with epilepsy will have the same hopes and dreams as other children, and seizures need not prevent them from reaching their goals.

your feelings as a parent

If your child is diagnosed with epilepsy you may have mixed emotions – for your child and for yourself. You may feel worried or relieved and it can take time to come to terms with a diagnosis and how it may affect family life. How you feel about the diagnosis may also change over time.

Our confidential helpline can offer you emotional support, information and time to talk through your feelings. Alternatively you might like to visit our website to find out more about epilepsy, or to contact other parents through our online forum.

Our helpline can also provide details of epilepsy support groups around the country.



Contact our helpline (see back page) or visit www.epilepsysociety.org.uk/forum

school and education

Epilepsy is a very individual condition, so how it affects a child's education can vary. Knowing as much as possible about your child's epilepsy can help you to make decisions with them about their education.

Telling staff at school about your child's epilepsy means they will know what to do if a seizure happens. It is important that the staff are aware of what is best for *your* child, so they don't assume that epilepsy affects everyone in the same way.

For some children, having epilepsy will not affect their ability to learn or achieve academically, but others may need extra time or support in class. For example, a child who has absence seizures may miss key points in lessons. Having a chance to catch up on what they have missed in class can be helpful if seizures happen frequently. Sometimes a child may need time to recover after a seizure, and may need to sleep. Seizures at night can disrupt sleep patterns and affect memory for some time afterwards. AEDs can also cause side effects that include tiredness and problems with memory or concentration.

If you feel that your child needs support at school you can talk to their teachers. Sometimes a teacher may approach you if they notice areas where your child needs extra help.

Special educational needs

A child has special educational needs if they have learning difficulties that need special help at school. This extra help should be available to anyone who needs it, and it is often called special educational provision. There may be a special educational needs co-ordinator (SENCO) at the school who can look at your child's needs, alongside the school's governing body (often the local authority education department).

If your child needs extra help, you, the school or the local authority can ask to have a statutory assessment which may produce a 'statement of special educational needs'. This statement describes all the help a child needs, including educational needs such as improving reading; non-educational needs such as transport to school; and regular reviews to see how a child is getting on.

Parent Partnership Services are funded by the Department of Education and give information, advice and support to parents and carers of children and young people with special educational needs. They also provide information on how individual needs are identified by schools and the local authority.



Visit www.direct.gov.uk



Visit www.parentpartnership.org.uk

information for teachers

Because epilepsy varies so much from person to person, it can be helpful to find out as much as possible about a child's epilepsy to avoid making assumptions about how their condition might affect their learning.

If parents feel supported by the school, they may be more likely to give information about their child's epilepsy.

Equality Act 2010

The Equality Act came into force in October 2010. The Act replaces and brings together lots of different equality laws, including the Disability Discrimination Act 1995 (DDA).

Epilepsy is a condition that is covered by the Equality Act, even if a person's seizures are controlled with medication.

This means it is against the law for education and training providers to discriminate against people with disabilities. This includes nurseries and playgroups, primary and secondary schools, and further and higher education.

The Equality Act covers extra curricular activities. It also covers how the curriculum is delivered and so methods of teaching need to treat all pupils fairly and not put pupils with a disability at a disadvantage. However, the Equality Act does not cover the content of the curriculum.



Visit www.equalityhumanrights.com

Computers and lights

For most people with epilepsy, using a computer will not trigger a seizure. Up to 5% of people with epilepsy have photosensitive epilepsy, where seizures are triggered by flashing or flickering lights or by geometric patterns such as checks or stripes.

Computers and TVs with a flat screen do not flicker and so are less likely to trigger seizures than screens that flicker. However, fast-moving or flashing *images* on the screen could be a trigger. Other photosensitive triggers include flickering overhead lights, and sunlight creating patterns through blinds.



[See our factsheet *photosensitive epilepsy*.](#)

Exams and tests

Whether a child's epilepsy affects their ability to do exams or tests depends on their individual epilepsy. If they are likely to have seizures in stressful situations, or at certain times of the day, this may affect how they perform in exams or tests. Tiredness, or memory or concentration problems may also affect exams. Discussing concerns with the child and their parents may help to decide whether special arrangements are needed for exams.

Practical activities and lessons

Safety is important for all children, especially during practical activities and lessons, such as science or PE.

Epilepsy does not need to stop a child from doing an activity, as long as they are safe. Those responsible for their care need to know how their epilepsy affects them, and what to do if a seizure happens. This also applies to extra curricular activities.

If a child has seizures, you can discuss any concerns about activities with them and their parents. Doing a risk assessment is also important. Useful questions to ask include the following.

- What are the risks to safety for any child involved in this activity?
- What happens to the child during their seizures?
- Do they have a warning (know a seizure is going to happen)?
- What would help make the activity safer for them?



See our website for more about risk assessments.

Swimming

It is essential that the swimming teacher and lifeguards fully understand a child's epilepsy so they can quickly see if the child is having a seizure in the water.

Some schools use a 'buddy system' which pairs up pupils so that everyone has someone to look out for them in the water.

This may help a child feel they are being treated the same as the other children, as well as increasing everyone's safety in the water.

Medication at school

Most children with epilepsy take AEDs to prevent seizures (see page 7). AEDs are usually taken once a day, or twice a day with a 12 hour interval, which usually means this happens outside school hours.

If a child needs to take AEDs at school, having an individual health care plan for the child means that their medication can be managed and given effectively. This plan needs to be arranged by the school and agreed with the school's governing body and the child's family.

Sample health care plans and other forms relating to giving medication at school can be downloaded for free as part of the Department for Education (DfE) publication 'Managing medicines in schools and early years settings' (2005).



Visit www.education.gov.uk/schools/pupilsupport/pastoralcare

Emergency medication

Usually a seizure will stop by itself. However, if a seizure continues for more than 30 minutes (or one seizure follows another with no recovery in between) this is known as status epilepticus or 'status'. Status during a tonic clonic (convulsive) seizure is a medical emergency and needs urgent treatment.

Children who go into status may be prescribed emergency medication to help stop prolonged or repeated seizures.

There are two emergency medications used to treat status. Both these drugs are sedatives, which have a calming effect on the brain.

- Rectal diazepam – given rectally (into the bottom).
- Buccal midazolam – given into the buccal cavity (the side of the mouth between the cheek and gum).



Contact us for details of our emergency medication booklets *buccal midazolam* and *rectal diazepam*.

If a child has emergency medication there should be a care plan (protocol) in place for giving them emergency medication at school.

Anyone giving these drugs needs specialist training to learn how to do this. Epilepsy Society can provide emergency medication training for school nurses delivered by professional trainers.

Alternatively, you may be able to arrange this through the local authority or the child's medical professionals.



For information about our training call 01494 601 305 or visit www.epilepsysociety.org.uk

How will other pupils feel about epilepsy?

Generally, people feel more confident about epilepsy when they understand it, and know what to do if someone has a seizure. Learning about epilepsy in the classroom can be a good way to introduce information about the condition, without any children with epilepsy feeling that they are singled out.



We run free awareness-raising sessions for schools. Call 01494 601 391 for details.



further information

Epilepsy Society information

Buccal midazolam

Childhood epilepsy syndromes

Diagnosis

Ketogenic diet

Leisure

Medication for adults (for children aged 13 and over)

Medication for children

Photosensitive epilepsy

Rectal diazepam

Safety

Seizure diary

Seizures

What is epilepsy?

Your epilepsy – now and next

Visit our website for a full list of books available from Epilepsy Society.



other organisations

ACE (Advisory Centre for Education)

Information line: 0808 800 5793

(Monday to Friday 10am to 5pm)

www.ace-ed.org.uk

Independent advice centre for parents.

Contact a Family

Helpline: 0808 808 3555

www.cafamily.org.uk

Support and information for families of children with medical conditions.

Equality and Human Rights Commission

Helplines: 0845 604 6610 (England)

0845 604 5510 (Scotland)

0845 604 8810 (Wales)

www.equalityhumanrights.com

Information on education and the Equality Act 2010.

IPSEA (Independent Panel for Special Education Advice)

Helpline: 0800 018 4016

www.ipsea.org.uk

Free independent educational advice for parents of children in England and Wales.

National Parent Partnership Network

Information line: 0207 843 6058

www.parentpartnership.org.uk

Confidential free information, support and advice for parents and carers of young people with special educational needs.

Staying Positive – young people’s workshops

Information line: 01225 731 414

www.staying-positive.co.uk

Free courses for young people with any health condition run by the Expert Patients Programme (EPP CIC).

what to do if a seizure happens

How you can help a child during a seizure may depend on the type of seizures they have.

If a child seems confused or vacant, stay with them, talk calmly and quietly and gently guide them away from any danger.

During convulsive (tonic clonic) seizures

- try to keep calm;
- check the time to see how long the seizure lasts;
- move objects away from them if they are likely to hurt themselves;
- put something soft under their head to protect it;
- **after** they have stopped shaking put them gently into the recovery position;
- stay with them until they have recovered;
- **don't** hold them down;
- **don't** put anything in their mouth; and
- **don't** move them, unless they are in direct danger.



For more information about how you can help during a seizure see our *first aid* leaflet.



See our factsheet *the recovery position*.

Every effort is made to ensure that all information is correct. Please note that information may change after printing. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.

cares

A full life for everyone affected by epilepsy.

informs

Website, leaflets, dvds – call 01494 601 392.

researches

Pioneering medical research.

campaigns

Shaping the future of epilepsy.

connects



Forum, Facebook, Twitter and app.

Volunteer, become a member, fundraise.

educates

Awareness, schools, training for professionals.

understands

Medical and care services.

listens

helpline 01494 601 400

Monday to Friday 10am to 4pm

Confidential. National call rate.

Information and emotional support.

Epilepsy Society

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