An overview of epilepsy in children and young people


Abstract
The role of the nurse is vital in the management of childhood epilepsy. Nurses play a key role in supporting the child and the family and ensuring that important relevant and accurate information is identified, recorded and reported to the team responsible for the medical management.

Aims and intended learning outcomes
This article aims to give readers an overview of epilepsy and its management in children and young people. After reading this article and completing the time out activities you should be able to:
- List the different types of seizures and describe their presentation.
- Describe the relevant information about any seizures that you observe to aid accurate diagnosis.
- Manage seizures effectively and recognise potential emergency situations.
- Discuss the different treatment options available for epilepsy.
- Evaluate the impact having epilepsy may have on a child and his or her family.

Introduction
Epilepsy is a chronic neurological condition that affects 63,400 people in the UK aged 18 and under (Joint Epilepsy Council (JEC) 2011). It is characterised by recurrent epileptic seizures originating in the brain.

An epileptic seizure is a transient occurrence of signs and/or symptoms resulting from abnormal, excessive or synchronous neuronal activity in the brain (Fisher et al 2005). This activity results in an alteration in motor activity, sensation, behaviour or consciousness. There are more than 40 different types of seizure (JEC 2011). Seizures usually last from a few seconds to a few minutes and are self-limiting.

Causes of epilepsy
In approximately 60 per cent of cases, the cause of epilepsy is not known (Epilepsy Research UK 2011).

The types of epilepsy fall into three categories: those with a genetic cause (idiopathic epilepsy); those where epilepsy is the secondary result of a separate structural or metabolic condition (symptomatic epilepsy); and those where the cause is unknown (cryptogenic epilepsy) (Berg and Scheffer 2011).

Causes of epilepsy include damage to the brain as a result of injury, deprivation of oxygen at birth, infections such as encephalitis or meningitis, malformation or degeneration of the brain and brain tumours. Metabolic causes include low blood glucose, calcium and drugs (including alcohol). Genetic conditions such as tuberous sclerosis may also be a cause.

Now do time out 1.

Defining epilepsy
In 2005 the International League Against Epilepsy and the International Bureau for Epilepsy defined epilepsy as a brain disorder ‘characterised by an enduring predisposition to generate epileptic seizures and by the neurobiologic, cognitive, psychological and social consequences of this condition’. With this in mind, explain why you think epilepsy is more than just a health condition?

Different types of seizures
Classifying which seizure type(s) a child has experienced is important for the future management and outcome of the child’s epilepsy. Seizure types fall into two main categories: generalised seizures and focal (partial) seizures (Figure 1).
**Generalised seizures** In generalised seizures the whole brain is affected by changed electrical activity and the child becomes unconscious of their surroundings. The following are some examples of generalised seizures.

*Tonic-clonic seizures* Tonic-clonic seizures usually start with a cry and a loss of consciousness, resulting in the child going stiff and falling to the ground. The ‘tonic’ or stiff phase then leads to a ‘clonic’ or jerking phase. Finally there may be confusion, often followed by sleep. The child may be incontinent of urine.

*Tonic seizures* In tonic seizures the muscles stiffen and, if standing, the child will fall heavily, usually backwards, and will often receive injuries to the back of the head. There is no jerking.

*Atonic seizures* In atonic seizures the muscle tone is lost, causing the child to flop and fall heavily to the ground and, although recovery is swift, the child will often experience a head or facial injury.

*Myoclonic seizures* Myoclonic seizures usually occur shortly after waking or before retiring to bed when the child is tired. The muscles jerk rather as if the child has had some sort of electric shock. There is a brief, and hardly noticeable, loss of consciousness. These seizures may occur in clusters in which numerous seizures can occur over a few minutes, or even a couple of hours.

**Absence seizures** Absence seizures usually begin in childhood or adolescence and may occur many times a day and provoke a brief ‘trance-like’ state. The child will stare blankly and be unresponsive for usually five to ten seconds. Recovery is immediate and these episodes may go unnoticed. The child’s failure to respond when being spoken to during a seizure often results in the child being told off for not paying attention.

**Focal (partial) seizures** Focal refers to the seizure coming from one area of the brain. Symptoms that occur during a focal seizure depend on where in the brain the abnormal burst of electrical activity occurs and the function for which that area is responsible (Figure 2). Consciousness may be impaired and, in contrast to absence seizures, children may experience a state of confusion following the seizure.

Now do time out 2.
Temporal lobe epilepsy Temporal lobe epilepsy can start in children of any age. The child will have a warning such as epigastric sensations (butterflies in the stomach), an odd smell or taste, fear or confusion afterwards. Because the temporal lobes are responsible for feelings, emotions and memory, children experiencing this form of epilepsy may experience a variety of feelings or emotions, including déjà vu and jamais vu. Children may also experience seizures that, on occasion, may generalise into tonic-clonic seizures. Most children will respond well to antiepileptic drugs. For those who do not respond to medication, treatment in the form of surgical resection has a good success rate (Azrimanoglou et al. 2002).

Frontal lobe epilepsy Although the symptoms associated with seizures arising from the frontal lobe will vary in nature depending on which part of the frontal lobe is involved (for example, seizures involving the motor areas of the brain can produce strange movements that occur on the opposite side of the body from the abnormality), the seizures usually occur in clusters with many brief seizures occurring per night that start and end abruptly. They may also produce weakness in certain muscles including those used in speech, which can last from minutes to hours following the seizure. These seizures usually occur during sleep and can present in a strange and dramatic manner involving head turning, thrashing around or cycling movements of the legs.

Occipital lobe epilepsy Seizures occurring in the occipital lobe usually present with sight-related symptoms, such as rapid eye blinking, seeing patterns, flashing lights or colours. Seizures can spread from the occipital lobe to the temporal or frontal lobes of the brain, which changes the characteristics of the seizure, making it hard to recognise as occipital lobe epilepsy. These seizures may also spread, causing generalised tonic-clonic seizures.

Parietal lobe epilepsy Seizures coming from the parietal area are usually sensory and result in strange sensations such as tingling or warmness. They often occur down one side of the body and some people report that their limbs feel bigger or smaller than usual. There may also be areas of numbness of the body during the seizure.

Seizure triggers For some children certain situations, such as failing to take medication, or taking alcohol or recreational drugs, may increase the chance of a seizure occurring. Other triggers may include illness, fever, tiredness, stress, excitement or menstruation. Flickering/flashing lights (photosensitivity) is a trigger in only 3 per cent of children with epilepsy (JEC 2011). Seizure triggers can occur in all types of epilepsy, but are more of a feature in particular epilepsy syndromes.

Managing convulsive seizures Many people say that when they first witnessed a child having a tonic-clonic seizure they found it a
terrifying experience and that they thought the child was going to die. Perhaps the most difficult thing for an observer is the fact there is little that they can, or should do.

Now do time out 3.

### Parent’s experience

Think back to situations where you have helped a parent make sense of witnessing seizures in their child. Why was it important to help them express their full range of emotions? What followed next? Was this a process of developing explanations that they could share with others, and who might they usefully share this with?

If the child is aware of an impending seizure, they should be encouraged to sit or lie down to reduce the risk of injury. The child should be protected from any danger, such as sharp edges, hot pipes, traffic and so on. If possible, the child should remain where they are and any problematic objects should be moved out of the way instead. Placing something soft under their head or cradling their head in your hands will protect it from banging. The child’s dignity and privacy should be maintained as much as possible by shielding them from the view of onlookers.

When a seizure is taking place it is important to note the time the seizure starts and ends. The child’s movements should not be restrained but, if possible, any tight clothing around their neck should be loosened. Nothing should be placed in the child’s mouth. A seizure cannot be stopped but should simply be left to run its course. Once any jerking has stopped, the child should be placed in the recovery position.

Now do time out 4.

### Emergency treatment

Write down a list of the circumstances that would prompt you to call an ambulance to a child having a seizure. Describe what information will need to be given to the paramedics and how this might influence the child’s treatment during and after a seizure.

If the seizure occurs outside a hospital environment, an ambulance need only be called if the seizure lasts for five minutes (or for two minutes longer than is usual for the child), if the child has repetitive seizures without regaining consciousness in between, or if there is an injury, breathing problems or recovery is slow (Reuber et al 2009).

### Diagnosis of epilepsy

The medical team will need to ascertain whether the event was an epileptic seizure, if it was, what type of seizure occurred and whether the child has an epilepsy syndrome identifiable on the basis of age of onset, seizure type and specific electroencephalogram (EEG) characteristics and other features (National Institute for Health and Clinical Excellence (NICE) 2012).

Once these questions have been addressed, further discussion will allow the doctor to make a differential diagnosis. If not epilepsy, this could be a behavioural outburst, faint, tic, movement disorder and/or night terrors.

Now do time out 5.

### Eyewitness information needed for epilepsy diagnosis

**Before the event:**
- Where did the event take place?
- What was the child doing immediately before the event?
- Did they complain of any symptoms before the event occurring?
- Did they have a fever?
- Were they sitting, standing or lying down?
- Were they awake or asleep?

**During the event:**
- When did it begin?
- What happened first?
- Was there a fall, if so, did they fall backwards or forwards?
- Were they stiff or floppy?
- Was there a change in their breathing or colour?
- What movements did they make? Were they trembling, making rapid movements of the arms or legs, or were the limbs jerking rhythmically?
- What level of awareness or responsiveness did they have?
- Was there tongue biting or other injury?
- Was there any urinary incontinence?
- How long did the event last?
- What did their eyes do?
- Did they lose awareness?

**After the event:**
- What level of alertness did the child have?
- Were they confused?
- Were they sleepy following the event and, if so, for how long?
- Was there any weakness following the episode?
Continuing professional development

Eyewitness account of a seizure The diagnosis of epilepsy almost entirely depends on the clinical history and the doctor’s interpretation of the events that have occurred. According to Chadwick (2002), an accurate eyewitness account of an event is essential because the results of an initial medical examination will often be normal. The results of any further investigations will be interpreted with reference to the description of the event. A diagnosis of epilepsy is incorrectly made in 20–31 per cent of cases and up to 40 per cent of children referred to a tertiary clinic do not have epilepsy (JEC 2011). An accurate clinical history is therefore vital and should include the information shown in Box 1 (page 31).

An initial medical examination will often be normal and the results of any further investigations will be interpreted with reference to the description of the event. Further investigations may include an EEG (routine, ambulatory and/or videotelemetry) and neuroimaging (magnetic resonance imaging (MRI) and/or computerised tomography (CT)). Gaillard et al (2009) and NiCe (2012) provide useful information on the different scanning methods.

Comparison of scans

Compare the advantages and disadvantages of MRI and CT scans. Which scan do you think is better in aiding the diagnosis of epilepsy? When, and why, would each type of scanning be used?

Treatment

Antiepileptic drugs Whether to treat epilepsy with antiepileptic drugs will depend on a number of factors, such as the type of seizures that the child has experienced, how often they occur and, if established, the epilepsy syndrome. A syndrome is a group of characteristic signs and symptoms, such as age at onset of seizures, seizure types, developmental history and EEG findings which, if they occur together, can suggest a particular syndrome.

The impact of having seizures will vary dramatically, depending on the age of the child. For example, a toddler is less likely to be left unattended than an older child who may want to climb, swim and ride a bike. The consequences of an adolescent losing a driving licence could have a major impact on the young person’s independence issues and self-esteem.

Although antiepileptic medication will not cure epilepsy, it is designed to prevent seizures from occurring. The main aim of treatment is to stop all seizures while minimising side effects. Nonetheless, 15–25 per cent of children with epilepsy will have medically intractable epilepsy (Terra-Bustamante et al 2005). Where seizures cannot be stopped without side effects, the aim is to minimise the number of seizures and any adverse effects of the treatment.

Some medications work better for certain types of seizures than for others (Garnett et al 2009). Finding the right medication is sometimes a lengthy and frustrating process because the first drug to be tried may not prove to be the best option. There is no test to identify which drug will be best.

The use of one antiepileptic drug at a time (monotherapy) is generally recommended, and adding more antiepileptic drugs (polytherapy) should only be considered when attempts at monotherapy have failed to result in freedom from seizures (NiCe 2012). Commonly used antiepileptic drugs include: carbamazepine, sodium valproate, lamotrigine, phenytoin, oxcarbazepine, ethosuximide, gabapentin, levetiracetam, tiagabine, topiramate, phenobarbital, primidone, clonazepam, lacosamide, zonisamide, vigabatrin, retigabine and acetazolamide.

Side effects Different antiepileptic drugs can have different side effects, some of which can be unpleasant. Only a small number of children experience side effects and these may subside after the initial introduction of the medication. The most common side effects include those listed in Box 2.

Diet The ketogenic diet is a high-fat, low-carbohydrate and controlled-protein diet, which may be considered for children whose seizures are not being controlled by medication (NiCe 2012). This diet is not effective for everyone, but for some it results in an improvement in seizure control.

Box 2 The most common side effects associated with antiepileptic drugs

- Memory, learning and attention problems.
- Drowsiness and lethargy.
- Dizziness or unsteadiness.
- Double vision.
- Changes in mood or behaviour.
- Increase or decrease in appetite.

With more than 20 antiepileptic drugs available, what factors do you think will need to be taken into account when prescribing them? Can you envisage any situations when giving antiepileptic medication may not be the best option for a child with epilepsy?
Although the exact way the diet works is not known, it causes metabolic changes and ketone bodies become the fuel for the brain's energy demands (Hartman 2008). Ketone bodies are chemicals that are produced by the liver as by-products when fatty acids instead of sugar are broken down for energy. These chemicals increase when fasting occurs. It is the production of ketone bodies that is thought to alleviate seizures.

There are two types of ketogenic diet: the classical ketogenic diet and the medium-chain triglyceride ketogenic diet. The choice of diet used will depend on the age of the child and their normal food intake. Two alternative diets are in the early stages of being used for some children. The modified Atkins diet has been found to be effective and well tolerated (Kossoff et al 2006). The low glycaemic index treatment also appears to be an effective treatment for childhood epilepsy (Pfeifer and Thiele 2005).

**Vagus nerve stimulation** The vagus nerve stimulator may be used in children who are resistant to medication and who are not suitable for surgery. Although it is not known exactly how it works, impulses on the vagus nerve seem to desynchronise seizure activity in the brain (Kutscher 2006).

The left vagus nerve is stimulated by a small programmable device, implanted just below the collar bone which delivers intermittent stimulation at a pre-programmed rate. The device may also be activated by placing a vagus nerve stimulator magnet over the device for about a second – if applied at the onset of a seizure it may interrupt a seizure or reduce its severity (Kotagal 2011).

**Surgery** Neurosurgery may be considered if antiepileptic drug treatment has been shown to be ineffective and the results of investigations show that: seizures arise from a specific part of the brain which can be clearly defined and removal of this area will not cause any further problems; there is evidence of medical, social and/or educational disability as a result of seizures; the child's quality of life will be likely to improve after surgery; and there is an acceptable risk-benefit ratio for undergoing surgery.

The success of surgery varies depending on the type of surgery being performed but, in many cases, the earlier surgery is carried out, the better the result (Cross 2002).

The most common type of surgery is resective surgery (Cross 2002) and involves removing lesions, structural abnormalities or parts of the brain that are thought to be responsible for generating seizures. These operations can range from small cortical resections to a complete hemispherectomy and include:

- Lesionectomy – removal of a lesion or area of injury or damage to the tissue structure (for example a tumour or a cyst).
- Focal resection – removal of the area of the origin of seizures.
- Hemispherectomy – one side of the brain is either removed or disconnected. It is used to treat severe epilepsy in children where they already have significant damage to that hemisphere.

Palliative procedures do not provide a cure, but aim to limit the spread of seizure activity or to reduce seizure frequency. This surgery restricts the spread of seizure activity by disconnecting the area of the brain from which the seizure arises from the surrounding area. Examples of this type of surgery include:

- Corpus callosotomy – the fibres that connect the two halves of the brain called the corpus callosum are cut to prevent the seizure activity spreading throughout the brain. It is usually performed on children who mainly have debilitating tonic or atonic seizures that result in frequent falls or injuries.
- Multiple subpial transections – fine cross section cuts are made across areas of the brain thought to be causing the seizures. This ‘cross hatching’ can prevent the spread of seizures without affecting vital functions. Now do time out 8.

### Other treatments

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<th>Time out 8</th>
<th>Other treatments</th>
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<td>Find out more about the treatments other than medication available for managing epilepsy and make a table comparing each treatment considering suitability, cost, availability, prognosis and disadvantages.</td>
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**Status epilepticus** The vast majority of seizures are self-limiting, however, on occasion a prolonged seizure may occur. Status epilepticus is defined as a seizure or a series of seizures lasting for 30 minutes or longer without the person regaining consciousness (International League Against Epilepsy 2010). This is a medical emergency. Although any type of seizure may develop into status epilepticus, generalised tonic-clonic seizures (convulsive) progressing into status epilepticus are the most serious.

**Treatment** The longer a seizure has been going, the harder it is to stop. It is therefore usually a good idea to treat a generalised tonic-clonic seizure with emergency medication after five minutes. NICE guidance on managing epilepsy (NICE 2012) includes a protocol for treating convulsive status epilepticus.
Continuing professional development

The most commonly used emergency drugs are benzodiazepines which have an anticonvulsant effect. Diazepam (0.5mg/kg) is given via the rectal route and midazolam (0.3mg/kg) is given into the buccal cavity (Chin et al 2010). Sudden unexpected death in epilepsy

There are approximately 1,000 epilepsy-related deaths in the UK per year and sudden unexpected death in epilepsy (SUDEP) accounts for approximately half of these (JEc 2011). SUDEP is said to have occurred when someone with epilepsy dies suddenly and unexpectedly for an unknown reason with, or without, evidence of having had a seizure. It usually occurs at night when there are no witnesses. There is no obvious explanation for the death even with a post-mortem examination (Johnston and Smith 2007).

Although rare and unpredictable, certain factors increase the risk of SUDEP. Young adults who live alone and those who 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 and frequent changes in medication can also increase the risk, as well as a sudden withdrawal of medication (Hanna et al 2002).

Now do time out 9.

Informing patients of risks

Read the information available on the Epilepsy Bereaved website (www.sudep.org) and discuss with colleagues the advantages and disadvantages of telling a parent or young person about the risk of sudden unexpected death in epilepsy. Decide at which point you think this information should be given to them.

Emotional issues

There are many emotional and behavioural issues that may arise for children and young people with epilepsy. These will vary considerably for each individual according to the type and frequency of seizures, and their age, stage of development and level of confidence. Emotional problems may increase in the teenage years if epilepsy is not well controlled.

Some children need support for emotional issues from professionals such as the child’s doctor and local child and adolescent mental health services team. Many schools also have confidential counsellors who may be able to provide appropriate support (Tracy et al 2007).

Anxiety Increased anxiety levels may be caused by a wide variety of issues such as:

Fear of the seizures and fear of their body being ‘out of control’ during a seizure.

Being dependent on adults for care when their friends are becoming increasingly independent.

Fear of being hospitalised.

Coping with medication and possible side effects.

Coping with a change in medication and even, for the seizure-free, coming off medication.

A lack of understanding from friends and, sadly, even teasing or bullying.

Coping with overprotective parents or carers.

Anxiety levels in a child can be reduced when an atmosphere is created that encourages them to voice any concerns or negative feelings. If the child knows they are being listened to and taken seriously, it will reassure them that epilepsy is something that, with support from those around them, they can and will cope with, but it does not define who they are.

Depression This is more common in children with epilepsy than in those without. Rutter et al (1999) reported psychiatric disturbances in as many as 33 per cent of children with epilepsy. The earlier that depression is treated the better. If depression is not recognised and treated, it may have a bigger impact on the child’s quality of life than their epilepsy. Once it has been identified, depression can be treated effectively. It may be that counselling, psychotherapy or family therapy will help the child to recover or, in some cases, antidepressant medication may be prescribed.

Behavioural problems There are thought to be several reasons why behavioural problems are more common in children with epilepsy than those without (Kanner et al 2010). The child may be fearful, stressed and anxious about having seizures. It may be that they are not achieving at school. Frustration may play a part if there are learning or language difficulties. The area of the brain that controls emotions and behaviour may be abnormal and not function as it should. There may be abnormal epileptic activity going on which inhibits normal brain function, resulting in verbal and physical aggression. Some antiepileptic drugs may alter the chemical balance in the brain that regulates behaviour. Sometimes there may be changes in behaviour, personality and mood for minutes or days before seizures (known as a prodrome).

If a child starts to exhibit behavioural problems, the child’s epilepsy team should be informed as soon as possible and a diary of events should be recorded to help them identify any potential cause for the behaviour. If medication is thought to be part of the problem, the child’s neurologist will decide whether a reduction in the dose, or a change of medication is needed.
Conclusion
Epilepsy is a complex condition that is commonly misdiagnosed, with diagnosis often being reliant only on an accurate eyewitness account and the clinical history (JEC 2011).

Every child’s epilepsy is unique. Treatment will vary depending on the type and frequency of seizures and the impact that having seizures will have on the child’s life. The most common treatment is medication, given with the aim of stopping or minimising seizures, but that also may also cause side effects. Medical professionals are sometimes guilty of becoming focused on controlling a child’s seizures, without addressing some of the accompanying problems that may have a bigger impact on a child’s quality of life. Emotional issues for children with this condition will vary considerably.

Bearing all this in mind will help healthcare professionals to help a child cope with what can be a difficult and complex condition. Nurses not only have an important role in supporting the child with epilepsy and family; they must also ensure that important, relevant and accurate information is identified, recorded and reported to aid the correct treatment of the condition.

Find out more

Cyberonics: www.cyberonics.com
International League Against Epilepsy: www.ilae.org
Matthew’s Friends (dietary treatments for epilepsy): www.matthewsfriends.org.uk
Young Epilepsy: www.youngepilepsy.org.uk

References

Terra-Bustamante V et al (2005) Surgically amenable epilepsies in children under 5 years old. Epilepsia. 46, Suppl 8, 135 (Abst. 2.197),