

Epilepsy

Overview Description

The chapter will raise awareness about epilepsy and give practical advice for teaching staff in order to encourage good practice to ensure the best possible outcome for the children and young people.

Epilepsy is defined as a condition of repeated seizures which are produced by temporary changes in the electrical function of the brain, with seizures, rather than fits, being the preferred term.

Epilepsy affects around 600,000 people in the UK and 75% of people with the condition will have their first seizure before the age of 20. It is therefore likely that most adults working within education settings will come into contact with a pupil with epilepsy, at some time during their career.

Most children and young people with epilepsy can be treated with Anti-seizure Medication which can keep the frequency and severity of seizures under control. This allows most them to live a full, unimpaired life. For some children, whose epilepsy is not controlled, this can cause more difficulties in every day functions and will require further supervision. Anti-seizure medication is usually taken once or twice a day.

Types of seizures:

There are many types of seizures and the type of seizure depends on whether only part of the brain is affected (focal seizures) or whether most/all of the brain are affected (generalised seizures):

Focal seizures:

In this type of seizure, the child/young person remains conscious throughout. They are usually seen as a "warning sign" that another seizure is on its way. They are categorised by a "rising" feeling in your stomach, a tingling sensation, in your arms and legs and sudden stiffness/twitching. This may also include involuntary bodily movements, such as jerking.

Generalised seizures:

- **Tonic Clonic Seizures** are the most well-recognised seizure. The child/young person will fall to the ground and be stiff (tonic), There is then a period of rhythmical jerking, shaking or a tremor (clonic phase). After a period of time, the jerking should stop and may be followed by a period of sleep. The clonic phase should be no longer than 5 minutes, it continues for longer than 5 minutes, an ambulance should be called. Be aware that a major tonic-clonic seizure is thought to reduce learning capacity for up to 30 days after the seizure.

Generalised seizures continued:

- **Absence seizures** may be difficult to detect as it involves the child/young person losing concentration and becoming unaware of their surroundings for a few seconds. Sometimes there will be few symptoms but their eyes may flicker and they lose consciousness. This is the most common seizure in children with epilepsy and can happen many times a day.
- **Atonic seizures** occur when the child/young person loses muscle tone, causing them to collapse. This can cause injuries, particularly head injuries, as they usually are unable to brace/protect themselves in the fall.
- **Tonic Seizures** are where the child/young person's body goes stiff. They may shout out and stop breathing. These are relatively short, lasting around 60 seconds.
- **Myoclonic seizures** involve sudden contractions of the muscles which can present as single sudden movements or a series of jerks, mostly in the arms.

Some children/ young people with epilepsy may regularly have long seizures. If this is the case, they are often given medication from their doctor. There should also be an epilepsy management plan.

What might trigger a seizure?

For many people with epilepsy, seizures can occur without any obvious trigger. However, certain circumstances or the use of certain substances can sometimes come before a seizure. These triggers will differ from person-to-person and include:

- stress
- lack of sleep
- menstruation
- flashing lights (this is an uncommon trigger that affects only 3% of people with epilepsy, and is known as photosensitive epilepsy)
- dehydration/hunger
- forgetting to take medication

Some children and young people with epilepsy may also be triggered or more affected by sensory input. They may be particularly sensitive to loud noises or touches may feel more intense. This is because the temporal lobes are responsible for processing and co-ordinating sensory responses. This may lead to behavioural responses to sensory input.

Keeping a seizure diary is a good way to help find out what might trigger seizures. Parents and staff should record every time the child has a seizure. Over time, triggers may become apparent.

How can epilepsy impact children and young people?

All children and young people with epilepsy will be affected in different ways and to different degrees of severity. Due to the many types of seizures, differing frequency and severity of seizures between children, the effects of their epilepsy will differ. Many children and young people with epilepsy can live full, independent lives once their epilepsy is well managed.

Cognition and Learning:

Many children and young people with epilepsy have the same cognitive abilities as those without epilepsy and their condition should not be presumed to affect their academic potential. However, there may be reasons linked to the frequency and type of seizures, or the type of medication that may cause more barrier to learning.

However, around 1 in 5 people (20%) with epilepsy also have a learning disability (Epilepsy Society, 2023), which may mean that they find it more difficult to learn than other pupils (refer to learning disability area of this toolkit for more information). Learning disability and epilepsy are not thought to cause one another but link to the same underlying brain functioning. Epilepsy can also be a result of an Acquired Brain Injury which can also affect cognitive functions (see this area of the toolkit for more information).

Some children and young people may have difficulties accessing learning for a period of time after a seizure due to the effects on their cognitive functioning. For example, research suggests that children and young people who experience Tonic Clonic Seizures may have impaired cognitive functioning for up to 30 days after the seizure. Anti-epileptic drugs can also suppress brain functioning, such as, processing speed, sustained attention and memory.

Attention difficulties are also frequently observed in children with epilepsy (Sanchez-Carpintero et al, 2003). Be aware that children who experience Absence Seizures may appear to be daydreaming or distracted during a seizure.

Social, Emotional and Mental Health:

Research suggests that children and young people with epilepsy can experience greater feelings of depression, social anxiety, obsessive compulsions and low self-esteem (Baker et al., 2005). This research also found that a higher frequency of seizures is associated with low self-esteem (Baker et al., 2005). Generalised anxiety can also be common in children and young people with Epilepsy due to the unpredictability of seizures.

Children and young people with epilepsy may feel that they lack control over their lives or may find it more difficult to engage in normal day-to-day tasks especially those that involve risk. For example, children and young people with epilepsy may try to create order in their lives for example using ritualised or obsessional behaviour. Or, children and young people with epilepsy may be reluctant to engage in learning activities that are outside of their normal experience.

Epilepsy Management within Education Settings:

Epilepsy Management Plan:

All staff members should be made aware of any student who has epilepsy. An Epilepsy Management Plan (EMP) is important to ensure all staff understands the types of seizures that the student experiences, the usual prevalence of seizures and how to respond once a seizure begins. Advice from medical professionals should be used as part of the EMP.

In the event that a child or young person does have a seizure in an educational setting or provision, as part of the EMP, it is helpful to record information about the details of the seizure. This can include:

- the date/time
- length of seizure
- type of seizure (you may not know this by name but describe what was seen)
- recovery time
- triggers/ warning prior to seizure

The EMP should be completed collaboratively with parents and health professionals, such as, the epilepsy nurse and/or PIMS team and circulated to all staff members. Examples of a seizure log and Epilepsy Management plan can be found on the Somerset Epilepsy Toolkit (2020).

Spotting the Signs of a Seizure:

Often a seizure can occur without a trigger. Therefore, it is important that staff are confident in spotting signs that a seizure is about to begin. Signs that a seizure has started include a child or young person presenting any of the following:

- seeming to daydream and not take in information
- falling down suddenly for no obvious reason
- eyes rolling or blinking very fast/eyes flickering
- repeated movements that may look out of place
- head nodding as if falling asleep
- stopping what they are doing and staring at nothing for a moment/ appears confused.

Support During a Seizure:

You cannot stop a seizure from happening so it is important that all staff feel comfortable ensuring that the student is safe during their seizure. Support during a seizure will depend on the type of seizure that the child or young person has experienced.

As part of the EMP, a plan for how staff respond during a seizure is essential. This plan should be made in cooperation between education staff, parents/carers and epilepsy professionals, such as, epilepsy nurses. It is important that staff respond calmly to seizures and reassures the student, as well as fellow students. If the student

experiences convulsions, staff need to ensure that the student has the physical space to move and that they won't come to further harm.

Training

Senior leaders or management should ensure that staff are appropriately trained and receive regular training updates to support in the management of children and young people's epilepsy. New staff who encounter the child should also receive this training. Staff can access free online training, such as the course ran by 'Epilepsy Action'.

Adaptations to curriculum or teaching and learning approaches

School and education is often an important part of children and young people's daily lives. It provides a safe routine and structure which is especially beneficial for children and young people with epilepsy who often seek routine due to the natural changeability of their lives.

Children and young people with epilepsy should have the opportunity to engage in all activities within their education setting. Discussions about what children and young people can engage in and what adaptations or additional support required should involve the young person and their family.

Children and young people with epilepsy may need more support with exams. If they are likely to have seizures in stressful situations or at certain times of the day, this may affect their performance in exams or tests. Tiredness, or memory or concentration problems may also affect exams. Discussing concerns with the child and their parents may help to decide whether they need any special arrangements for exams.

Recreational activities, such as sports and music can enhance wellbeing for all children and young people and it is a misconception that children and young people with epilepsy cannot join in with sports activities. There is some evidence that regular exercise may actually improve seizure control by reducing stress that can trigger seizures (Pimentel, Tojal and Morgado, 2019).

Some examples of adaptations might include:

- **Swimming:** Children and young people with epilepsy may need to be accompanied to the swimming pool by an adult who is knowledgeable about the type of seizures and emergency procedure during a seizure. Staff may need to inform the lifeguard about the CYP.

Adaptations to curriculum or teaching and learning approaches continued

- Involvement in trips, including overnight stays: It is encouraged that children and young people with epilepsy can be included in trips, holidays and residential sessions with reasonable adjustments. Parents and staff should consider:
 - o Medication and who/how this will be administered
 - o An up-to-date Epilepsy Management Plan
 - o All staff need to be aware of the EMP and follow this in the event of a seizure.
 - o Seek advice from Epilepsy Professionals if felt needed.

It may also be helpful to educate and support other students to know and understand more about a child or young person's epilepsy. This can reduce social anxiety and exclusion and increase empathy and support for the student. This will need to be discussed, designed and agreed with the child/young person and the family. This could include what a seizure is, why they occur and how the children

Useful Organisations, Resources and Links

Children and young people with epilepsy may benefit from being able to share their experiences with other children and young people with epilepsy, through local support groups. National epilepsy charities can offer support and produce publications that may help children and young people to understand their epilepsy. Counselling may help some children and young people with epilepsy.

Manchester's Epilepsy Service: <https://www.manchesterlco.org/services/childrens-community-services-citywide/childrens-epilepsy-service/#1665397059329-34574b90-8216>

Epilepsy Action has a range of resources from e-learning to online support groups and a telephone helpline <https://www.epilepsy.org.uk/support-for-you>

A local support group can be accessed here: <https://www.eventbrite.co.uk/o/epilepsy-actionmanchester-talk-and-support-group-71476295073>

Young Epilepsy Charity offer support for young people/ carers with Epilepsy and offer training to school staff <https://www.youngpilepsy.org.uk/> . Access free e-learning here: <https://www.youngpilepsy.org.uk/professionals/education-professionals/training-courses>

The Edmonton Epilepsy Association has produced a series of educational booklets about epilepsy: guidance for parents, children and young people friendly books, information for teenagers with epilepsy, epilepsy and first aid/safety <https://edmontonepilepsy.org/>

“Epilepsy for teachers” free training course by Epilepsy Action
<https://learn.epilepsy.org.uk/courses/epilepsy-for-teachers/>

Teacher’s guide to Epilepsy <https://www.epilepsyscotland.org.uk/wp-content/uploads/2021/07/Teachers-guide.pdf>

References

Baker, G. A., Spector, S., McGrath, Y., & Soteriou, H. (2005). Impact of epilepsy in adolescence: a UK controlled study. *Epilepsy & Behavior*, 6(4), 556-562.

Epilepsy Society (2023) <https://epilepsysociety.org.uk/learning-disabilities>

Pimentel, J., Tojal, R., & Morgado, J. (2015). Epilepsy and physical exercise. *Seizure*, 25, 87-94.

Sánchez-Carpintero, R., & Neville, B. G. (2003). Attentional ability in children and young people with epilepsy. *Epilepsia*, 44(10), 1340-1349.