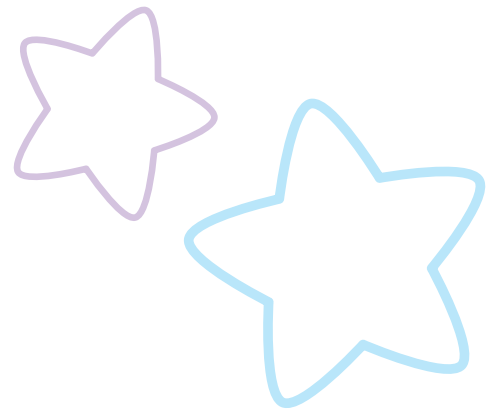


Guide for Schools

Understanding Epilepsy







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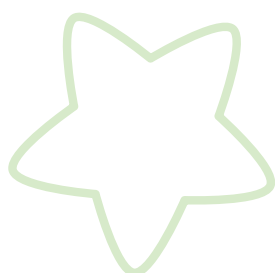
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“As a national charity we work to support the 63,400 children and young people aged 18 and under with epilepsy who are at schools and colleges across the UK. Research findings on the effects of epilepsy, and the level of support provided by both the NHS and schools, show that these young people often achieve well below their potential.”

David Ford, Young Epilepsy Chief Executive





Introduction

Young Epilepsy is a national charity providing education, medical and support services for children and young people with epilepsy and other neurological conditions. We work in partnership with Great Ormond Street Hospital for Children NHS Trust and the University College London's Institute for Child Health.

Young Epilepsy's campus in Lingfield, Surrey includes residential and day provision at St Piers School, St Piers Further Education College and the world class Neville Childhood Epilepsy Centre, which offers a range of diagnostic, assessment and rehabilitation services. As well as coordinating a paediatric epilepsy research programme, Young Epilepsy has an information service which provides a helpline along with epilepsy training and support for teachers, health professionals and families.

Epilepsy Education 4 Schools

Our team of Education Officers work with schools to raise awareness of epilepsy among children and young people. We hope to allay any fears or misunderstandings that they may have, which will enable them to focus on their friendships rather than the medical condition. Many issues in the PSHE curriculum around relationships, tolerance, self awareness and managing feelings are addressed through this work. Epilepsy and the medication used to control seizures can cause memory, learning and behavioural problems, so it is vital that schools provide the right support if they are to meet the needs of these children as set out in Every Child Matters. It is a sobering fact that almost 50% of children with epilepsy underachieve given their IQ levels.⁽¹⁾ We provide training for teachers and support staff to help them in this endeavour.



Section

“Epilepsy can affect anyone, at any age and from any walk of life. It is one of the most common serious neurological conditions.”

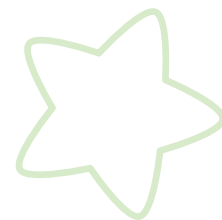
Joint Epilepsy Council (JEC)



1

Understanding epilepsy





What is epilepsy?

Epilepsy is the medical term used for someone who has a tendency to have recurrent seizures. Abnormal excess electrical activity in part or all of the brain is called a seizure. This abnormal electrical activity can affect movement, sensation, mood, memory, consciousness and behaviour. Seizures may present in a variety of ways such as twitching of the limbs, stiffness, loss of consciousness or brief 'absences' where the brain switches off but the person appears normal. With over 40 different types of seizure, the condition can vary hugely, depending on which part of the brain is affected.

For some young people, seizures can cause learning problems or the medication can lead to unwanted side effects.

Epilepsy is a condition involving the brain that leads to recurrent seizures.

Approximately 63,400 children and young people aged 18 and under have epilepsy in the UK. In most cases the condition can be controlled by antiepileptic drugs and the young person can attend mainstream school. For some young people, seizures can cause learning problems or the medication can lead to unwanted side effects. Added to that the stigma may leave many children and young people battling low self-esteem, bullying and a lack of understanding from both peers and adults.





Understanding seizures

A seizure is a sudden electrical discharge in the brain which results in an alteration in sensation, behaviour or consciousness. Seizures can take many forms because the brain is responsible for such a wide range of functions. Symptoms that occur during a seizure depend on where in the brain this abnormal burst of electrical activity occurs.

Causes of epilepsy

Although there are many known causes of epilepsy, in around 60% of cases there is no known cause. Those epilepsies with a known cause are called 'symptomatic' and are categorised into two main groups: those caused by brain injury or disease and those that have an hereditary factor.

Structural/metabolic causes (by injury or disease)

E.g. Birth trauma, lack of oxygen to the brain (hypoxia), bleeding in the brain (intercranial haemorrhage), brain tumour, head injury, stroke, reduced levels of sugar in the blood (hypoglycaemia), reduced levels of calcium (hypocalcaemia), infections in the brain (meningitis & encephalitis), alcohol and drug misuse

Genetic/hereditary causes

E.g. Inherited low seizure threshold, genetic condition that causes epilepsy (tuberous sclerosis), genetic epileptic syndrome (benign rolandic epilepsy, temporal lobe epilepsy, juvenile myoclonic epilepsy)

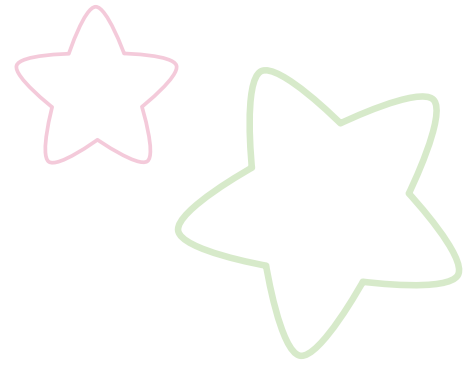
Remission

Most adults who had seizures as a child do not have seizures as an adult. The remission rate for epilepsy is about 60-80%. Approximately 70% of children with epilepsy have their seizures well-controlled by taking antiepileptic medication⁽²⁾. The remaining 30% of children have poor seizure control and may continue having seizures into adulthood. When doctors refer to 'well-controlled' epilepsy, they mean that the child has not had a seizure for a year, although they do make allowances for possible 'break through' seizures when a medication is being withdrawn.



Guide for Schools

Understanding Epilepsy



Identifying seizures

Seizures are divided into two main types:

Focal seizures

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

Generalised seizures

All of the brain is affected from the start and the child will be unconscious, if only briefly.

Sometimes a seizure can start in one part of the brain (focal seizure) but then spreads to the rest of the brain. This is known as a **bilateral convulsive seizure**.

Frontal lobes

Responsible for: movement, emotion, behaviour, personality, planning, problem solving and executive functions.

Parietal lobes

Responsible for: integrating sensory information, orientation, visiospatial processing and manipulation of objects.

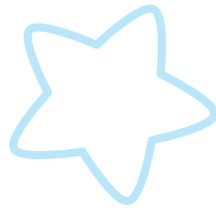


Temporal lobes

Responsible for: analysis of auditory and visual information, processing of speech and memory.

Occipital lobes

Responsible for: vision and the perception of form, movement and colour.



Focal seizures

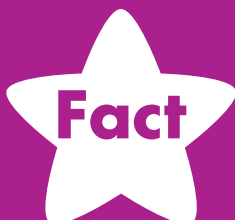
Focal seizures are the result of intense electrical activity occurring in a particular area of the brain. These seizures are described according to their manifestations, particularly whether they cause movement (motor) or sensation (sensory) symptoms to the child. The common symptoms for each of the areas of the brain are described below. There may be some impairment of consciousness with these seizures, but sometimes the child may be fully aware of their surroundings.

Temporal lobes: responsible for auditory perception, speech, memory and high level visual processing. Seizures may cause a disruption to any of these functions and the child's feelings/emotions may be affected. They may experience strange tastes or smells, tummy pains or get the feeling of déjà vu. They may also wander or perform aimlessly movements such as plucking at clothes or chewing. The child is often confused following temporal lobe seizures. Some children describe not being able to understand what people are saying to them, like they are talking a foreign language.

Frontal lobes: responsible for personality, emotions, behaviour, planning, problem solving, executive functions. Seizures can vary in nature depending on which part of the frontal lobe is involved. They tend to start and stop abruptly and the child may present with strange dramatic movements (head turning, posturing of arms) or muscle weakness (including speech musculature). These seizures often occur in sleep.

Parietal lobes: responsible for integrating sensory information, orientation, visuospatial processing and manipulation of objects. Seizures involving the parietal lobes tend to result in strange sensations, including tingling or warmness, or areas of numbness may be reported.

Occipital lobes: responsible for processing visual information, recognising shapes and colours. Seizures involving the occipital lobes may result in the child seeing patterns or flashing lights. Occasionally a temporary blindness may be the symptom.



Around 600,000 people in the UK have epilepsy, that's one in every 103 people. ⁽¹⁾



Generalised seizures

Absence

Absence seizures are usually very brief and last between 5-10 seconds, but they can be longer. During this time the child is unconscious and unaware of their surroundings. These seizures manifest as a sudden onset of staring with, or without, eye blinking or lip smacking. Absences can occur many times, possibly hundreds, in a day and can be difficult to spot, often being mistaken for daydreaming. A child in a classroom may miss essential pieces of information but be unaware that there is something wrong.



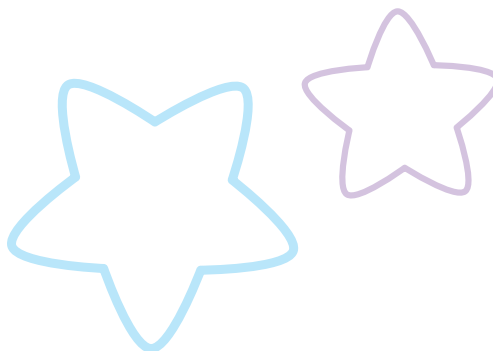
Tonic clonic

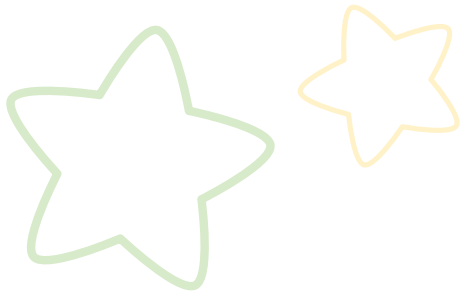
This is probably the type of seizure that most people think of when you talk about epilepsy. Like all generalised seizures it is caused by electrical discharges firing simultaneously throughout the brain. This seizure has two phases: the 'tonic' phase followed by the 'clonic' phase.

Tonic phase: the person goes rigid as their muscles contract. They may let out a cry as air is pushed out of the lungs but they are not in any pain. Consciousness is lost and the person falls to the ground, often backwards. Breathing may become laboured or stop. 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.

As the seizure comes to an end the rhythmical jerking stops and the muscles relax. The person will regain consciousness but it can take some time to return to normal. Incontinence may have occurred during the tonic phase and they may be confused. Often the person needs sleep.



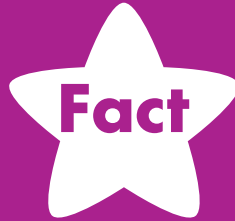


Tonic

This seizure is just like the tonic phase of the tonic clonic seizure described previously. The tone in the muscles increases and the person goes rigid with loss of consciousness. If they are standing then they will fall to the ground with the consequent risk of injury. Tonic seizures are generally very short (less than 20 seconds) and often occur at night.

Atonic

In this seizure the person loses all tone in their muscles and drops to the ground, often falling forwards. They are often referred to as drop attacks. Although the seizure is very brief and the person can often continue with normal activities quite quickly following the seizure, there is significant risk of facial and head injuries.



Over half the deaths of children and young people with epilepsy are avoidable.⁽³⁾

Protective headwear, such as helmets, may be recommended to prevent injury. In severe case a helmet with a face guard may need to be worn.

Myoclonic

These seizures are sudden brief muscle contractions or jerks that can affect any muscle group but often involve one or both arms or the head.

Clonic

Clonic seizures are rhythmic muscle contractions typically involving the upper extremities, neck and face.





Seizure profiles

Although a child can have more than one different seizure type, for the most part, each time they have a particular seizure it will look the same. It can be helpful to think of it as a 'seizure signature' so it is really important that all those working with the child get to know their seizures well so that they know what to expect. Any differences in their usual pattern of seizures may indicate that the epilepsy is evolving, so should be reported to the medical team at the earliest opportunity. Medication levels may require adjustment, particularly as the child grows. Although a child will often not know what their own seizures look like, they will be able to tell you how it makes them feel and what they may experience immediately before or after a seizure. Some children tell us that they can hear what those around them are saying well before they are able to respond.



Status epilepticus

A seizure is not normally a medical emergency and the vast majority of seizures are self-limiting. However on occasions a medical emergency known as status epilepticus can occur.

Although any type of seizure may develop into status epilepticus, generalised tonic clonic seizures progressing into status epilepticus are the most serious.

Those who experience frequent convulsive seizures are more likely to go into status epilepticus, a medical condition where the seizure lasts for more than 30 minutes or the child does not regain consciousness between seizures. The child will be at significant risk of sustaining damage to the brain. This is a **medical emergency and potentially life threatening and requires prompt medical treatment.**



Triggers

There is often no apparent reason why a seizure occurs at one time and not another. However, some people find that certain triggers make a seizure more likely. These triggers are not the cause of epilepsy, but they may trigger a seizure on some occasions.

These triggers need to be taken into account when planning activities. If a child is more likely to have seizures when they are tired, it may be possible to arrange

for them to start school later on some days, particularly if they have had seizures overnight. Regular sleep patterns are important so this needs to be taken into consideration when planning residential trips for example. Encouraging children to eat healthy snacks during break times will keep blood sugar levels balanced. If stress is a significant trigger of seizures then teaching stress management and relaxation skills may be beneficial.

Possible triggers include:

- illnesses which cause fever, such as flu or infections
- stress, anxiety, excitement or boredom
- lack of sleep or tiredness
- irregular meals (low blood sugar)
- heavy drinking or recreational drugs
- some medications such as antidepressants and antipsychotics
- changes in antiepileptic medication, or failing to take it
- menstruation
- flickering lights (strobe lighting or video games).



Auras and prodromes

The term **aura** is often used to describe the feeling a child may experience prior to having a generalised seizure. If they learn to recognise it, it may help them to get to a safe place to prevent any injury. An aura is a focal seizure that produces sensory symptoms such as a strange taste or smell or a feeling of being anxious. Not all tonic clonic seizures are preceded by an aura, many happen without any warning at all.

The term **prodrome** is used to describe changes in a child during the hours or even days before a seizure happens. They may be irritable and 'just not themselves'. Parents are often very good at identifying subtle changes in the child and any information that you can obtain from parents about a child's behaviour in the days prior to a seizure will help you to look out for any warning signs.

Many people say that the first time they saw a seizure it was a terrifying experience and they thought the person was going to die.



Witnessing a seizure

An accurate eyewitness account of a seizure will assist the doctors in making a diagnosis. If you witness a child having a seizure at school it is helpful to document a detailed description of what happened. It is best to describe what you saw rather than trying to categorise it and risk missing out important information.

A witnessing a seizure form is included in the resource section of this Guide, along with:

- an individual healthcare plan
- seizure description chart and record of seizures
- record of emergency medication.

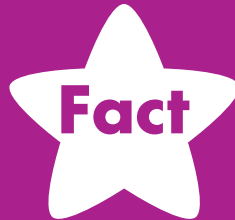
If you have any worries about a child in your class or in your care then it is important to voice your concerns to the appropriate staff at your school – the SENCO is often a good person to start with. Concerns also need to be sensitively addressed with parents. Seizures can be difficult to spot, with absences often being mistaken for daydreaming and focal seizures taken for difficult or unusual behaviour. Even some generalised seizures may be put down to clumsiness or falls. Careful observations are vital. If any child shows deterioration or plateauing in their learning, then this should be reported. Changes in mood and behaviour are also indicators that a child may need further investigation.

Extra copies of these forms can be downloaded from our website youngepilepsy.org.uk/what-we-do



Photosensitive epilepsy

Photosensitive epilepsy is actually quite rare and only affects 5% of those with epilepsy.⁽⁴⁾ It can be diagnosed during EEG (electroencephalogram) investigations where the brain waves are recorded through small electrodes placed on the surface of the head. Photosensitive epilepsy is where a seizure is triggered when a child is exposed to lights that flicker at a particular range of flashes per second (3-50Hz). Television can be a common trigger, but by watching the TV in a well lit room and sitting further away from the screen and using a remote, the risk is reduced. LCD televisions are less likely to trigger seizures than plasma screens which often have high contrast levels.



There are around 63,400 children and young people aged 18 and under with epilepsy in the UK. That's an average of one in every primary school and five in every secondary school.⁽¹⁾

Computer monitors are unlikely to trigger seizures, although the images on them may if they are flashing at the rate known to trigger seizures. The same applies to interactive whiteboards used in schools.





Individual healthcare plans

Every child with epilepsy requires an individual healthcare plan for the school setting. It should contain information about the child, describe their usual seizures, how their condition should be managed and detail possible triggers and how these can be managed. It should also consider the effects of their condition on their day to day performance at school, including any medication side effects.

A clear emergency treatment protocol must also be included. Where emergency medication has been prescribed and may need to be administered in school, staff should be given appropriate training in the administration of emergency medication.



Treatment of epilepsy

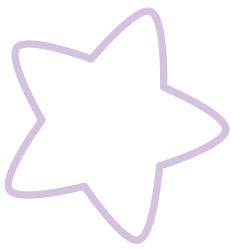
The main objective of treating epilepsy is to **enhance quality of life** by stopping all seizures with minimal side effects. Where the seizures cannot be stopped without side effects, the main aim is to minimise the number of seizures, especially tonic clonic, tonic and atonic seizures and to minimise the adverse effects of treatment.

Epilepsy should be treated in order to **reduce the risk of injuries** and accidents associated with it, along with the serious risk of mortality. Every year in the UK about 1000⁽³⁾ people die of epilepsy related causes: 370 of those deaths are children and young adults. Over half of these deaths are avoidable.

There are several different treatments available for the treatment of epilepsy:

- Medication: antiepileptic drugs (AEDs)
- Dietary therapies
- Vagus Nerve Stimulation
- Neurosurgery.

Every child with epilepsy requires an individual healthcare plan for the school setting.



Antiepileptic drugs (AEDs)

Medication is the first line of treatment for epilepsy. For about 70% of those with the condition, good seizure control can be achieved through the regular use of AEDs. Medications are usually taken twice a day (morning and evening). Some medications can have an effect on the child's classroom performance, along with other more common side effects. These effects are more likely to occur when a new drug is introduced, particularly if the starting dose is too high or the medication is increased too quickly. Side effects are also more likely to occur in children taking more than one medication (polytherapy).

There are a number of frequently used drugs in the treatment of epilepsy. The most common ones are listed below with their brand names.

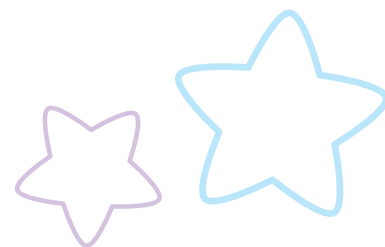
- Carbamazapine (Tegretol)
- Lamotrigine (Lamictal)
- Levetiracetam (Keppra)
- Sodium valproate (Epilim)
- Topiramate (Topomax).

More information can be found at youngepilepsy.org.uk/all-about-epilepsy

Common side effects of antiepileptic drugs:

- drowsiness and lethargy
- memory difficulties
- nausea
- dizziness
- coordination problems
- mood and behavioural changes
- double vision
- changes in appetite and weight
- rash (rare, but potentially very dangerous).





Emergency treatment of seizures

Some children may need to bring medication into school for the emergency treatment of seizures. Seizures are treated if they last two minutes longer than is usual for that child or if there is a cluster of seizures without the child regaining consciousness in between seizures. It is good practice to treat seizures after five

minutes to avoid the child going into status epilepticus. If a seizure lasts for more than five minutes it may be difficult to stop. Each child should have an emergency treatment protocol that is documented and familiar to all staff working with them. **Staff who may need to administer emergency medication should be trained on how to do so.**

Any staff who may be required to administer emergency medication to treat seizures should be trained to do so. Young Epilepsy offers emergency medication training, endorsed by the Joint Epilepsy Council. The full day course includes teaching and practical sessions as well as a written assessment.

For details visit youngepilepsy.org.uk/what-we-do or email epilepsytraining@youngepilepsy.org.uk or speak to our training administrator on **01342 832243 ext 296**.



Off-site visits

Emergency medication needs to be with the child at all times so, when going on any off-site visits, medication must be taken in a sealed bag with the emergency treatment protocol. It should be kept safe by a responsible adult.

There are two main forms of emergency treatment for prolonged seizures: **buccal midazolam and rectal diazepam**.

Buccal midazolam

Midazolam belongs to the group of medicines called benzodiazepines. When it is used as an emergency medication for seizures, midazolam is usually given via the buccal route. This is where the medicine is placed in the mouth between the side of the gums and cheek (called the buccal mucosa) and it is quickly absorbed through the cheek lining. It is not intended that the medication is swallowed, but if it occurs accidentally, it will not cause any harm. This medication can be prescribed in pre-prepared oral syringes. No needles are used with the syringe. Each child is prescribed a dose that is correct for their weight and it should only be given as prescribed by the child's doctor.

Side effects of buccal midazolam:

- drowsiness and sedation, although recovery is fast
- short term memory loss
- breathing difficulties (unlikely if correct dose is given).

The advantages of giving buccal midazolam over rectal diazepam are that it is much easier to administer. The potential unpredictable absorption of rectal diazepam due to constipation or bowel movements is avoided and it is much more socially acceptable. Staff who may be required to administer buccal midazolam should receive training on how to do so.

Rectal diazepam

Diazepam also belongs to the group of medicines called benzodiazepines and it is used for terminating seizures. It is available in pre-prepared rectal tubes of four different strengths (2.5mg, 5mg, 10mg and 20mg). Each child is prescribed a dose that is correct for their weight and it should only be given as prescribed by the child's doctor.

Side effects of rectal diazepam:

- drowsiness and sedation
- headaches
- unsteadiness and dizziness
- confusion
- slurred speech and hangover effect
- breathing difficulties (unlikely if correct dose is given).



Storage and disposal of medication

It is important that all medications are stored safely and that you always have sufficient supply. As with all medication it should be kept in a safe place where children cannot see, or gain access to it. It should be stored at room temperature, away from heat, bright light or direct sunlight. Always replace the cap on medication immediately after use to prevent spillage or evaporation of the liquid. It is important to check the expiry date regularly and, if out of date, return any unused medication to a pharmacy. Do not flush it down the toilet or dispose of it in a sink. Used syringes must be disposed of in appropriate container that should be provided with the medication.



Dietary treatments

Dietary treatments for epilepsy have been around for the best part of a century. There are four main varieties of the ketogenic diet, all specifically designed to stimulate biochemical changes in the body which are usually associated with starvation.

During starvation, the body first uses its store of glucose and glycogen, then begins to burn the stored body fat. When there is not sufficient glucose available, the fats cannot be completely burned and ketone bodies are left as the residue of incompletely burned fat. Ketogenic diets provide fat from outside the body, by eating a diet high in specific fats, for the body to burn, but limits the available carbohydrate so that ketones build up. It is the high level of these ketones which appears to suppress seizures.

The classical ketogenic diet is a specially formulated diet that is high in fat, contains adequate protein and is low in carbohydrates. The other diets are modified versions of this, using different ratios of long and medium chain triglyceride fats in the diet.

All dietary treatments for epilepsy must be done under strict medical and health professional guidance. The diet requires close supervision by a dietician and also motivation and commitment from the child and family. It is important that those working with a child in school have clear guidelines to follow and it is usually helpful to meet with the family in order to find out how the child can be supported in school.



Vagus Nerve Stimulation (VNS)

Vagus nerve stimulation (VNS) is an add-on treatment for epilepsy used in conjunction with AEDs or the ketogenic diet. A small device, similar to a cardiac pacemaker, is implanted under the skin below the left collar bone. This is connected via a lead to the vagus nerve in the left side of the neck. The VNS stimulates the vagus nerve at intervals to reduce the frequency and intensity of seizures. The device is programmed to deliver regular intermittent stimulation but in addition, a magnet can be passed over the device to activate it so as to interrupt or reduce the severity of a seizure. The effect of this device may be cumulative and it may take between 18 months to three years to see the full effect.

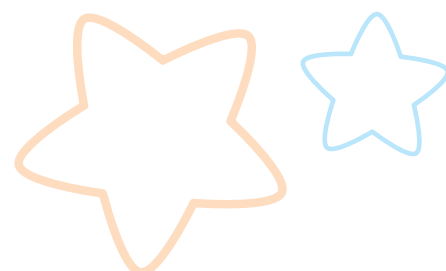
Possible side effects of Vagus Nerve Stimulation:

- hoarseness
- throat discomfort
- coughing
- swallowing difficulties.



Neurosurgery

Epilepsy surgery may be considered when drug treatment has been ineffective. Detailed investigations are required to identify the part of the brain where the seizures originate. The aim of surgery is to safely remove the area in the brain proven to be producing the seizures. Epilepsy surgery has the potential to 'cure' epilepsy.



Guide for Schools

Understanding Epilepsy



First Aid for seizures

It is important that you stay calm and follow some simple steps:

- note the time the seizure commences
- if the person is aware that they are going to have a seizure try and guide them to a place of safety.

For a generalised seizure where there is loss of consciousness:

Do...

- move any hazards out of the way to protect the person from injury/harm
- loosen tight clothing from around their neck
- put something soft under the person's head to protect them from banging it. If nothing is available, cradle their head in your hands or laps
- let the seizure run its course
- when the jerking has stopped, place them in the recovery position
- note the time the seizure stopped.

Don't...

- restrain their movements
- attempt to move the person (unless there is unavoidable danger, e.g. hot pipes)
- put anything (including your fingers) in their mouth.



For a focal seizure where consciousness is altered:

Do...

- remain calm
- guide the person away from danger
- stay with the person until they are fully recovered.

Don't...

- try to restrain them
- shout or grab at them, they may interpret this as threatening and become aggressive
- give anything to eat or drink.

Try and make a note of the time the seizure commenced and how long it lasted for.

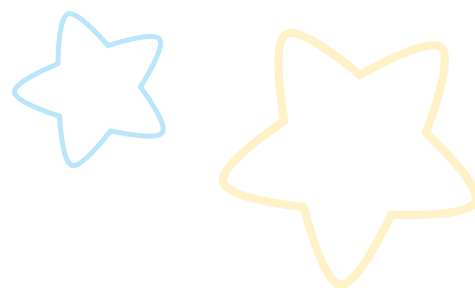


Most seizures stop without the need for treatment, so it is not necessary to call an ambulance. The person may need a quiet area to rest until they are fully recovered.

When to call an ambulance for a seizure (any type) Dial 999 when:

- a seizure lasts for **more than five minutes** even if emergency medication has been given
- if the person has **repeated seizures** without fully regaining consciousness in between seizures
- if a seizure lasts for **two minutes longer than is usual** for that person
- if they are **injured**
- if you know it is the person's first seizure
- if you have given emergency medication.





Risk assessment and safety

Accidents happen whether a child has epilepsy or not. It is a part of life. There are additional risks for children with epilepsy and therefore when risk assessments are carried out for school activities, special consideration needs to be given to the child with epilepsy. Children with epilepsy should be encouraged to live a normal life but there may be certain high risk factors that need to be taken into account when planning activities.

Risk factors for accidents:

- unpredictable and severe seizures
- presence of underlying neurological condition (head injury, learning difficulties)
- possible medication side-effects (tiredness, dizziness, double vision, memory difficulties)
- additional physical difficulties (poor coordination)
- possible emotional disorders (anxiety, depression).

It is important to consider the following:

- be familiar with the child's seizure pattern
- know the potential triggers
- adapt the equipment and environment if necessary
- assess the level of supervision required
- know what the risks are and when, where, why and how they may occur
- ensure seizure first aid is well understood by those involved.

Each school will need to do their own risk assessment for their particular circumstances, but there are some general guidelines that are worth following. If a child's seizures are not well-controlled it

may be best to avoid activities in which loss of consciousness could put the child or others at risk, or have a high risk of head injury. Other activities can be managed by putting the appropriate levels of supervision in place and taking sensible precautions. Specific advice on sporting activities is available from Young Epilepsy.

Certain activities require specific comment:

- **Swimming** – a competent swimmer should swim with and monitor a child with epilepsy. Inform the lifeguard when you arrive that the child has epilepsy. Any child who has a seizure in water should be checked by a doctor, even if they appear to be unaffected



- **Bathing** – young children should always be supervised and older children should shower if possible. If showering is not an option they should have a shallow bath with someone with them, or sitting outside with the bathroom door kept unlocked
- **Cycling** – a helmet should always be used and cycling should be avoided on busy roads. It is advisable to cycle with a friend
- **Climbing** – if seizures are still occurring, the risks should be considered and weighed against the benefits of this activity. In general it is not advisable for a child to climb higher than their own height. Supervised climbing activities where safety devices and ropes are used can be safe as long as the instructors are made aware that the child has epilepsy and all the safety guidelines are followed.

There is no reason why young people with epilepsy should be excluded from most sporting activities. Good risk assessment will enable all young people to have full access to the curriculum.

Sudden Unexpected Death in Epilepsy (SUDEP)

Thankfully this condition is **rare** and affects only a few children and young people.

Sudden unexpected death in epilepsy is said to have occurred when someone with epilepsy dies suddenly and unexpectedly for no known reason with, or without, evidence of having had a seizure. It usually occurs at night when there are no witnesses. There is no obvious explanation for the death, even with a post-mortem examination.

Although rare and unpredictable, certain factors increase the risk of SUDEP. Young adults who live alone and experience poorly controlled tonic-clonic seizures during sleep can be at greater risk. The

need for more than one antiepileptic drug to control seizures with abrupt or frequent changes in medication can also increase the risk, as well as sudden withdrawal of medication.

Remember that SUDEP is **rare**, but the risk factors show the importance of encouraging children to take the medication regularly as prescribed.

About 1,000 people die each year from epilepsy related causes (more than AIDS and cot death combined). It is estimated that there are 500-600 SUDEP deaths each year. Other deaths in epilepsy are due to accidents, status epilepticus and suicide.

Section

“It has affected me quite a lot but people who understand what epilepsy is, accept the fact that I can still do things.”

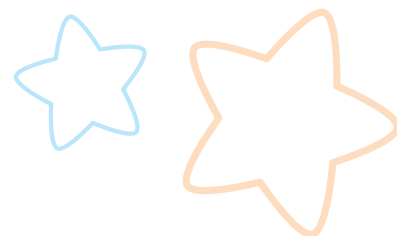
Rhys (15)



2

The impact of epilepsy

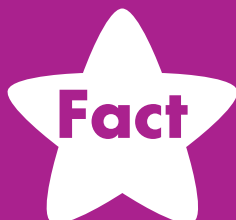




In the classroom

There are a number of things to consider when planning for a child with epilepsy in your class. You will want to ensure that the child is safe and that everyone knows what to do should a seizure occur. However both epilepsy and its treatment can have a significant impact on a child's ability to learn.

Childhood epilepsy varies in type and degree of severity and most children with uncomplicated epilepsy can have a normal, active childhood with the help of a few safety precautions. All children should have access to the full curriculum and be encouraged to participate in social activities.



Independent research carried out on behalf of Young Epilepsy found that 51% of parents believe the condition has a “significant” impact on their child's education. Of those questioned, 46% said their child had missed classes. Only 40% were aware of staff at their child's school receiving special epilepsy training.

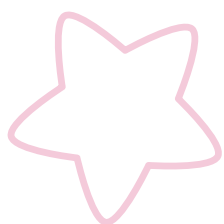


Generally, the earlier seizures begin, the more likely learning and behaviour will be affected. Parts of the child's brain continue to develop until just before adolescence, so functions performed by these developing parts may be disrupted by seizure activity.

Learning difficulties are not an automatic consequence of epilepsy. Many children with epilepsy will achieve both academically and socially. Some children will, however, experience varying degrees of learning difficulty and their individual needs must be identified and met by health and education authorities responsible for their wellbeing.

Learning and cognitive difficulties may be directly related to the types of seizures that the child experiences. The duration and frequency of seizures, as well as the time taken to recover from the seizure, can all have an impact on the child's performance in the classroom.

A child's emotional well-being can also affect learning and classroom performance. More information on the psychosocial effects of epilepsy can be found on page 38.



Children with epilepsy may experience difficulties with:

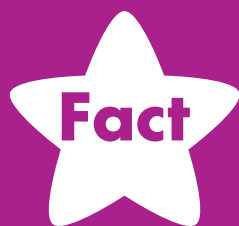
- visual and/or verbal learning processes
- reading, spelling, rote learning, speech and language, perceptual problems, numeracy
- problem solving and memory recall
- motor ability – handwriting may be poor and performance slower
- psychosocial problems – low self esteem, frustration, anxiety and poor motivation
- maintaining consistency in learning
- inappropriate behaviour - attention seeking or withdrawal.

Guide for Schools

Understanding Epilepsy



Occasionally children with epilepsy may experience regression in areas in learning including language and memory, or global loss of skills. If this occurs it needs to be fed back to the medical team responsible for looking after the child as it may indicate that medication levels require adjustment or further investigation is required.



16% of those with epilepsy aged 5-15 have an emotional disorder such as depression compared to just 4% of their peers.⁽⁶⁾

Children and young people with epilepsy may experience all the common behavioural and emotional problems such as depression, anxiety, ADHD, autistic spectrum disorder, obsessional behaviour and challenging behaviour.

Further difficulties can be created by unrealistic expectations (above or below the child's abilities) by parents, teachers and peers. In addition antiepileptic medication may affect attention, cognitive function, memory and motor skills.





Learning Strategies

The most common difficulty for students with epilepsy is problems with memory. Whether they are caused by seizures or general mental slowing from epilepsy medications, these memory problems can make learning very frustrating. Understanding these difficulties is crucial for effective learning. Detailed assessment of memory function may be beneficial and can be carried out by an Educational Psychologist.

Some useful strategies are outlined here:

- mnemonic strategies: use verbal, visual and symbolic techniques as memory aids. The acquisition of facts and procedural knowledge is governed by memory and the most effective measures for memory development are rehearsal related
- verbal repetition: this leads to the consolidation of skills learnt in mastering a task. Unconsolidated skills are not likely to be generalised to other learning tasks
- visual demonstrations and diagrams
- colour coded notes or highlighting to categorise material
- word associations with pictures and objects (pictures of reference)
- rhymes and songs (songs of reference)
- active participation with the material that is trying to be remembered
- learning to stay calm when memory blanks
- cueing: proves effective particularly with listening activities. Warn the child ahead of time of the purpose of the activity. Knowing the purpose helps the child stay on task
- breaking tasks down into most basic steps. Establishing teaching and learning stages that need to be achieved if the child is to succeed
- group work develops listening and talking skills, encourages interaction with peers in problem solving and allows students to ask questions and learn from each other
- reviewing the processes used in solving a complex task can be very helpful for the student.



Guide for Schools

Understanding Epilepsy



What teachers can do to support pupils

Before the pupil arrives:

- be pro-active – arrange to meet with your pupil and parent/carer before they join your class/school
- ask them what you can do to support them and explain any of their specific difficulties
- discuss seizure types and how they should be dealt with, undertaking relevant training as necessary.



During lessons

Before you start:

- ensure you can see the pupil's reaction to instructions – they may be experiencing an absence or focal seizure
- check that pupil is not sitting near visual distraction e.g. windows
- allow pupil access to your lesson notes if appropriate.

Explaining the task:

- be clear about the purpose of any task
- break down tasks into smaller steps
- breakdown your targets into smaller, achievable steps
- allow pupil to repeat tasks - repetition means they have a better chance of mastering a task or remembering
- allow more time for pupil to complete task.





Teaching strategies:

- use group work. This will help the pupil to listen and contribute. It encourages them to problem solve with friends and helps them to learn from other pupils by asking questions
- use lined paper for writing and appropriate writing aid
- integrate speech and language therapy/ occupational therapy programmes into lessons where possible
- give written instructions for pupils with poor auditory memory
- utilise the pupil's strengths.

At the end of the lessons:

- ensure that the pupil has not missed anything
- give the pupil the opportunity to take work home to complete
- accommodate erratic performance – children may have good and bad days.



What pupils can do to support themselves

There are a lot of techniques that pupils can learn that will help them to get the most out of their classroom experience. Simply encouraging them to ask for help may be the most useful technique! Listed below are other strategies that can be modelled and taught:

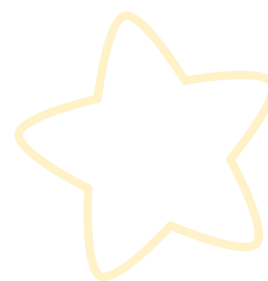
- use visual clues, such as photos or objects to prompt their memory
- use sticky notes with messages to jog memory
- use a visual timetable or 'now and next' board
- keep a notebook and make notes during or just after a conversation or lesson and use as a prompt
- make cue cards if they have to speak in class
- highlight notes or text books as a reminder of key facts
- use rhymes or songs to support memory
- keep calm, don't rush
- once they have learnt a skill through repetition they have a better chance of applying it to other areas or subjects
- be hands on as much as possible – making learning a practical experience makes it easier to remember a skill
- revise in short bursts using the methods mentioned earlier – sticky notes, highlighting
- use a voice recorder for notes.



What the parent or carer can do to support their child

- develop a good working relationship with the class teacher or tutor – ensure that information is shared fully
- if appropriate, ensure their child is fully involved in meetings with the teacher or tutor and able to give input into what they require
- less emphasis on homework and more emphasis on developing social skills, independence, integration during evenings and weekends and having fun!
- work on self esteem
- don't forget the siblings.

Above all: Keep cool, be calm and collected and talk about the problem





Managing inappropriate behaviour in the classroom

It is always better to pre-empt inappropriate behaviour with proactive interventions to avoid a situation escalating. Addressing the needs of the child and giving them support or strategies to help compensate for any lack of skills will help. Providing lots of opportunity to boost self-esteem and rewarding desirable behaviours will have a positive effect. By knowing the child well, and any potential triggers, inappropriate behaviours can be shaped into appropriate behaviours.

It may be necessary to manage inappropriate behaviour with reactive interventions. De-escalation techniques such as distraction are simple and effective. Do not focus on the behaviour but be aware of any secondary rewards that may be achieved as a result of inappropriate behaviour. Physical intervention should only be used to keep the child and those around them safe and the protocols within each school setting must be followed. If an incident occurs, then look and learn from what happened before, during and after the behaviour. It may help you to put in place some proactive strategies to avoid repeated incidents.





Psychosocial effects of epilepsy

The psychosocial effects of epilepsy depend on a number of factors including the child's personality, along with the types of seizures, and the efficacy and side effects of treatment. Any additional health problems including learning difficulties and the relationship with healthcare professionals can also have an impact on the well-being of the child. The attitudes of their school, family and friends also play an important role.

When a diagnosis of epilepsy is made, the child and their family may go through periods of stress, denial, sadness, grief, anger and even relief at being given a correct diagnosis.



Child's experience

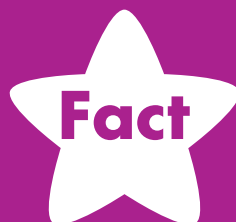
- bullying
- stigma & social isolation
- fear of injury/death
- over protection
- exclusion from activities
- poor relationships with siblings/peers.



Resulting effects

- low self-esteem
- lack of independence and fear of failure
- behavioural difficulties
- denial
- noncompliance with medication
- psychiatric disorders.

Poor self-image and low self-esteem can be the result of these experiences. In some cases behavioural difficulties can occur which may include noncompliance with medication. Psychiatric disorders, including anxiety and depression, may be seen and require specialist support and treatment.



Up to 50% of children with epilepsy in the UK may underachieve given their IQ. ⁽⁷⁾



Section 2

The impact of epilepsy

These children and young people may require counselling and the specialist psychological support provided by Child and Adolescent Mental Health Services. Some will have received some support and advice, along with information and education from an Epilepsy Nurse Specialist, but this is not always the case.

The most important overriding principle is to **encourage children with epilepsy to lead as normal a social life as possible.**

Parents sometimes find this extremely difficult and need encouragement to overcome their worries. A risk assessment on each activity should help put the activity into context. Relatively few restrictions are necessary for children with epilepsy and they should be encouraged to participate in, and enjoy, a full social life. Seizures are less likely to occur when they are engaged in satisfying mental or physical activity.



Section

“I anticipate that following this training, children with epilepsy will have a more positive school experience.”

Year 3 Teacher

3

Further support





Training

Young Epilepsy offers whole day training courses at their conference facilities in Lingfield, Surrey and at a variety of locations across the UK. Training is tailor-made for education, health and

social care professionals. Topics covered include general epilepsy awareness and emergency medication training. There are also a wide range of resources available at youngepilepsy.org.uk/what-we-do

Resources

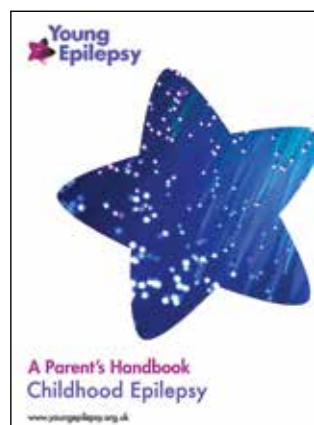
Young Epilepsy provides a range of free resources for children and young people, parents and carers of children and young people with epilepsy and professionals.



Parent handbooks

Two parent handbooks are available that contain information about childhood epilepsy, useful sample forms and signposting to further information and resources.

- newly diagnosed epilepsy
- complex epilepsy

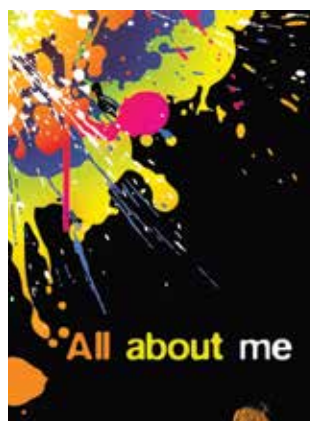
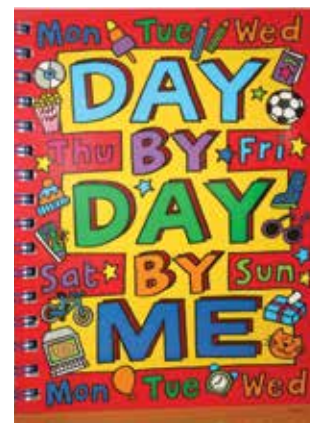


Seizure diaries

Two seizure diaries are available aimed at helping children and young people take control of their epilepsy.

- seizure diary for children
- seizure diary and handbook for teenagers

Find out more at youngepilepsy.org.uk/all-about-epilepsy



Young Epilepsy app

The Young Epilepsy app is an information, support and management tool specifically designed for young people with epilepsy, their parents and carers.

Available on Android and iOS, key features include:

- a Learn section tailored for either parents or young people
- a Diary which records seizures, logs symptoms, creates charts and gives appointment and medication reminders
- a Profile section which stores personalised information about a child's epilepsy, including emergency protocols
- the function to share information on the app via email.



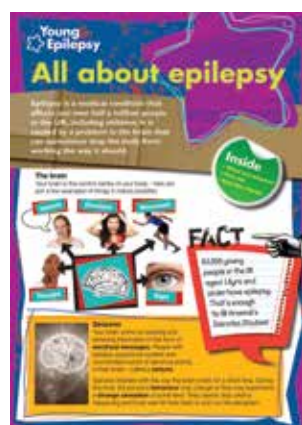
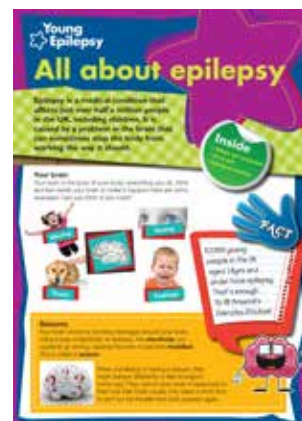
Download our FREE app:
youngepilepsy.org.uk/app

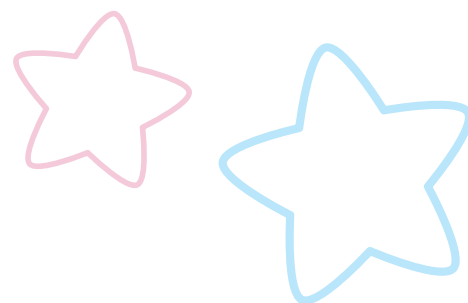
Resources for schools

Young Epilepsy has a range of resources for schools to aid teaching about epilepsy:

- all about epilepsy magazines for primary and secondary aged pupils
- assembly and lesson resources
- fun and interactive e-learning activities

For these resources, and more, go to youngepilepsy.org.uk/resources-for-schools





Young Epilepsy's Champions Campaign

At Young Epilepsy we want to create better futures for young lives. A national charity, Young Epilepsy has over 100 years' experience as a centre of expertise for all young people with epilepsy. Research findings on the effects of epilepsy and the level of support provided by both the NHS and schools show that these young people often get a raw deal. They can experience a triple whammy of the condition itself, limited support from schools and the NHS, and the stigma that epilepsy still – wrongly – attracts.

Young Epilepsy's Champions Campaign is pressing policymakers, health trusts, local authorities and schools to provide improved services and support for the 63,400 young people with epilepsy across the UK.

Can you go the extra MILE?

We're asking everyone who undertakes Young Epilepsy training to 'go the extra MILE' and champion epilepsy in your school.

Join our campaign and we will support you to make the most of your training by developing best practice and policy where you work. Our Education Action Plan will point you in the right direction and our campaign staff can work with you and offer advice and support.

To find out more visit our web pages at youngepilepsy.org.uk/what-we-do or ring the campaign team on **01342 831340**

Together we can make a difference that sees better futures for young lives with epilepsy.

Schools and teachers can go the extra MILE for young people with epilepsy by:

Monitoring achievement and behaviour

- Keep careful and appropriate records of students with epilepsy
- Changes in behaviour or levels/ rates of achievement can be due to epilepsy and should be recorded
- Tackle any problems early

Including the child in activities and providing a buddy

- Offer support in school with a mentoring or buddying system to help broaden understanding of the condition
- Avoid isolation and stigma - allow students to take a full part in all outings and activities
- Make necessary adjustments e.g. exam timings, coursework deadlines, timetables

Liaising fully with parents and health professionals

- Let parents know what is going on in school - good information sharing is vital
- Ask for information about a student's health care - it helps you to fully meet their needs

Ensuring staff are epilepsy aware and trained to deal with a seizure

- Know exactly what to do if a student has a seizure
- Raise awareness across the whole school community - provide information to students, parents and staff

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

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

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After the seizure (briefly describe each of the following)					
Level of alertness:					
Immediately following seizure:					
5 mins after seizure:					
Maintenance of alertness					
Confusion					
Muscle weakness					
Duration of event					
Total Recovery Time					
Treatment given	Medication:	Dose:	Time given:	Response:	
Parents informed					
Signed					
Print Name					
Date		Time			

Individual healthcare plan

Name _____ Date of birth _____ Age _____

■ Diagnosed condition/s _____

■ Allergies _____

■ Special dietary requirements _____

■ Routine medication

Drug _____ Dose _____ Time _____

Drug _____ Dose _____ Time _____

Drug _____ Dose _____ Time _____

Drug _____ Dose _____ Time _____

■ Information on how to give medication _____

■ Activities that should be avoided _____

■ Activities that require special precautions _____

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■ Possible triggers for seizures _____

■ Warning signs that seizures might be about to happen _____

■ Description of typical seizure/s _____

■ Action to be taken during and after a seizure _____

■ Seizures normally last _____ minutes.

Emergency medication should be given if the seizure has not stopped after _____ minutes,

or if _____

■ The emergency drug to be given is _____

The dose to be given is _____

It should be given orally

rectally

into the buccal cavity (between the cheek and the teeth)

Circumstances when emergency medication should NOT be given _____

■ Circumstances when a second dose of emergency medication may be given _____

The second emergency medication to be given is _____

It should be given orally

rectally

into the buccal cavity (between the cheek and the teeth)

■ Named individuals who may give emergency medication

1. _____

2. _____

3. _____

4. _____

■ You should call an ambulance/doctor if _____

■ Please call _____ if the following situation occurs

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■ This plan has been agreed and consent is given for emergency treatment by:

Child/young person/parents/guardians/prescribing doctor

Name _____ (prescribing doctor)

Signature _____ Date _____

AND

Name _____ (child/young person)

Signature _____ Date _____

AND

Name _____ (parent/guardian)

Signature _____ Date _____

AND

Name _____

Signature _____ Date _____

Position in relation to child _____

■ Date this health care plan should be reviewed _____

■ Additional Information/instructions _____

Seizure description chart

(Seizure record chart overleaf)

Name _____ Date of birth _____

■ Description seizure type 1

■ Description seizure type 2

■ Description seizure type 3

■ Description seizure type 4

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Seizure record chart

Name _____

Date of birth _____

Month _____

Year _____

	Total
Seizure type 1	
Seizure type 2	
Seizure type 3	
Seizure type 4	

Date	Time	Seizure type	Awake/asleep	Emergency medication	Possible trigger	General comments
1						
2						
3						
4						
5						
6						
7						
8						
9						
10						
11						
12						
13						
14						
15						
16						
17						
18						
19						
20						
21						
22						
23						
24						
25						
26						
27						
28						
29						
30						
31						

Record of the use of emergency medication

Name _____ Date of birth _____ Age _____

■ Date medication given _____

■ Time seizure started _____

Type of seizure _____

■ Number of seizures (if occurring in a cluster) _____

■ The emergency drug, dose and route given _____

■ Emergency drug given by whom _____

Time emergency drug was given _____

■ Time seizure stopped _____ Length of seizure _____

Comments _____

■ Time ambulance called (if required) _____

Ambulance called by _____

■ Second dose emergency medication given at _____

Second dose emergency medication given was (name, dose and route) _____

Comments _____

■ Time parents/guardians informed _____

Parents informed by whom _____

■ Person responsible for another supply of emergency medication _____

■ Comments _____

Record of the use of emergency medication

Name _____ **Date of birth** _____ **Age** _____

■ Date medication given _____

■ Time seizure started _____

Type of seizure _____

■ Number of seizures (if occurring in a cluster) _____

■ The emergency drug, dose and route given _____

■ Emergency drug given by whom _____

Time emergency drug was given _____

■ Time seizure stopped _____ Length of seizure _____

Comments _____

■ Time ambulance called (if required) _____

Ambulance called by _____

■ Second dose emergency medication given at _____

Second dose emergency medication given was (name, dose and route) _____

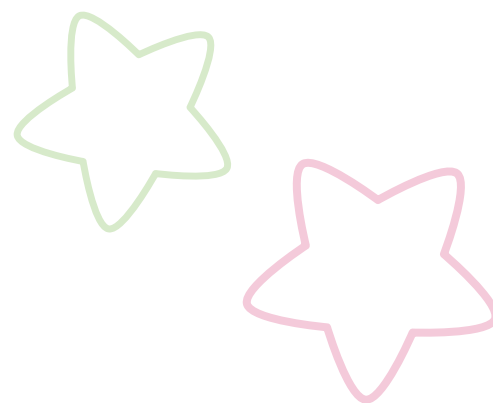
Comments _____

■ Time parents/guardians informed _____

Parents informed by whom _____

■ Person responsible for another supply of emergency medication _____

■ Comments _____



Contact us

Epilepsy Education 4 Schools
Young Epilepsy
St Piers Lane
Lingfield Surrey
RH7 6PW

Tel: 01342 832243 ext 511/295
Email: epilepsyeducation@youngepilepsy.org.uk
Website: youngepilepsy.org.uk

Young Epilepsy's helpline and email enquiry service

Our helpline and email enquiry service offers information and support to young people with epilepsy, their parents and carers as well as the professionals in education, health and care who work with them.

This is a confidential service, and all enquiries, are dealt with by trained staff with knowledge and understanding of epilepsy in children and young people and the issues this may raise.

If you would like to speak with someone about childhood epilepsy, call our epilepsy information helpline on **01342 831342** (Monday to Friday, from 9am to 1pm) - national call rate. You can also email your question to **helpline@youngepilepsy.org.uk**

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Better futures for young lives with epilepsy



Check out our Facebook page: facebook.com/youngpilepsy



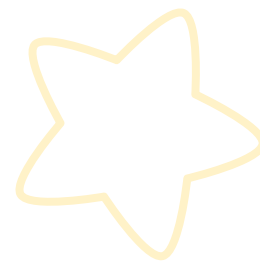
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Watch us on YouTube: youtube.com/youngpilepsy



Download our FREE app: youngpilepsy.org.uk/app



Childhood Epilepsy Helpline: 01342 831342

Monday to Friday 9am – 1pm

Email: helpline@youngpilepsy.org.uk

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