

**epilepsy
society**

children

A guide for parents and teachers



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This symbol means further information is available. You can find any further updates at epilepsysociety.org.uk/epilepsy-childhood

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 and Tuesday 9am to 4pm,
Wednesday 9am to 7.30pm. National call rate.

a guide for parents and teachers

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').



See our leaflet *what is epilepsy?*

Epilepsy in childhood

In the UK, epilepsy affects around 1 in every 200 children and young people under the age of 18. 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.

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

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 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. This kind of structural change is sometimes called symptomatic epilepsy.

Some researchers now believe that the chance of developing epilepsy is probably always genetic to some extent, in that anyone who starts having seizures has always had some level of genetic tendency to do so. This level can range from high to low and anywhere in between.

Even if seizures start after a brain injury or other structural change, this may be due to *both* the structural change *and* the person's genetic tendency to have seizures combined. This makes sense if we consider that many people might have a similar brain injury, but not all of them develop epilepsy afterwards.

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 usually 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. The GP may refer your child 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 an AED that suits 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.



See our booklet and chart *medication for epilepsy*.

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.

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*.

Epilepsy surgery

It may be possible for some children to have epilepsy surgery depending on the type of epilepsy they have and where in the brain their seizures start.

Epilepsy surgery (also called neurosurgery) involves removing a part of the brain to stop or reduce the number of seizures a child has.



See our factsheet *epilepsy surgery*.

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. Keeping a diary of their seizures can help to see if there are any patterns to when seizures happen.

If you recognise triggers, avoiding them as far as possible may help reduce the number of seizures your child has.



Contact us for a free *seizure diary* or visit epilepsysociety.org.uk/app to download our app which includes a seizure diary.

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

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. 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 their 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 pages 17 and 18).



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 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 of 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 for young people *your epilepsy – now and next* or visit healthtalk.org/young-peoples-experiences

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. Encouraging your child to talk 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 may not necessarily 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. It can take time to come to terms with a diagnosis and how it may affect family life. You may feel worried or relieved. How you feel about the diagnosis may also change over time.

Our helpline can offer you emotional support, information and time to talk through your feelings. Or you might like to visit our website to find out more about epilepsy.



Contact our helpline (see back page), visit epilepsysociety.org.uk, or see our *just diagnosed* information pack.



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 during 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 or disabilities

A child has special educational needs (SEN) if they have learning difficulties or disabilities that make it harder for them to learn than other children of the same age. Every school has a special educational needs co-ordinator (SENCO) who can look at your child's needs with you and with people who work with your child, such as their teacher. The school will usually provide SEN support.

If your child needs extra help, you, or your child's school, can ask the local authority for an Education, Health and Care (EHC) needs assessment. The assessment includes talking to you and your child about what support you think your child needs. It will also include asking for information and views from people who work with your child, such as teachers, doctors or educational psychologists. This may produce an EHC plan, a document that brings together your child's education, health and social care needs. Your child must have special educational needs to be eligible for a plan.

The Information Advice and Support Services Network (IASSN) for children and young people is funded by the Department for Education (DfE) and gives information, advice and support to schools and local authorities, parents, carers, children and young people with special educational needs.



Visit cyp.iassnetwork.org.uk/in-your-area

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.



See our factsheet *recording seizures*.

Equality Act 2010

The Equality Act aims to protect people against discrimination. Epilepsy 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 epilepsy. 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 epilepsy at a disadvantage. However, the Equality Act does not cover the *content* of the curriculum.



Visit equalityhumanrights.com for information and guidance on education providers' responsibilities.

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 and 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 necessarily 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 (see page 19). 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?



Visit [epilepsysociety.org.uk/
risk-assessment](https://www.epilepsysociety.org.uk/risk-assessment)

Swimming

It is essential that the swimming teacher and lifeguards fully understand a child's epilepsy, so that 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.



See our leaflet *leisure*.

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 their own healthcare plan 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 healthcare plans, and forms relating to giving medication at school, can be downloaded as part of the Department for Education (DfE) guidance on 'Supporting pupils with medical conditions at school'.



Visit [gov.uk](https://www.gov.uk)

what to do if a seizure happens

How you can help a child during a seizure depends 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 (because there may be a risk of status epilepticus – see page 20);
- move objects away from them so that they don't hurt themselves;
- put something soft under their head to protect it;
- don't hold them down;
- don't put anything in their mouth;
- don't move them, unless they are in direct danger;
- after they have stopped shaking put them gently into the recovery position; and
- stay with them until they have recovered.



See page 20 for when to call an ambulance. See our leaflet *first aid* and our factsheet *the recovery position* or visit epilepsysociety.org.uk/recovery-position-video.

When to call an ambulance

Usually when someone has a convulsive (tonic clonic) seizure there is no need to call an ambulance. However, always call 999 for an ambulance if:

- it is the person's first seizure;
- they have injured themselves badly;
- they have trouble breathing after the seizure;
- one seizure immediately follows another with no recovery in between;
- the seizure lasts **two minutes longer** than usual for that person; or
- the seizure lasts for **five minutes** and you do not know how long their seizures usually last.

Status epilepticus or 'status'

If a seizure continues for more than five minutes and this is not usual, or one seizure follows another with no recovery in between, this is known as status epilepticus or 'status'. Status during a tonic clonic seizure is a **medical emergency** and needs urgent treatment.

Emergency medication

Children who have gone into status before 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.



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 emergency medication 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 601 438 or visit epilepsysociety.org.uk/epilepsy-training

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.

further information

Epilepsy Society information

Childhood epilepsy syndromes

Diagnosis

Emergency medication – buccal midazolam

Emergency medication – rectal diazepam

Epilepsy surgery

First aid

Just diagnosed

Ketogenic diet

Leisure

Medication for epilepsy

Photosensitive epilepsy

Safety

Seizure diary

Seizures

The recovery position

Recording seizures

Risk assessment

What is epilepsy?

Your epilepsy – now and next

**[Visit epilepsysociety.org.uk/
children-and-parents-reading-list](https://www.epilepsysociety.org.uk/children-and-parents-reading-list)**

other organisations

ACE (Advisory Centre for Education)

[ace-ed.org.uk](https://www.ace-ed.org.uk)

Independent advice and information about education issues for parents.



Contact a Family

Helpline: 0808 808 3555

cafamily.org.uk

Support and information for families of children with disabilities or medical conditions.

Equality and Human Rights Commission

Equality Advisory Support Service (EASS)

0808 800 0082

equalityhumanrights.com

Information on the Equality Act 2010.

Information Advice and Support Services Network

cyp.iassnetwork.org.uk/in-your-area

Provides information, advice and support to schools and local authorities, parents, carers, children and young people with special educational needs.

IPSEA (Independent Parental Special Education Advice)

ipsea.org.uk

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

Staying Positive Programme

0800 988 5560

03333 445 840 (if calling from a mobile)

selfmanagement.org

Free courses for young people with any long-term health condition.

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. 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.

epilepsy society

epilepsysociety.org.uk

A full life for everyone affected by epilepsy.

research

Pioneering medical research.

treatment and care

Individualised medical and care services.

information

Website, apps, leaflets, DVDs.

Call 01494 601 392.

education

Awareness, training for professionals.

connect with us



Volunteer, become a member, fundraise.

helpline 01494 601 400

Monday and Tuesday 9am to 4pm,

Wednesday 9am to 7.30pm.

Confidential, national call rate.

Information and emotional support.

Epilepsy Society

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Epilepsy Society is the working name of The National Society for Epilepsy
registered charity no. 206186