

Childhood epilepsy



A Guide for Parents



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Inside

Monitoring seizures at night

Information to keep your child safe while sleeping



How should schools be supporting your child?

Make sure your child is fully included at school



Q&A: Medication

Frequently asked questions surrounding medication and vaccinations





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Foreword

Epilepsy is the most common neurological condition worldwide. It is complex and having a diagnosis does not always provide immediate answers.

Epileptic seizures can be truly terrifying to see. Families often feel alone and experience high levels of anxiety. The unpredictable nature of the condition often leaves families feeling a lack of control. As a family, learning to understand your child's epilepsy can be a daunting and difficult journey.

This handbook is one of a great many tools that Young Epilepsy has developed using research and consultation, with real families, to give you support in making informed decisions. The aim is to help you, one step at a time, as you navigate some of the new places and situations in which you will find yourself.

This guide has been created to help you understand how epilepsy presents, how to keep your child safe and tell you about available treatments. We also hope it will provide you with information on living with a child with epilepsy and managing their condition, at school and at home.

We hope you will find it useful as you begin your journey.

Professor Helen Cross OBE, The Prince of Wales's Chair of Childhood Epilepsy





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Introduction

This guide has been designed to give parents the basic information they need when caring for a child with epilepsy.

Caring for a child who is experiencing seizures can be distressing. The biggest challenge you will face is the fear of the unknown, so having some knowledge and information about epilepsy will help you to feel more confident. In the beginning it is likely you will not know much about the condition, or how it will affect your child and their future. Remember that living with epilepsy does not mean your child cannot enjoy a full and rewarding life.

This guide has been written by experts from Young Epilepsy, Great Ormond Street Hospital and University College London Great Ormond Street Institute of Child Health. It would also not have been possible without the help of a great 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 you would like to speak to someone, contact our helpline by phone, text or email:

 **01342 831342**

 **07860 023789**

 **helpline@youngepilepsy.org.uk**



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What is epilepsy?

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

This disruption causes seizures. Epilepsy is the medical term used when someone has a tendency to have recurrent seizures. A one-off seizure does not necessarily mean the person will develop epilepsy.

Epilepsy affects approximately 112,000 young people, aged 25 and under, in the UK alone. The first thing to know is that around three quarters of children will either outgrow their epilepsy or have it well controlled by antiepileptic medication. It is not necessarily a barrier to success.

Is it epilepsy?

Epilepsy can be difficult to diagnose. Doctors are reliant on eyewitness accounts of possible seizures to help them decide whether or not a child has epilepsy. Children can have unexpected events affecting movement, breathing or alertness for reasons other than epilepsy so other possible causes need to be considered.

Any investigations carried out are used to support a diagnosis or classify the seizures. For more information go to **Diagnosing epilepsy** on page 13.

What causes epilepsy?

It is perfectly normal to want to understand why your child has epilepsy and what may have caused it. Your doctor may be able to advise you on this. However, in around 60% of cases a specific cause is not found.

Cases with an identifiable cause predominantly fall under two categories: those that are caused by brain injury or brain disease (structural or metabolic causes) and those in which genetics are a factor.

Brain injury or diseases that may cause epilepsy:

- birth trauma – which can result in low oxygen levels (hypoxia) and subsequent damage to brain tissue
- abnormal development of the brain during pregnancy
- premature birth – which can cause haemorrhages (bleeds) in the brain tissue
- damage to the brain as a result of head injury
- infections of the brain (encephalitis) or brain linings (meningitis)
- brain tumours
- metabolic (biochemical) disorders such as low blood glucose, abnormal calcium metabolism or the effects of drugs (particularly alcohol)
- autoimmune disorders, where specific antibodies affect the brain

Genetic factors that may cause epilepsy:

- genetic abnormalities that cause epilepsy
- epilepsy syndromes with a genetic basis (such as Benign Rolandic Epilepsy or Juvenile Myoclonic Epilepsy)



TOP TIPS

Most genetic causes arise from a gene mutation in an individual. Very few epilepsies are inherited and there is often no family history of epilepsy.

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

Seizures can take many forms because the brain is responsible for such a wide range of the body's functions. What a seizure looks like will depend on where in the brain the burst of electrical activity occurs. Seizures may cause your child's limbs to twitch or their muscles to become very stiff or floppy. 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 stop what they are doing and stare. There really are a lot of ways a seizure can manifest itself.

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. For more information see **Managing seizures** on page 15.

Different types of seizure

There is a common misconception that epilepsy only involves someone falling to the floor and shaking. It is much more varied than this as there are over 40 different types of seizure and everyone's epilepsy is unique to them.

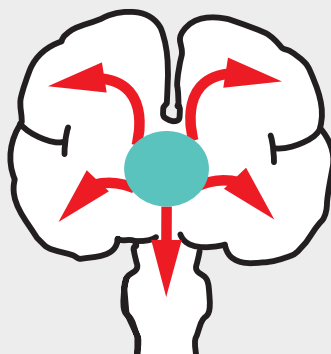
Identifying which type of seizure your child has experienced is really important as it will help the medical team to decide on the best course of treatment.

Young Epilepsy's free app includes an easy-to-use seizure video function, symptom log and diary which can help you to keep track of any suspected seizures.



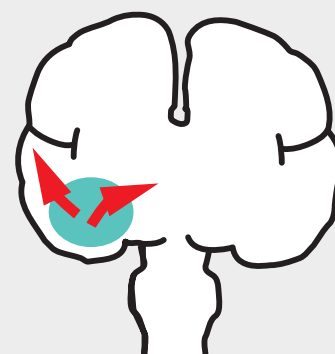
Seizures fall into two main groups:

Generalised seizures

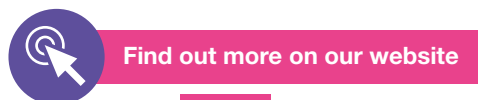


Both sides of the brain are affected from the start and the child will be unconscious, even if only briefly.

Focal seizures



Only part of the brain is affected. The symptoms and level of awareness depend on the area of the brain involved.





Generalised seizures

Generalised seizures occur when both sides (hemispheres) of the brain are affected by abnormal electrical activity and the child becomes unconscious.

Tonic seizures

Tonic means an increase in tone or tightness. In these seizures the muscles rapidly constrict, causing the child's limbs and body to become rigid. They may lose balance and fall to the ground, usually backwards, with consequent risk of injury. Tonic seizures are generally short (less than a minute) and the child recovers rapidly. They often occur at night.

Atonic seizures

Atonic is the opposite of tonic. During an atonic seizure there will be a loss of all muscle tone, which causes the child to suddenly flop forward and fall. These are sometimes referred to as 'drop attacks' and can appear quite dramatic as the child falls heavily to the ground. Although the seizure is very brief (less than 15 seconds) and the child can often continue with activities quite quickly, following the seizure, there is a significant risk of facial or head injuries. Protective headwear may be recommended to prevent injury if these seizures occur frequently.

Tonic-clonic seizures

Traditionally, these seizures were referred to as 'grand mal' which means 'great illness'. Now, however, the name tonic-clonic goes some way to describe the actual physical symptoms that

occur during the seizure. This is probably the type of seizure most people think of when they hear about epilepsy. Like all generalised seizures, they are caused by electrical discharges firing simultaneously throughout the brain. This type of seizure has two phases, the tonic phase followed by the clonic phase.

Tonic phase: The child becomes rigid as their muscles contract. They may let out a cry as air is pushed out of their lungs but they are not in any pain. Consciousness is lost and they will usually fall to the floor if standing, often backwards. Breathing may become laboured or stop momentarily. As their breathing pattern changes they may lose colour and the skin around the mouth may appear blue, as there is less oxygen than usual in the lungs.

Clonic phase: The muscles then relax and tighten rhythmically, causing the body and limbs to jerk or convulse. As the seizure comes to an end, the rhythmical jerking stops and the muscles relax. The child will regain consciousness but is often confused and it can take some time for them to return to normal. They may also have been incontinent or bitten their tongue. Often the child will be exhausted and need to sleep.

Myoclonic seizures

'Myo' means muscle and 'clonic' means jerk. When myoclonic seizures occur, the muscles contract rapidly rather as if the child has had a very brief shock-like contraction. Myoclonic

seizures usually occur shortly after waking (sometimes known as a 'messy breakfast') or before going to bed when the child is tired. During myoclonic seizures there is a loss of consciousness but, as these seizures tend to last less than a second, it is hardly noticeable. Sometimes myoclonic seizures occur in clusters.

Absence seizures (typical)

Absence seizures used to be referred to as 'petit mal' seizures. They often begin in childhood and do not usually continue into adulthood. They may occur many times a day and provoke a brief 'trance-like' state. The child will stare blankly into space and be unresponsive usually for 5 to 10 seconds. Recovery is immediate and the child continues what they were doing so the seizure may go unnoticed. Their failure to respond, when they are spoken to, often results in the child being told off in school for not paying attention or for daydreaming. The child is unaware of their seizure afterwards. This seizure type is associated with characteristic changes in EEG (electroencephalogram) recordings.

Absence seizures (atypical)

These atypical seizures do not start or finish as abruptly as typical absence seizures. The seizures usually last longer and may have additional features such as changes in muscle tone. These changes may result in small movements, such as a slight nodding of the head or a chewing action and the child may continue to respond to their surroundings. These atypical absence seizures are often associated with other seizure types and/or learning disabilities.

Focal seizures

Focal seizures are the result of intense electrical activity occurring in an area on one side of the brain, namely the 'focus' of the seizure. These seizures are described according to their manifestations, particularly whether they cause changes in movement (motor symptoms) or sensation (sensory symptoms) for the child. What the seizure looks like depends on where in the brain it comes from and what function that area is responsible for. There may be some impairment of consciousness with these seizures although sometimes the child may be fully aware throughout. Focal seizures can spread to affect the whole brain, resulting in a generalised seizure known as a 'bilateral convulsive seizure'.

Temporal lobe epilepsy

This is the most common type of epilepsy that causes focal seizures and it can start in children of any age. The temporal lobes are primarily responsible for smell and auditory perception, language and memory. Seizure activity focussed in this area of the brain means the child may experience a sudden strange mix of feelings, emotions or thoughts they might find difficult to describe. These may include

a feeling of déjà vu, butterflies in the stomach, nausea, odd smells or tastes. These sensations may occur alone or may be a precursor (aura) to further seizure activity that impairs consciousness.

These complex seizures may cause unusual movements, such as lip smacking or finger fumbling. They may also develop into tonic-clonic seizures and tend to be followed by confusion.

Frontal lobe epilepsy

The frontal lobes are a large area of the brain responsible for emotional behaviour, personality, planning, problem solving and some high level cognitive functions, as well as the control of movement. Seizures that arise from this part of the brain will vary in nature depending on which particular part of the frontal lobe is involved. They will often occur in clusters that start and end abruptly. They may produce weakness in certain muscles, including those used in speech, or cause sudden movements in the limbs, such as the flinging out of an arm. Seizures usually occur during sleep and can present in very strange and dramatic ways including head turning, grimacing, thrashing around or cycling movements of the legs.



Occipital lobe epilepsy

This lobe, in the posterior part of the brain, is responsible for processing visual information and recognising shapes and colours. Occipital lobe seizures are less common than other focal seizures. They usually present with vision-related symptoms such as rapid eye blinking, seeing patterns, flashing lights or colours. Seizures can spread to the temporal or frontal lobes. When this happens the characteristics of the seizure change, often making it hard to recognise as occipital lobe epilepsy.

Parietal lobe epilepsy

The parietal lobes are responsible for interpreting sensory information, spatial orientation as well as artistic and musical appreciation. Seizures arising from this part of the brain usually result in strange sensations and are often referred to as sensory seizures. These may present as tingling or warmth often occurring down one side of the body. There may be areas of numbness or an unusual feeling of a difference in the size of the limbs.



Seizure triggers

Sometimes, when a child has epilepsy, certain situations may make a seizure more likely to occur. These are called triggers and vary from child to child.

Commonly reported triggers include:

- overtiredness
- illness or fever
- stress and anxiety
- overexcitement
- ingestion of alcohol or taking recreational drugs
- changes in medication or missed doses
- menstruation
- flashing or flickering lights

If you are aware of your child's seizure triggers, it can make it easier to predict when seizures are more likely to occur.

Febrile seizures

Febrile seizures (also known as febrile convulsions) may occur in children between the ages of 6 months and 6 years. These seizures can happen when a child has a high temperature. A diagnosis of epilepsy is not usually made in these children as they are often isolated events with a known cause. However, some children may have additional risk factors that make it likely they will develop other types of seizure. These risk factors include abnormal development prior to the first febrile seizure or a family history of non-febrile seizures.



TOP TIPS

Focal seizures can spread to affect the whole brain, resulting in a generalised seizure known as a 'Bilateral Convulsive Seizure'.



Photosensitive epilepsy

Only about 5% of children with epilepsy are sensitive to flashing or flickering lights, geometric shapes or patterns. A flicker rate of between 5 and 30 times a second is the frequency most likely to cause problems.

Other triggers, commonly encountered in these children, include sunlight reflecting on water or the effect caused as the child passes by light shining through a row of trees or railings.

If your child has been diagnosed with photosensitive epilepsy, the following precautions would be advisable.

- If playing a video game, sit your child in a well-lit room, at least 3 metres from a TV screen or 1 metre from a computer screen.
- If possible, your child should use a remote control to change TV channels. If they approach the TV, encourage them to cover one eye with the palm of their hand.

- Do not allow your child to play a game on-screen when they are tired. Tiredness can increase the chance of your child having a seizure.
- Encourage your child to take regular breaks and rest between on-screen games. You could suggest a 10 minute break following 45 minutes of play.
- Consider buying a liquid crystal display (LCD) or 100 Hertz television (the number of times a flash or flicker occurs a second is measured in Hertz). These are less likely to trigger photosensitive seizures than plasma screens which often have high contrast levels.



TOP TIPS

If your child has photosensitive epilepsy and you think a flashing light or bold pattern will trigger a seizure, cover one of their eyes and turn them away from the stimulus to reduce the neuronal stimulation.



Non Epileptic Attack Disorders (NEADs)

NEADs differ from epilepsy as they do not occur as a result of disruption to electrical activity in the brain. NEADs can look the same (or similar) to epileptic seizures but it is important to remember the cause is different. They can be linked to anxiety, stress or stressful situations and may be mistaken for fainting or panic attacks which can include hyperventilation. NEADs are taken very seriously by medical professionals and can be treated successfully.



Epilepsy syndromes

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 age of onset of seizures, types of seizures, EEG (brain wave pattern) changes in between or during seizures along with other tests such as MRI brain scan or genetic investigations.

With the rapid advances in genetics more syndromes are being recognised. Here are a few of the more common syndromes and you can find further information on others, seen in children, on our website.



[Find out more on our website](#)

Childhood Absence Epilepsy

This syndrome affects up to 12% of children with epilepsy. Absence seizures, with loss of awareness lasting several seconds, tend to recur throughout the day. The seizures, though frequent, tend to be brief and respond well to medication. This type of seizure tends to start between the ages of 4 and 9 years and 90% will grow out of their seizures by adolescence. Development tends to be normal in these children though concentration at school may be affected. Sometimes they may develop other seizure types.

The diagnosis is usually made by a combination of clinical history, triggering of seizures by hyperventilation and EEG testing.

Juvenile Myoclonic Epilepsy (JME)

This syndrome starts most commonly between the ages of 12 and 18 years. It is associated with myoclonic jerking movements of the limbs. Many children have tonic-clonic or absence seizures as well. Seizures are often triggered by tiredness, stress or alcohol and up to 40% of children are photosensitive. There may be a genetic link with JME occurring in other family members. There are usually changes seen on an EEG and medication is usually effective. This form of epilepsy often continues to adulthood though usually becomes less severe.

Benign Rolandic Epilepsy

This form of epilepsy tends to start between the ages of 3 and 10 years. It has a good outcome with most children becoming seizure-free by the age of 15. Typically, children have two or three focal seizures affecting the mouth and face, usually at night or soon after waking, which often results in dribbling, gurgling or difficulties

with speech. These can develop into tonic-clonic seizures. Usually, children are otherwise well with no significant learning impairment. Diagnosis is based on description of the seizures and sometimes accompanying EEG changes. Some children do not need medication, especially if they have infrequent seizures at night, but for others medication can help to control their symptoms.

Panayiotopoulos Syndrome

This usually starts between 3 to 5 years of age, though sometimes a little older. Seizures occur very infrequently and are characterised by nausea and vomiting, sweating, dilated pupils and drooling. It is often associated with turning of the head, or eyes, to one side and sometimes clonic movements of the limbs. The child may become unresponsive and these seizures tend to be prolonged, often lasting 20 to 30 minutes or more. This syndrome is diagnosed by the typical seizure pattern and EEG which shows spikes, mainly in the occipital area of the brain. Children are otherwise well and development is normal. As seizures are so infrequent, nearly always stopping within 2 to 3 years, medication is often not necessary.

Diagnosing epilepsy

Although there is no single diagnostic test for epilepsy, a number of investigations are used.

The results of these tests, together with eyewitness accounts of seizures or film recordings, will be considered when making a diagnosis. The investigations also aim to look for an identifiable cause and to help determine the best treatment.

Your doctor will want to know details of the whole episode, including what happened before, during and after the seizure. They will need to ask you lots of questions when you meet them. If you can film any episodes (on your phone) this can be very helpful, but always ensure your child's care needs are met before worrying about capturing an event on film. Make a note of how long seizures last. It will also be helpful if you can keep a description of exactly what happens to your child during a seizure or suspected seizure.



TOP TIPS

When going for an ambulatory EEG, remember to dress in clothes that are easy to remove, e.g. with buttons or zips, so they do not cause problems going over the head.

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, the computer records the electrical activity occurring in the brain. It can give the doctor detailed information about any seizures that take place.

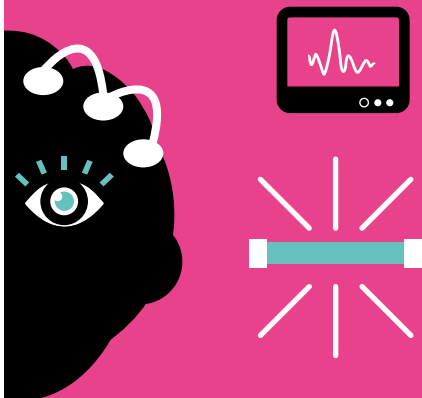
It is a painless investigation but can take time. The EEG is most useful when it is used alongside video recordings so your doctor can observe what is going on in the brain and, at the same time, witness how your child is behaving.

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 to identify an **epilepsy syndrome** as well as assist the doctor in deciding on the most appropriate treatment.



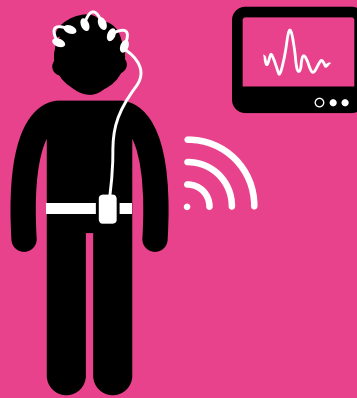
Routine EEG

The recording lasts for around 30 minutes to an hour and is done whilst your child is awake. They may be asked to open and close their eyes, watch a strobe light (to look for photosensitivity) or to breathe heavily (hyperventilate) to see how the brain responds.



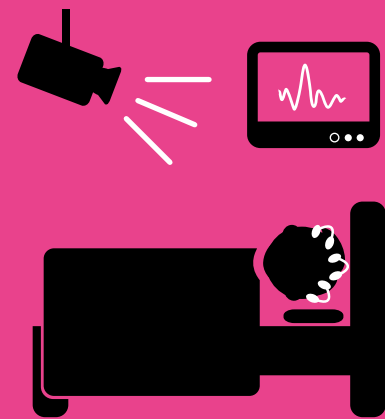
Ambulatory EEG

The electrodes are placed on the head and connected to a small mobile unit carried in a bag around the waist. The child may go home for several hours or sometimes days. They can carry on as normal and the EEG records activity throughout the day and night. Data is downloaded back at the hospital.



Video telemetry

Your child has to stay in a special room during this procedure whilst the EEG is recorded simultaneously with a video. It usually involves an overnight stay in a hospital or specialist centre.



Brain scans

Brain scans are used to give a detailed picture of the brain's structure. This can be helpful in identifying any areas of the brain that have not developed perfectly, or any area of damage to brain tissue. MRI (Magnetic Resonance Imaging) scanning, which uses magnetic fields, is the technique of choice for investigating epilepsy. If the child presents with a sudden illness or seizures, CT (Computerised Tomography) scanning may be used as this can be done more quickly and is readily available. CT scans use low-dose radiation X-rays.

Scans are only carried out when the benefits of doing so outweigh the risks. They are relatively safe and painless, although your child may require sedation as they need to be very still in order to obtain a clear image.

Sometimes an injection is given as part of the procedure. A dye is injected into the bloodstream which highlights the blood vessels in the brain.

The scans identify whether there is any structural abnormality in the brain, for example as the result of a 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.

Blood tests

In some children, blood tests may be performed to exclude other diagnoses, or in an attempt to find the underlying cause of the epilepsy. If these tests are required then all blood samples can usually be taken in one go.



TOP TIPS

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

Managing seizures

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


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

1




Stay calm and make sure your child is in a safe place with space to move freely. Ensure 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. Gently tilt their head back as 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 you can administer at home. Paramedics will 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...



Changes in breathing



Movements of the arms and legs



How long it takes for your child to fully recover

Head movements



Eye movements



Medication given



How long the movements or behaviours last



Changes in skin colour



Changes in how your child responds to you



It is also helpful to note what your child was doing before the episode started and where it happened.



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



Keeping records

It is important to monitor any unusual behaviour in your child as it could be seizure-related. Recording abnormal, or strange, movements and behaviour can help to build a clearer picture of your child's epilepsy, resulting in treatment that is better targeted to their seizures.

The free Young Epilepsy app is a tool which can be used to help keep accurate records of your child's epilepsy. It includes an easy-to-use seizure video function, symptom log, diary and medical prompts as well as discreetly stored emergency and contact details.

Sudden Unexplained Death in Epilepsy (SUDEP)

Thankfully this condition is uncommon, affecting 1 in 1000 people with epilepsy. It only occurs rarely in children.

SUDEP is said to have occurred when someone, with epilepsy, dies suddenly and unexpectedly for an unknown reason with, or without, evidence of having had a seizure. It usually occurs at night when there are no witnesses. There are known to be changes in heart rate and breathing during tonic-clonic seizures but there is no obvious explanation for death in SUDEP.

Although rare and unpredictable, certain risk factors increase the risk of SUDEP. Young adults living alone, who have poorly controlled tonic-clonic seizures during sleep, can be at greater risk. Abrupt or frequent medication changes, the need for more than one antiepileptic drug or sudden withdrawal of medication can also increase the risk.

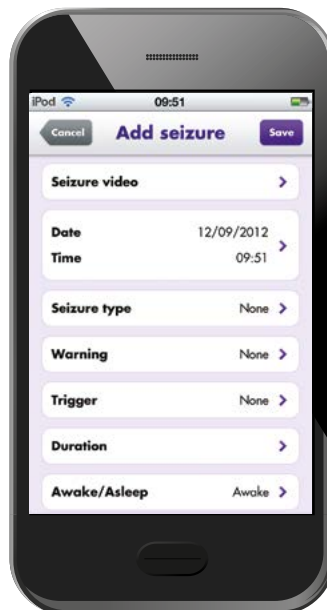
Remember SUDEP is rare but action can be taken to reduce the risks. It is important to encourage your child to take their medication regularly, reliably and to avoid adjusting the dose without consulting a doctor. Identifying seizure triggers (e.g. overtiredness or alcohol) and avoiding them can help. If your child is away from home, encourage them to confide in friends about their epilepsy and to explain to them what to do in the event of a seizure.



Use our app



Factsheet available on website





★ Treatments for epilepsy

Antiepileptic medication is the first line of treatment for epilepsy, although there are other options available that may be considered if seizures prove drug resistant.

Medication

The most common treatment for epilepsy is medication. Medicines used to treat epilepsy are 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 used on adults before they are licensed for use in children. Your doctor will choose the best one for your child based on a number of factors. These include the types of seizure they are experiencing, which syndrome they have, the likelihood of seizures recurring and the benefits or potential adverse effects of the treatment.

It is not usual to start treatment after just one seizure unless it occurred for a clear reason which makes it very likely that further seizures will follow.

How do AEDs work?

Antiepileptic drugs work by creating an environment in the brain making 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 everyday functioning. During seizures a combination of processes can disrupt the delicate balance within the brain and this results in sudden bursts of electrical activity. AEDs are designed to maintain a better balance so this disruption is prevented. Some AEDs enhance particular chemical processes within the brain and others work by blocking or inhibiting different chemical processes.

Finding the right medication for your child may take some time, so it is important to persist. AEDs are always introduced at a very low dose and then gradually increased. This process 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 you follow the plan given to you by your doctor. The optimum dose for your child is decided using a calculation based on your child's height 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 your child's other body systems, such as their liver, are responding to the medication.

Medications don't always work and your child may continue to experience seizures even when they are taking the optimum dose. If there is no change in the frequency of the seizures, your doctor will recommend trying an alternative AED.

When another AED is introduced, it may be as an 'add-on' to an existing medication which is continued. Alternatively, it may replace the existing medication, which will need to be gradually reduced. This can be very frustrating as starting and stopping medications can take a long time, but it is important to be patient and stick to the plan.



TOP TIPS

An **individual Healthcare Plan (IHP)** or an **RCPCH Epilepsy Passport** can help to ensure any important information about your child and their epilepsy is available in an emergency.

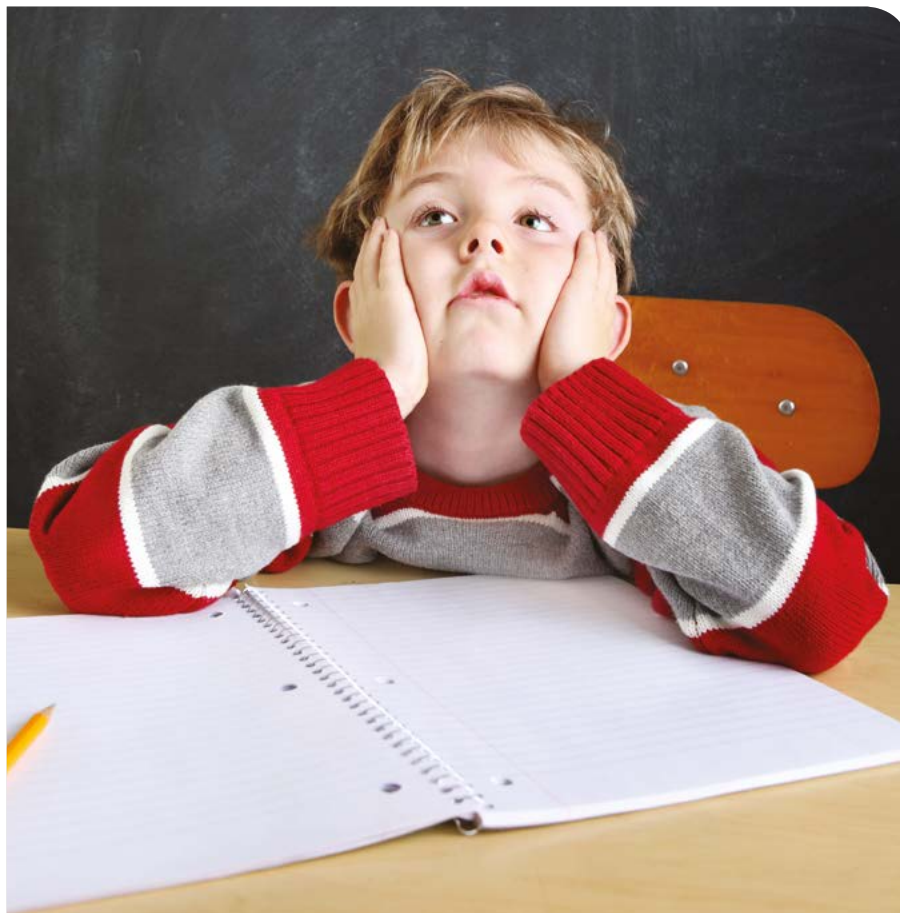
Side effects of medication

As with all medications, AEDs 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.

Some common side effects of AEDs include:

- drowsiness or lethargy
- irritability or mood swings
- changes in behaviour
- weight loss or gain and appetite changes
- difficulty concentrating, learning and memory problems
- dizziness or unsteadiness
- hair loss

It is important you keep a record of any responses to medication, changes in behaviour or potential side effects so you can tell your doctor. Monitoring behaviour is especially relevant in younger children as they may not be able to tell you if they are feeling nauseous, but they may be irritable or off their food.



TOP TIPS

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

Taking medication

Most medications will be available in a form suitable for your child. Those most likely to be 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, but it is best to check with the pharmacist before doing this. **Slow-release tablets should not be crushed.**

- It is important the medication is given regularly and at set times each day to maintain constant blood levels to optimise seizure control.

- If your child has been taking medication regularly, do not stop it suddenly without advice from your doctor.
- Always keep a record of the different medications your child has been prescribed. We can believe we remember which medication was given in the past, but we forget all too easily. It is best to have a record of when a medicine was started and stopped, the dose given and the results and side effects it had.
- Always check you have enough medication for your child so you do not run out.



Use our app

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 seizures prove drug-resistant.

Neurosurgery

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

- medication is ineffective
- the results of detailed investigations show the seizures are coming from a specific part of the brain
- removal or disconnection 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 plenty of opportunities to discuss the risks and benefits with your child's doctor and surgeon. It is likely your child will need help too and a play specialist can spend time with your child to help them understand what will happen.

Depending on the type of epilepsy and area from which the seizures originate, there are a variety of surgical procedures that may be performed.



Vagus Nerve Stimulation

Vagus Nerve Stimulation (VNS) can be used alongside other treatments, such as medication, and is considered 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 there can be 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.

Ketogenic Diet

Dietary treatments for epilepsy have been around for over a hundred years. There are a number of specialised diets available. They are all based on the same principle of using a controlled diet to enable the body to produce ketones by metabolising fats. This diet, used alongside AEDs, may not be effective for everyone but, for some, it may improve seizure control 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



Factsheet available on website



Factsheet available on website



Factsheet available on website



Deep Brain Stimulation

This is a procedure that may be considered for those whose seizures are poorly controlled on antiepileptic drugs and for whom other surgery is not suitable. It involves electrodes being inserted into a part of the brain where there is epileptic activity. These are attached to extension wires under the skin leading to a neurostimulator in the chest. Impulses from this, controlled by a programmer, can stimulate the part of the brain with epileptic activity. However, as the evidence for its efficacy is limited and there is a risk of side effects, careful consideration is taken before this option is commenced. There is currently restricted availability for this procedure.

Complementary medicine and alternative therapies

Finding a way to control your child's seizures with no side effects would be ideal. Some people turn to complementary therapies such as homeopathy, aromatherapy, massage, acupuncture, chiropractic treatment, yoga or relaxation therapy to help their child's epilepsy. There is no conclusive scientific evidence these therapies reduce seizures. As a result, most doctors will not recommend them.

It is important to discuss with your doctor first if you are planning to see an alternative therapist.

If stress is one of your child's triggers for seizures, it may be that massage with certain essential oils will help relaxation. It is important that any therapist is qualified or regulated and knows about your child's epilepsy and their treatment.

Be aware that although some oils have been reported as beneficial, others may make seizures worse. It is important not to change your medication without consulting your doctor and to consider the possibility of an increase in seizures. Some herbal remedies, for example St John's Wort, may interact with antiepileptic drugs and affect seizure control, so always take medical advice before starting anything new.



Factsheet available on website

External Trigeminal Nerve Stimulation (eTNS)

This is a newer procedure not yet widely available in the UK. An external stimulator attached to patches on the forehead triggers impulses along the trigeminal nerve. This sends signals to specific brain regions to prevent seizures. It is designed to be worn at night and has been used in those aged 9 years and upwards with drug-resistant epilepsy, as an addition to antiepileptic drugs. Current results suggest a greater than 50% reduction of seizures in some individuals and further trials will show if benefits persist long term.





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

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

If a dose of medication is missed and you remember up to three hours after missing the dose, give the forgotten dose immediately. If you remember only at, or near, the time 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, you should 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 you seek urgent medical advice from your doctor or pharmacist. Some medicines may not cause much of a problem if an

extra dose is taken, but others may cause side effects if the blood levels rise even a little.

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.

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 ask 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 change to your medication or its dose, 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, so consult a pharmacist or doctor before giving this to your child.

Can my child have the usual childhood vaccines?

Children can be safely immunised with routine childhood vaccines if their condition is stable. If still being investigated, children can have their immunisations postponed.

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

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 high temperature can occur within 24 hours of the DTP vaccine and regular paracetamol for 24 hours after the vaccine may prevent this. With the MMR vaccine, a temperature rise may occur up to a week after.

Are meningococcal and HPV vaccines safe?

Teenagers and students are offered a meningococcal vaccine to protect against meningitis. This can safely be given if seizures are stable and any fever after the immunisation can be treated with paracetamol. Girls aged 12 to 13 years are offered the HPV vaccine and this is usually administered at school. Occasionally, fainting with associated jerk-like movements has been reported afterwards. Lying down for 15 minutes post-immunisation can help to prevent this.





Working with professionals

When you have a child with a health condition, you will suddenly find yourself in a new place where it seems everyone is speaking a language you don't yet understand. There is a lot to learn and it can feel very daunting.

The professionals you will meet are highly trained specialists who know a lot about epilepsy and the brain, but remember 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 ask you for information about what has been happening. Remember there is no diagnostic test for epilepsy, so the doctors rely on information from you and your observations of any suspected seizures.

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

Who's who?

If you were at home when your child first had a seizure, or suspected seizure, then it is likely you will have seen a **paediatrician** (children's doctor) in the accident and emergency department.

However, some children may be seen by their **GP** first and then referred to a paediatrician at the local hospital.

Your paediatrician will be your main doctor and will keep your GP informed about diagnosis and treatment. You should still see your GP if you have any other health concerns. If you have a **health visitor**, they will also be kept informed. Your paediatrician may arrange for your child to have some investigations. They will decide on the best course of treatment to be prescribed and inform your GP.

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 are additionally trained in epilepsy and are known as having a

special interest in the condition. At the hospital you may also see an **epilepsy nurse specialist**. This is an experienced nurse who has completed additional training 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 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 and may discuss other treatment options or medications with you. They will write to your paediatrician and GP to keep them informed so they can monitor your child's treatment.

Preparing for consultations and appointments - top tips from parents

It is worth spending some time preparing for any appointments with your child's doctor. Write down any questions 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 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 seizures, including any suspected seizure activity you may be concerned about. It's easy to think you will remember it all, but it is very easy to forget. (Young Epilepsy has a free app you can use, or you can download record forms from the website.)

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

Ask about emergency medication and, if it is prescribed, make sure you understand when it should be given – it 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. This could include 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 years and what the impact will be on your child's development.



[Find out more on our website](#)





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Living with epilepsy

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

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 or even a quick daytime nap can help recharge your batteries. Even these simple things can seem unachievable at times and the effort required can feel like it outweighs the benefits. It is worth making this effort as you will feel better for it and it will benefit the rest of your family.

Family and friends can be a great source of support, although there may be times when you feel they don't understand the challenges you are facing. Some parents 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 go through a range of feelings when their child is diagnosed with a medical condition and it can take some time to find the new 'normal'. Initially you may feel a sense of grief or even shock at the diagnosis. Some parents experience feelings of guilt, but it is important to accept that you are not to blame.

When worry and anxiety take over and you feel overwhelmed, it is important you recognise you need support too. There may be some periods when you feel low or even depressed. If this persists, you need to seek some help – make an appointment to talk to your GP.

You will also find you become an expert on lots of things you never expected. Over time you will find positive ways of coping. With the knowledge you acquire you may even begin to support others as they start their journey.



TOP TIPS

Make the most of your appointments: remember your epilepsy diary, speak up if you feel changes are needed to improve seizure control, discuss any side effects you think your child is experiencing.

A good night's sleep

In order to face the day you need to start after a good night's sleep. Extreme tiredness can be really hard on your physical, mental and emotional health. If you find you are not getting sufficient sleep, then try to rest when you can – you really will feel better for it. Enlisting friends and family to help with meals, household chores and looking after other children from time-to-time can give you some respite.

The experience of a serious medical condition is a stressful event for any family. For the child, concerns about seizures at night and anxieties about their epilepsy in general can affect their sleep. 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. Creating the right environment, by avoiding electronic devices and televisions in the bedroom and ensuring it is dark and quiet, will help.



Sleep development

The general advice in the table below also applies to children with epilepsy. If your child has a specific sleep problem, or you have a particular concern, do talk to your child's GP or paediatrician for further advice. Sleep develops just like many other skills. Sleep patterns and requirements change dramatically over the first months and years of life. These patterns will continue to develop and mature right up to late adolescence. The following table shows you what to expect and gives some general tips on things you can do to encourage sleep.

Age	Night-time sleep/ 24 hours	Naps/ 24 hours	Milestones in sleep behaviour	General advice
Newborn to 2 months	10 to 19 hours of sleep per 24 hours. Sleep periods separated by 1 to 2 hours awake both during the day and at night time.		Sleep gradually aligns with periods of dark.	Place baby to sleep on his/her back, on a firm surface.* Encourage natural light exposure in the morning.
2 to 12 months	9 to 10 hours. Average 2 to 6 wakings a 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 special stuffed toy).	Put baby into cot, drowsy but awake. Aim to wean off night feeds/ bottles by 6 months. Avoid sleep-onset associations that require parental intervention (e.g. rocking, verbal soothing).
12 months to 3 years	9.5 to 10.5 hours.	2 to 3 hours in total; decreasing from 2 to 1 nap per day.	Increasing importance of ritual and routine.	
3 to 5 years	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.
6 to 12 years	9 to 10 hours.	Daytime napping, sleepiness or dozing off are not normal in this age group. This may suggest a problem with sleep quantity or quality.	Circadian preference (i.e. whether a person is a natural 'owl' or 'lark') begins to emerge.	Avoid television at bedtime and do not have a TV set in the bedroom. Avoid caffeine-containing drinks (e.g. Coke, Pepsi).
12 to 18 years	9 to 9.5 hours. Most get 7 to 7.5 hours due to early school start times.	None.	The onset of puberty brings a natural sleep phase delay (i.e. tendency to stay up or wake up about 2 hours later than in middle childhood).	Electronic devices (e.g. mobile phones, gaming systems) should not be used near bedtime. Encourage efficient time management rather than 'staying up' to complete homework.

* apart from this point, which applies up to the age of 18 months, advice applies to all subsequent age groups as well.

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



Monitoring seizures at night

You will very naturally be anxious if your child 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. Seizures occurring during the night are often referred to as nocturnal seizures.

There are also some types of seizure that tend to occur on waking, such as infantile spasms. 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.

Many parents are particularly anxious about nocturnal seizures as it is not possible to be with your child all the time. Parents need sleep too. Disturbed sleep may be inevitable when caring for a child who has seizures overnight but many parents like the added peace of mind a seizure monitor or assistive technology equipment may give them.

There are a number of devices on the market designed to alert you to the onset of seizures.

Every child is different and so you must be sure to consult your doctor, or epilepsy nurse specialist, if you are considering purchasing any night-time safety equipment.

Basic audio-visual equipment

The simplest form of device is a listening monitor, such as a baby monitor. This allows you to hear any sounds from your child's room, but remember some seizures may be silent and therefore you may miss them. You can also have a monitor with a camera, so you are able to see your child. However, neither of these devices will directly alert you to a possible seizure.

Monitors detecting movements associated with seizures

Several devices on the market monitor movements associated with seizures, including muscle spasms. A special sensor pad is placed under the mattress of the bed or cot and settings are tailored so its sensitivity levels can be altered to detect even the small movements associated with some seizures.

When movements are detected, an alarm is activated on the base unit or a mobile pager. The settings are programmed for each individual and take into account other movements that may be associated with turning over or adjusting sleep position. An adjustable delay control

feature allows these movements to be detected without triggering the alarm. As an additional feature some monitors include a microphone to detect any vocalisations or sounds that may occur before or during a seizure.

There are also digital movement sensor monitors available which provide a discreet way to monitor seizures. The monitor itself can fit into the palm of a hand and is equipped with high performance sensors able to identify seizure-induced movements, whilst ignoring sleep activities. Any detected irregularities alert the parent or carer via a radio system.

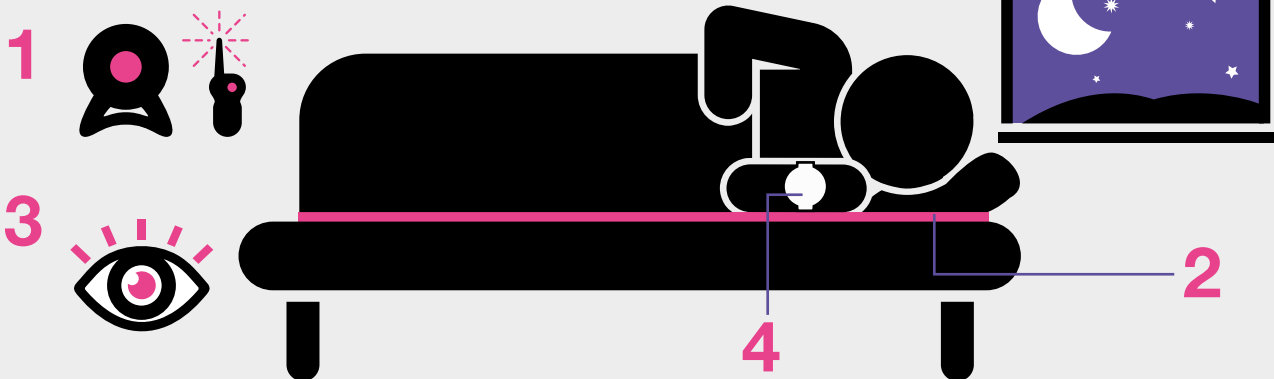
Multi-symptom monitoring

These monitors are often designed to detect a number of symptoms associated with seizures – including bed wetting and salivation. They can also be activated if the child leaves the bed, if the child falls out of bed during a seizure or leaves the bed in a confused state. There is no one-size fits all solution, but the sensors used in each monitor are personalised according to the needs of the child.

Monitors that detect changes in heart rate

Some research has reported there are often changes in heart rate at the onset of a seizure. A device is now available that monitors heart rate overnight. A small sensor is worn on the wrist or ankle and uses Bluetooth technology to connect to a base unit (dedicated iPad) running an app which sends an alert if the heart rate alters from the set parameters.

Ways to monitor seizures at night



1 Basic audio-visual equipment



Remember some seizures may be silent and therefore you may miss them using baby monitors.

2 Monitors that detect movements associated with seizures



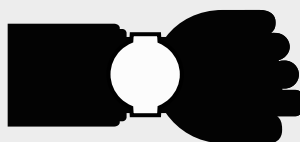
A special sensor pad is placed under the mattress of the bed or cot and, when movements are detected, an alarm is activated on the base unit or a mobile pager.

3 Multi-symptom monitoring



Monitors detect a number of symptoms that may be associated with seizures – including bed wetting and salivation. They can also be activated if the child leaves the bed.

4 Monitors that detect changes in heart rate



A small sensor is worn on the wrist or ankle and an alert is triggered if the heart rate alters from the set parameters.

Finding the right solution for you

There are a number of manufacturers of assistive technology devices designed to alert you when seizure-like activity occurs. It is important to contact a number of them to find out which will be most suitable

for your child. 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.

As with all medical devices, seizure monitors undergo rigorous testing and must be compliant with certain ISO standards. A list of manufacturers and suppliers of monitors is available from our website.



Find out more on our website



Sleepovers

Having sleepovers can be an important part of your child's social development. If you are anxious about your child going to a sleepover, in case they have a seizure, the best thing is to discuss concerns with the other parents as well as your child so they understand your reasons for being wary. An easy solution may be to have the sleepover at your house but inevitably circumstances will mean it needs to be at a friend's house at some point – such as for birthday parties. An initial step may be to pick your child up at an agreed time before bedtime and then work up to them staying overnight.

There are ways to reduce your anxiety and ensure your child's safety.

- Make sure the friend's parents are aware your child has epilepsy, knows what their seizures look like, how to manage them and check the parents are comfortable doing this.
- Discuss with your child whether the other children at the sleepover should know about their epilepsy. It is important they know to get an adult if a seizure occurs.
- Where relevant, discuss the management of any triggers with the friend's parents and your child – such as staying up too late and playing computer games for long periods without a break.



Explaining epilepsy to your child

It can be difficult to explain to your child what a condition like epilepsy will mean for them, especially when you are learning about it and coming to terms with it yourself. How you respond to the diagnosis can influence how your child copes with their epilepsy.

It is important to be open with your child. Most children cope better when they understand what is going on. How much you talk about it will depend on your child's age and level of understanding, as younger children may be overwhelmed with too many facts. Keep explanations easy to understand and be as positive as you can. It can help to 'normalise' their epilepsy, explaining that it affects many children.

Encourage your child to ask questions and to express feelings about their concerns. They may be anxious about all the unknowns, not being in full control or being 'different'. Help your child accept epilepsy for what it is and show it

is a manageable condition. It helps to support their participation in activities and sports they enjoy so they see how they can do things like other children.

There are many good resources and story books available, which you can read through with your child, to help explain seizures. If your child enjoys using a computer, there are some practical websites with forums where young people can contact others in a similar position and exchange information.

Siblings may also find it difficult and frightening when a child has seizures. They may feel isolated, anxious or helpless. Explaining things to them, discussing their feelings and encouraging questions may help to resolve any build-up of jealousy, fear or resentment.

It is also important to encourage friends and relatives to learn about the subject, so you may find yourself providing relevant information for them as well.



Balancing risk and safety

Taking part in sports and activities is important for all children. You should encourage your child to enjoy a full social life with as few restrictions as possible. Seizures are less likely to occur when children are engaged in activities they enjoy.

It is important to take sensible precautions, assess risk with each activity and consider ways of making each one as safe as possible, while avoiding being overprotective. Imposing too many restrictions can affect your child's self-esteem and increase the likelihood of anxiety and depression.

Things to consider when assessing risk:

- your child's age
- your child's capabilities
- frequency of seizures
- any auras or warnings prior to seizures
- types of seizures
- triggers for seizures
- consequences if a seizure happens during the activity

Swimming

Ensure a competent swimmer (who is aware of the seizures) swims with your child and is watching them at all times. At the start of the session, inform the lifeguard about your child's epilepsy. If possible, try to choose less crowded times for swimming.

Bathing

Children should be supervised in the bath at all times. Older children should use a shower where possible, preferably one with a seat. If an older child has a bath, keep the water shallow and ensure someone is outside the door, which should be unlocked and preferably ajar, so they can hear if a seizure occurs.

Other sensible precautions include:

- plastic, not glass, shower screens or a shower curtain
- a water temperature regulator set to between 37–40°C to prevent scalding
- bathroom doors hung so they open outwards to ensure your child will not be trapped in the event of a seizure

Cycling

Take precautions when your child is out on a bike. Ensure they are always accompanied and avoid busy roads. They should always wear a helmet.

Playing

Children should be encouraged to go out with their friends but you should discourage your child from climbing trees or anything higher than their own height.

Sleep

If your child has seizures at bedtime, it may be helpful to have bed guards. A solid design rather than slats will prevent limbs becoming trapped. To reduce injuries if your child falls out of bed, you can lower the height of the bed or put a mattress at the side to cushion any fall.

Some parents decide they would like a safety or anti-suffocation pillow. These are normally made of soft, highly porous foam that permit greater airflow than conventional pillows. They have a gentle rippled surface which provides an abundance of air cavities between the surface of the pillow and the net cover. These pillows should not be used for babies or children under three years old.

Safety precautions to take around the house

- Radiator and fire guards, preferably with rounded edges, should be secured in place.
- A cooker guard should be fitted and back hobs used when possible, with pan handles turned inwards and towards the back.
- Glass in doors, low windows and furniture should be safety glass if possible. If not, a protective film to cover the surfaces can reduce risk of injury.
- Fitting corner edge guards to furniture can reduce injury during seizures.



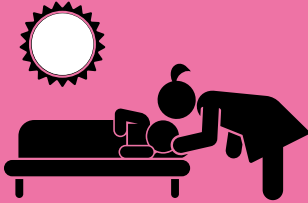
TOP TIPS

It is helpful to have bathroom doors that swing out, so change hinges if necessary. Always ensure any internal lockable doors can be opened from the outside.

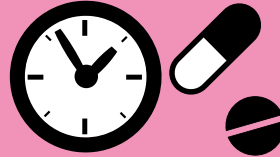


Travelling and holidays

There is no reason why you should not travel with your child in the same way as with other children, though it is important to consider taking the following precautions to make things easier.



Avoid letting your child become overtired or dehydrated from travelling and the heat. If your child is going to be staying up late at night, encourage them to have a sleep during the day.



Give your child their medication at regular intervals and make gradual adjustments to the time difference of the country you are visiting.



If your child has rescue or emergency medication prescribed for prolonged seizures, check the expiry date and have it with you at all times.



If you are travelling by plane, you should take your child's medication in your hand luggage in case your hold luggage is lost or delayed. Inform the airline about your child's condition. If your child has medication in liquid form, check with the airline regarding the rules about taking liquids on board.



Carry a doctor's letter with details of your child's condition and the medication they take, preferably translated into the language of the country you are visiting.



As the names of medicines vary in different countries, take medication in its original packaging and be familiar with the scientific (generic) name.



Before you leave for a holiday, make sure your holiday insurance covers emergency medical treatment for your child's epilepsy. 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 is going to be away from you for any periods during the holiday, a medical alert bracelet with details of their seizures would be useful.



Take extra medication with you, in case your return journey is delayed.

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. This can be downloaded from www.ibe-travelhandbook.org



Learning and behaviour

An epilepsy diagnosis is not necessarily a barrier to success; many children with the condition will achieve both academically and socially.

Although learning difficulties are not an automatic consequence of epilepsy, children with the condition are at greater risk of learning and behavioural issues than those without it. However, these difficulties are often missed because of the pressing medical needs of epilepsy.

You can learn more about the difficulties children with epilepsy face in school by reading Young Epilepsy's CHES (Children with Epilepsy in Sussex Schools) report. It is free to download from our website.



[Find out more on our website](#)

Effects on learning and behaviour

Children with epilepsy may experience difficulties with:

- visual, verbal and short-term memory
- sentence comprehension
- reading
- spelling
- speech and language
- mathematics and problem solving
- motor ability, e.g. handwriting and coordination
- maintaining consistency in learning
- psychosocial problems, e.g. low self-esteem, frustration, anxiety and poor motivation
- behaviour, e.g. hyperactivity, inattention and impulsivity

The impact epilepsy can have on learning and behaviour is often underappreciated. For children with epilepsy to thrive both academically and socially, it is vital these difficulties are identified and addressed, early on, by health and education authorities responsible for their well-being.





What causes learning and behavioural problems in children with epilepsy?

The four main factors that contribute to learning and behaviour issues in children with epilepsy are:

- seizure-related factors
e.g. tiredness
- side effects of antiepileptic drugs
- additional co-occurring conditions (comorbidities)
- psychosocial issues
- underlying cause of the epilepsy

How seizure-related factors impact learning and behaviour

The seizures themselves

The majority of seizures will disrupt a child's ability to learn because they either cause the person to become unconscious or alter their awareness. Even if a child retains complete awareness during a seizure the physical, sensory or cognitive symptoms experienced may still disrupt their ability to concentrate, process information or participate in learning activities.

Learning difficulties may be directly related to the types of seizures that the child experiences.

Some specific examples include:

- **Absence seizures** – although brief, these seizures can occur frequently and cause the child to miss out on parts of their lessons.
- **Tonic-clonic seizures** – a child is likely to miss out on lessons after this type of seizure for various reasons. These include feeling extremely tired, the risk of injury, side effects of emergency medication and the possibility of admission to hospital.
- **Temporal lobe seizures** – some temporal lobe seizures can cause temporary problems with memory, including short-term, verbal and visual memory.



In addition, seizures can result in longer term issues with learning and behaviour as a result of interference with brain development. In some cases, the child may find it difficult to make learning gains, either in general or in specific areas. For others, a decline in learning or behaviour in specific areas may be observed. The extent to which this happens, if at all, is unique to each child and depends on the age of onset of their epilepsy and the frequency, duration or severity of their seizures.



Build-up to a seizure

The term 'prodrome' is used to describe changes observed in some children during the hours, or even days, before a seizure happens as the level of electrical activity gradually builds up. Behaviour changes may be noticed such as irritability, anxiety or becoming withdrawn. In addition, learning may be affected as the child's ability to process information, as well as their memory and concentration, may be affected.

Not every child will have a noticeable prodrome, whereas for some it may be very prominent. It is important that anyone involved in the care of a child, who has epilepsy, thinks about their behaviour prior to a seizure and whether there are any noticeable changes. If the child has quite a reliable prodrome, then it may be possible to adapt activities prior to their seizure to assist learning, boost safety and ensure inclusion.

Recovery after a seizure

It is not uncommon for children to feel extremely tired, have a headache and experience muscle weakness following a seizure, as their brain and body recovers. In addition to these physical symptoms, the child may also feel confused and experience problems with memory, processing and concentration. For some children, these problems last for a few hours, or even days. The exact nature of the child's recovery will be unique to each child and dependent on many factors including the type of seizure experienced, its duration and severity.

Sleep disruption

It is not uncommon for children with epilepsy to experience disturbances in brain electrical activity during sleep, which may or may not be accompanied by a seizure. In addition, some antiepileptic drugs can cause disturbances to sleep.

Disrupted sleep patterns in children can interfere with memory formation and emotional learning. This can result in the child being tired and possibly experiencing problems with memory and emotional well-being the following day.

How antiepileptic drugs can affect learning and behaviour

Some antiepileptic drugs can cause side effects that may affect a child's learning and behaviour.

These include:

- drowsiness and lethargy
- slower information-processing
- poor attention
- memory difficulties
- problems with movement and coordination
- mood changes

Not all children will experience side effects as a result of antiepileptic medication.

Side effects are more likely to occur when a new drug is first introduced, if a child takes more than one antiepileptic drug or if the dosage is changed. It is important for those involved in the care of the child to be aware

that learning and behaviour may fluctuate as the child grows and medication dosages are altered accordingly, so the support provided can also be adjusted.

How additional comorbidities affect learning and behaviour

A **comorbidity** is the presence of one or more additional disorders alongside a primary condition or illness. Recent research from Young Epilepsy has shown that 60% of children with epilepsy meet the diagnostic criteria for at least one such comorbidity. There are certain comorbidities that children with epilepsy have a higher probability of developing.

Common comorbidities with epilepsy include:

- Autistic Spectrum Disorder (ASD)
- Attention Deficit Hyperactivity Disorder (ADHD)
- Developmental Coordination Disorder (DCD)
- emotional disorders, such as depression and anxiety

Having a comorbidity can complicate both the treatment and management of epilepsy, as well as the co-occurring condition. It can also result in further learning and behavioural difficulties. It is important appropriate interventions are put in place to manage these.



Epilepsy and Autism

The characteristics of autism vary widely, as do its effects. However, every child on the autism spectrum will show some of the characteristics in the table. On average, approximately a quarter of children with autism develop epilepsy, compared to less than 1% of children without the condition.

If a child with autism has any of the following risk factors, their chances of developing epilepsy are increased.

These include:

- **Learning difficulties** – the greater the degree of learning difficulties, the higher the risk of developing epilepsy.
- **Age** – the risk of developing epilepsy increases at adolescence.
- **Presence of other neurological conditions**
- **Presence of certain genetic conditions** – such as Fragile X Syndrome and tuberous sclerosis.

There are many theories for the higher incidence of epilepsy amongst children with autism, many of which are related to genetic factors.

Characteristics associated with Autism	
Prefers to spend time alone	Difficulty interacting with others
Poor motor co-ordination	Absence of empathy
Hypo-sensitivity to certain sensory stimuli	Hyper-sensitivity to certain sensory stimuli
Repetitive behaviour and movements	Failure to use imaginative and pretend play
Favours routine and resists changes	Rarely using gestures or facial expressions
Obsessive interests and excessive attachment to objects	Failure to understand social rules and conventions
Problems using language to communicate – may be delayed or lost	Problems adapting to change and unfamiliar situations as well as planning for the future

Medication and management issues

Some antiepileptic drugs have a negative effect on mood, potentially worsening any behavioural issues a child with autism may already have. Consequently, the decision around which behaviour management techniques to use may not be straightforward. Some of the more subtle seizure symptoms, such as not responding to verbal or visual stimuli as well as repetitive behaviours, can mimic behaviours seen in autism. As a result, many parents of children with autism find it hard to distinguish between the unusual behaviour their child exhibits and seizure activity. This could also delay the initial diagnosis of epilepsy.

Sleep complications

Both autism and epilepsy can interfere with sleep. As a result, poor quality sleep may worsen a child's behaviour or ability to learn and could trigger more seizures. If your child is experiencing problems with sleep, it is important to discuss it with your healthcare team to see if anything can be done to help.

‘Autism is a lifelong, developmental disability that affects how a person communicates with and relates to other people, and how they experience the world around them.’

National Autistic Society



Epilepsy and ADHD

The diagnosis of Attention Deficit Hyperactivity Disorder (ADHD) is made when a child shows abnormally high levels of inattention and/or hyperactivity and impulsiveness.

ADHD has three subtypes:

- predominantly inattentive type
- predominantly hyperactive-impulsive type
- combined inattentive and hyperactive-impulsive type

Some common characteristics of ADHD include:

- hyperactivity
- impulsive behaviour
- inattention
- difficulty learning new things
- performance may often depend on task
- disorganisation
- difficulty modifying behaviour in different settings
- specific learning disabilities
- problems with executive functions

Whilst ADHD affects between 3 and 5% of school age children, as many as 20–40% of children with epilepsy also have ADHD. The predominantly inattentive type is thought to be more common in children with epilepsy.

Explanations for the higher incidence of ADHD amongst children with epilepsy include:

- the side effects of antiepileptic drugs (including inattention, hyperactivity and mood problems)
- a common biological and/or genetic problem that causes both ADHD and epilepsy
- the effect of seizures and/or ongoing abnormal electrical activity on the brain
- psychosocial issues stemming from having epilepsy

Medication and diagnosis issues

A question still remains as to whether treatment of ADHD with stimulants is entirely safe for children with epilepsy or whether they increase seizure frequency. In cases where seizure control is poor and there is a history of tonic-clonic seizures, seizure frequency should be monitored closely in the months following stimulant introduction.

Some of the side effects of antiepileptic drugs, such as hyperactivity, inattention and aggression, can mimic some of the symptoms seen in ADHD. Furthermore, some seizure symptoms mimic behaviours seen in ADHD and vice versa. These factors may result in a delay to the diagnosis of either condition, or even misdiagnosis. For example, absence seizures are frequently misdiagnosed as ADHD.

Emotional disorders

Emotional issues, such as depressive and anxiety disorders, are some of the most common comorbidities within epilepsy.

Risk factors that may increase the chances of a child with epilepsy developing an emotional disorder are:

- adolescence
- taking more than one antiepileptic drug
- poor seizure control
- temporal and frontal lobe epilepsy
- family history of emotional disorders
- other medical conditions, especially those associated with epilepsy
- younger age of seizure onset
- female gender
- social problems
- side effects of antiepileptic drugs
- effect of seizures and/or ongoing abnormal electrical activity on the brain
- psychological and social issues stemming from having epilepsy



Managing challenging behaviour

Whatever the cause of challenging behaviour, positive behaviour management strategies are often effective. Children with epilepsy may experience problems with brain function and development, which means they may need more support to learn self-control and acceptable behaviour than you might expect of other children their age. They may also be more sensitive to issues around them.

Promoting good behaviour (proactive interventions)

- Address the child's needs to avoid frustration.
- Ensure appropriate, consistent expectations.
- Model good behaviour and communication.
- Reward desirable behaviours – this does not always have to be a physical treat. It could be stickers, praise, time with you, privileges or responsibility.
- Boost self-esteem.



TOP TIPS

Explaining to your child's friends about their epilepsy will mean they will feel more confident about spending time together. Children, like adults, are more positive and keen to help if they understand what is happening.

Pros and cons of punishing unwanted behaviour

Pros: Punishing unwanted behaviour can result in the behaviour you want in the short term because you are in charge and have authority.

Cons: Punishing unwanted behaviour does not address the cause, so different unwanted behaviours are likely to result. It also teaches the child that punishment is acceptable, so they may use it against others.

Working out the best strategies for each behavioural problem is not easy and may not be the same for every child or on every occasion. General positive measures to reduce the number of difficult behaviours is a good start before focussing on specific problems.

Reacting to challenging behaviour - reactive strategies

- Remove the trigger if possible.
- De-escalate situations by distracting your child. However, make sure you discuss the behaviour at a later time when they are less emotionally charged.
- Try not to focus on the wrong behaviour, instead state the desired behaviour.
- Recognise the feelings behind your child's behaviour and show empathy.
- Give clear choices and explain the consequences for each.

How to show your child empathy when dealing with difficult behaviour:

- make eye contact
- get down to their level
- give them your undivided attention
- find, acknowledge and validate the feeling behind the behaviour, e.g. 'I can see you are angry and that can't feel very nice'
- try not to fix the problem

Rewards vs Bribes

Rewards motivate the child to behave the way we want, but also reinforce that they have done what was wanted. An agreement is made and rewards are given consistently once the desired behaviour has occurred.

Bribes are inconsistent rewards for changes in the immediate behaviour, often for bad behaviour to stop. They can work in the short term but they do not teach long-term good habits. Bribes are often given before the good behaviour has even started, which teaches children that bad behaviour gets rewarded.



Using play to promote positive behaviour

Play gives a child the opportunity to be in control. A child with epilepsy has so much in their lives that is out of their control. Through the medium of play they can take back some ownership of their life, explore their own feelings as well as reactions to their condition and experiences.

Play needs to be positive and rewarding. It needs to help build confidence and self-esteem whilst allowing a child to explore both themselves and the world around them. Play gives children a chance to practise controlling their behaviour and learn about their emotions and reactions. Play can assist learning and self-development.

There are several stages or types of play that can be identified as children develop:

- intensive interaction
- non-directive play
- directive play
- imaginative play
- play therapy
- games with rules
- positive redirection

For more information about these types of play and how they may benefit your child – please read our fact sheet ‘**Epilepsy and play**’.



Factsheet available on website

Dealing with psychosocial and emotional issues

There are many issues that may arise for children and young people with epilepsy. These will vary considerably with each individual according to the type and frequency of seizures, age, stage of development, level of confidence and the people that surround them.



Encourage communication of concerns and anxieties

Here are some strategies to help support your child emotionally:

- Create a regular time slot to discuss how the day or week has gone. Involve the whole family and try sharing some small problems your child could help you with. Even if they do not share their own concerns at this point, they will learn it is okay to talk about problems.
- Would they find it easier to share their concerns in a way other than talking - perhaps writing it down?
- Identify a few adults in their life with whom they could talk through any anxieties. Make sure they understand you are okay that they may not always feel comfortable talking to you about certain issues.
- Try not to immediately fix their problems or anxieties. Sometimes talking about their anxieties may help them find their own solutions. Ask them what they think could be done to address problems and if they would like help with it.

Learn about epilepsy

- Help your child to understand their condition.
- It is also a good idea for the whole family and close friends to understand the condition. Your child would then feel surrounded by people who are aware and know what to do in the event of a seizure.
- Educating everyone involved in caring for your child, as well as peers at school, is vital to raise awareness, reduce stigma and promote their inclusion.
- Young Epilepsy can provide training to school staff and pupils with a range of resources available on our website for a variety of audiences.

Encourage self-management

- When your child is ready, encourage self-management of some aspects of their condition. This will help them to accept their diagnosis and prepare them for transition to adult services.
- This may include things such as: keeping a diary of their seizures and any side effects from medications, asking questions at their appointments and setting reminders to take their medications.

Encourage communication with other young people with epilepsy

- Being in touch with other young people with epilepsy can encourage the child to be more open about their condition, reduce feelings of isolation and provide them with some positive social experiences.
- Some charities run events for this purpose or, alternatively, online forums may be useful.

Encourage participation in activities and a normal social life

- This is something parents understandably find extremely difficult and children may need encouragement to overcome their worries.
- Leading as normal a social life as possible can help reduce the negative feelings of being different, improve social relationships, reduce the sense of isolation and encourage openness about epilepsy from the first diagnosis.
- Some people find seizures are less likely to occur when they are engaged in satisfying mental or physical activity.

Provide specialist help

- Children and young people who are significantly affected by emotional issues may require professional help.
- Advice can be sought from your child's school, GP or epilepsy nurse specialist.
- Your local Child and Adolescent Mental Health Services (CAMHS) team can provide counselling and specialist psychological support.



TOP TIPS

Remember children may show emotional distress in different ways – some may become withdrawn whilst others may become irritable and have temper outbursts. If your child shows any signs of emotional distress, discuss it with their healthcare team as soon as possible so strategies and treatments can be put into place to minimise its long-term impact.



How should schools be supporting your child?

All children should have access to the full curriculum and be encouraged to partake in social activities.

Individual Healthcare Plans (IHPs)

Every child with epilepsy should have an Individual Healthcare Plan that describes their medical condition, how it is best managed and the impact it has on their learning and behaviour. This plan should be developed jointly between the school and a healthcare professional. However, the responsibility for its implementation remains with the school.

As childhood epilepsy can be an extremely fluctuating condition, IHPs should be reviewed annually, or sooner if circumstances have changed.



[Find out more on our website](#)



TOP TIPS

After a meeting with your child's school follow up with a letter or email, summarising the points discussed. This can clarify your child's care plan for you and the school. Making sure everyone knows the important information can save you hours of worry at home.

Supporting learning and behavioural needs

Prompt identification of learning and behaviour needs in children with epilepsy is vital so appropriate support can be put into place. Young Epilepsy have developed a screening tool to enable early identification and monitoring of areas of concern. The Assessment of Behaviour and Learning in Epilepsy (ABLE) tool may aid decisions for either SENCO level support or, if significant concerns are identified, an application for a statutory Education, Health and Care assessment. If your child has a specific educational need, this

assessment should be carried out by the Local Authority (you can request this).

As the result of this assessment, an Education, Health and Care Plan (EHCP) may be written specifically for your child. It describes your child's needs, what should happen to meet those needs and their educational provision. All professionals who support your child work together to form this plan which is reviewed every year. The aim of this plan is to ensure your child gets the support they need to make progress and achieve their full potential.

EHCPs for children with epilepsy should:

Consider the factors contributing to learning and behaviour difficulties:

- seizures
- treatment side effects
- psychosocial issues
- comorbidities

Recognise that children with frequent seizures or who take several medications may:

- have difficulty in making learning gains
- experience fluctuations in learning and behaviour
- experience declines in learning

Appreciate that even after medication is discontinued and a child is completely seizure-free, underlying brain conditions may persist and thereby continue to affect learning.



In some cases, children with additional learning needs may qualify for extra support during exams. The exact nature of any support provided will depend on the specifics of your child's needs, as well as the type of exam and the exam board involved. In many cases, your child would need to undergo an assessment to determine whether or not they qualify.

Training school staff

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. Part of this guidance states that staff supporting your child must have appropriate training to ensure they understand your child's condition and its impact on their life.

Ideally, school staff should be aware of the following:

- seizure types and how to identify them
- seizure management
- what to record when witnessing a seizure
- the impact of epilepsy on learning and behaviour
- what should be included in an IHP
- the importance of risk-assessing activities and the types of safety precautions that can be put in place to ensure full access to the curriculum

If your child's doctor thinks they are at risk of prolonged seizures, they may be prescribed emergency medication that can be given at home or at school. If this is the case, staff at your child's school will require appropriate training on how to administer this.

Training school pupils

Much of the stigma and exclusion associated with epilepsy comes from a lack of understanding about the condition. Training all school children, in particular the classmates of children with epilepsy, is important for dispelling common myths, tackling stigma and promoting safety and inclusion.



TOP TIPS

Young Epilepsy can provide epilepsy training for both school staff and pupils. There is also a range of resources on our website to enable schools to do this themselves. Emergency medication courses are also available. information contact epilepsytraining@youngepilepsy.org.uk

Inclusion

Epilepsy is a disability and is covered by the Equality Act 2010. This statutory guidance, alongside that in the document 'Supporting pupils at school with medical conditions 2014', means schools must ensure all children with epilepsy have full access to education, school trips and physical education and they are not discriminated against or victimised.

Furthermore, schools must:

- make reasonable adjustments to ensure these children are not put at a substantial disadvantage compared with their peers
- support their social and emotional wellbeing, as well as their education

Good risk assessment will enable all children to have full access to the curriculum and not feel excluded. Many activities can be managed by putting the appropriate levels of supervision in place and taking sensible precautions.

It is important to inform your child's school if they have been unwell or if anything regarding their epilepsy changes, including any medication adjustments. This is so they can adjust activities or levels of supervision if, and where, appropriate.

Record keeping

An accurate eyewitness account of what happened before, during and after a seizure will assist doctors in making a correct diagnosis, help in recognising patterns and changes in a child's condition early on, and may impact management and treatment. Where possible, it is important that anyone involved in the care of your child records their observations every time your child has a seizure.



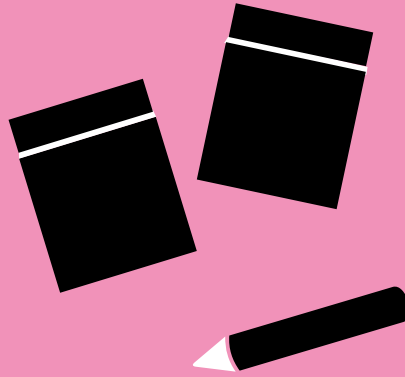
Use our app



How can you support your child's memory and learning at home?



Help them break tasks into smaller manageable pieces.

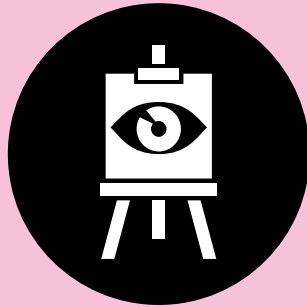


Use post-it notes to break ideas into smaller chunks and to provide a visual aid.



Try using memorable phrases or songs to help them remember facts.

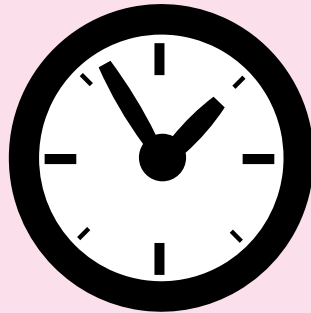
Encourage the use of visual aids such as checklists, flashcards, diagrams, mind maps and colour coding.



Recap as much as possible.



Allow adequate thinking time after you ask a question to allow time for processing.



Make sure revision time is broken into short sessions (ideally 20–30 minutes at a time) and is not when they are tired or hungry.





Epilepsy, adolescence and beyond

At a time when many adolescents suffer from low self-esteem and a lack of confidence, those with epilepsy may also have feelings of anger, isolation and being different from their peers to add to their difficulties.

Becoming independent

Parental overprotection during adolescence may make relationships more strained. Your teenager will have a strong desire to 'fit in' with their peers. Encouraging them to lead as full a life as possible, with few restrictions, will lessen their feeling of isolation. The more independence they have, the more 'in control' they will feel which will lessen the impact of epilepsy on their way of life.

This is also a period where rebellion may become more of an issue. This may have serious implications for a teenager with epilepsy as it is not uncommon for young people to resist taking their medication, either in defiance or in denial of their condition. In addition, they are also more likely to be exposed to alcohol, recreational drugs and erratic sleep patterns.

Young people may also become more concerned about the side effects of antiepileptic drugs, such as weight gain or weight loss.

All these can result in increased seizure frequency or loss of seizure control. Alcohol can be consumed in moderation, but teenagers should be made aware that skipping medication in order to increase alcohol intake will have serious consequences.

For those of driving age, knowing a seizure can delay their chance of being able to drive – by another year – can deter them from behaviours which may increase seizure risk.

There are specific issues that may relate to contraception and pregnancy.

These may include:

- worry about having seizures during sexual activity
- how some antiepileptic drugs can affect hormonal contraception
- effect of antiepileptic drugs on an unborn child
- impact of pregnancy on seizure control

- likelihood of a baby inheriting epilepsy
- issues involving parenthood with epilepsy (e.g. breastfeeding and safety)

Ensure your teenager is well-informed and understands about their epilepsy. Encourage them to tell close friends about their condition and what to do if they should have a seizure. This will ease some of your anxieties. If they are involved in activities without their friends, consider a personalised medical bracelet.

There are some good teenage websites and forums allowing your teenager to interact with others in the same position.

A confidential helpline is also available at Young Epilepsy –

 **01342 831342**

 **07860 023789**

 **helpline@
youngepilepsy.org.uk**



Issues affecting young women

Hormonal changes occurring in adolescence may affect your daughter's epilepsy. Some seizures may stop at puberty and some may change in frequency. For some women hormonal changes may cause seizures related to the menstrual cycle, which is known as catamenial epilepsy. If you think your daughter's seizures occur at a common time within her menstrual cycle (it may not be during her period), ensure you keep an accurate seizure record and discuss this with her epilepsy nurse or consultant. Medication doses may be adjusted to take this cyclical variation into account.

AEDs, contraception and pregnancy

Some antiepileptic drugs can reduce the effectiveness of the contraceptive pill, 'morning-after' pill and contraceptive implants. These antiepileptic drugs, known as 'enzyme inducers', include carbamazepine, oxcarbazepine, phenobarbitone, phenytoin, primidone and topiramate. They cause the contraceptive hormones to be removed more quickly from the body. For this reason, girls taking these drugs are usually given contraceptive pills with a higher level of oestrogen and advised about other methods of contraception. This should be discussed with a family planning doctor.

Some antiepileptic drugs can affect foetal development, so changes may be made to medication and doses prior to a pregnancy. For this reason pregnancies should be

planned well in advance and monitored from an early stage. It is important that all teenagers are given information about the effects of AEDs on contraception and pregnancy before they become sexually active.

Sodium valproate

Research has shown the AED sodium valproate can cause serious developmental problems in babies, when taken during pregnancy. The Medicines and Healthcare products Regulatory Agency (MHRA) has advised that girls and women should only be treated with sodium valproate if nothing else works. As your daughter approaches adulthood, you may wish to discuss with her the importance of seeking medical advice before planning a pregnancy. Sodium valproate may be called valproate or valproic acid. You may also know it as a brand name such as Epilim, Episenta or Epival.



★ Q&A: Commonly asked questions about epilepsy and adolescence

When will my child move from paediatric to adult services?

The transition from paediatric to adult services usually occurs between 16 and 18 years of age.

Will my child just suddenly start attending an adult clinic?

In some regions there are adolescent transition clinics to which your child may be referred, but this is not always the case. These allow the transition to be a more gradual process with staff from both the children's and adult services being involved. A complete review of the young person's diagnosis and treatment should take place at around the time of transition.

How will adult health services differ from paediatrics?

Paediatric health services often deal with a variety of issues your child has, not just their epilepsy. However, adult services will only deal with the specified medical issue and will refer you to other specialists for additional issues. Your child will

be encouraged to become more involved in making decisions about the medical issues affecting them.

How can I help my child prepare for transition to adult services?

You could help your child prepare for transition by encouraging them to take increased responsibility for their medical care and appointments from an early age. They could start by:

- making their own clinic appointments
- having some time alone with their doctor or epilepsy specialist nurse
- ordering repeat prescriptions
- keeping an up-to-date seizure diary
- recording any side effects of medications
- making a note of questions they'd like to ask their doctor or epilepsy specialist nurse
- managing their own medication (with supervision)

What are the current rules about epilepsy and driving?

If your child has seizures when they are awake as well as when they are asleep, they can apply for a driving licence after being seizure-free for 12 months. If your child has nocturnal seizures and it has been at least 3 years since they have had a seizure while awake, they can apply for a licence. Your child may still be able to drive if they experience certain seizure types which do not affect consciousness, attention and their ability to control a vehicle. For more information check the DVLA website.

What benefits can my child apply for once they are 16?

A Personal Independence Payment (PIP) may be able to help with some of the extra costs caused by epilepsy, once your child turns 16. The payment your child receives will depend on how their epilepsy affects their life. Get help with filling out the application form from local agencies, parent support groups and Citizens Advice. If your child lives alone, there may be additional disability payments they are eligible for.



For more information, check the website **GOV.UK/pip**.

Can my child get help with the cost of public transport?

Yes. A disabled person's bus pass offers concessionary travel. Contact your local council for more information about bus passes in your area. A disabled persons railcard provides a third off tickets and can be used to travel anywhere at any time. To apply, visit **www.disabledpersons-railcard.co.uk**. Your child will need to provide proof of their condition when applying for either of these. A letter from your clinic or consultant usually works.

It's best my child doesn't drink any alcohol, right?

People with epilepsy can drink alcohol but should only do so in moderation. In fact it is recommended they consume no more than 2 units of alcohol in 24 hours. There are many reasons for this, including excess alcohol can stop epilepsy medication from working, alcohol can trigger seizures in some people and epilepsy medications can increase the effect alcohol has on the body.



Higher education

Going to university is a huge change for anyone. Often young people live away from home for the first time, make new friends and settle into a way of life different to what they are used to.

Lifestyle changes, such as these, can have an impact on epilepsy control so young people need to take them into consideration. Lack of sleep and exposure to stress, both of which are common in students, need to be carefully managed. Medication should continue to be taken regularly and students should be advised to avoid omitting doses. Alcohol is fine in moderation, but they should be aware of any effects on their seizure control and avoid binges; they may find their medication potentiates the effect of alcohol on their body. Recreational drugs are known to increase seizure risk and should be avoided.

Ensure your child is aware of the small increased risk of SUDEP, particularly if their seizures are uncontrolled. Also encourage them to tell friends about their epilepsy. This will help them to feel more supported and make it easier for them to follow a lifestyle conducive to better epilepsy control.

Epilepsy can affect a student's memory and concentration, so they may find they could benefit from extra support. The university's student disability



services can advise about accessing practical support, such as dictaphones, or academic support, such as lecture handouts, or arranging extra time for exams. They can also help with applications for funding. Disabled Students' Allowance can help to cover some of the extra education costs related to epilepsy.

All the changes can be difficult for a young person with epilepsy. They may find their confidence is low or start to feel quite anxious or depressed. They can call the university's nightline service if they need emotional help or have queries about practical issues.

Young Epilepsy is working with colleges and universities across the UK, to raise awareness of epilepsy and to support young people as they transition into higher education. It aims to identify the higher education institutions going the extra mile to improve their understanding of epilepsy, the impact it can have on their students and what they can do to best support them. You can learn more about the Epilepsy Friendly scheme by going to youngpilepsy.org.uk/EFM or calling our helpline on **01342 831342**.

Getting a job

Epilepsy itself should not be a barrier to applying for and getting a job. When considering an application, a young adult should think about their qualifications, strengths, experience and how their epilepsy impacts them in everyday life.

Some jobs may not be suitable for a young person with epilepsy if their seizures could put themselves or others at risk of harm, for example jobs involving working at a height, near water or in the armed forces. Other jobs may be dependent on having a driving licence so good seizure control is an important factor.

Local Jobcentre Plus offices can offer information about training and employment. They also have Disability Employment Advisors who can help to find work or to gain new skills for a job. Remploy also have specialist advisors

providing services online to help with recruitment skills and interview preparation. Find out more at www.remploy.co.uk.

Sometimes people find it difficult to tell an employer about their epilepsy. They worry about the impact it will have, either on the success of their application or the way people treat them at work. The Equality Act 2010 protects people with disabilities, including epilepsy, from such discrimination. Part of this Act states that people no longer have to disclose their disability on an application form when applying for a job.

In addition, employers have to make 'reasonable adjustments' to avoid people with disabilities from being put at a disadvantage. This may include adjusting working hours or providing specialist equipment.

Some people find it easier to mention epilepsy on their initial application form, whereas others prefer to wait until they have a job offer before disclosing their diagnosis. The advantage of telling an employer about their epilepsy is that it will allow the employer to make necessary adjustments to ensure their safety.





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 to ensure your child has all of the things 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 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 you are required to bring with you (e.g. birth certificate or passport as proof of identity). It is worth noting 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** website or by calling **0345 712 3456** and ordering a printed form by post.

VAT relief

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

You can learn more about VAT exemption for disabled people by going to the **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; this includes antiepileptic medication.

Information, Advice and Support Services Network (IASS Network)

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

Blue Badge

The Blue Badge scheme is designed to help people with mobility issues to park closer to the places 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 three 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 **GOV.UK** website and search for 'Blue Badge'.

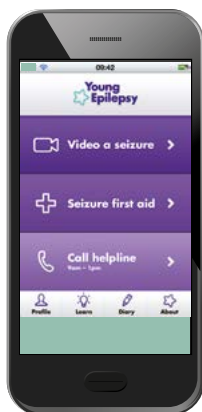


Useful resources

Young Epilepsy is continually developing a range of resources to help you record and share important information about your child. Below are some examples. All of these forms can be downloaded in full from youngepilepsy.org.uk

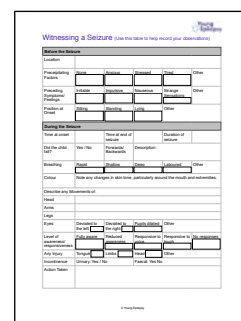
Young Epilepsy App

An innovative, free app that can be tailored to the needs of each young person or child with epilepsy. It includes an easy-to-use seizure video function, symptom log, diary and medical prompts as well as discreetly stored emergency and contact details.



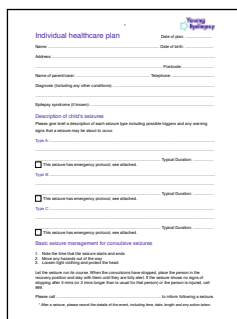
Witnessing a Seizure

Witnessing a seizure can be stressful and it is easy to forget some of the details. This form can help you to record your observations before, during and after a seizure so you can build a better picture of a child's epilepsy.



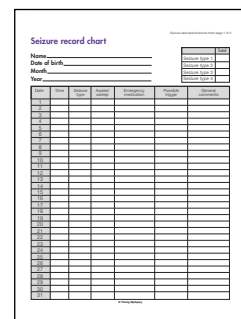
Individual Healthcare Plan (IHP)

This document contains personalised information about your child's epilepsy, the impact it has on their learning as well as protocol for emergency situations. All children with epilepsy should have an IHP at school.



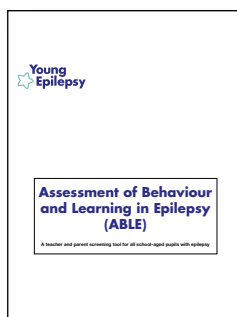
Seizure Record Chart

This chart records the frequencies and types of any seizures. It can identify patterns in seizure activity which can help to give doctors a better idea of how best to treat your child.



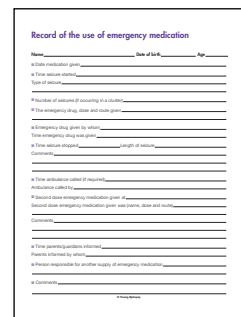
ABLE

The Assessment of Behaviour and Learning in Epilepsy (ABLE) tool is for parents and teachers. This straightforward questionnaire helps assess a young person's needs to ensure they receive the right holistic support.



Record of Emergency Medication

This document is designed so you can keep a record in the event of your child requiring any emergency medication.



With thanks to

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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 and resources, as well as training for professionals. We 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/parent-guide**

Better futures for young lives with epilepsy and associated conditions



Find out more here: youngpilepsysshop.org



Check out our Facebook page: facebook.com/youngpilepsy



Follow our tweets: twitter.com/youngpilepsy



Watch us on You Tube: youtube.com/youngpilepsy



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



Find us on Instagram: 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

Text: 07860 023789

Young Epilepsy

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Email: info@youngpilepsy.org.uk

youngpilepsy.org.uk

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