

# London epilepsy guide for schools

## Improving care for children and young people with epilepsy



February 2016

Healthy London Partnership – Transforming London's health and care together

## About this document

This document is intended to enable schools to manage children and young people with epilepsy effectively in an early years or school setting. Recommendations and guidelines contained within are derived from clinical practice across London and from contributions from stakeholders across London.

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**In partnership with:**



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# 1 Introduction

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## Purpose

Healthy London Partnership formed in April 2015. It has been working across health and social care, and with the Greater London Authority, Public Health England, NHS England, London's councils, clinical commissioning groups, and Health Education England. We have united to amplify the efforts of a growing community of people and organisations that believe it is possible to achieve a healthier, more liveable global city by 2020. Healthy London Partnership is focused on transformation programmes, one of which is the Children and Young People's (CYP) Programme. Our vision is for an integrated system for health and care services, which promotes health and well-being and can be easily navigated by children, their families and health professionals to achieve the best outcomes.

## What is your responsibility?

The Children and Families Act 2014 introduced a legal duty on schools to look after children with medical conditions. Schools must make arrangements to support pupils at school with medical conditions and understand what they are required to provide. For epilepsy this involves making sure staff are trained how to manage seizures, guaranteeing equality of access and ensuring inclusion for opportunities provided during school activities. School governing bodies have a duty to ensure that these arrangements are in place.

## Summary of recommendations

- Every child with epilepsy should have an Individual Healthcare Plan (IHP). This should include what to do in the event of a seizure (and especially prolonged seizures), as well as other tailored advice for that individual young person.
- Children and young people should be supported throughout their education, recognising the impact that epilepsy has on learning, behaviour, mental health and wellbeing.
- Prompt identification of learning and behaviour needs in children with epilepsy is vital.
- Each school should have an up-to-date medical conditions policy.
- Children and young people with epilepsy should have appropriate supervision depending on their individual needs.
- Children under 5 need consideration of 1:1 support at school (in the absence of a parent). This may need an Education Health Care Plan (EHCP) to support and may need funding.
- Primary schools (6 years+) Children and Young People require support to manage their epilepsy in school in line with the Children and Families Act 2014.
- In secondary school the student will be largely independent but may require intermittent support.

## 2 Epilepsy at school

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The Children and Families Act 2014 introduced a legal duty on schools to look after children with medical conditions. This includes children with epilepsy and so it is essential that all early years, school staff and those who support younger children in the school or after school activity setting have an awareness of this condition and how to manage its health, learning and behavioural impact.

### Introduction

Epilepsy is a medical condition where a child or young person may have repeated seizures. While many people have an impression of what a seizure looks like, there are actually many different ways that a seizure can manifest.

- **School staff need to know how to manage seizures and to risk assess activities to ensure the child's safety and inclusion.**

Epilepsy is not just a medical condition. Many children experience learning and behaviour problems due to the effects of seizures, epilepsy medications as well as with the underlying cause of the epilepsy.

- **School staff should be aware of the unique impact of epilepsy on a child or young person, taking care to recognise the individual's needs and to support them appropriately so that they can achieve their potential.**

Added to that, stigma of having epilepsy can leave some children battling low self-esteem, exclusion, discrimination and a lack of understanding from both peers and adults.

- **School staff having better knowledge and awareness of epilepsy (and its effects) will help to decrease the stigma that children and young people can experience.**

### What is epilepsy?

- Epilepsy is a condition that causes a person to have recurring seizures.
- With over 40 different types of seizure, the condition can vary hugely depending on which part of the brain is affected.
- Approximately 63,400 children and young people aged 18 and under have epilepsy in the UK. In London, this means about 2,000 children and young people (1 per cent).
- The average primary school in London will have approximately one to two pupils with epilepsy; secondary school have four to five pupils; and special needs schools many more.
- In most cases the condition can be controlled by antiepileptic drugs but these can have unwanted side effects.

- Some children with epilepsy may require emergency medication if they are at risk of having a convulsive seizure that lasts longer than five minutes.
- Up to 95 per cent of school-aged children with epilepsy have significant difficulties with learning or behaviour
- Emotional disorders, such as depression and anxiety disorders, are commonly seen in children with epilepsy

# 3 Preparing to support a child with epilepsy in school

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## Individual healthcare plans

Every child with epilepsy should have an Individual Healthcare Plan (IHP) that describes their condition and how it is best managed. This document should be drawn up between the:

- child's school (teachers, school nurse, or SENCO if appropriate),
- parents
- child's epilepsy healthcare team (consultant, epilepsy specialist nurse or senior trainee)
- child themselves.

Once this document is signed by all involved, it should be made readily available to all members of relevant staff.

The Individual Healthcare Plan should include:

a) Background information:

- the child's diagnosis
- a clear description of the child's seizures, frequency and duration
- classification of epilepsy type
- any known seizure triggers and 'warnings' prior to a seizure
- regular medications (including doses and usual timings)
- any related health problems

b) Emergency plan:

- what to do in the event of a seizure and when to call an ambulance
- when and how to administer emergency medication should it be required, the dose required and where it is stored
- who is trained to administer emergency medication
- who to contact in the event of an emergency
- what the child is like after a seizure and the follow up care recommended

c) Related support:

- details of any problems with learning and behaviour and how these will be supported at school
- support the child requires to manage their epilepsy
- what plans need to be put in place for any school trips (including overnight) or other school activities outside of the normal timetable

d) Date to review the plan.

Childhood epilepsy can be an extremely fluctuating condition and therefore a child's IHP should be reviewed annually or before if any details require alteration (e.g. changes in medication).

[Please see this online example Individual Healthcare Plan provided by Young Epilepsy.](#)

**Further examples can be found in Appendix 2: References and additional reading.**

## Training

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 children with long term medical conditions must have appropriate training to ensure they understand conditions such as epilepsy and the wider impact they can have.

Basic epilepsy training should be provided to staff; depending on local availability, this could be via an appropriately trained school nurse (who has undergone specific epilepsy training themselves), or perhaps via the local epilepsy specialist nurse. Some epilepsy organisations can also provide training directly for wider members of school staff.

Examples of topics covered include:

- different seizures types in epilepsy
- what to do in the event of a seizure
- first aid training
- how to administer emergency medication
- the impact of epilepsy
- Buccal midazolam/emergency medication training

For information on the training Young Epilepsy can provide to school staff and pupils, please visit [www.youngpilepsy.org.uk/training](http://www.youngpilepsy.org.uk/training)

There is also online learning for schools and people with epilepsy and their families. Available from Epilepsy Action here <http://learn.epilepsy.org.uk/courselist/>



## 4 Managing the medical aspects of epilepsy in schools

### Awareness of seizure types

There are over 40 different types of seizures. Different seizure types can affect movement, sensation, mood, memory, consciousness and behaviour to differing extents. Seizure types fall into two main categories: generalised seizures and focal seizures.

Generalised seizures affect the whole brain and usually result in a loss of consciousness. Types of generalised seizures include:

Type of generalised seizure	Symptoms
<b>Absence</b>	Sudden termination of activity, staring into space and unresponsive for usually 5-10 seconds
<b>Atonic</b>	A sudden loss of muscle tone and a fall
<b>Clonic</b>	Rapid repetitive muscle twitching and a fall
<b>Myoclonic</b>	Sudden jerks in sets of muscles of the body
<b>Tonic</b>	Stiffening of the limbs and a fall
<b>Tonic clonic</b>	Initial stiffening and a fall, then rhythmical jerking of the body

Focal seizures are seizures which arise from just one localised area of the brain, and hence the symptoms experienced will depend on which part of the brain is affected. Children do not lose consciousness during focal seizures, however they may display altered awareness and confusion.

Type of focal seizure	Possible symptoms
<b>Temporal lobe</b>	<ul style="list-style-type: none"><li>• Strange feelings, emotions or thoughts</li><li>• Alterations in visual or verbal memory</li><li>• Strange smells and tastes</li><li>• Confusion with semi purposeful movements such as plucking at clothes, repeated swallowing or lip smacking</li><li>• Alteration in awareness</li></ul>
<b>Occipital lobe</b>	<ul style="list-style-type: none"><li>• Visual disturbance - seeing coloured spots, lights and patterns</li><li>• Hallucinations</li></ul>
<b>Parietal lobe</b>	<ul style="list-style-type: none"><li>• Feeling that a part of the body is getting bigger or smaller</li><li>• Strange sensations down one side of the body, such as pins and needles, numbness or heat.</li></ul>
<b>Frontal lobe</b>	<ul style="list-style-type: none"><li>• Weakness, stiffness or jerking in part of the body</li><li>• Confusion and dramatic movements of the body such as leg cycling, head turning and arm posturing</li></ul>

Some children may experience bilateral convulsive seizures. This starts with a focal seizure of a certain type and then progresses onto a generalised seizure, as the electrical activity spreads to affect the entire brain.

## Awareness of seizure triggers

For some children, certain triggers may make it more likely that they will have a seizure. Examples of seizure triggers may include:

- Illness (particularly when accompanied by a fever);
- stress, anxiety, excitement or boredom;
- lack of sleep or tiredness;
- loud noises;
- changes in anti-epileptic medication, or failing to take it;
- menstruation;
- flickering lights (rare only 4% are affected by this).
- Natural lights which are within the photosensitive range  
<https://www.epilepsy.org.uk/info/photosensitive-epilepsy>

Most importantly, any triggers should be identified on the child's IHP so that they can be appropriately managed and taken into account when planning activities. For example:

- 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;
- if stress is a significant trigger of seizures then teaching stress management and relaxation skills may be beneficial.

## Daily epilepsy medication

The most common treatment for epilepsy is to use anti-epileptic drugs, and 70% of people who take this medication will stop having seizures. Anti-epileptic drugs are usually taken once or twice a day outside of school hours. They are prevention rather than a cure, and therefore need to be taken regularly over a long period of time.

Anti-epileptic drugs can have side effects, although these usually subside after their initial introduction. Some common side effects include:

- drowsiness or lethargy
- mood and behaviour changes
- appetite changes
- dizziness or unsteadiness
- memory, learning and attention problems

As children with epilepsy grow, they are likely to require alterations to their anti-epileptic drugs and as a result, some side effects may temporarily re-emerge. In some cases, school staff may be the first to notice changes to a child's mood, behaviour and learning and this should be fed back to parents. It is important that parents communicate recent medication changes to the school to help manage any side effects and the increased risk of a seizure in some cases.

Anti-epileptic drugs may not work for all children with epilepsy. In these cases, alternative treatment options may be considered including brain surgery and special diets.

## 5 What to do in the event of a seizure

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The following procedures are general guidance only and the child's IHP should detail what to do specifically for them in the event of a seizure.

### For focal seizures

You should:

- record the time the seizure starts and stops (and hence the duration)
- move any hazards out of their immediate vicinity
- try to guide them away from any hazards
- stay with them until they are fully recovered
- NOT restrain their movements
- NOT shout or grab at them.

### For generalised seizures

You should:

- record the time the seizure starts and stops (and hence the duration)
- move any hazards out of their way
- loosen tight clothing from around their neck
- put something soft under their head
- let the seizure run its course
- when the jerking has stopped, place them in the recovery position
- stay with them until they are fully recovered
- NOT restrain their movements
- NOT attempt to move them unless there is unavoidable danger
- NOT put anything in their mouth.

### When to call an ambulance

A child's individual healthcare plan should detail under what circumstances you need to call an ambulance in the event of a seizure. However, the general guidance is that you should seek urgent medical attention if a child:

- has a seizure type they have never had before
- is not breathing or is blue around the lips
- has a seizure lasting for more than 5 minutes
- has repeated seizures without regaining consciousness in between
- is not responding to you after the seizure has stopped
- is injured.

## Emergency medication for prolonged seizures

Some children may have medication in school to be used in the event of prolonged seizures. This is usually administered if a generalised convulsive seizure (tonic-clonic seizure) lasts longer than 5 minutes, or two minutes longer than is usual for the child. The reason for this is that most seizures stop by themselves after 5 minutes. The longer seizures continue, the harder they are to stop.

If a convulsive seizure lasts for more than 30 minutes, or if the child has clusters of convulsive seizures without regaining consciousness in between, it is a life threatening emergency called status epilepticus. Emergency treatment of the seizure early on can help prevent status epilepticus.

A child's IHP should detail under what circumstances emergency medication should be given. A child will only be prescribed emergency rescue medication if they have experienced prolonged seizures previously. Staff who may need to administer emergency medication should be trained on how to do so and a record should be kept.

## Witnessing a seizure

There is no definitive diagnostic test for epilepsy. Diagnosis is based on eye witness accounts of seizures, clinical history and the results of investigations such as brain scans and electroencephalograms (EEGs, brain wave tests).

If you witness a child having a seizure at school it is helpful to document a detailed description of what happened before, during and after the seizure if at all possible.

**An example of what to record when you witness a seizure can be found on Young Epilepsy's website, at**

**<http://www.youngepilepsy.org.uk/315-describing-a-seizure-1.html>**

Other children at school may also witness a classmate having a seizure. Generally, an open and honest explanation will help to lessen any fears and decrease stigma. However, it is crucial to consider the confidentiality of the young person with epilepsy. Some may not want to disclose their condition.

## Non-epileptic seizures

It is important to be aware of non-epileptic seizures (NES), which consist of changes in behaviour or consciousness and may, to an observer, resemble epileptic seizures. However, NES are not accompanied by the electrical changes in the brain seen in epilepsy. Importantly, many young people with NES also have a diagnosis of epilepsy. As such, it is important that IHPs for these children make clear which events are epileptic seizures (requiring emergency management as mentioned previously in this guidance), and which events are NES.

## 6 Risk assessment and inclusion

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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 2015](#),' means that schools must make reasonable adjustments to ensure all children with epilepsy have full access to education, sports and school trips and that they are not put at a substantial disadvantage. Of particular importance to epilepsy, schools must also support a child's social and emotional wellbeing.

Studies show that children with epilepsy who are more mentally and physically engaged, are less likely to have seizures. Good risk assessment will enable all children to have full access to the curriculum and not feel excluded. Although many activities can be managed by putting the appropriate levels of supervision in place and taking sensible precautions, there may be certain high risk factors that need to be taken into account when planning activities.

If a child's seizures are not well-controlled, they should:

- avoid activities in which loss of consciousness could put them or others at risk
- avoid activities that have a high risk of head injury
- not climb higher than their own height if safety devices are not in use
- have 1:1 supervision when swimming.

### Special consideration for school trips

Trained staff should ensure they take the child's IHP and any emergency medication required.

Be aware of possible seizure triggers associated with the trip, such as excitement, fatigue, irregular eating and altered sleeping patterns. In terms of residential trips, discuss with parents if any special requirements are needed for nocturnal seizures and seizures on waking. Baths are not a safe option, and so showers are recommended when on school trips.

# 7 Managing the learning and behavioural impact of epilepsy in schools

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## How does epilepsy affect learning and behaviour?

Although learning difficulties are not an automatic consequence of epilepsy, children with the condition are at greater risk of learning and behavioural difficulties than those without. Young Epilepsy have found that:

- 60% of school children with epilepsy have a behavioural disorder;
- 58% have memory underachievement;
- 42% underachieve in the area of processing speed;
- 42% underachieve in at least one academic area, with the greatest difficulty in mathematics and sentence comprehension.

Overall, 95% of the children had a significant difficulty in at least one area of learning or behaviour.

Learning and behavioral problems can be attributed to several factors including:

- the effects of abnormal levels of electricity and seizures on the brain;
- medication side effects;
- additional co-morbidities (e.g. ADHD, autism and emotional and anxiety disorders);
- psychosocial issues linked to having epilepsy.

## Supporting learning and behaviour

Prompt identification of learning and behaviour needs in children with epilepsy is vital. 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 also supports decisions for either SENCO level support or, where significant concerns are identified, an application for Education, Health and Care assessment.

## Supporting psychological impact

Epilepsy has a huge impact on a child or young person's emotional and psychological well-being. This must be recognised with appropriate support considered and put in place as required.

## Key responsibilities

### Head teacher

The head teacher should ensure:

- A supporting medical conditions policy is in place and is being effectively implemented.

- All staff are aware of their responsibilities within the medical conditions policy.
- All staff who need to know are aware of a child's epilepsy and their IHP.
- Sufficient numbers of staff are trained in seizure first aid and the administration of emergency medication (such that an appropriately trained staff member is always practically close enough to respond in the event of a seizure).
- Staff are aware of the impact epilepsy can have on learning and behaviour.
- All children with epilepsy have an IHP and that this includes details of how epilepsy affects their learning and behaviour if they do not have a statement or EHCP.
- Activities and school trips are appropriately risk assessed and that safety precautions and/or enhanced supervision is put in place to enable children with epilepsy to participate fully in all aspects of school life, including physical and extra-curricular activities.

## Parents and carers

Parents and carers should:

- Liaise with their child's headteacher and healthcare team to provide the school with up-to-date information about their child's epilepsy and treatment.
- Be involved in the development and review of their child's individual healthcare plan, supplying information about their seizures, triggers, seizure management and how their learning and behaviour is affected by their condition.
- Inform the school of any changes to their child's condition, including changes to seizure types, emergency protocols, seizure triggers and aeds.
- Inform the school if they think their child is at an increased risk of a seizure on a particular day – for example if they are over tired, stressed or ill and these are known seizure triggers).
- Keep the school supplied with appropriately labelled and in date emergency medication.

## Pupils

Where appropriate, pupils with epilepsy should

- Be involved in the development and review of their IHP.
- Be encouraged to share information on how their epilepsy impacts their school life and their social and emotional wellbeing.

## School staff

School staff should ensure:

- They undergo appropriate training on how to administer emergency medication before they take on the responsibility to do so.
- Be familiar with the IHP of any pupils in their care.
- They regularly assess and monitor the learning and behaviour of a child with epilepsy as this may fluctuate over time.



- They refer any children showing significant problems with learning and behaviour for an Education Healthcare Assessment.
- Activities and trips are risk assessed in reference to the specifics of a child's epilepsy.

## **School nurses**

School nurses, in some cases with the help of Epilepsy Specialist nurses, can provide the following to schools:

- Advice and information for the development of IHPs and risk assessments;
- Training on basic seizure first aid and administration of emergency medication.

# Appendix 1: Legislation

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## The Children and Families Act 2014

Section 100 of the Children and Families Act 2014 introduced a legal duty on schools to look after children with medical conditions. This is inclusive of children with epilepsy. Schools must make arrangements to support pupils at school with medical conditions and have regard to the statutory guidance: Supporting pupils at school with medical conditions

## The Education Act 2002

Sections 21 and 175 detail how governing bodies of maintained schools must promote the wellbeing of pupils and take a view to the safeguarding of children at the school.

## Section 3 of the Children Act 1989

This places a duty on a person with the care of a child to do all that is reasonable in the circumstances for the purposes of safeguarding and promoting the child's wellbeing. With relation to a child with epilepsy, this will mean knowing what to do in the event of an emergency.

## Legal duties on local authorities

Local authorities have legal responsibilities to help make sure schools can meet the duties relating to children with epilepsy. These duties both refer to all children in the local authority and they do not depend on the kind of school the child attends.

## Section 10 of the Children Act 2004

This is a particularly important piece of legislation if schools are struggling to get the support and training they need to allow them to look after a child with epilepsy properly.

Section 10 essentially means the local authority must make arrangements to promote cooperation between the authority and relevant partners. Relevant partners include the governing body of a maintained school, the proprietor of an academy, clinical commissioning groups and the NHS Commissioning Board.

They must make arrangements with a view to improving the wellbeing of children, including their physical and mental health, protection from harm and neglect, and education.

## Section of 17 of the Children's Act

This gives local authorities a general duty to safeguard and promote the welfare of children in need in their area. If a school is looking after a child with epilepsy so poorly that the child is put in danger, the local authority must step in.

## Legal duties on the NHS

### Section 3 of the NHS Act 2006

This gives Clinical Commissioning Groups (CCGs) a duty to arrange for the provision of health services to the extent the CCG considers it necessary to meet the reasonable needs of the persons for whom it's responsible.

What this means is that CCGs should provide the healthcare the people in its area need, if these needs are reasonable.

This section also provides for CCGs to arrange such services as it considers appropriate to secure improvements in physical and mental health of, and in the prevention, diagnosis and treatment of illness, in the persons for whom it's responsible.

In relation to children with epilepsy this means that a CCG should, within reason, make sure support and health care is in place to improve their health or at least keep them healthy. Poor management of epilepsy at school will obviously affect the health of a child. If a school is unable to get the support it needs to help manage a child's epilepsy successfully then both the local authority and the local CCG have a responsibility to the child's health and welfare.

### Equality Act (2010)

The equality act says that types of discrimination are illegal, defining discrimination as when a person with a disability is treated less favourably, because of his or her disability, than a person who does not have a disability.

The Equality Act 2010 defines a disability as a 'physical or mental impairment' that has 'a substantial and long term adverse effect' on an individual's ability to carry out 'normal day-to-day activities'. A substantial adverse effect is a negative effect that is more than trivial, and the effect is long-term if it has lasted or is expected to last for more than twelve months. Whilst only a court or tribunal can decide whether a person with epilepsy is covered by the definition, in many cases epilepsy is covered by the definition in the Act.

Education and early years providers have a duty to make reasonable adjustment for people with disabilities and failure to make reasonable adjustments is a form of discrimination. The Act covers all schools and providers of early years settings that are covered by the early years framework in England, including maintained (non-fee paying) and fee-paying schools.

## Appendix 2: References and additional reading

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- Epilepsy Action  
<https://www.epilepsy.org.uk>
- Epilepsy Action: My Epilepsy Care Plan  
<https://www.epilepsy.org.uk/sites/epilepsy/files/professionals/G216%20-%20EPILEPSY%20CARE%20PLAN%20PDF%20V1.pdf>
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[https://www.gov.uk/government/uploads/system/uploads/attachment\\_data/file/306952/Statutory\\_guidance\\_on\\_supporting\\_pupils\\_at\\_school\\_with\\_medical\\_conditions.pdf](https://www.gov.uk/government/uploads/system/uploads/attachment_data/file/306952/Statutory_guidance_on_supporting_pupils_at_school_with_medical_conditions.pdf)
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[www.youngepilepsy.org.uk](http://www.youngepilepsy.org.uk)

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- Emma Sebastian, Education Training Lead, Young Epilepsy
- Kerry Robinson Consultant Paediatrician Whittington Health, and Deputy Chair of North Thames Paediatric Epilepsy Network
- Neil Williamson, Epilepsy Nurse Specialist (Children), University Hospital Lewisham

## Glossary

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<b>AEDs</b>	Anti-epileptic drugs; daily medicine used to prevent epileptic seizures.
<b>CCGs</b>	Clinical Commissioning Groups
<b>CCN</b>	Community children's nurse
<b>CYP</b>	Children and young people
<b>Electroencephalogram (EEG)</b>	A test that records the electrical activity in the brain. It does not provide a diagnosis of epilepsy, but is useful for seizure classification and deciding on the type of seizures.
<b>Emergency rescue medication</b>	Medication that is used to terminate a prolonged generalised convulsive seizure.
<b>Epilepsy</b>	A chronic neurological condition that results in recurrent seizures.
<b>Ketogenic diet</b>	A high fat, low carbohydrate, controlled protein diet used in the treatment of medication resistant epilepsy
<b>NICE</b>	National Institute of Health and Care Excellence
<b>NES</b>	Non-epileptic seizures
<b>Seizure</b>	An alteration in sensation, behaviour, movement or consciousness. the direct result of a change in the electrical activity on the brain
<b>Seizure trigger</b>	Something that may increase the likelihood of aa seizure.
<b>SENCO</b>	Special educational needs co-ordinator
<b>Status epilepticus</b>	Any seizure lasting for at least 30 minutes or repeated seizures lasting for a total of 30 minutes or longer, from which the person does not regain consciousness between each seizure.
<b>Warning/Aura</b>	A feeling that may experienced that always precedes a seizure. This may be a funny feeling, smell, taste or sensation.