

**EPILEPSY  
ACTION**

# **YOUR CHILD AND EPILEPSY**





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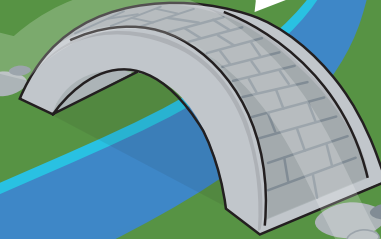
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## The first seizure

Watching your child have a seizure can be a difficult experience. But you are not alone.

We are Epilepsy Action, and we're here for everyone who is affected by epilepsy.

This booklet is for anyone who cares for a child with epilepsy. It contains basic information about epilepsy. It also has useful tips from other parents and carers about adjusting to life with the condition.

You can find much more information about epilepsy on our website at [epilepsy.org.uk](http://epilepsy.org.uk)

If you would like to speak to one of our friendly, trained advisers, call **0808 800 5050**.



**I know how scary it is, and honestly it is very hard for other people to truly understand unless they have been through it themselves.**

**But please remember, you are not alone, the amazing supportive team at Epilepsy Action will always be with you every step of the way.**

### What is epilepsy?

Epilepsy is a condition that affects the brain and causes seizures. If your child has been diagnosed with epilepsy, it means they have had at least one seizure and are likely to have more.

Epilepsy can affect anyone at any age, but it is most often diagnosed in children or older people.

There are about 1 in 230 children and young people with epilepsy in the UK. This means there is a large community of families affected by epilepsy.

### What causes epilepsy?

Epilepsy can be caused by many different things that affect the brain.

For some children, epilepsy might begin after they have had a brain injury or an infection.

For others, it could have a genetic cause or may be caused by other health conditions.



For about **1 in 2 people** with epilepsy (around 50%), there is no clear cause.

### What are seizures?

A seizure happens when there is a sudden, intense burst of electrical activity in the brain. Messages in the brain become mixed up for a short time. This can cause changes to how our body moves, or how we think and feel.

Seizures can last from a few seconds to minutes. After a while, the seizure stops and the brain and body recover.

### Types of seizure

There are lots of different types of seizures. Some common types include:

- Tonic-clonic seizures
- Focal seizures
- Absence seizures
- Atonic seizures
- Tonic seizures

Each type of seizure affects people differently. A person having a seizure may or may not be aware and able to respond. It depends on the type of seizure.

Over time you will build up an awareness of what your child's epilepsy looks like, and how long their seizures tend to last.

### Filming your child's seizure

Filming a seizure can feel uncomfortable. But these videos often give doctors important information about the type of epilepsy your child may have.

Tips for filming a seizure:

- Capture as much detail as you can. Include your child's face, if possible
- Talk gently to your child during the seizure. This can help to show whether your child is aware and able to respond
- Choose someone in advance to be the designated filmer. This can help to avoid confusion in the moment
- Store the video safely on your phone or a memory stick so it's easy to share at appointments without needing Wi-Fi



Seizure first aid



Seizure types

Find seizure first aid at:  
[epilepsy.org.uk/firstaid](http://epilepsy.org.uk/firstaid)

Find out more about different seizures:  
[epilepsy.org.uk/seizures](http://epilepsy.org.uk/seizures)

## How to talk about epilepsy with children

It can be hard to explain epilepsy in a way that children understand.

Some children may find their own ways to explain their seizures or how they feel. You could use those words too.



**Use your child's language if they have their own words to describe what happens during a seizure.**

**Check they understand exactly what people mean when they say things like 'look out for side effects'.**

We have lots of free resources online to help you talk to your child about epilepsy.

These include free books you can order or download, videos, and animations.

**Visit:** [epilepsy.org.uk/kids](http://epilepsy.org.uk/kids)



Free resources

## What happens next?

You might have lots of questions right now:

### “Will my child stop having seizures?”

This can depend on the type of epilepsy your child has. Epilepsy can often be a lifelong condition. But many children's seizures are well controlled with the right treatment.

Overall, epilepsy medicines will completely control seizures for around 2 in 3 children.

Some children will also naturally stop having seizures as they grow older.

### “Will my child be able to stop taking epilepsy medicines?”

Some children may be able to gradually stop taking epilepsy medicines if they have been seizure free for at least 2 years.

But this depends on individual circumstances and when is the right time for your child. Your epilepsy specialist will be able to give you more information.

## Looking after you

An epilepsy diagnosis for your child can take time to come to terms with. Lots of people find it helpful to talk to others – for support, advice or just a listening ear.

Whatever you need, we can help. Call our friendly team who will tailor support for you.

### Support for you

For advice and information, or just a friendly chat, we're here to help:

**Freephone:** 0808 800 5050

**Email:** [helpline@epilepsy.org.uk](mailto:helpline@epilepsy.org.uk)

**Visit:** [epilepsy.org.uk/helpline](http://epilepsy.org.uk/helpline)

**Live chat:** Visit [epilepsy.org.uk](http://epilepsy.org.uk) to chat to a member of the team.

### Don't want to talk to anyone right now but still want epilepsy information?

Our free online course for parents and carers of children with epilepsy is designed to be completed at your own pace.

It is packed with info, advice and tips: [training.epilepsy.org.uk](http://training.epilepsy.org.uk)



**It won't be quick, but you are going to come through.**

**Something like this happens and all of a sudden you realise there are other people like you.**

## Diagnosis & treatment

Getting a diagnosis can sometimes take a long time.

### Tests and scans

Here are some different tests your child might need. It may help to explain to your child what will happen to reassure them.

**EEG test:** This test uses small sticky wires placed on your child's head. A computer then records the electrical activity in their brain.

Sometimes the EEG test includes things that might trigger a seizure, like blowing on a windmill or looking at flashing lights. The team will discuss with you what they plan to do before the test.



**After some investigations, my son had a series of generalised seizures which quickly lead to the diagnosis.**

**I remember things moving so fast after this, that I was really struggling to process the vast amounts of information we were given.**

**In time we became glad that we finally knew what was happening and our ongoing concerns had been verified.**

**Magnetic resonance imaging (MRI) or computed tomography (CT) scans:** These scans can help doctors look at the structure of the brain. They do not hurt, but MRI scans can be very noisy. You need to lay very still during the scan to get a clear picture. Some children may be given a medicine to help them relax and lay still.

Other tests like **blood tests** and **genetic tests** can help doctors understand more about your child's epilepsy, and how to treat it.

You can find child-friendly information and videos explaining EEGs at: [epilepsy.org.uk/eeg](http://epilepsy.org.uk/eeg)



**Treatments and tests can all seem to proceed very slowly, and it can be frustrating.**

**But we have seen that sometimes, going slowly can help learn more about your child's seizures. It can also be important for getting medication doses at the right level.**



EEG  
information



**EEG test:** This test tells doctors about electrical activity in the brain. It helps them find out more about your child's seizures. EEG stands for electroencephalogram.

## How is epilepsy treated?

### Epilepsy medicines

Many children's seizures are well controlled with epilepsy medicines. These are also called anti-seizure medications, or ASMs.

It can take some time to find the right medicine. Your child may need to try more than one together to find the right combination.

Parents tell us they develop different methods to stick to a medication routine.

Some use pillboxes, while others set alarms on phones or smart speakers.

### Side effects

Like all medicines, epilepsy medicines can cause side effects for some people. Others don't experience any side effects at all.

Common side effects of epilepsy medicines:

- Tiredness
- Dizziness

- Feeling sick
- Mood and behaviour changes, such as feeling anxious or irritable
- Feeling foggy, or 'slowed down'
- Memory problems
- Weight changes

Many side effects are mild and improve over time. Some may last for longer.

Epilepsy medicines help to control seizures. They do not cure epilepsy. If your child stops taking their epilepsy medicine, their seizures might come back.

**Do not stop taking epilepsy medicines without speaking to a doctor first.**

Talk to your child's doctor or epilepsy nurse if they have side effects that are hard to manage.

They might be able to make changes to the medicines that can help. Perhaps by changing dose, or timings.

## "My child is very young. How can I help them take their epilepsy medicines?"

It is sometimes possible to crush tablets in yoghurt, honey, or mashed potato, or give medicine in orange juice. Your doctor, pharmacist, or epilepsy nurse can tell you what to do.



The Medicines for Children website also has lots of information about epilepsy medicines.

It explains things like how to give them, and what to do if your child vomits soon after taking the medicine.

[medicinesforchildren.org.uk](http://medicinesforchildren.org.uk)

## "Is my child's behaviour linked to their epilepsy, their medicine, or just their developmental stage?"

It can be difficult to know, especially if your child is very young. It might help to keep a diary of anything you are concerned about. You can use it to track any patterns and discuss this with the epilepsy specialist.



**I would definitely recommend writing down anything you think doesn't seem quite right.**

**And try and film as much as you can, so when you see the doctor you are well prepared. This always helps me.**

## Epilepsy syndromes

An epilepsy syndrome is a group of signs and symptoms that tend to happen together. This can include some types of seizures.



Around **1 in 2 children** and young people with epilepsy will be diagnosed with an epilepsy syndrome.



Epilepsy syndromes

If your child is diagnosed with an epilepsy syndrome, it can give important information about their condition. It also means doctors will have a better idea of the best way to treat the epilepsy.

We have more detailed information about epilepsy syndromes:

[epilepsy.org.uk/syndromes](http://epilepsy.org.uk/syndromes)

## Other epilepsy treatments

Some children still have seizures even when taking epilepsy medicine.

If this happens, your child may be referred to a more specialist centre to investigate different treatment options:

### New medicine options

Finding out more about your child's epilepsy can give new insights into the most effective medicines for them.

### Epilepsy brain surgery

Surgery can reduce or completely stop seizures.

### Vagus nerve stimulation

This is when a device is placed under the skin. It can help to reduce seizures alongside epilepsy medicines.

### Ketogenic diet

A special medical diet that can reduce seizures for some children.

### Rescue medicine and status epilepticus

Some children may be at risk of status epilepticus. This is when a seizure goes on too long, or one seizure directly follows another.

Your child may be prescribed a rescue medicine if they are at risk of status epilepticus. This is also called emergency medicine.

The rescue medicine is given during a long seizure to try to stop it.

If your child is prescribed a rescue medicine, then anyone who cares for your child will need to be trained to administer it. This includes someone at your child's school or nursery.

Your child's epilepsy nurse or doctor can advise you on who can give this training. The school nurse, or an epilepsy nurse can sometimes do it.

We also have a list of training providers online:

[epilepsy.org.uk/status-epilepticus](https://epilepsy.org.uk/status-epilepticus)

The Children's Epilepsy Surgery Service (CESS) is a specialist NHS service. It helps children access epilepsy brain surgery and other non-drug treatments. Your doctor can tell you if your child can be referred. [epilepsy.org.uk/cess](https://epilepsy.org.uk/cess)



## Adjusting as a family

Epilepsy can mean big changes for the whole family. But families with epilepsy tell us that over time, things do get better.



**I think I began to adapt to life with seizures once I had a better understanding of them, how many different types there are, how they presented and what to do when my child had them.**

**Researching and contacting Epilepsy Action for support made a big difference! I also realised that with the right support the children could still enjoy playing with friends and doing many things they enjoyed.**

### Supporting your child

Every child's needs are different. Your child might find it difficult to come to terms with epilepsy, which is natural.

Feelings of anger, anxiety and sadness are all normal. Especially when going through big changes like this.

With younger children these feelings might appear as physical symptoms. Like tummy aches, or changes in behaviour.

Find helpful info and videos about epilepsy and anxiety at: [epilepsy.org.uk/anxiety](https://www.epilepsy.org.uk/anxiety)

But your child may need some extra help if their feelings or worries are starting to affect their daily life.

Ask your child's doctor or epilepsy nurse if you are worried about how your child is coping. A key aim of epilepsy care is to help with your child's mental health and wellbeing, and they should be able to help.

### Supporting siblings

Siblings may need help to come to terms with their brother or sister's epilepsy too.

We have a webpage just for siblings of children with epilepsy. It has stories from other children, and answers to questions that siblings may want to ask.

My brother or sister has epilepsy: [epilepsy.org.uk/siblings-support](https://www.epilepsy.org.uk/siblings-support)

Staying as calm as you can when your child has a seizure can help siblings to stay calm too.

Some parents tell us that giving a sibling a specific role during a seizure can help them to cope and feel included. It could be to get your phone so you can time the seizure. Or maybe just to go and watch TV.

### Managing seizure triggers

Seizure triggers are things that make seizures more likely in people with epilepsy.

Understanding any triggers which may affect your child can help to manage their epilepsy.

#### Common seizure triggers

Some common seizure triggers include:

- Tiredness
- Missing a dose of epilepsy medicine
- Stress
- Illness
- Hormonal changes
- Drugs and alcohol

Flashing lights or strong patterns can be a seizure trigger for 3 to 5 in 100 people with epilepsy (3-5%).

It can take a while to figure out different triggers. Some children may not have any noticeable triggers.

Keeping a seizure diary can help you understand possible seizure triggers. You can use it to record when and where your child has seizures.

Download a free seizure diary: [epilepsy.org.uk/diary](https://www.epilepsy.org.uk/diary)



**I guess the sleep thing can affect the whole family because it has to be a priority. That can be hard for any siblings.**

### Practicing daily habits

You cannot control whether your child has a seizure. But as time goes on you will learn ways to help manage them.

Things that have helped other families manage seizures include:

- Taking epilepsy medicines exactly as prescribed
- Practicing healthy sleep, eating and exercise habits
- Managing possible seizure triggers
- Remembering that these things may not always work, and you are doing the best that you can



Free seizure diary



My brother or sister has epilepsy

## Understanding SUDEP

SUDEP stands for sudden unexpected death in epilepsy. This is when someone with epilepsy dies unexpectedly, and there is no clear reason why.

SUDEP affects around 1 in 1000 people with epilepsy every year. Each person's risk is different. For many people, the risk is very low.

These things might increase the risk of SUDEP:

- Missing doses of epilepsy medicine – this can increase the risk of having a seizure
- Having uncontrolled tonic-clonic seizures
- Having seizures at night

## Find out about risk factors

Not every child with epilepsy will have a significant risk of SUDEP. But knowing about it can help to keep your child safe. Ask the doctor about SUDEP, and what you can do to help reduce any risks.

Risks can change as your child grows older. Keep having these conversations and include your child as they learn to manage their own condition.

## Using safety equipment

Some parents and carers use safety devices to help manage risks. There is not enough evidence to guarantee that these products work. But some families find it reassuring to use these alongside other safety measures.

## Monitors and alarms

Monitoring aids are designed to alert you if your child has a seizure.

Options can include:

- Wearable alarms and monitors
- Alarms with video monitoring
- Apps and seizure alert subscriptions
- Bed monitors
- Trained seizure dogs
- Other types of alarms and monitors

Some families can get a seizure monitor provided by their local authority. Some charities also offer free monitors.

## Safety pillows

Safety pillows are designed to help someone breathe more easily if they are lying face down when they have a seizure.

Find out more about safety at: [epilepsy.org.uk/safety-equipment](https://epilepsy.org.uk/safety-equipment)



Our support team tell us that SUDEP can be a number one worry for parents.

You do not have to face this alone. We can help. Call us on **0808 800 5050** for support.



Safety aids

## School and childcare

You will need to let anyone who cares for your child know about their epilepsy. This includes schools, clubs, and family and friends.

### Making a care plan

A care plan can help others understand your child's needs. It can include information like:

- The type of seizure that your child has and any possible triggers
- Medicines your child takes
- What to do if seizures last longer than usual
- Emergency contacts

Your child's doctor or epilepsy specialist should offer you a care plan. It might be part of a letter after your appointment. If not, you can ask for one.

We also have a free care plan template on our website:  
[epilepsy.org.uk/careplan](https://www.epilepsy.org.uk/careplan)

### Working with school or nursery

Talking regularly with the school or nursery can help to make sure your child gets the support they need.

Parents and carers tell us that quick check-ins about how your child is doing that day can really help.

You can also ask for more long-term adjustments to help with the effects of epilepsy or treatment.



**I have meetings with staff at school and keep them updated with seizures, appointments and medication changes.**

### Resources to help you

We have free resources online to help you work with your child's school or carer. These include:

#### Individual Healthcare Plan (IHP) template

A written plan about the support your child needs. Discuss with the school or nursery whether your child needs an IHP.

#### School trip checklist template

A checklist to help activity organisers complete a risk assessment. It can help to make sure your child can take part in school trips and activities.

School support resources:  
[epilepsy.org.uk/school-support](https://www.epilepsy.org.uk/school-support)

### Support with additional needs

Some children may have additional needs. This may be because of their epilepsy. Or it could be because of other health conditions alongside epilepsy that affect their learning and behaviour.

They may need extra support at home, or at school.

We have several free and supportive courses at:  
[training.epilepsy.org.uk](https://www.training.epilepsy.org.uk)

These include:

- A course for teachers to help schools understand how to support children with epilepsy
- Be Epilepsy Aware, a course for people with epilepsy and learning disabilities, and their family, friends, and carers

### Local authority support

Your local authority also has a duty to provide a range of services for children with additional needs. These may include:

- Short break services and play schemes
- Care at home
- Financial help
- Help with aids and adaptations

Your local authority can also carry out a 'home assessment'. This is for safety adaptations or equipment to help your child at home. They might be able to put up things like stair safety gates that are larger than usual.

To find out if your child is eligible for support, contact your local authority and ask for an assessment of their needs.

### Financial support

Depending on individual circumstances, you or your child may be entitled to certain benefits. These could include:

- Disabled Persons Railcard and other bus or travel passes
- Blue Badge for parking
- Disability Living Allowance or Personal Independence Payment (PIP)
- Carer's Allowance

Find out more at:  
[epilepsy.org.uk/benefits](https://www.epilepsy.org.uk/benefits)

### Your child's legal rights

Epilepsy may legally be considered a disability, even if your child's seizures are well controlled.

If this is the case, existing laws will protect your child from disability discrimination. Find out more at:  
[epilepsy.org.uk/your-rights](https://www.epilepsy.org.uk/your-rights)



School support resources



Download a care plan

## Activity and play

Most children and young people with epilepsy can still do the activities they enjoy. The aim is to think about safety while also helping them to do the things they like.

Doing a safety check before your child takes part in an activity can help. Consider things like:

- Is the activity well planned and supervised?
- Is there a care plan in place, in case your child has a seizure?
- Is anything else needed to help manage safety risks?



**My child with epilepsy is still a child with hopes and dreams. It's important for me to learn how to plan life according to this, rather than just my fears. I find asking how to do things with epilepsy is a better approach than listing what shouldn't be done.**



### Safety measures

Every child has different needs and you will know what is best for your child. Here are some common safety measures your child may need during activities. Especially if they are still having seizures.

**Water safety:** Always have someone in the water with them when swimming. Stay with them when they have baths. Showers are safest.

**Road safety:** When riding a bike keep away from busy roads or water. Always wear a helmet.

**Height safety:** Let young children climb only as high as their own height.

**Injury protection:** Use soft flooring and cushioning to protect against knocks and friction burns. Safety equipment like seizure helmets can sometimes be funded by the NHS.

Some sport activities have a governing body and rules around safety and medical conditions. We have more about this at: [epilepsy.org.uk/sport-leisure](http://epilepsy.org.uk/sport-leisure)

You can also talk to your child's doctor or epilepsy nurse if you are unsure.



**Encourage your child if they want to do a particular activity. Maybe do the activity with your child or just go and watch.**

**I found martial arts also helped me cope and improved my confidence and coordination.**

## Growing up



**Balancing the independence and privacy a teenager naturally wants and needs with keeping safe is our biggest challenge at the moment.**

**What helps is openly talking through concerns and agreeing how they plan to keep safe.**

Your child's needs will change as they grow older. Parents tell us that this can sometimes be a challenging time, as they help their child learn to take their own medicines, and stay safe.

### Preparing for change

Here are some things that may affect your child's epilepsy during their teen years. Speak to your child's doctor or epilepsy nurse if you have any concerns.

### Hormonal changes

Seizures can sometimes be affected by hormone changes. For example, during the menstrual cycle. Catamenial epilepsy is a pattern of seizures that worsen at certain times of this cycle.

### Contraception

Some epilepsy medicines can affect hormonal contraceptives. There are also rules around prescribing some epilepsy medicines when pregnancy is possible. Your child's doctor should talk to you and your child about this.

### Changes at school

Moving to secondary school can mean big changes. Teachers and classes change. Academic pressure can sometimes affect stress.

Reasonable adjustments like extra exam time or rest time can be useful. Particularly if school stress may trigger your child's seizures.



**Right now we are trying to keep everything as calm as possible for GCSE exams to minimise the number of seizures. This means taking a very low key approach and prioritising rest over extra revision sessions.**

### Growing independence

Most teenagers want to try new things. Teens with epilepsy may need to think a bit more about how things could affect their condition. Drugs, alcohol and lack of sleep can all be possible seizure triggers.

Parents and carers tell us that gradually, they do find ways to help their teens have fun while still taking responsibility. They also talk about how resilient their children have grown to be.



**My child understands how important her condition is. She has taken responsibility for it but does not want to be defined by it.**

### Moving to adult services

When your child reaches 16 to 18 years old, their epilepsy care will move from child to adult services. You might hear some clinics call this 'transition'.

This is an important time, as the young person becomes more involved in their care. It can help them to feel more confident about managing their condition.

### What to expect

Guidelines say that young people should be involved in planning their move to adult services. Their concerns should be heard and considered.

The move should be tailored to the needs of each person. Early planning can help.

Ask your child's doctor or specialist nurse if they have an agreed process for moving from child to adult services. They can also tell you how you can support your child.



**I've had a good experience with the transition from paediatric to adult services in my epilepsy care. I've felt comfortable talking to my epilepsy specialist nurses and doctors, they've helped with issues like medication and have been supportive.**

**I'd say just to make sure you take care of yourself, know your limits and what you are capable of, don't push yourself too much.**

**Live your life to its fullest at the present time, each day. And each day is a new day, an important thing to remember.**

We have worked with others to develop a series of free resources to help young people with epilepsy move to adult services. Find them at: [epilepsy.org.uk/transition](https://epilepsy.org.uk/transition)



Transition resources

## Becoming an adult

Being a parent or carer doesn't stop when your child turns 18.

Epilepsy Action has lots of resources to help you and your child as they move into adulthood.

### Thinking about the future

Sometimes the future can feel too much to think about. It is important that you and your family move at a pace that is right for you.

Please skip this page if it is not what you need right now.

You can also find out much more about these topics online on our info pages, whenever you need.



**We are being asked to think ahead to the future and start making long-term decisions about college, university, careers, and it can be difficult to do this.**

**Try to keep a sense of perspective; you don't really need to commit to future plans now. You can only make the best decision at any given time with the information you have at that time.**

### Further education

Many young people with epilepsy go on to college or university. All colleges should provide support for students with special educational needs and disabilities.

This could include giving your child teaching support to help with their learning. Or making changes so their epilepsy doesn't put them at a disadvantage, compared to other students.

As a student with epilepsy, your child may also be eligible for financial support through the Disabled Students Allowance (DSA).

### Work and epilepsy

Employers must keep all employees safe at work. Your child only needs to tell their employer about their epilepsy if they think it will affect the safety of themselves or someone else.

But telling an employer also means they can help make reasonable adjustments. Such as flexible working to help with tiredness as a seizure trigger.

## New horizons

### Driving

There are different rules for driving with epilepsy, depending on various factors.

If your child has seizures that affects their consciousness, they must be seizure free for at least 12 months before they are allowed to drive.

There are some cases where they still might be able drive, even if they are not seizure free.

For example, if they only have seizures in their sleep. Or if seizures do not affect their consciousness.

### Travelling and holidays

Parents and carers say that making time for rest and recovery during holidays can help.

For example, one parent told us they keep the first day of any holiday clear. This is so their child can catch up on sleep and rest.



**If my child goes with friends they have to agree to go on a later flight. Getting up in the middle of the night can be a trigger.**

### “Will my child need medical clearance to fly?”

Each airline has their own policy. Many follow International Air Travel Association (IATA) guidelines. These recommend that if a person has a tonic-clonic seizure less than 24 hours before the flight they will need clearance from their doctor to fly. Contact the airline before flying to check their policy.

### “How can I travel abroad with my child's epilepsy medicines?”

Carry epilepsy medicines in hand luggage in original packaging. Also take a copy of the prescription, and a letter from your child's doctor.

There may be restrictions on taking some epilepsy medicines in and out of the country. Visit GOV.UK and contact the embassy of the country you wish to enter for more information.

Having a sunflower lanyard can help with moving through public spaces like airports. You can get them for free from many supermarket chains, and travel hubs.

## 3 things you can do next...

- 1 Start a seizure diary – download it here: [epilepsy.org.uk/diary](http://epilepsy.org.uk/diary)
- 2 Learn about first aid for your child's seizure type: [epilepsy.org.uk/firstaid](http://epilepsy.org.uk/firstaid)
- 3 Sign up to our e-action newsletter: [epilepsy.org.uk/about/newsletter](http://epilepsy.org.uk/about/newsletter)



**First aid steps for my child's seizures:**

For support call us on **0808 800 5050**  
or go to [epilepsy.org.uk](http://epilepsy.org.uk)

## Quick guide to managing seizures

Prevention	Preparation
<p><b>Daily tasks to help manage seizures:</b></p> <ul style="list-style-type: none"> <li>• Use a seizure diary to track seizures and learn about triggers</li> <li>• Sleep as well as possible</li> <li>• Eat well and exercise</li> <li>• Take epilepsy medicines as prescribed</li> </ul>	<p><b>Be prepared:</b></p> <ul style="list-style-type: none"> <li>• Keep rescue medicine with you</li> <li>• Keep your child's care plan up to date</li> <li>• Order prescriptions in plenty of time</li> </ul>

During a seizure	After a seizure
<p><b>Practice basic seizure first aid, for example:</b></p> <ul style="list-style-type: none"> <li>• Keep the child safe and away from danger</li> <li>• Cushion their head if they are on the floor</li> <li>• Do not restrain them, or put anything in their mouth</li> <li>• Stay calm and time the seizure</li> <li>• Use rescue medicine if the seizure goes on too long, if prescribed</li> </ul>	<p><b>After seizure care:</b></p> <ul style="list-style-type: none"> <li>• Stay with the child until they are fully recovered</li> <li>• Reassure them as they come round. Tell them what has happened</li> <li>• They may want to sleep or be somewhere quiet</li> <li>• Record the seizure in their seizure diary</li> </ul>

**Emergency – Call 999**

- If you think your child is in status epilepticus and you do not have rescue medicine
- If you have used rescue medicine and their seizure does not stop
- If your child does not regain consciousness after a seizure
- If they have trouble breathing during the seizure
- If your child has a serious injury during the seizure

## EPILEPSY SAYS STOP. KIDS SAY GO.

We are Epilepsy Action. If your child is affected by epilepsy, we're here for you.

This booklet explains what epilepsy is, how it can be managed, and how you can support your child as they learn to live confidently with the condition.

We'd love to know what you think about this booklet. We'll use your feedback to improve the next one. Please let us know at [healthinfo@epilepsy.org.uk](mailto:healthinfo@epilepsy.org.uk)

**Thank you to all the families who shared their time and experience to create this booklet.**

Epilepsy Action  
New Anstey House  
Gate Way Drive  
Yeadon  
Leeds LS19 7XY

0113 2108800  
[epilepsy@epilepsy.org.uk](mailto:epilepsy@epilepsy.org.uk)

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