

Children with epilepsy



Epilepsy Action aims to improve the quality of life and promote the interests of people living with epilepsy.

Our work...

- We provide information to anyone with an interest in epilepsy.
- We improve the understanding of epilepsy in schools and raise educational standards.
- We work to give people with epilepsy a fair chance of finding and keeping a job.
- We raise standards of care through contact with doctors, nurses, social workers, government and other organisations.
- We promote equality of access to quality care.

Epilepsy Action has local branches in most parts of the UK. Each branch offers support to local people and raises money to help ensure our work can continue.

Your support

We hope you find this booklet helpful. As a charity, we rely on donations to provide our advice and information. If you would like to make a donation, here are some ways you can do this.

- Visit epilepsy.org.uk/donate
- Text ACT NOW to 70700 (This will cost you £5 plus your usual cost of sending a text. Epilepsy Action will receive £5.)
- Send a cheque payable to Epilepsy Action.

Did you know you can also become a member of Epilepsy Action from less than £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

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Introduction

Around one in 240 children under 16 in the UK has epilepsy. With a few sensible precautions, most will be able to do the things other children can do. However, some children have more complex epilepsy and need specialist help and support. This information will tell you about some of the issues that affect children with epilepsy, and where you can go for any help or support you need.

Epilepsy Action has more information about all the issues discussed.

About epilepsy

There are many types of epilepsy. If your child has epilepsy, it means they have a tendency to have seizures (sometimes called fits). Epilepsy can begin at any age.



About seizures

Electrical activity is happening in our brain all the time. A seizure happens when there is a sudden burst of intense electrical activity. This intense electrical activity causes a temporary disruption to the way the brain normally works, meaning that the brain's messages get muddled. The result is an epileptic seizure.

Your child's brain is responsible for all the functions of their body. What happens to them during a seizure will depend on where in their brain the seizure begins, and how widely and rapidly it spreads. For this reason, there are many different types of seizure and each child will experience epilepsy in a way that is unique to them.

Seizure classifications

There are many different types of seizure. They can be classed by where in the brain the epileptic activity starts. The International League Against Epilepsy, a world-wide organisation of epilepsy professionals, has compiled a list of the names of different seizure types. The names given to different types of seizures in this information are based on this list.

Giving seizures the right names is important for doctors, because specific drugs and treatments can help some seizure types but not others.



Focal (partial) seizures

In these seizures, the epileptic activity starts in just a part of a child's brain. They may stay alert during this type of seizure, or they may not be aware of what is happening. They may have unusual sensations or feelings. These are some examples.

- Flushing, sweating, going very pale, having a churning feeling in their stomach
- Seeing things as smaller or bigger than they really are
- Seeing or hearing something that is not actually happening
- Smelling non-existent smells
- Tasting non-existent tastes
- Feeling frightened, panicky, sad or happy
- Feeling detached from what is going on around them
- Feeling sick
- Having movements they can't control
- Chewing, smacking their lips, swallowing or scratching their head
- Fumbling with their buttons or taking their clothes off
- Having problems speaking or understanding
- Wandering off, without any awareness of what they are doing, or where they are going

Focal seizures can be very brief or last for minutes. Sometimes, focal seizures are a warning that you are going to have a tonic-clonic seizure. This is called an aura.

Generalised seizures

These seizures involve epileptic activity in both hemispheres (halves) of a child's brain. They will usually lose consciousness but this may be so brief that no-one notices. Their muscles may stiffen and/or jerk. They may fall down.

Tonic-clonic seizures

This is the most common and widely recognised generalised seizure. There are two phases to this type of seizure: the 'tonic' phase, followed by the 'clonic' phase.

The tonic phase

The child loses consciousness and, if standing, will fall to the floor. Their body goes stiff because all their muscles contract. They may also cry out because their muscles contract, forcing air out of their lungs. Their breathing patterns change, so there is less oxygen than normal in their lungs. Because of this, the blood circulating in their body is less red than usual. This causes their skin (particularly around their mouth and under their finger nails) to appear blue in colour (called 'cyanosis'). They may bite their tongue and the inside of their cheeks.

The clonic phase

After the tonic phase has passed, the clonic phase of the seizure begins. The child's limbs jerk now because their muscles tighten and relax in turn. They may occasionally lose control of their bladder and/or bowels. It is not possible to stop the seizure, and

you should not try to control their movements, as this could cause injury to their limbs.

After a tonic-clonic seizure, some people may be very confused, tired, or have memory loss. This is known as a post-ictal state, and can last from minutes to days.

Absence seizures

During an absence seizure, a child is very briefly unconscious. They appear to be daydreaming or switching off. They don't know what is happening around them, and they can't be brought out of it. Because anybody can daydream at any time, absences can be very hard to spot. Some children have hundreds of absence seizures a day, stopping them from fully taking part in daily activities. They could also miss tiny pieces of information or events. This may be mistaken for lack of attention or concentration.

Myoclonic seizures

The word myoclonic comes from 'myo' meaning muscle, and 'clonus' meaning jerk. So, if a child has a myoclonic seizure, their muscles jerk. These seizures can sometimes cause their whole body to jerk. More usually, they only cause jerking in one or both of the child's arms and sometimes their head. Although it may not be obvious, during the seizure, they are unconscious for a very brief time. Even though the seizures are brief, they can be extremely frustrating. For example, if a child is holding a drink when they have a myoclonic seizure, they are likely to spill it.

Tonic seizures

In a tonic seizure, all the child's muscles tighten. Their body stiffens and they fall over unless they are supported. Tonic seizures usually last less than 20 seconds and most often happen during sleep.

Atonic seizures (drop attacks or akinetic seizures)

In an atonic seizure, a child loses all muscle tone and drops heavily to the floor. The seizure is very brief and they are usually able to get up again straight away. They are not confused afterwards. Because they usually fall forward in an atonic seizure, they are at risk of banging their head on furniture or other hard objects. If your child has frequent atonic seizures, extra safety precautions – like protective headgear – make sense. Epilepsy Action can provide further information on this.



Febrile seizures

Febrile seizures happen to around three out of every hundred children under the age of five. They are usually linked to a childhood illness such as tonsillitis, or teething. Febrile seizures are not epilepsy. However, children who have had febrile seizures have a slightly higher chance of developing epilepsy later on than children in general.

Epilepsy syndromes

Some children have epilepsy as part of a syndrome. A syndrome is a group of signs and symptoms that, added together, suggest a particular medical condition. In epilepsy, examples of these signs and symptoms would be things like the age at which seizures begin, the type of seizures, whether the child is male or female and whether they have difficulties with learning.

If a child is diagnosed with a particular syndrome, it allows doctors to provide more information about what is most likely to happen to them in future years. This is not only from the point of view of the epilepsy, but also in relation to other features such as learning skills.

Seizures at different ages

Children can have different types of seizures, at different ages. In babies, seizures may not be obvious to an onlooker. Their seizures may show as changes in breathing patterns, or movements of their eyelids or lips. They may have bicycling movements of their legs, brief jerks or episodes of stiffening of their body and limbs. As their brain matures, older children have seizures that are more easily recognised, such as tonic-clonic seizures. Some babies and children can have several different types of seizures.

Diagnosing epilepsy

If your child has had a seizure, they will usually be seen by a paediatrician (children's doctor). To help decide whether your child has epilepsy, this doctor will ask what your child experienced before, during and after the seizure. They might ask whether you have taken a video recording of your child's seizure for them to look at. They will look at their medical history, and may arrange for them to have some of the following tests.

Electroencephalogram (EEG)

The EEG tells doctors about the electrical activity in the brain. During the EEG, a technician places harmless electrodes on the scalp, using a special glue or sticky tape. Then the electrodes are connected to the EEG machine, which records the electrical signals in the brain on a computer.

Computed tomography (CT scan)

This is a type of X-ray. It shows the structure of the brain. It doesn't show if your child has epilepsy. However, it might show an abnormality that could cause epilepsy.

Magnetic resonance imaging (MRI scan)

The MRI uses radio waves and a magnetic field, rather than X-rays. It can show if there's a structural cause for someone's epilepsy. The MRI is more powerful than the CT scanner, so it can pick up small or subtle abnormalities that the CT scanner can't find.

Not all children with epilepsy will need a CT or MRI scan.



Treating epilepsy

Epilepsy medicines

Most children with epilepsy are prescribed epilepsy medicines. The aim of treating seizures with epilepsy medicines is to control your child's seizures, so that they can get on with their life. There are many different epilepsy medicines available and your child's epilepsy specialist will recommend the best one for your child. They will make their choice by looking at your child's type of seizures, any other medical conditions they have, and your and your child's preferences.

It may take a while to find the right dose of the right medicine for your child. But once it is found, they have a very good chance of being seizure free. In fact, around seven in 10 children with epilepsy can become seizure free. Once their seizures are controlled, they will still usually need to take epilepsy medicine for a while. Sometimes, they may need to take it for many years.

Review

Your child should have a review of their epilepsy and treatment with their epilepsy specialist at least once a year. This is to make sure that they are still on the right dose of the right medicine for their epilepsy. It is also to make sure they are not having any side-effects from their epilepsy medicine.

Epilepsy surgery

Some children have seizures that are not controlled by epilepsy medicines. These children may be suitable for epilepsy brain surgery. The aim of epilepsy brain surgery is to control, or reduce, the number of seizures a child has and to improve their quality of life.

Diet

Generally, there is no specific diet for people with epilepsy to follow. However, some children with epilepsy can benefit from following the ketogenic diet.

The ketogenic diet is a high fat diet that can help to treat seizures in children with difficult to control epilepsy. One study of children with epilepsy who had been on the ketogenic diet for around 10 years, found that around seven out of 10 had fewer seizures than before.

Triggers

If your child is old enough, they might be able to recognise things that make their seizures more likely. These are called triggers. Tiredness, lack of sleep and stress are some of the more common triggers in children. A very small number of children with epilepsy have their seizures triggered by flashing or flickering lights. This is photosensitive epilepsy.

Some children say that they can avoid seizures by avoiding their triggers. But not all children have things that trigger their seizures.

NICE and moving to adult services

NICE (National Institute for Health and Care Excellence) is the independent organisation responsible for providing national guidelines on treatment and care for people using the NHS in England, Northern Ireland and Wales.

At some point during their teenage years, children with epilepsy will be transferred from children's services to adult services. This can be a big change, and NICE recommends that this is done through a transition clinic.

Some transition clinics are jointly run by adult and paediatric (children's) specialists, who will review your child's epilepsy and treatment. They should give your child any epilepsy information they need, and details of support groups that might be able to help them.



Risks of having epilepsy

Children with epilepsy are at risk of seizure related injuries. Children who have epilepsy because of another condition, or have only recently been diagnosed with epilepsy are at highest risk. This is because they are more likely to be having seizures than other children.

Every year, around 40 to 80 children in the UK die because of their epilepsy. For example, a child could have a seizure in a dangerous place. Or the seizure itself may be the cause of death. But the reasons for these deaths are not always known. Where a child with epilepsy has died suddenly, and no reason can be found, it is called sudden unexpected death in epilepsy (SUDEP).

Knowing about the risks means you can do things to keep the risks to a minimum. It's a good idea to talk to your child's doctor or epilepsy nurse about this.

Epilepsy and behaviour

Behaviour problems are common in children. This is true whether or not they have epilepsy. However, some children have behaviour problems that are related to their epilepsy or epilepsy medicine. If you are concerned about your child's behaviour, speak to their epilepsy doctor, epilepsy nurse, or health visitor, to see if they can help.



Learning and education

Many children and young people with epilepsy go to mainstream schools. And some do very well. However, some children with epilepsy don't achieve as much as they could. This may or may not be related to their epilepsy or epilepsy medicine. If you believe your child is not doing as well as they could, speak to their teacher or special educational needs co-ordinator (SENCO). They will be able to assess your child to try to find ways to help them. If they still have difficulties, you can ask for them to be assessed for special educational needs (SEN).

Special educational needs

If a child has SEN, it means they need some extra help or support to reach their full potential. There are three different SEN support frameworks for children in the UK, depending on where you live. Each of these frameworks will explain about SEN in that particular country, and will tell you what you should expect for your child.

England and Wales

Special educational needs (SEN) framework

Website: education.gov.uk

Scotland

The Education (Additional Support for Learning) Scotland Act 2009

Website: scotland.gov.uk

Northern Ireland

Code of Practice on the Identification and Assessment of Special Educational Needs and a Supplement to the Code of Practice

Website: northernireland.gov.uk

Unfair treatment and the law

If your child lives in the UK, there are equality laws that make it illegal to discriminate against them because of their epilepsy. The Equality Act covers children in England, Scotland and Wales. The Disability Discrimination Act (DDA) covers children in Northern Ireland.

The equality laws mean that anyone who provides any kind of goods or services must make sure that children with epilepsy are treated fairly.

The equality laws also mean that service providers may need to make reasonable adjustments to make sure that your child is not at a disadvantage because they have epilepsy. For example, a teacher could provide written information for them if they have missed some of their lesson because they have had a seizure.

Your child is covered by the equality laws if they have epilepsy now, or if they have had it in the past. The laws apply to them even if they take epilepsy medicines that control their seizures.

Local services

Local authorities have a duty to provide a range of services for children with epilepsy, who may have special needs. These services include the following.

- Medical care
- Day care
- Advice, information and counselling
- After school activities
- Help with transport and holidays
- Short term or respite care
- Cultural, social and leisure activities

Your family doctor, epilepsy specialist nurse, health visitor, staff at your local social services agency or local authority can advise you about these services.

Help and support for parents and carers

Coming to terms with your child's epilepsy

It's natural to feel anxious when you are told that your child has epilepsy. You may worry about how their epilepsy will affect them, and be concerned about side-effects from their epilepsy medicines. You may worry that family, friends, and neighbours will not know much about epilepsy, or how to deal with it. Finding out as much as possible about your child's epilepsy and treatment, and sharing that information with other people, could be helpful. Once they understand, they are more likely to offer you support.

Talking about your concerns

Your family doctor can give you information and advice, but is unlikely to have time for long discussions. You could ask whether there is a children's epilepsy specialist nurse attached to the epilepsy clinic. These nurses have a lot of experience of childhood epilepsy, and can offer you advice and support.

Another source of support is forum4e, Epilepsy Action's online community for people with epilepsy and their carers. You have to be 16 or over to join this forum. So, although your child may not be able to join, you could find it a real help for you, as a parent or carer.

Supporting your child with epilepsy

Some children deal with their epilepsy and seizures in a very matter of fact way. Others feel embarrassed about having seizures, particularly if they happen at school or with their friends. One of the best ways to support your child is by talking to them about their epilepsy, and finding out what their main concerns are. You could take information into school, so that staff can explain epilepsy to the other children. They can find information for themselves on Epilepsy Action's children's and teenage websites. Go to: kids.epilepsy.org.uk/education or youngpeople.epilepsy.org.uk

Further information

Epilepsy Action has more information about different aspects of epilepsy.

Other organisations

ACE Education Adviceline

For independent advice on a wide range of education issues

Tel: 0300 0115 142

Website: ace-ed.org.uk

Carers UK

Carers UK provide information, advice and support for carers

Tel: 0808 808 7777

Website: carersuk.org.uk

Contact a family

Supports the families of disabled children

Tel: 0808 808 3555

Website: cafamily.org.uk

Disabled Living Foundation

DLF can provide information about bed alarms, safety helmets and other equipment your child might need

Tel: 020 7289 6111

Website: dlf.org.uk

Independent Panel for Special Education Advice (IPSEA)

Offers free and independent advice on Local Authorities' legal duties to assess and provide for children with special educational needs

Tel: 0800 018 4016

Website: ipsea.org.uk

Local services

The following organisations can tell you more about services in your area.

England and Wales – your local Social Services office

Northern Ireland – Department of Health, Social Services and Public Safety

Scotland – your local Social Work Department

All of UK – your local Citizens Advice Service:

Tel: 0207 833 2181 (for details of your local branch)

Website: adviceguide.org.uk

Mencap

Supports people with a learning disability to live their lives as they choose

Tel: 0808 808 1111

Website: mencap.org.uk

NHS Choices

NHS Choices is the online 'front door' to the NHS. It is the country's biggest health website and gives all the information you need to make choices about your health

Website: nhs.uk

About this publication

This booklet is written by Epilepsy Action's advice and information team, with guidance and input from people living with epilepsy, and medical experts. If you would like to know where our information is from, or there is anything you would like to say about the booklet, please contact us.

Epilepsy Action makes every effort to ensure the accuracy of information in its publications but cannot be held liable for any actions taken based on this information.

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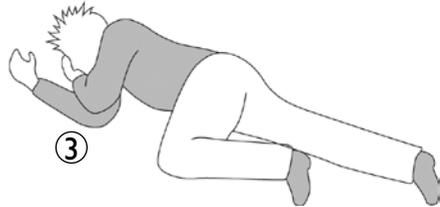
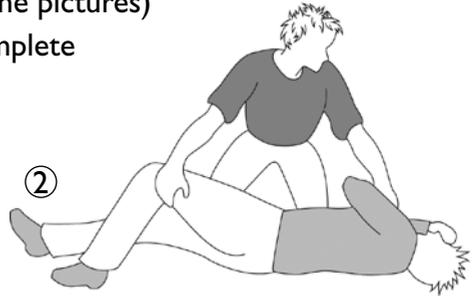
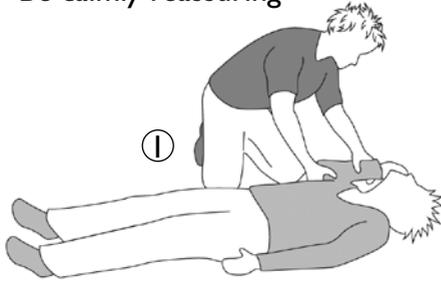
Epilepsy Action would like to thank Bernie Concannon, paediatric specialist nurse in epilepsy, Birmingham Children's Hospital for her contribution. Bernie Concannon has declared no conflict of interest.

First aid for tonic-clonic seizures

The person goes stiff, loses consciousness and falls to the floor.

Do...

- Protect the person from injury (remove harmful objects from nearby)
- Cushion their head
- Aid breathing by gently placing the person in the recovery position when the seizure has finished (see the pictures)
- Stay with them until recovery is complete
- Be calmly reassuring



Don't...

- Restrain the person's movements
- Put anything in their mouth
- Try to move them unless they are in danger
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call 999 for an ambulance if...

- You know it is the person's first seizure
- The seizure continues for more than five minutes
- One seizure follows another without the person regaining consciousness between seizures
- The person is injured
- You believe the person needs urgent medical attention

First aid for focal (partial) seizures

The person may not be aware of their surroundings or of what they are doing. They may pluck at their clothes, smack their lips, swallow repeatedly or wander around.

Do...

- Guide the person away from danger
- Stay with the person until recovery is complete
- Be calmly reassuring
- Explain anything that they may have missed

Don't...

- Restrain the person
- Act in a way that could frighten them, such as making abrupt movements or shouting at them
- Assume the person is aware of what is happening, or what has happened
- Give them anything to eat or drink until they are fully recovered
- Attempt to bring them round

Call 999 for an ambulance if...

- You know it is the person's first seizure
- The seizure continues for more than five minutes
- The person is injured
- You believe the person needs urgent medical attention

Further information

If you have any questions about epilepsy, please contact the Epilepsy Helpline.

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, e-books, fact sheets, posters, books and DVDs.

Information is also available in large text.

Please contact Epilepsy Action to request your free information catalogue. Or download a copy at epilepsy.org.uk/catalogue

Epilepsy Action's support services

Local meetings: a number of local branches offer support across England, Northern Ireland and Wales.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy. For people aged 16 years or over. Join at forum.epilepsy.org.uk

Epilepsy awareness: Epilepsy Action has a number of trained volunteers who deliver epilepsy awareness sessions to any organisation that would like to learn more about epilepsy. The volunteers are able to offer a comprehensive introduction to epilepsy to a range of audiences.

If you would like more information about any of these services, please contact Epilepsy Action. Contact details are at the back of this booklet.

Children with epilepsy

We would like to know if this booklet has been helpful to you.

As a result of reading the information, please let us know if you agree with any of the following statements. Tick any boxes that apply to you.

- I feel more informed about issues surrounding epilepsy.
- I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse.
- I feel more confident about talking about my epilepsy with other people.
- I have talked to my employer/colleague/teacher/family and they have improved how well they support me.
- I have used other Epilepsy Action services, such as the website, the Epilepsy Helpline, support groups or online community (forum4e).
- I have used other support services mentioned in the booklet, and found them helpful.

Please tell us how you think we can improve this information

Please return the completed form to:

Epilepsy Services, Epilepsy Action, FREEPOST LS0995, Leeds LS19 7YY

If you would prefer to tell us over the telephone, please contact the Epilepsy Helpline, freephone 0808 800 5050.

Thank you!

Epilepsy Action
FREEPOST LS0995
LEEDS
LS19 7YY

Registered charity in England (No. 234343)

How to contact the Epilepsy Helpline

Telephone the Epilepsy Helpline freephone **0808 800 5050**

Monday to Thursday 9.00 am to 4.30 pm Friday 9.00 am to 4.00 pm

Our helpline staff are Text Relay trained

Write to us free of charge at

FREEPOST LS0995, Leeds LS19 7YY

Email us at helpline@epilepsy.org.uk or visit our website:

epilepsy.org.uk Text your enquiry to **0753 741 0044**

Send a Tweet to [@epilepsyadvice](https://twitter.com/epilepsyadvice)

About the Epilepsy Helpline

The helpline is able to offer advice and information in 150 languages.

We provide confidential advice and information to anyone living with epilepsy but we will not tell them what to do. We can give general medical information but cannot offer a medical diagnosis or suggest treatment. We can give general information on legal and welfare benefit issues specifically related to epilepsy. We cannot, however, take up people's cases on their behalf.

Our staff are trained advisers with an extensive knowledge of epilepsy related issues. Where we cannot help directly, we will do our best to provide contact details of another service or organisation better able to help with the query. In doing this, Epilepsy Action is not making a recommendation.

We welcome comments, both positive and negative, about our services.

To ensure the quality of our services we may monitor calls to the helpline.

Epilepsy Helpline:

freephone 0800 800 5050

epilepsy.org.uk



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 <p>The Information Standard</p> <p>Certified member</p>	<p>This organisation has been certified as a producer of reliable health and social care information.</p> <p>www.theinformationstandard.org</p>
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Environmental statement

All Epilepsy Action booklets are printed on environmentally friendly, low-chlorine bleached paper. All paper used to make this booklet is from well-managed forests.