

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 as little as £1 a month? To find out more, visit epilepsy.org.uk/join or call 0113 210 8800.

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Introduction

In the UK, around one in every 240 children under the age of 16 will be diagnosed with epilepsy. Some of them will be babies, and some will be teenagers, with many others in between. And some children will have epilepsy as well as other conditions, including an epilepsy syndrome, learning disabilities, or an autistic spectrum disorder.

If a child has an epilepsy syndrome it means that they have a group of signs and symptoms that, added together, suggest a particular medical condition. In epilepsy syndromes, examples of these signs and symptoms are things like:

- The age the seizures began
- Their types of seizure
- Whether the child is male or female
- Whether they have learning difficulties

There are many epilepsy syndromes, and new ones are being identified all the time.

If you are caring for a child with epilepsy, this information is for you.

Your child has been diagnosed with epilepsy

This can be a confusing time. You might be shocked to hear that your child has a condition called epilepsy, or you might be relieved to be told that what has been happening now has a name. But what exactly does epilepsy mean? It means that a child has had at least one seizure and is at risk of having more. And although some children will have epilepsy for life, other children will grow out of it.

What are seizures?

Electrical activity is happening in our brain all the time. A seizure happens when there is a sudden burst of intense electrical activity in the brain. This is often called epileptic activity. The epileptic activity causes a brief disruption to the way the brain normally works, so the brain's messages become mixed up. The result is an epileptic seizure.

Different types of seizure

There are many different types of seizure. They are classified by where in the brain the epileptic activity starts. Some seizures affect just a part of the brain: these are called focal or partial seizures. And some seizures affect the whole of the brain: these are called generalised seizures.

Some types of focal seizure that affect children:

- Temporal lobe seizures
- Frontal lobe seizures
- Occipital lobe seizures
- Parietal lobe seizures

Some types of generalised seizure that affect children:

- Tonic-clonic seizures
- Absence seizures
- Myoclonic seizures
- Tonic seizures
- Atonic seizures (drop attacks)

Getting the name right

It's important to find out the right name for your child's seizures or syndrome, so that you can explain their epilepsy to people who might look after them. There's information on the Epilepsy Action website about different types of seizure.

Go to: epilepsy.org.uk/info/seizures-explained

Febrile seizures

Febrile seizures are not epilepsy; they are seizures that are caused by a high temperature. This is often during a childhood illness such as tonsillitis. They happen to around three in 100 children under the age of five. If your child has had febrile seizures, they have a slightly higher chance of developing epilepsy later on than children in general.

How is epilepsy treated?

Epilepsy medicines

You have probably already talked with your child's doctors about how their seizures should be treated. The most common way is with epilepsy medicines. These are introduced slowly, and gradually increased until they get to the right level. They are taken every day.

Daily epilepsy medicines

It can be worrying when you are told your child needs to take epilepsy medicines every day, sometimes for several years. And some parents, when they see the list of possible side-effects would rather their child didn't take them. But for most children, the benefits of taking epilepsy medicines are greater than the possible side-effects from the medicine. This is because some seizures can be unpleasant and can cause injury. And some children feel embarrassed about having seizures, especially in front of their friends, so prefer to try the medicines instead.

There is a range of different epilepsy medicines available to treat children. The one your child is given will depend on:

- Their age and sex
- The types of seizure or syndrome they have
- Whether they have any other medical conditions

Sometimes, if one epilepsy medicine doesn't control a child's seizures, another might be added. Or the first medicine may be

swapped over to a different one. This will take some time to do. But with the right dose of the right medicine, around seven in every 10 people with epilepsy can have their seizures controlled.

Epilepsy medicines for seizures that last a long time

Many children have seizures that last for less than five minutes and stop without any treatment. But some children have seizures that last longer than five minutes. Seizures that last longer than 30 minutes or a cluster of shorter seizures that last for 30 minutes or more can cause damage to the brain, or even death. In both cases, this is known as status epilepticus. Seizures lasting for more than five minutes need treating before they turn into status epilepticus.



The two most commonly used medicines to prevent status epilepticus are midazolam and diazepam. Midazolam is given by a dropper, inside the child's cheek or nose. This can be given by anyone who has been trained to do it, as well as healthcare professionals. If diazepam is given by a healthcare professional, they will usually give it by injection. But it can be given by non-healthcare professionals with the right training. In this instance it will usually be given rectally (into the back passage).

If your child has been prescribed emergency medicines to stop their seizures, the doctor who prescribes the drug should write a care plan. This will show exactly when and how much emergency medicine needs to be given.

For first aid information, including when to call an ambulance see page 26.

Treatment review

To make sure your child is still on the best treatment for their epilepsy, they should have a review of their epilepsy and treatment at least once a year. This is particularly important when being transferred from children's to adult services, as their treatment may be different from when they were younger.

Other ways of treating epilepsy

In the UK, if your child's epilepsy is difficult to control, they may be considered for epilepsy brain surgery. This is done by very specialist surgeons at one of four Children's Epilepsy Surgery

Service (CESS) centres. Before surgery is considered, your child will have to go through a very thorough assessment. And only once it has been decided that surgery could reduce, or stop their seizures, without causing any other problems, would it become an option.

You can see a film about children who have had epilepsy surgery: epilepsy.org.uk/info/treatment/epilepsy-surgery/children

If surgery isn't possible for your child, the doctor may discuss the possibility of vagus nerve stimulation (VNS) or the ketogenic diet.

VNS therapy involves a small electrical device, like a pacemaker, which is implanted under the skin of your child's chest. The device sends electrical impulses to their brain through a nerve in their neck called the vagus nerve. The aim is to reduce the number of seizures they have and make them less severe.

The ketogenic or modified diets are higher in fats and lower in carbohydrates than a typical diet. If none of the other treatment has stopped or reduced your child's seizures, they may be offered a trial of one of these diets.

George has an epilepsy syndrome and uses the ketogenic diet. To see his story go to: epilepsy.org.uk/involved/campaigns/seize-control/our-stories/George



Risks of having epilepsy

Telling other people about your child's epilepsy

For your child's safety, it's important to tell anyone who will be caring for them about their epilepsy and seizures. Depending on their age, you might need to talk to their childminder, teacher, out of school activity leaders, and other members of your family.

When talking to other people, it's important to be as honest and open as you can about what happens before, during, and after your child's seizures. To help you with this, you could write up an epilepsy care plan with your child's doctor or epilepsy nurse. Information in the care plan will tell people what they need to do to keep your child safe. It will also give information about the medicines they take, and who to contact in an emergency.

Contact Epilepsy Action for a copy of a care plan.

For an online learning pack about different types of seizure in school go to: epilepsy.org.uk/learn

Seizure-related injuries

"My sister has epilepsy and we have to think about her before we can go anywhere. I know it's to keep her safe, but it's hard on me and my brother too."

Sam

If your child is still having seizures, they may be at risk of being injured during a seizure. This is more likely if they have learning disabilities or their epilepsy is part of another condition.

Although it's not possible to prevent all their injuries, there are safety precautions you could try, to keep your child as safe as possible.

[Epilepsy Action has information about being safe when you have epilepsy.](#)

SUDEP

Every year, around 40 – 80 children in the UK die because of their epilepsy. Some children die because they have a seizure in a dangerous place. Or the seizure itself could have caused their death. But, for some children who die, no cause can be found. When a child with epilepsy dies suddenly, and no reason can be found, it is called sudden unexpected death in epilepsy (SUDEP).

The good thing is that knowing about the risks means you can do things to keep these to a minimum. It's worth talking to your child's doctor or epilepsy nurse about any risks for your child.



Learning, behaviour and epilepsy

Learning

Some children and young people with epilepsy don't achieve as much as they could. This is because they have some learning difficulties that might, or might not, be directly related to their epilepsy. Several studies have found that these learning difficulties mainly affect a child's reading, writing, and maths. In some children, their spelling or comprehension work is also affected.

It's important that your child's teachers know about their epilepsy, to make sure they are assessed and receive all the help they need.

Behaviour and epilepsy

All children have times when they don't behave as we want them to. They might have temper tantrums, be aggressive or damage things. With some help from the adults in their lives, most children will learn to behave better in time. But sometimes, a child's difficult or unusual behaviour is related to their epilepsy or epilepsy medicines.

If you suspect your child has behaviour problems, their epilepsy specialist or school should be able to offer them extra support.

Related conditions

A recent study of school children in West Sussex who were still having seizures showed that six out of 10 of them had some symptoms of at least one of the following conditions:

- Attention deficit hyperactivity disorder (ADHD)
- Autism spectrum disorder (ASD)
- Developmental co-ordination disorder (DCD)
- Depression or anxiety

Only two in 10 of these children had been formally diagnosed with one of these conditions, so were not getting the services they needed. If you believe your child might be affected, speak to their school, and their doctor or epilepsy nurse. They should be able to assess your child and provide any services they need.



Unfair treatment and the law

In the UK, there are equality laws that make it illegal to discriminate against people with epilepsy. The Equality Act protects children in England, Scotland and Wales. The Disability Discrimination Act (DDA) protects children in Northern Ireland.

The equality laws state that anyone who provides goods or services must make sure that children with epilepsy are treated fairly. And service providers may need to make reasonable adjustments so that your child is not disadvantaged because they have epilepsy. A reasonable adjustment would be their teacher providing written information for them if a seizure has caused them to miss part of a lesson.

Your child is likely to be protected by the equality laws if they have epilepsy now, or have had in the past. The laws apply to them if:

- They have epilepsy that has a substantial effect on their day-to-day activities **or**
- Their epilepsy would have a substantial effect if they were not taking their epilepsy medicine **or**
- They have a type of epilepsy that is not currently causing any problems or needs epilepsy medicine, but could come back **or**
- Their epilepsy has lasted, or is expected to last, for at least 12 months

Local services

Some children with epilepsy have more needs than other children. The local authorities in the different countries of the UK have a duty to provide a range of services for children in need. These are likely to include:

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

If your child has more needs than other children, speak to your family doctor, epilepsy specialist nurse, health visitor, or staff at your local social services agency, or local authority. They can tell you more about these services.



Help and support for parents and carers

It's natural to have concerns when you are told your child has epilepsy. You might worry about how their epilepsy will affect them, or be concerned about side-effects from their epilepsy medicines. You might worry that family, friends and neighbours will not know much about epilepsy, or how to deal with it. Finding out as much information as possible about your child's epilepsy and treatment, and sharing it 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 about your child's epilepsy, but probably won't have the time for long discussions. If there is an epilepsy specialist nurse attached to your child's epilepsy clinic, they should be able to offer you advice and support. Otherwise, you could speak with an adviser at Epilepsy Action.



Supporting your child with epilepsy

“It was a shock being told I had epilepsy. And it made me scared to go out with my friends. Jasmine”

Some children deal with their epilepsy and seizures in a very matter-of-fact way. Others feel embarrassed about having seizures, especially if they happen at school, or with their friends. You can support them by talking to them about their concerns. You could take information into school, so that staff can explain epilepsy to the other children.

Some children have triggers for their seizures. These can be things like late nights, tiredness, not eating well, stress or being unwell. In some children, avoiding triggers can reduce their number of seizures. You could work with your child to see if they can identify any triggers, and help them to decide how to avoid them.

If your child wants to find their own information, they can look on Epilepsy Action’s children’s and teenage websites. Go to: kids.epilepsy.org.uk or youngpeople.epilepsy.org.uk

Supporting brothers and sisters (siblings)

Having epilepsy in the family affects everyone, not just the child with seizures. Some brothers and sisters of children with epilepsy need more information about what is happening to their sibling. They may feel anxious about seeing a seizure, or not really understand what is going on. Epilepsy Action has some information that might help them. Go to: epilepsy.org.uk/sister or epilepsy.org.uk/brother



Sources of further information

ACE Education Adviceline

Ace offers 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

Citizens Advice

Citizens Advice provides advice to everyone on their rights and responsibilities. Check the website or your local phonebook for details of your nearest Citizens Advice service.

Telephone advice in England: 03444 111 444

Telephone advice in Weales: 03444 77 20 20

Website: citizensadviceguide.org.uk

Contact a family

Contact a family supports families with disabled children.

Tel: 0808 808 3555

Website: cafamily.org.uk

Disabled Living Foundation

The Disabled Living Foundation provides information about suppliers of specialist equipment to help with everyday living. Their website is called Living made Easy.

Tel: 0300 999 0004

Website: livingmadeeasy.org.uk/children

Dyspraxia Foundation

The Dyspraxia Foundation offer support and advice to about living with development coordination disorder.

Tel: 01462 454986

Website: dyspraxiafoundation.org.uk

IASS Network

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

Website: iasnetwork.org.uk

Independent Panel for Special Education Advice (IPSEA)

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: contact your local Social Services office
- Northern Ireland: contact Department of Health, Social Services or Public Safety department
- Scotland: contact your local Social Work department

Mencap

Mencap supports people with a learning disability to live their lives as they choose.

Tel: 0808 808 1111

Website: mencap.org.uk

National Autistic Society

The National Autistic Society offers impartial, confidential advice and support on autism for anyone affected by, or researching autism.

Tel: 0808 800 4104

Website: autism.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

YoungMinds

YoungMinds is committed to improving the emotional wellbeing and mental health of children and young people.

Tel: 0808 802 5544

Website: youngminds.org.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 this booklet, please contact us.

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Dr Amanada Freeman has no conflict of interest to declare.

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 on their side (in the recovery position) when the seizure has finished (see picture)
- 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 **or**
- The seizure continues for more than five minutes **or**
- One seizure follows another without the person regaining consciousness between seizures **or**
- The person is injured **or**
- You believe the person needs urgent medical attention

First aid for focal (partial) seizures

The person is not 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 **or**
- The seizure continues for more than five minutes **or**
- The person is injured **or**
- You believe the person needs urgent medical attention

Further information

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

Epilepsy Action has a wide range of publications about many different aspects of epilepsy. Information is available in the following formats: booklets, fact sheets, posters, books and DVDs. Information is also available online at epilepsy.org.uk/info

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.

Coffee and chat groups: these give people living with epilepsy the chance to meet new people, share experiences and learn more about life with epilepsy.

forum4e: our online community is for people with epilepsy and carers of people with epilepsy 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 you have found this booklet helpful.

As a result of reading the information, please let us know if you agree (tick yes) or disagree (tick no) with any of the following statements.

Yes	No	
		I feel more informed about issues to do with epilepsy
		I feel more confident about talking to my GP/epilepsy specialist/epilepsy nurse/other (cross out those that don't apply)
		I have talked to my employer/colleague/teacher/family/ other (cross out those that don't apply) and they have improved how well they support me
		I have used other Epilepsy Action services, such as the website, the Epilepsy Action Helpline, support groups or forum4e

Please tell us how you think we can improve this information

Please return the completed form to:

**FREEPOST RTGS-LEYK-XGCK, Epilepsy Services, Epilepsy Action,
New Anstey House, Gate Way Drive, Yeadon, Leeds LS19 7XY**

You can also give us feedback online. Visit epilepsy.org.uk/feedback

Thank you.

epilepsy *action*

**FREEPOST RTGS-LEYK-XGCK,
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Registered charity in England (No. 234343)

Ways to contact the Epilepsy Action Helpline



freephone 0808 800 5050

We are usually open 8.30am to 5.30pm, Monday to Friday. Our helpline staff are Text Relay trained and we are able to offer advice and information in 150 languages. To ensure the quality of our service, we may monitor calls.



helpline@epilepsy.org.uk

Email us your question about epilepsy. We aim to reply within 48 hours (on work days)



0753 741 0044

Text us and we aim to send a text reply back to your phone within 24 hours (on work days)



@epilepsyadvice

Tweet us with your question and we will tweet back (on work days)



New Anstey House, GateWay Drive, Yeadon, Leeds, LS19 7XY

Write to us and we aim to reply within seven working days

About the Epilepsy Action Helpline

We do:

- Provide confidential advice and information about epilepsy to anyone
- Give general medical information
- Give general information on legal and welfare benefit issues related to epilepsy

We do not:

- Tell people what to do
- Offer a medical diagnosis or suggest treatment
- Take up people's legal cases on their behalf

If we cannot help you directly with a query, we will do our best to provide details of other organisations that may be able to help. In doing this, Epilepsy Action is not making a recommendation.

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

Epilepsy Action Helpline:

freephone 0808 800 5050
epilepsy.org.uk



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