



Children

A guide for parents and teachers.

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For further information visit
epilepsysociety.org.uk/children

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01494 601 400.**

A guide for parents and teachers

Epilepsy is a neurological condition where a person has a tendency to have seizures that start in the brain.

The brain is made up of millions of 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.

Visit [epilepsysociety.org.uk/what-epilepsy](https://www.epilepsysociety.org.uk/what-epilepsy)

Epilepsy in childhood

In the UK, epilepsy affects around 60,000 children and young people under the age of 18. Epilepsy can start at any age, including in 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. Febrile seizures (convulsions), due to a sudden rise in body temperature when a young child is ill, can happen in childhood but these are not the same as epilepsy. These are not usually serious but it's important to get medical help if your child has a seizure.

Visit [nhs.uk/conditions/febrile-seizures](https://www.nhs.uk/conditions/febrile-seizures)

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 and generalised seizures. Focal seizures start in 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. However, some may be more common in childhood (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, 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.

For more detail about seizure types visit epilepsysociety.org.uk/epileptic-seizures

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.

Visit epilepsysociety.org.uk/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 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.

Visit epilepsysociety.org.uk/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-seizure medication

Most people with epilepsy take anti-seizure medication (ASM) to control their seizures. The paediatrician can discuss with you whether ASM is the best option for your child. Although ASM aims to stop seizures from starting, 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 ASM that suits them. Like all drugs, ASMs 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 ASM, 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.

[Visit epilepsysociety.org.uk/medication-epilepsy](https://www.epilepsysociety.org.uk/medication-epilepsy)

Although ASM works well for many children, this doesn't happen for every child. If ASM doesn'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 ASMs, the ketogenic diet may help to reduce the number or severity of their seizures. The diet is a medical treatment, often started alongside ASMs, and is supervised by trained medical specialists and dietitians.

[Visit epilepsysociety.org.uk/ketogenic-diet](https://www.epilepsysociety.org.uk/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.

[Visit epilepsysociety.org.uk/epilepsy-surgery](https://www.epilepsysociety.org.uk/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.

Call our helpline for a free seizure diary or visit [epilepsysociety.org.uk/seizure-diaries](https://www.epilepsysociety.org.uk/seizure-diaries)

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 and Social Care 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 ASM 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 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 ASM. If you have concerns about changes in your child's behaviour, you may want to talk to their doctor or epilepsy specialist nurse.

Sport and 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).

Visit [epilepsysociety.org.uk/safety](https://www.epilepsysociety.org.uk/safety) and [epilepsysociety.org.uk/sports-and-leisure](https://www.epilepsysociety.org.uk/sports-and-leisure)

Can epilepsy change over time?

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 ASM 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.

[Visit epilepsysociety.org.uk/young-people-and-epilepsy](https://www.epilepsysociety.org.uk/young-people-and-epilepsy) and [healthtalk.org/epilepsy-in-young-people](https://www.healthtalk.org/epilepsy-in-young-people)

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 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 cover) or visit epilepsysociety.org.uk

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

[Visit councilfordisabledchildren.org.uk](https://www.councilfordisabledchildren.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 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 children and young 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.

**[Visit epilepsysociety.org.uk/
photosensitive-epilepsy](https://www.epilepsysociety.org.uk/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/living-epilepsy/risk](https://www.epilepsysociety.org.uk/living-epilepsy/risk)

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 in the same way as the other children, as well as increasing everyone's safety in the water.

[Visit epilepsysociety.org.uk/sports-and-leisure](https://www.epilepsysociety.org.uk/sports-and-leisure)

Medication at school

Most children with epilepsy take ASM to prevent seizures (see page 7). ASMs 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 ASM 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 from the government website.

[Visit gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3](https://www.gov.uk/government/publications/supporting-pupils-at-school-with-medical-conditions--3)

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 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.

Visit epilepsysociety.org.uk/first-aid and epilepsysociety.org.uk/recovery-position

When to call an ambulance

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

- it is their 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
- you do not know how long their seizures last.

Status epilepticus or 'status'

If a seizure continues for more than five minutes, 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.

Emergency medication is a sedative and has a calming effect on the brain.

Although it is rare, it can cause breathing difficulties, so a child must be closely watched until they have fully recovered.

If a child has been prescribed 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 provides epilepsy awareness, seizure management and emergency medication training.

For more information visit [epilepsysociety.org.uk/training-courses-epilepsy](https://www.epilepsysociety.org.uk/training-courses-epilepsy)

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

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 child with epilepsy feeling that they are singled out.

Further information

ACE (Advisory Centre for Education)

ace-ed.org.uk

Independent advice and information about education issues for parents.

Contact a Family

Helpline: 0808 808 3555

contact.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

equalityadvisoryservice.com

Information on the Equality Act 2010.

IPSEA (Independent Parental Special Education Advice)

ipsea.org.uk

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

Young Epilepsy

youngepilepsy.org.uk

A charity which campaigns for children's rights, delivers health services and research that improves diagnosis and treatments. They support children and young people throughout school, college, and university and provide information, friendly advice, and practical help for living everyday life.

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epilepsy society

Helpline

01494 601 400

helpline@epilepsysociety.org.uk

Confidential, national call rate.

Information and emotional support.

Visit epilepsysociety.org.uk/helpline
for opening hours.

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