

# Epilepsy in Infants and Young Children

## A Guide for Parents

 **Young Epilepsy**

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**Inside**

### Treatments for epilepsy

Information about different epilepsy treatments and how they can affect your child



### Managing seizures

A few simple steps to make sure that your child is safe in the event of a seizure



### Living with epilepsy

Tips for coping with epilepsy in day-to-day life





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contents  
page



previous  
page



next  
page

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# Foreword

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Epilepsy is a condition that affects around 1 in 500 children under the age of four years. Seeing your baby have a seizure can be distressing and can lead to high levels of anxiety. Epilepsy is a complex condition and having a diagnosis does not always provide immediate answers.

I see many babies and infants in my work at Great Ormond Street Hospital and support for parents is essential. We have written this guide to help you understand how epilepsy presents in babies and infants, how to keep your baby safe and tell you about the treatments that are available. We also hope it will provide you with information on life with a young child with epilepsy and help you navigate some of the new places and situations in which you will find yourself.

This handy guide brings together all the key information you need to know in one place. Although it has been written by experts, it draws on the experience of many other parents who have already started their journey. They have shared with us their top tips for helping you cope in the early years of having a child with epilepsy.

We hope that you find it useful.





# Contents

<b>Introduction</b> .....	5	<b>Commonly asked questions about medication</b> .....	22
<b>What is epilepsy?</b> .....	6	<b>Your developing baby</b> .....	24
Is it epilepsy? .....	6	Stages of development .....	25
<b>What is a seizure?</b> .....	7	<b>Living with epilepsy</b> .....	26
<b>What are the causes of epilepsy in infants?</b> ...	8	A good night's sleep .....	26
<b>What is an epilepsy syndrome?</b> .....	9	Sleep development .....	28
<b>How do seizures manifest in babies and infants?</b> .....	10	Seizure monitors .....	29
Subtle seizures .....	10	Getting out and about .....	29
Motor seizures .....	11	Keeping your child safe .....	30
Febrile seizures .....	11	<b>Benefits and support</b> .....	34
Infantile spasms .....	11	<b>Taking care of yourself</b> .....	35
<b>What tests can be done?</b> .....	12	<b>Preparing for the future</b> .....	36
EEG (electroencephalogram) .....	13	Childcare .....	36
Brain scans .....	13	Starting nursery or preschool .....	37
<b>Managing seizures</b> .....	14	Getting ready for school .....	38
<b>Treatments for epilepsy</b> .....	16	<b>Witnessing a seizure</b> .....	39
Medication .....	16	<b>Individual healthcare plan</b> .....	40
Other treatments for epilepsy .....	18	<b>With thanks to</b> .....	42
<b>Working with professionals</b> .....	19	<b>More information and support</b> .....	42
Preparing for consultations/ appointments – top tips from parents .....	21		



# Introduction

This guide is designed to give you the basic information you need to care for a young child with epilepsy.

Caring for a baby, infant or young child who is experiencing seizures can be distressing. Like most people you will probably be new to epilepsy and, in the beginning, it is likely that you will not know much about the condition. The greatest challenge that you will face is the fear of the unknown, so having some knowledge and information about epilepsy will help you to feel more confident.

This guide has been written by experts from Young Epilepsy and Great Ormond Street Hospital, with the help of many parents who have told us what they would have liked to have known when their child was first diagnosed.

If you have any specific questions or if you feel that you would like to speak to someone, contact our helpline by phone, text or email:



**01342 831342**



**07860 023789**



**helpline@youngpilepsy.org.uk**



## LOOK OUT FOR THESE ICONS



**Top tips**



**More detail on our website**



**Downloadable factsheet**

[youngpilepsy.org.uk/infant-guide](http://youngpilepsy.org.uk/infant-guide)



# What is epilepsy?

Epilepsy is a neurological condition that interrupts the normal electrical activity that our brains use to communicate with the rest of the body.

This disruption causes seizures, of which there are over 40 different types. Epilepsy in babies and infants is different to epilepsy in older children and adults, as the brain is immature and developing rapidly.

## Is it epilepsy?

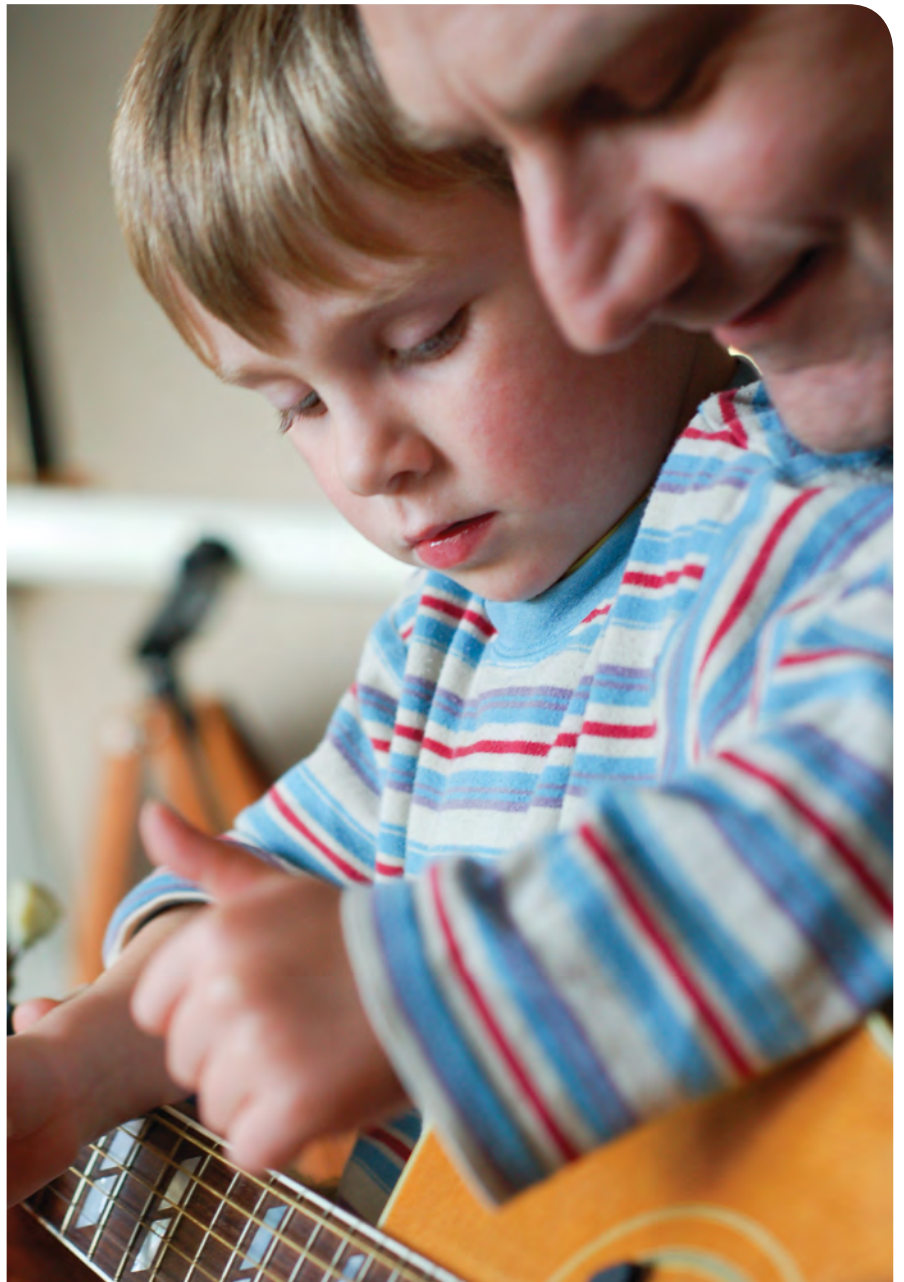
It can be difficult to diagnose seizures in infants. There may be other causes of an infant having unexpected attacks affecting movement, breathing or alertness that need to be considered.



## TOP TIPS

'Try and get together with other parents of children with epilepsy. It is easy to feel isolated, but it is really important to remember that you are not alone and that there are other people who are going through the same processes as you are.'

**If you are feeling isolated and want to talk to someone, try calling the Young Epilepsy Helpline on 01342 831342 or emailing [helpline@youngepilepsy.org.uk](mailto:helpline@youngepilepsy.org.uk)**



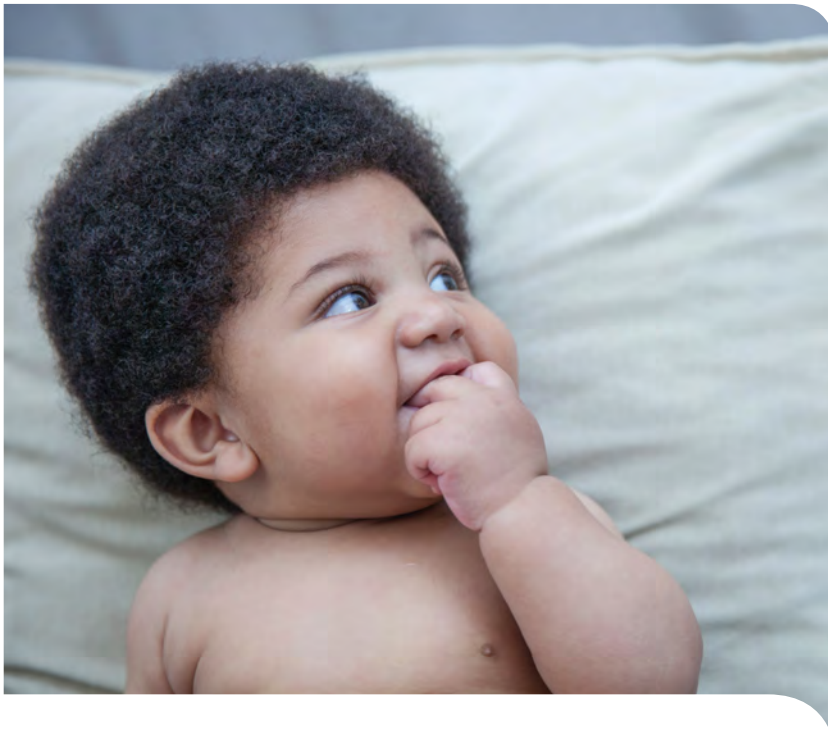


# What is a seizure?

A seizure is a sudden episode of electrical activity in the brain that can cause involuntary muscle movements or changes in sensation, behaviour or consciousness.

Seizures usually only last for a brief period of time, but as they occur out of the blue and your child is not responding in their usual way, it can be very distressing.

They can take many forms because the brain is responsible for such a wide range of the body's functions. In fact, there are over 40 different types. What a seizure looks like will depend on where in the brain the burst of activity occurs. Seizures may cause your child's limbs to twitch,



their muscles to become very stiff or floppy or they may lose consciousness and fall to the floor and shake. They may experience strange sensations, such as an odd smell or taste or they may just stop what they are doing and stare for a few moments. There really are a lot of ways that a seizure can manifest itself. You can find out more in the section '[How do seizures manifest in babies and infants?](#)' on [page 10](#).

Most seizures usually last from a few seconds to a few minutes and stop without any treatment. Some may go on for longer and medication will be needed to stop them. See '[Managing seizures](#)' section on [page 14](#).



# What are the causes of epilepsy in infants?

There are many different causes of epilepsy in infants, although unfortunately in most cases (60%) the cause remains unknown.

As with epilepsies in older children, these are grouped according to the possible cause:

- structural or metabolic
- genetic
- unknown

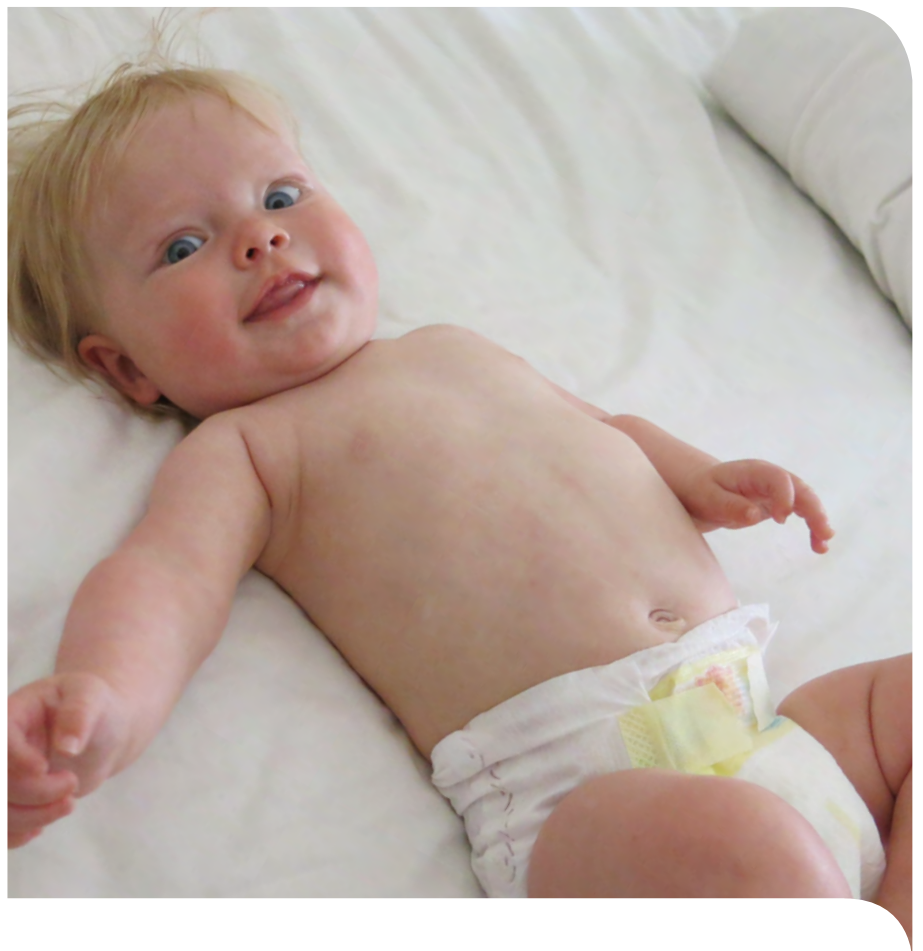
Epilepsy in infants can have a number of possible causes, although sometimes no cause is found. Those that are most common include:

- premature birth - which can cause haemorrhages (bleeds) in the brain tissue
- birth trauma - which can result in low oxygen levels (hypoxia) and subsequent damage to brain tissue
- serious infections involving the brain
- abnormal development of the brain structure
- genetic conditions, for example tuberous sclerosis

Investigations carried out aim to try to identify a cause but this is not found in all infants.

If the cause of the epilepsy is known, it will help your child's doctor to better predict how your baby will develop and what the outlook is for controlling the seizures.

Some seizures in babies and young children only occur for a short period of time, some may return later on and in some cases seizures can continue throughout childhood.





# ★ What is an epilepsy syndrome?

A syndrome is a group of symptoms and signs that occur together and indicate a specific disease or condition.



An epilepsy syndrome is diagnosed by the combination of several features, such as the age of onset, type of seizures, the EEG (brain wave pattern) changes in between or during seizures and other tests such as MRI brain scan or genetic investigations.

There are a number of epilepsy syndromes that occur in infants. The medical team working with you and your child will be looking to see if their symptoms indicate that they have a syndrome.

The diagnosis of a specific syndrome can help the doctor to better predict how your child is likely to respond to treatment and what you can expect over the coming years. It may also be helpful for you to have contact with other parents with experience of a particular syndrome.

With the rapid advances in genetics, more syndromes are being diagnosed and it is now recognised that changes in genes may manifest with epilepsy in infancy.

You can find further information on the following syndromes, that are seen in infants, on our website.

[West's Syndrome \(infantile spasms\)](#)

[Dravet Syndrome \(SMEI\)](#)

[Ohtahara Syndrome \(early infantile epileptic encephalopathy\)](#)

[Aicardi Syndrome](#)

[Lennox-Gastaut Syndrome](#)

[Landau-Kleffner Syndrome](#)

[Sturge-Weber Syndrome](#)



Find out more on our website

# ★ How do seizures manifest in babies and infants?

Seizures in babies and infants can be difficult to recognise as they are often quite subtle.



Due to the immaturity of the brain, lots of babies have brief jerks or facial movements that may be suggestive of epilepsy in older children, but are a normal part of the developing baby. These movements are more likely to be seizures if they are not triggered by activity, do not stop with gentle moving of the limbs or if they occur recurrently in the same pattern.

There are a number of different types of seizures that are seen in this group.

## Subtle seizures

These usually involve eye movements such as blinking, fluttering, rolling, rapid movements or a fixed gaze. These can occur on their own or with other subtle movements such as sucking, chewing, lip smacking or tongue protrusion. Movements of other parts of the body can also occur such as strange rowing, swimming, cycling or thrashing of the arms and legs.



## Motor seizures

**a. Tonic seizures:** these cause sustained contractions of the face, limbs or other muscles, or extension of the trunk. They can occur in one muscle or lots of muscles at the same time, on one or both sides of the body.

**b. Clonic seizures:** these seizures involve rhythmical jerking of the muscles and may occur in just the face or limbs. If the jerking movements last a long time, the baby may experience a temporary weakness on the side of the body that has been involved. This is called Todd's paralysis and usually resolves quickly.

**c. Myoclonic seizures:** these are very rapid single jerks that are not rhythmical, but can be repetitive. They may be seen in just a finger, a limb or the whole body. Healthy babies can have lots of myoclonic movements during sleep.

**d. Spasms:** these are similar to the seizures described above, they are slower than myoclonic seizures but faster than tonic seizures.

Any seizures in babies and infants may also be accompanied by what are known as '**autonomic changes**'. These are changes in the automatic functions of the body such as heart rate, breathing rate and blood pressure. Although these may change during a seizure, the baby will still be breathing.

It can be very distressing to see your baby experiencing seizures but remember that they are usually brief, lasting from around 10 seconds to 1 – 2 minutes. If a seizure lasts longer than this it is important to get medical help immediately.

There is more information on how to take care of your child during a seizure in the section [on page 14](#) – '[Managing seizures](#)'.

As your baby develops and grows, their seizures may change and begin to look more obvious.

## Febrile seizures

From around 6 months to 6 years of age, febrile seizures (also called febrile convulsions) may occur. These seizures happen when a child has a fever or temperature. A diagnosis of epilepsy is not usually needed in these children as they are often isolated events with a known cause, but some children may have additional risk factors that mean they are likely to have other types of seizure. The risk factors include abnormal development prior to the first febrile seizure and a family history of non-febrile seizures.

## Infantile spasms

Infantile spasms are a type of seizure which typically occur in babies under 1 year of age. They involve sudden stiffening of the arms and sometimes legs, so the baby may flex forward or extend backwards. Often several spasms occur over a few minutes. The baby may seem distressed or irritable during or after these. Parents often report that their baby has shown a change in alertness, is less socially interested, or is making fewer sounds than usual before the onset of the spasms or when these start. Sometimes infantile spasms are misinterpreted as colic. If you are concerned, arrange for your doctor to check your baby. [It is also helpful if you can take a recording of the episodes](#), whilst ensuring your baby's well-being.

If your baby is having infantile spasms, early diagnosis and treatment is important. Specialist investigations will include EEG, brain MRI, blood, urine and lumbar puncture tests. There are many different underlying causes of infantile spasms. In some infants, despite extensive investigations, a cause is not found. The treatments available for infantile spasms include steroids and vigabatrin. These require monitoring by your infant's paediatrician and with guidance from a paediatric neurologist.

# ★ What tests can be done?

Although there is no single diagnostic test for epilepsy, a number of investigations are used. These help your doctor to make a diagnosis of epilepsy.

Doctors also aim to look for an identifiable cause and to help determine the best treatment. These investigations, together with eyewitness accounts of seizures or DVD recordings, will help with diagnosis.

Your doctor will want to know details of the whole episode, including before, during and after the seizure. They will therefore ask many questions when you meet them. If you can record the episodes this can be very helpful, but always ensure that your child's care needs are met before worrying about a recording. It is helpful if you can keep a description of exactly what happens to your child during an attack.



## TOP TIPS

'If you are going into hospital for an investigation, make sure that you pack a bag with plenty of snacks and drinks for both you and your child – there may be a lot of hanging around.'





## EEG (electroencephalogram)

An EEG is a useful tool in the diagnosis of epilepsy. A number of small electrodes, attached by wires to the EEG computer, are placed on the surface of your child's head with a sticky paste or glue. They may be kept on for a short time (up to an hour) or for a much longer period (several days).

Whilst the EEG is taking place, it looks at the electrical activity in the brain and can give the doctor detailed information about any seizures that occur. It is a painless investigation but can take time. The EEG is most useful when it is used alongside video recordings so your doctor can observe what is going on in the brain and at the same time witness how your baby or child is behaving.

Results of the EEG may show where in the brain the electrical activity starts and if particular patterns of activity are occurring. This can help identify a syndrome as well as assist the doctor in deciding on the most appropriate treatment.



## TOP TIPS

To remove any leftover glue after the EEG, use plenty of conditioner when you wash your baby's hair and gently ease it out.



## Brain scans

Brain scans are used to give a detailed picture of the brain's structure. They can be helpful in identifying if an area of the brain has not developed properly or if there is an area of damage to the brain tissue. MRI (Magnetic Resonance Imaging) is the technique of choice for investigating epilepsy. If the child presents with a sudden illness or seizures, CT may be used as this can be done more quickly and is readily available. MRI scans use magnetic fields and CT scans use low dose radiation X-rays. They are only carried out when the benefits of doing so outweigh the risks.

Both scans are safe and painless, although your child will need to be sedated as they are required to be very still to get a clear picture.

Sometimes an injection is given as part of the procedure. A dye is injected into the bloodstream, usually through the hand or foot in a baby, which highlights the blood vessels in the brain.

The results of scans are used to identify if there is any abnormality in the brain or if there has been any damage, for example, as the result of lack of oxygen or a bleed. Understanding the potential cause of seizures will help with the diagnosis of epilepsy and guide decisions about the best course of treatment.



# Managing seizures

Watching your baby or child having a seizure can be very frightening even if it only lasts for a few seconds.

**Most seizures stop without the need for any treatment, but it is important that a few simple steps are followed to keep them safe.**

1



Stay calm and make sure your child is in a safe place with space to move freely and there is nothing in the way that may hinder their breathing. It is also important to record how long the seizure lasts, so try to remember to start timing.

2



Let the seizure run its course ... don't restrict their movements or put anything in their mouth.

3



Once the seizure ends, put your child onto their side to recover. This will help to keep their airway clear.

4



Make a note of what happened leading up to, during and after the seizure ended.

It is important to seek urgent medical attention by calling 999 for an ambulance if your child:

- has never had a seizure before
- is not breathing or is blue around the lips
- has a seizure lasting for more than 5 minutes
- is not responding to you after the seizure has stopped
- has sustained an injury during a seizure

Seizures that last for longer than 5 minutes need treating with an emergency or rescue medication. This is because the longer a seizure goes on the harder it is to stop. When a seizure lasts for more than 30 minutes it becomes a condition known as status epilepticus. This is a medical emergency as the body systems are under such prolonged stress.

If your child's doctor feels your child is at risk of prolonged seizures, you will be prescribed an emergency medication that you can administer at home. It is better to give this medication as soon as it is needed, rather than waiting until an ambulance arrives. Paramedics will then be able to monitor your child and further medication can be given, if needed, at the hospital.



**Find out more about emergency medications and watch a short film on our website**



## TOP TIPS

### Keeping accurate records of possible seizures:

As soon as you can, take some time to sit down and write a description of exactly what happened.



### Make a note of any changes in...



Breathing



Movements of arms and legs



How long it took for your baby to fully recover

Head movements



Eye movements



Medication given



How long the movements or behaviours lasted



Skin colour



Changes in how your baby responds to you



It is also helpful to note what you were doing before it started and where it happened.



Don't forget to keep a diary with the exact times and dates.

# Treatments for epilepsy

Antiepileptic medication is usually prescribed as the first line of treatment, although there are now a number of potential options.

## Medication

The most common treatment for epilepsy is medication. Medicines that are used to treat epilepsy are often referred to as 'antiepileptic drugs' or AEDs. They do not cure epilepsy or treat the cause, but they aim to reduce the likelihood of seizures occurring.

There are a large number of AEDs available in the UK and most are taken by adults before they are given to children. The important information you need to know about AEDs is that your doctor will choose the best one for your baby or child based on a number of factors. These include the types of seizure they are experiencing or which syndrome they have, the likelihood of seizures recurring, as well as the benefits or potential adverse effects of the treatment.

It is not usual to start treatment after just one seizure unless a cause is identified which makes it likely that more seizures will follow.

## How do AEDs work?

Antiepileptic drugs work by creating an environment in the brain that makes it less likely that a seizure will occur. The brain is a very complex organ and many intricate structures and processes are involved in its day-to-day functioning. During seizures a combination of processes disrupts the delicate balance within the brain which results in sudden bursts of electrical activity. AEDs are designed to maintain a better balance so that seizures are prevented. Some AEDs enhance particular chemical processes and others work by blocking or inhibiting them.

Finding the right medication for your baby or child may take some time, so it is important to be patient. AEDs are always introduced at a very low dose and then gradually increased. This allows the body to get used to the medication and reduces the chance of adverse side effects. Increasing the dose to the right level may take a few months and it is vital that you follow the plan given to you by your doctor. The optimum dose for your child is decided using a calculation based on their size and weight.







For some AEDs it is important to check how much medication is in the bloodstream, so regular blood tests will be needed. Your doctor may also need to monitor how other body systems (such as the liver) are responding to the medication.

Medications don't always work and your baby or child may still experience seizures. If there is no change in the frequency of the seizures, then your doctor will recommend trying another AED. When this is introduced, it may be as an 'add-on' to an existing medication. Alternatively it might replace the existing medication, which may need to be gradually reduced before the new AED can be started. It can be very frustrating as starting and stopping medications takes a long time, but it is important to be patient and stick to the plan.

### Side effects of medication

As with all medications, antiepileptic drugs can have side effects. You should receive a patient information leaflet with the medication which lists any known side effects and how likely they are to occur.

In babies and young children it is important to observe how they respond to the medication and note any changes to their normal behaviour. They won't be able to tell you if they are feeling nauseous but they may be irritable or off their food.

Side effects of AEDs may include tiredness, irritability or mood swings, weight loss or gain and difficulty concentrating. It is important that you keep a record of any changes in behaviour or potential side effects of the medication so that you can tell your doctor.

### Taking medication

You can get most medications in a form that will suit your baby or child, although most medications that are prescribed for young children will come in a liquid form. Some medications come in a sprinkle form and some tablets may be crushed into food or dissolved in water, but it is best to check with the pharmacist before doing this. Slow release tablets should not be crushed.

It is important that the medication is given regularly and at set times each day to maintain the levels in the system.



## TOP TIPS

If your child develops a rash soon after, or within a month, of starting the medication, this can be the sign of an allergic reaction and it is important that you seek urgent medical attention. An allergic reaction can be serious.



## Other treatments for epilepsy

Although medication is usually the first line of treatment for epilepsy, there are other options available that may be considered if medications are not reducing seizures. You can find out more about each of these treatments on our website.



Find out more on our website

### Neurosurgery

Brain surgery may be considered as a treatment for epilepsy if:

- medication is ineffective
- the results of detailed tests and assessments show that seizures are coming from a specific part of the brain
- if removal of this area will not cause further complications

The decision for your child to have surgery is not an easy one and the team working with you will support you. You will have lots of opportunities to discuss the risks and benefits with your doctor and the surgeon. It is likely that your child will need preparing too and a play therapist can spend time with your child using play to help them understand what will happen.



Factsheet available on website

### Vagus Nerve Stimulation

Vagus Nerve Stimulation (VNS) can be used alongside other treatments such as medication and is used when seizures are very frequent. A small device, similar to a cardiac pacemaker, is implanted under the skin near the collar bone and is connected to the vagus nerve in the neck. By stimulating the nerve at regular intervals, the frequency and intensity of seizures may be reduced. It often takes around a year before improvements in seizure control are observed and it can have side effects. This treatment has been used in children as young as six months of age, but it is more commonly used in older children.



Factsheet available on website

### Ketogenic diet

Dietary treatments for epilepsy have been around for over a hundred years. There are a number of specialised diets that are used, but all are based on the same principle of using a controlled diet to enable the body to produce ketones – a chemical that reduces seizures. This diet may not be effective for everyone, but for some it may result in a reduction in seizures, with fewer side effects than other treatments. Any dietary treatments for epilepsy should only be used under the supervision of a consultant and specialist dietician.

For more information, visit

[www.matthewsfriends.org.uk](http://www.matthewsfriends.org.uk)



Factsheet available on website

# Working with professionals

When you have a child with a health condition, all of a sudden you may find yourself in a new place where it seems that everyone is speaking a language that you do not yet understand.

There is a lot to learn and it can feel very daunting.

The professionals you will meet are often highly trained specialists who know a lot about epilepsy and the brain, but remember that you are the expert on your child. Only you know if their behaviour is unusual for them.

The doctors and nurses will help you to understand more about your child's health condition but they will also rely on you for information about what has been happening. Remember that there is no diagnostic test for epilepsy, so the doctors rely on your observations of any suspected seizures.

You are likely to see them a fair bit, so it is worth developing a good relationship so you can talk openly about your concerns, hopes and fears.

## Who's who?

If your baby had seizures in the first few days of life, you will probably have met a **Paediatrician** (children's doctor) or **Neonatologist** (doctor specialising in premature or very young babies) at the hospital.

If you were at home when your child first had a seizure, or suspected seizure, then it is likely that you will have seen a Paediatrician in the Accident and Emergency Department. However, some babies may be seen by their **GP** or **Health Visitor** first and then referred to a Paediatrician at your local hospital.

The National Institute for Health and Care Excellence (NICE) publishes guidelines on how children with epilepsy should be managed by doctors. The latest guidance states that a specialist should see all children who present with seizures within two weeks of the first seizure. As epilepsy is one of the most common neurological conditions in childhood, many Paediatricians have had additional training in epilepsy and are known as having a special interest in epilepsy.



## TOP TIPS

There are some useful forms to help you keep a record of any seizures and observations available to download from our website. The Young Epilepsy mobile app is also a great tool for keeping track of seizures as well as medication details and appointments. Just search 'Young Epilepsy' on your app store (available for iOS and android devices).





Your Paediatrician will be your main doctor and they will keep your GP informed about diagnosis and treatment. You should still see your GP if you have any other health concerns. Your Health Visitor will also be kept informed. Remember to take your 'red book' to appointments with all of your health professionals so that it can be kept up to date. Your Paediatrician may arrange for your baby or child to have some investigations and tests, and they will prescribe the antiepileptic drug treatments.

At the hospital you may also see an **Epilepsy Nurse Specialist**. This is a local neurology nurse who is experienced in epilepsy. They are often your first port of call if you have any concerns or questions between appointments. You will be given a contact number for them and they are happy to be called. They are often very experienced at supporting families and can answer most questions. If there are specific queries they cannot answer, they may be able to speak to the Paediatrician about your concerns.

Some babies and young children will need to be seen by a more specialist doctor and your Paediatrician may refer you to a clinic at a specialist centre or hospital (tertiary level care) to see a **Paediatric Neurologist**. This specialist may request further tests or investigations or may discuss other treatment options or medications with you. They will write to your Paediatrician to keep them informed so they can continue to prescribe the same medication and care for all your child's needs.





## TOP TIPS

### Preparing for consultations/appointments

'It is worth spending some time preparing for any appointments with your child's doctor. Write down any questions that you have in advance as it is easy to forget them when you are in the clinic or are distracted by your child.'

'No question is silly or irrelevant. Make sure you ask as you may regret it if you don't.'

'Make sure that you get answers to all your questions from the doctor and don't be afraid to ask for clarification if there is something you don't understand.'

'Keep a record of all seizure activity, including any suspected seizure activity that you may be concerned about. It's easy to think that you will remember it all, but it is very easy to forget. (Young Epilepsy has an app that you can use, or you can download record forms from the website).'

'Agree a care plan with your doctor and make sure that you understand it before you leave. Managing multiple medications can be confusing so make sure it is written down in a way that you can easily follow.'

'Ask about emergency medication and if it is prescribed make sure that you understand when it should be given – this can be written down into what is known as an 'emergency protocol'. This document will then be used if your child is admitted to hospital.'

'Although your doctor doesn't have a crystal ball, it's OK to ask about the future. You can ask about the long-term prognosis, whether your child's seizures are likely to become controlled or if they will grow out of them, what you should expect over the coming months or year and what the impact will be on your baby's development.'



[Find out more on our website](#)





## ★ Q&A: Commonly asked questions about medication ...

### **Can my child have the usual childhood vaccines?**

Children can be safely immunised with the routine childhood vaccines if their condition is stable. If still being investigated, infants can have their immunisations postponed until their seizures are stabilised. Some vaccines can cause a rise in body temperature which can occasionally trigger a febrile seizure, especially in children with a family history of these. The vaccine can still be given as normal with monitoring and treatment of a temperature rise as necessary. A temperature can occur within 24 hours of the DTP vaccine and regular paracetamol for 24 hours after the vaccine may prevent this. With MMR, a temperature rise may occur up to a week after.

### **What do I do if I have forgotten to give my child their medication?**

If a dose of the medication is missed and you remember up to 3 hours after missing the dose, give the forgotten dose immediately. If you remember only at, or near, the time that the next dose is due, just give your child the usual dose.

### **What should I do if my child is sick or spits out the medication?**

If your child vomits within 15 minutes of taking a dose of medication or you are able to identify it in the vomit, then give the dose again. If you are not able to identify the medication, do not give it again. If you are concerned, speak to your pharmacist or GP.

### **What should I do if I have given too much medication?**

If you have given too much medication, it is important that you seek urgent medical advice. Some medicines may not cause much of a problem if an extra dose is taken, but others may cause side effects if the levels in the blood rise even a little. If you are concerned that too much has been taken, seek advice from your pharmacist or doctor straight away.

### **What should I do if my child has diarrhoea?**

Continue with the same dose of medication and keep your child hydrated with fluids. Consult your GP if your child becomes unwell or is not drinking, the diarrhoea is severe, or it does not settle within 24 hours.

### **Why do medicines have two different names and which one should I be getting?**

Most medications have both a brand name and what is known as a generic name, usually the chemical name of the active drug. When new drugs are developed the manufacturers have exclusive rights to make that drug for a set period of time as they have invested in the research, development and testing over many years. This results in a branded drug. Once this period is finished, other manufacturers are allowed to make the same drug and it is then called by its generic chemical name.

Generic drugs are generally cheaper but it is important for those on antiepileptic drugs to remain on the branded version as children in particular are very sensitive to any changes. Your consultant and GP will be able to prescribe the branded medication.

### **Who should I contact if I have a problem with my child's medication?**

If you are uncertain about any dose changes, then check with your GP who will receive details about your consultation

**For non-emergency number queries, you can call the NHS on 111 to speak to an adviser.**



from the Paediatrician. If you are worried about side effects that your child is having, then your GP, Epilepsy Specialist Nurse or pharmacist are all possible points of contact. Changes in medication doses are usually initiated by the Paediatrician or Neurologist.

### **Can my child take other medicines at the same time?**

Most of the common medications used in young children are safe to take alongside antiepileptic drugs, but you should always tell the pharmacist if you are buying over-the-counter medicines. Your GP will know what medications your child is on, but if your consultant has made a recent medication change or the dose has changed, then you should tell your GP. With most AEDs, the normal dose of paracetamol or ibuprofen will not cause any problems. However, ibuprofen and other anti-inflammatory drugs may increase the effects of phenytoin (anticonvulsant), so consult a pharmacist or doctor before giving this to your child. Aspirin should not be given to children as it can cause complications.



# Your developing baby

Having seizures in early life may have an impact on your baby's development but this is not an inevitable consequence.

Just like any other baby or young child it is important that you encourage their development through play and stimulation.

Often parents of young children with epilepsy are anxious about triggering seizures through excitement or distress. This is a very natural concern but it is highly unlikely. We don't always know why seizures occur at one time and not another. It is important to maintain as normal a routine as possible and encourage your baby to engage in as many day-to-day experiences you can. Similarly it is important to encourage routines and maintain boundaries as your child develops.

If you have any concerns about your baby's development, then talk to your Health Visitor. It is also important to tell your child's consultant when you see them. They will be observing how your baby develops and assessing their progression at clinic appointments. They will want to know how your child's communication skills, learning and motor skills are developing.







## Stages of development

This table shows the ages and stages that babies and young children develop skills. Not all children develop at the same rate, but you can use this information to help encourage skills by looking at what comes next.

Age	Cognition/learning	Communication	Social	Motor
<b>0 to 6 months</b>	Turns head towards lights. Startled by sudden noises. Cries when hungry.	Focuses on a speaker's face. Begins to make pleasure sounds.	Begins to smile. Shows preference for social stimuli.	Lifts head and shoulders when lying on tummy. Developing head control in supported sitting.
<b>3 to 6 months</b>	Follows dangling toy. Reaches to grasp with both hands.	Turns to familiar voices. Begins to make babbling sounds.	Enjoys bathing and caring routines. Shows recognition of carer's facial expression.	Brings hands together in centre over chest. Kicks legs vigorously.
<b>6 to 9 months</b>	Reaches for rattle when offered and deliberately shakes to make sound. Shows understanding of cause and effect.	Babbling becoming established. Pauses in response to 'No'. Reacts to 'Where's mummy?' by looking.	Follows adult pointing to an object or person. Enjoys rough and tumble play.	While lying on back, raises head up and moves arms up to be lifted. Rolls from back to front, then front to back a little later.
<b>9 to 12 months</b>	Grasps string to pull toy. Watches whilst toy is partially hidden, then finds it.	Vocalises with meaning. Follows commands in context, e.g. 'Clap hands'.	Plays peek-a-boo. Offers or shows objects to initiate interaction with others.	Sits on floor and manipulates toys. Attempts to crawl. Pulls to standing.
<b>12 to 18 months</b>	Points with index finger at objects of interest. Builds tower of two blocks after demonstration. Begins to search for hidden objects.	Points to pictures in familiar books when named. Uses first words.	Waves 'bye-bye' on request. Enjoys joint play with adult, actively switching attention between object and adult.	Can rise to sitting from lying with ease. Walks around furniture. Walks with one hand held.
<b>18 to 24 months</b>	Spontaneous to and fro scribble with pencil. Builds tower of three blocks. Begins to show preference for using either right or left hand.	Follows two-part commands, e.g. 'Where's the dog's nose?'. Uses two word phrases. Chatters to self during play.	Acts out familiar routines in play. Recognises self in mirror. Dependent on familiar adult.	Walks well carrying toy. Enjoys climbing and can climb on to chair and turn around to sit. Runs rather carefully though rarely falls.
<b>2 to 3 years</b>	Can match shapes in simple puzzle. Engages in situational make-believe activities.	Uses 50+ recognisable words appropriately. Listens with interest to more general conversation. Carries out simple instructions.	Joins in nursery rhymes. Constantly demands parent's attention.	Runs safely. Good fine manipulation skills – picks up tiny objects. Throws and kicks a ball.

# ★ Living with epilepsy

Day-to-day life with a young child can be stressful for any parent, but even more so for those with a health condition. It is entirely normal to worry about your child and how you will cope.

When worry and anxiety take over and you feel overwhelmed, it is important that you recognise that you need support too.

Family and friends can be a great source of support, although there may be times when you feel that they don't understand the challenges that you are facing and professional support may be beneficial. Some parents also find it helpful to meet or talk with other parents of children who have had

similar experiences. Your Epilepsy Nurse Specialist may know of a local support group you can join, or you may find one of the online parent forums a good way to connect with others.

Many parents have told us what their biggest concerns and stresses have been and shared their experiences with us. The next few sections have been guided by what we have learnt from them.

## A good night's sleep

In order to face the day you need to start with a good night's sleep. Extreme tiredness can be really hard on your physical, mental and emotional health. Disturbed sleep in the early days is inevitable as your baby adapts to the rhythm of day and night. Try and rest when you can – you really will feel so much better for it. Enlist friends and family to help with meals, household chores and looking after other children.





The experience of a serious condition or receiving a diagnosis of a chronic medical condition is a stressful event for any family. For the child, this may result in temporary regression to 'younger' behaviour, such as requiring the presence of a parent to fall asleep. Setting limits and enforcing rules may for a time become a secondary concern to your child's physical health. However, in the long term, good sleep (or the best sleep possible) is integral to the management of epilepsy. The general advice in the next table also applies to children with epilepsy. If your child has a particular sleep problem, or you have a specific concern, do talk to your child's GP or Paediatric Neurologist for further advice.

Sleep develops just like many other skills. Sleep patterns and requirements change dramatically over the first months and years of life, continuing to develop and mature right up to late adolescence. The following table shows you what to expect and gives some general tips on things that you can do to encourage sleep. You will very naturally be anxious if your baby has seizures and will want to keep a close eye on them, even whilst they are sleeping. Around 20-40% of seizures in childhood occur in sleep (this is much higher than in adults) and some epilepsy syndromes are characterised by mainly night-time seizures (often referred to as nocturnal seizures). There are also some types of

seizure that tend to occur on waking, such as infantile spasms, so it can be helpful if you make a note of when seizures are happening to help your doctor look for any patterns.

Tiredness and sleep deprivation are commonly reported triggers for seizures, so it is important to establish good sleep habits. Although antiepileptic medications may affect sleep, effective treatment of seizures is likely to improve sleep quality in the long run.



## TOP TIPS

'Ask questions! There is no such thing as a silly question. Don't ever leave somewhere wishing that you had asked something.'

'Listen to what doctors have to say and make notes. If you do not understand something that they are saying then ask them to clarify for you.'

## Sleep development

This table shows how babies sleep patterns change as they grow. It is important to remember that not all children develop at the same rate, but you can use this to give you a rough idea of the different milestones in their sleep behaviour.

Age	Night-time sleep/ 24 hours	Naps/ 24 hours	Milestones in sleep behaviour	General advice
<b>Newborn to 2 months</b>	10 to 19 hours of sleep per 24 hours; sleep periods separated by 1 to 2 hours awake, day or night.		Sleep gradually aligns with periods of dark.	Place baby to sleep on their back, on a firm surface*. Encourage natural light exposure in the morning.
<b>2 to 12 months</b>	9 to 10 hours with an average of 2 to 6 wakings per night; may not always wake parents.	3 to 4 hours in total; initially in 4 periods, decreasing to 2.	Develops ability to self-soothe (e.g. thumb sucking). Develops sleep-onset associations (e.g. a favourite stuffed toy).	Put baby into cot drowsy but awake. Aim to wean off night feeds/ bottles by 6 months. Avoid associations that require parental intervention (e.g. rocking, verbal soothing).
<b>12 months to 3 years</b>	9.5 to 10.5 hours.	2 to 3 hours total; decreasing from 2 to 1 nap per day.	Increasing importance of ritual and routine.	
<b>3 to 5 years</b>	9 to 10 hours.	About 25% of 4 year olds may still nap.	Starting school may require a shift in sleep schedule.	Reading as part of the bedtime routine may encourage better sleep. Avoid television at bedtime and do not have a TV set in the bedroom. Avoid drinks containing caffeine.

\* This point applies to babies up to the age of 18 months.

Reference: A Clinical Guide to Pediatric Sleep: Diagnosis and Management of Sleep Problems by Jodi A. Mindell and Judith A. Owens (Lippincott Williams & Wilkins 2010).



## Seizure monitors

There are lots of monitoring devices you can use to give you that added peace of mind, but you need to make sure you choose one that is suitable for your child, detects the types of seizure they experience and works for you and your family. The simplest form of device is a listening monitor (such as a baby monitor). This allows you to hear any sounds but devices that include a video camera, so you can see your child, are usually preferred.

Some devices monitor movement and the sensitivity levels can be altered so they pick up even the small movements associated with some seizures – a sensor pad is placed underneath the mattress and attached to a small unit where the sensitivity can be adjusted. If movement occurs that is likely to indicate a seizure, an alarm is set off on a mobile pager.

There are a number of manufacturers of this type of device. They will spend some time with you finding out about your particular needs to assess whether their device will work for you. They will need to know some basic information such as the weight and height of your child and what their typical seizures look like. If a seizure does not involve any movement, this type of monitor won't be suitable. Other devices monitor heart rate and/or breathing as sometimes there is a change in these during a seizure.

As with all medical devices, seizure monitors undergo rigorous testing and must be compliant with certain ISO (International Organization for Standardization) standards. A list of suppliers of monitors and other safety equipment (including anti-suffocation pillows for children over the age of 3 years) is available from our website.



Factsheet available on website

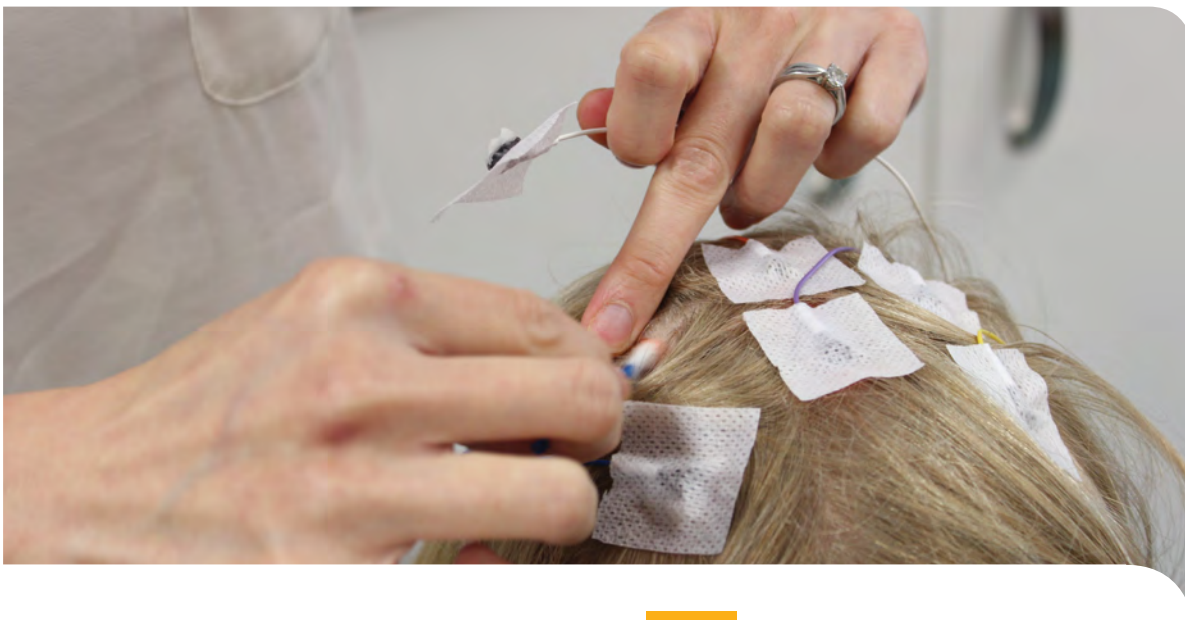
## Getting out and about

For your own health, as well as that of your child, it is important you get out and about. Sometimes a day out can feel like a military operation and the key to success is often careful planning.

Depending on how long you are going to be out of the house, you may need to pack your child's regular medication as it is important to keep to regular dose times.

You may have emergency or rescue medication you need to take too. Plenty of drinks and snacks are usually a necessity for any outing with small children. You may find it reassuring to know there will be a quiet place nearby that you can take your child to if they need to rest or sleep.

Your council website is a good place to look for details about groups for parents and children; alternatively you can check with your local leisure centre for activities such as messy play, early movement groups or swimming classes.





## Keeping your child safe

Children with epilepsy should be encouraged to take part in activities just as other children would be. Remember that accidents happen whether you have epilepsy or not and are a part of growing up and developing skills. There are some activities though that may have increased risk for a child who has seizures and they will need careful supervision.

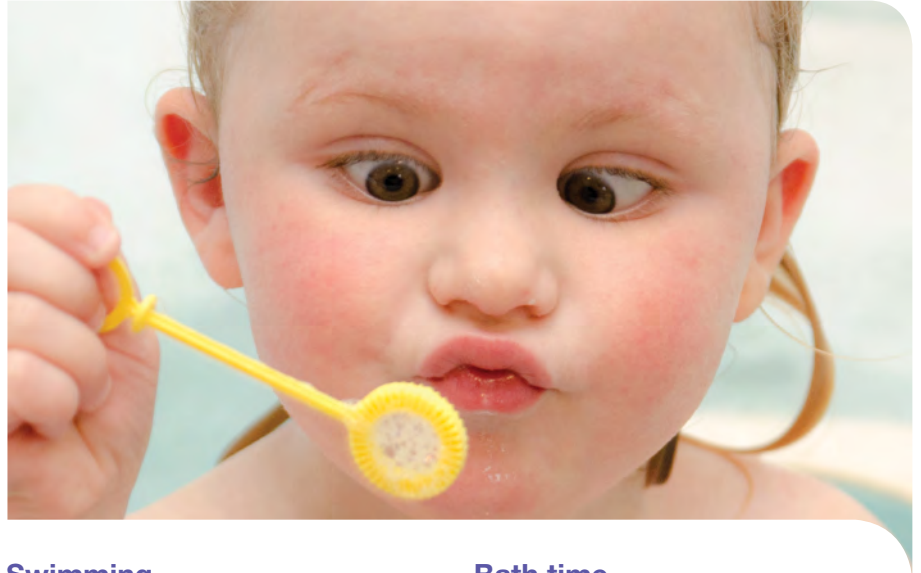
By thinking about the potential risks and taking sensible safety precautions, you will make every activity as safe as possible without being overprotective. You also may need to adapt activities or be more cautious if your child's development is delayed or they have difficulties with coordinating their movements.

### Climbing

Children love to climb but falling from a height can have serious consequences. Supervise your child when they are climbing up the slide at the park or on a climbing frame. As they get older and more independent, it may be best to avoid high climbing frames if they have frequent or uncontrolled seizures. Visit soft play centres where there is little chance of falling from a height.

### Learning to ride a bike

Riding a bike takes a lot of balance and coordination. Make sure that your child has a well-fitting helmet to protect their head. Find a local park where your child can have a go on the grass. Scooters are great too, but a helmet is still essential.



### Swimming

It is a great experience for babies and children to be in the water and develop water confidence. Having epilepsy need not stop a child swimming altogether but some special measures must be taken to ensure their safety.

Your child must be very closely supervised in the water. As seizures may involve a loss of consciousness, you must stay with them and keep their head above the water if they have a seizure. A wet and slippery baby may be more difficult to hold, so call for help. It is always worth telling the lifeguard or swimming teacher before you get into the water, so they know that you may need their help. Even as your child develops swimming skills, it is best to have someone in the water with them who is just an arm's-length away if they need help.

### Bath time

Splashing in the bath is fun and it helps develop skills, language and concepts. Young children must be very closely supervised and never left alone in the bath even for a moment. Make sure that you are prepared for bathtime and have everything you need to hand. It's a great opportunity to give your little one some undivided attention too. As your child gets older, it is recommended that they take a shower instead.

### Triggers

Keeping a careful note of when your baby or child has seizures may help you to identify if there are any particular triggers for their epilepsy. For example, some parents find that their child is more prone to having seizures when they are tired or hot. Similarly, if your child is unwell seizures may not be as well controlled as normal, so it is important to keep their temperature down. For some it may be the light flickering through the trees or a sensitivity to the reflection of water – it can be different for everyone, so [make sure you keep a record.](#)



## TOP TIPS

'Don't be worried if your child does not respond immediately to treatment, finding the correct balance of treatment for your child can take a long time, be patient and stick with it.'

'Read all the literature from Young Epilepsy and make sure you know what you and your child are entitled too.'

'You will go through lots of emotions and that is normal. You will feel selfish for worrying about how to cope but that doesn't mean you are a bad parent.'

'It is often more distressing for the parent or the people seeing the seizure, the child often has little recollection of the event.'

'Let people know about your child's epilepsy, this way there will be less shock if a seizure occurs. It can make you feel more at ease knowing that people are aware and know what to do.'

'Take one day at a time.'



## Going on holiday

A holiday can be a good experience for the whole family and travelling with a child with epilepsy just needs some extra planning. Here are some things to consider when planning your trip:

- Before you leave, make sure that your holiday insurance covers emergency medical treatment for your child. Some insurance companies may need a letter from your doctor, so it's worth allowing plenty of time before you go to organise these things.

- If your child has been prescribed emergency or rescue medication for prolonged seizures, check the expiry date and have it with you at all times.
- If you are travelling by plane, take all your child's medication in your hand luggage in case your hold luggage gets lost or is delayed. If the medication is in liquid form, check the current rules with your airline and inform them of your child's condition.

- Because the names of drugs vary in different countries, make sure that you take medication in its original packaging and be familiar with its generic name.
- Take extra medication in case your return journey is delayed.
- If travelling abroad, make sure you give your child their medication at regular intervals and make gradual adjustments to the time difference of the country you are visiting. If crossing time zones, ask advice from your pharmacist and plan ahead for any changes, you will need to do the same on your return.
- It is helpful to take a letter from your doctor with details of your child's condition and their medication. If possible get it translated into the language of the country that you are visiting – there are websites that offer this service.
- Avoid your child becoming overtired or dehydrated from the travelling and heat – keep drinks to hand and find opportunities for rest.



## TOP TIPS

'Make time for yourself - speak to your friends and family and do not be afraid to ask for help if you need it. Burning yourself out is not good for anyone.'





- If your child is going to be staying up late at night, encourage daytime rests to avoid overtiredness.
- If your child is going to be away from you for any period, make sure those supervising your child know of their seizures, any triggers you are aware of and what to do if they have any.
- ***The Traveller's Handbook for People with Epilepsy***, produced by the International Bureau for Epilepsy (IBE), has useful information and epilepsy first aid instructions translated into 13 languages. These can be downloaded from [www.ibe-travelhandbook.org](http://www.ibe-travelhandbook.org)





# Benefits and support

Having a child with a disability can put pressure on you financially. In the UK, benefit schemes and support networks are in place to help ease that pressure and ensure your child has all of the things that they need.

## Disability Living Allowance (DLA)

DLA for children can help with the extra costs of looking after a child who has difficulties with mobility or who requires more looking after than a child of the same age who does not have a disability.

There are two components to DLA – a care component and a mobility component and the amount that you get for each will depend on your child’s physical ability and their day-to-day needs. It may be that your child needs an assessment to check their eligibility, in the event of this you will receive a letter explaining where you must go and what paperwork that you are required to bring with you (e.g. birth certificates or passports as proof of identity). It is worth noting that your child will need to have an epilepsy diagnosis for at least 3 months before you can apply for DLA.

You can apply by completing a form online at the [GOV.UK](https://www.gov.uk) website or by calling 0345 712 3456 and ordering a printed form in the post.

## VAT Relief

If your child is disabled or has a long-term illness then you will not need to pay VAT on a range of goods, including seizure alarm systems and equipment that has been designed solely for disabled people.

You can learn more about VAT exemption for disabled people by going to the [GOV.UK](https://www.gov.uk) website or by calling HM Revenue and Customs on 0300 123 1073.

## NHS Low Income Scheme (LIS)

If you are on a low income or benefits, you may be able to claim back any travel expenses you incur whilst attending hospital appointments. For more information you can call the Low Income Scheme helpline on 0300 330 1343.

## Free Prescriptions

If you live in the UK all children are eligible for free prescriptions, including antiepileptic medication.

## Information, Advice & Support Services Network (IAS)

Formerly known as the National Parent Partnership Network (NPPN), IAS provides information, advice and support to disabled children and their parents. IAS is funded by the Department for Education and there should be an IAS service within each local authority. You can find out more about IAS and the closest service to you by visiting their website: [www.iassnetwork.org.uk](https://www.iassnetwork.org.uk)

## Blue Badge

The Blue Badge scheme is designed to help people with mobility issues to park closer to the places that they need to go. Your child may qualify for a Blue Badge if they receive the higher rate of the mobility component of the Disability Living Allowance. If your child has severe epilepsy and is under the age of 3 then they may also be eligible.

For more information about the scheme and to find out if your child qualifies for a Blue Badge, go to the website [GOV.UK](https://www.gov.uk) and search for ‘Blue Badge’.

# Taking care of yourself

Life is very busy and most parents we meet spend very little time looking after themselves; their children and family come first.



In order to be there for everyone else, you do need to take care of yourself. An occasional evening out together or even a quick daytime nap whilst your child is sleeping can help recharge your batteries. Even these simple things can seem unachievable at times and the effort they may take to organise can feel like it outweighs the benefits they will provide. But you are worth it, you will feel better for it and it will benefit the rest of your family.

Many parents go through a range of feelings when their child is diagnosed with a condition and it can take some time to find the new 'normal'. You may feel a sense of grief initially, or even shock at the diagnosis. Feelings of guilt are also felt by many parents but you are not to blame.

Some parents experience periods of feeling low or even depressed. If this persists you

need to get some help – make an appointment to talk to your GP.

You will also find that you become an expert on lots of things you never expected, all whilst maintaining being a parent and a partner. Over time you will find positive ways of coping and with the knowledge you acquire you may even begin to support others at the start of their journey.

# ★ ★ ★ ★ Preparing for the future

Thinking about what the future holds can be daunting.



You may feel like you are facing a vast mountain to climb and you have so many questions that you are looking for answers too. It is okay to feel this way; it's a natural part of coming to terms with what is happening to your baby or child.

Nursery and school may feel a long way in the future, but it is helpful to start planning early. It really will be here before you know it.

## Childcare

If you are using any childcare services, including family and friends, it is important to tell them about your child's epilepsy. They will need to know what to expect if your child has a seizure whilst in their care.

Tell them how to recognise the onset of a seizure and how to deal with it. They should also be made aware of any possible triggers. It is helpful to have all this information written down.



**Download a template from our website**

It will give you peace of mind knowing that they are confident to deal with any situation that arises.



## Starting nursery or preschool

Before your child starts nursery or preschool, arrange to meet with the person in charge to talk with them about your child's epilepsy. Again a written plan will really help them to understand what to expect and what they should do. If your child is prescribed an emergency or rescue medication, then any staff who might administer it must have been trained to do so. The nursery can be expected to make 'reasonable adjustments' to ensure that your child is included within the activities provided. If your child's development is delayed or if they are not making the progress you would expect,

it is likely your doctor will have already referred your child to your local child development team. Other professionals who specialise in supporting the development of young children, such as Occupational Therapists, Speech and Language Therapists, Physiotherapists and Educational Psychologists, may see your child so they can assess the child's progress. They will work with you to help you to support the development of your child's skills. They will also visit the nursery to help the team there to understand how best to work with your child.

To enable the best possible start to school life your local authority, who will be responsible for your

child's education, may be asked to carry out an Education, Health and Care Assessment.

This is the process that is used to identify and support any child who may have special educational needs or a disability. Having the assessment will help identify if any additional support is needed when they start nursery or school. Any professionals already involved with your child will be part of that process. If as a result of this assessment the local authority decides your child needs additional support, over and above what the school provides for all children, a plan will be put into place.

## Getting ready for school

It is vital the school your child will be attending is prepared for them to start. [The Children and Families Act 2014](#) brought in new statutory guidance on ‘Supporting pupils at school with medical conditions’ that must be implemented by all schools. You can ask to see the school’s policy relating to this, so you can see what they have put in place to ensure any child with a medical condition gets the most out of school life and is well looked after. Any child with a medical condition must have an Individual Healthcare Plan that describes their condition and how it is managed. It must also include information on how the condition impacts on their learning and development.

Epilepsy is a condition that affects the brain and as a result many children with epilepsy will have some difficulties in certain areas of learning, such as memory. It is important that the school recognises and identifies any potential areas of learning that are at risk. The guidance also states that the staff supporting your child must have appropriate training to ensure they understand your child’s condition and its impact on their life.

If your child has significant additional learning needs, they may also have an Education, Health and Care Plan. This document is written specifically for your child following an Education, Health and Care Assessment. You and your child will be central to the process and your aspirations for your child are an important part of this. All professionals who support your child work together to form this plan which is reviewed every year. The aim is to ensure that your child gets the support they need to make progress and achieve their full potential.



[Download a template from our website](#)



### TOP TIPS

The Assessment of Behaviour and Learning in Epilepsy (ABLE) questionnaire is a screening tool that helps parents and teachers to identify potential areas of concern that are known to be at risk in children with epilepsy. It was developed following research into the identification of educational difficulties in a group of children with epilepsy by the research teams at Young Epilepsy, Great Ormond Street Children’s Hospital and Institute of Child Health. You can download a copy from the Young Epilepsy website.



## Witnessing a seizure (Use this table to help record your observations)

Before the seizure					
Location					
Precipitating Factors	None	Anxious	Stressed	Tired	Other
Preceding symptoms/feelings	Irritable	Impulsive	Nauseous	Strange sensations	Other
Position at onset	Sitting	Standing	Lying	Other	
During the seizure					
Time at onset					
Did the child fall?	Yes/no	Forwards/backwards	Description		
Breathing	Rapid	Shallow	Deep	Laboured	
Colour	Note any changes in skin tone, particularly around the mouth and extremities				
Movements	Describe any movements of:				
	Head				
	Arms				
	Legs				
	Eyes	Deviated to left?	Deviated to right?	Pupils dilated?	Comment
Level of awareness/responsiveness	Fully aware	Reduced awareness	Responsive to voice	Responsive to touch	No responses
Any injury?	Tongue	Limbs	Head	Other	
Incontinence	Urinary: yes no			Faecal: yes no	
Time at end of seizure			Duration of seizure		
Action taken					



# Individual healthcare plan

Date of plan.....

Name..... Date of birth.....

Address .....

..... Postcode .....

Name of parent/carer .....

Contact number for parent/carer.....

Diagnosis (including any other conditions): .....

## Description of child's epilepsy

Epilepsy syndrome (if known): .....

Brief description of seizure(s), including typical duration(s) - please use additional sheet(s) if necessary:

.....  
.....

Possible triggers for seizures: .....

Warning signs that seizures may be about to happen: .....

.....  
.....

Action to be taken during a seizure: .....

.....  
.....

Description of recovery: .....

.....  
.....

## Current medication

Drug..... Strength..... Form.....

Directions .....

Drug..... Strength..... Form.....

Directions .....

Drug..... Strength..... Form.....

Directions .....





# Emergency treatment protocol

Name ..... **Date of birth** .....

Emergency medication should be given if a convulsive seizure has not stopped after ..... minutes.

Or if .....

.....

.....

.....

The emergency medication to be given is .....

The dosage to be given is.....

It should be given  orally  rectally  into the buccal cavity (between cheek and gums/teeth)

Circumstances when emergency medication should NOT be given:

.....

.....

.....

.....

Circumstances when a **second** dose of emergency medication may be given:

.....

.....

.....

.....

The second emergency medication to be given is.....

The dosage to be given is.....

It should be given  orally  rectally  into the buccal cavity (between cheek and gums/teeth)

## AN AMBULANCE SHOULD BE CALLED IF

.....

.....

.....

.....

.....



## ★ With thanks to

This guide has been made possible thanks to a generous donation from The True Colours Trust.



The True Colours Trust

Dr Sarah Aylett and Epilepsy Nurse Specialists Emma Ninnis and Mark Heathfield at Great Ormond Street Hospital NHS Trust for their valuable input into this guide.

Additional photography provided by Claire Ward-Dutton, Jenny Foster and Dee Andrews from [Small Beans Photo School](#).

To the great many parents who were willing to share their experiences and top tips with us – **thank you**.

## ★ More information and support

Young Epilepsy is the national charity working exclusively on behalf of children and young people with epilepsy. We are a leading provider of specialist health and education services, and offer support, information resources, training for professionals and also campaign to improve access to, and quality of, health and education services.

The Young Epilepsy website has a wealth of information to support you at every stage of your child's development. We often add new information and update our resources so it's worth checking regularly. You can also sign up to receive our email newsletter, which will keep you up-to-date and tell you about new resources for families. If you have a specific question, or just want to talk to someone – **we are here for you**.

 **01342 831342**

 **07860 023789**

 **helpline@youngepilepsy.org.uk**

 **[youngepilepsy.org.uk/infant-guide](http://youngepilepsy.org.uk/infant-guide)**



# Better futures for young lives with epilepsy and associated conditions



Find out more here: [youngpilepsyshop.org](http://youngpilepsyshop.org)



Check out our Facebook page: [facebook.com/youngpilepsy](https://facebook.com/youngpilepsy)



Follow our tweets: [twitter.com/youngpilepsy](https://twitter.com/youngpilepsy)



Watch us on You Tube: [youtube.com/youngpilepsy](https://youtube.com/youngpilepsy)



Visit your app store and search: **Young Epilepsy**



Find us on Instagram: [instagram.com/youngpilepsy](https://instagram.com/youngpilepsy)

We hope you have found this resource useful, we welcome feedback and suggestions so if there is anything that you would like to share, you can do so by clicking [HERE](#).

## Young Epilepsy Helpline

Call: 01342 831342 (Monday – Friday, 9am–1pm)

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

Text: 07860 023789

## Young Epilepsy

St Piers Lane, Lingfield, Surrey, RH7 6PW

Tel: 01342 832243 Fax: 01342 834639

Email: [info@youngpilepsy.org.uk](mailto:info@youngpilepsy.org.uk)

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

Young Epilepsy is the operating name of The National Centre for Young People with Epilepsy.

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Registered Charity No: 311877 (England and Wales).

Publication No: 360