

Epilepsy – more than seizures?

There are 40 types of epilepsy. **Emma Tingley** of the charity Young Epilepsy explains the range of symptoms, and the impact of seizures and medication on learning and memory

It's difficult to imagine what it must be like when, all of a sudden, the world is turned off. The clock keeps ticking but you are unaware of time passing. While we all daydream, it is very confusing to be switched off for a few seconds many times a day and potentially not even realise that it has happened.

When time stands still

This may sound like something from a science fiction movie, but for some children living with epilepsy, it can be a regular occurrence. They may lose the thread of a story, or be unable to make sense of instructions. Weirdly, they can find that people are no longer in the same place they were before time stood still.

This is what happens in an absence seizure and it is just one of over 40 types of epileptic seizure. With one in every 220 school-aged children diagnosed with the condition, the likelihood of a child in your school having epilepsy is high.

What is epilepsy?

Epilepsy is a disorder of the brain as complex as the brain itself. It is characterised by a tendency to have recurrent seizures.

The brain communicates with the body by sending electrical messages through a complex network of specialised nerve cells. Electrical signals are generated and regulated by a delicate balance of chemicals. When there is an imbalance between stimulation and inhibition, an excessive firing of cells occurs like an electrical storm in the brain – a seizure – that results in an alteration of sensation, behaviour or consciousness.

Some normal bodily functions may stop during a seizure, while other functions might start unnecessarily without the person having conscious

control over them. The symptoms depend on where in the brain the electrical storm is happening and how much of the brain is involved.

As most seizures occur without warning, anyone working with a child with epilepsy needs to know what that child's seizures are like and the simple steps that are needed to keep the child safe (see box on page 25). There are two main groups of seizures: focal and generalised.

Focal seizures

Focal seizures involve electrical activity in just one part of the brain while the rest continues to function. The symptoms will depend on where in the brain the electrical activity is occurring. The person will retain some level of consciousness, although they may seem confused. They may also start behaving unusually as unwanted functions are stimulated or they may react to distracting or uncomfortable sensory disturbances, which other people cannot see.

One parent of an 11-year-old boy recounted how her son was frequently in trouble for uncontrollable fits of laughter, which his teacher naturally assumed were due to illicit off-task activities. At other times he complained of 'feeling strange', complaints which were largely ignored. Subsequent medical investigations revealed that he was having frequent focal seizures, so the teacher helped the class to be tolerant and understanding.

What is 'normal'?

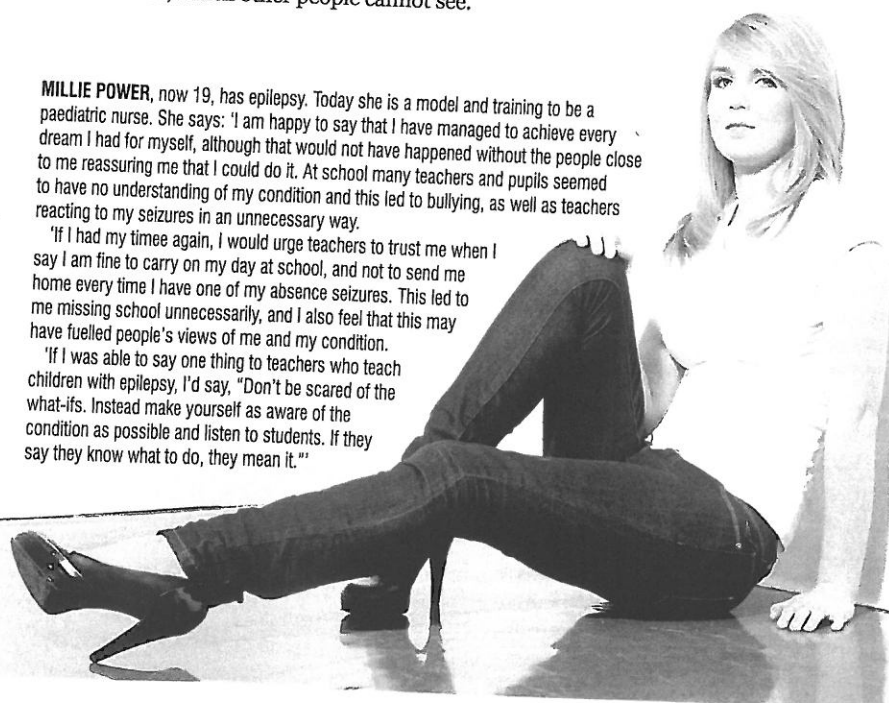
This boy made valiant efforts to describe what he thought was 'wrong', but many people in his situation find it hard to know what 'normal' is.

For example, when seizure activity is focused in the occipital lobe, the part of the brain where images are processed, it can cause visual disturbances. The person may see lines or dots, for example,

MILLIE POWER, now 19, has epilepsy. Today she is a model and training to be a paediatric nurse. She says: 'I am happy to say that I have managed to achieve every dream I had for myself, although that would not have happened without the people close to me reassuring me that I could do it. At school many teachers and pupils seemed to have no understanding of my condition and this led to bullying, as well as teachers reacting to my seizures in an unnecessary way.'

'If I had my time again, I would urge teachers to trust me when I say I am fine to carry on my day at school, and not to send me home every time I have one of my absence seizures. This led to me missing school unnecessarily, and I also feel that this may have fuelled people's views of me and my condition.'

'If I was able to say one thing to teachers who teach children with epilepsy, I'd say, "Don't be scared of the what-ifs. Instead make yourself as aware of the condition as possible and listen to students. If they say they know what to do, they mean it."'



“A nine-year-old pupil didn't realise that she was seeing things that no one else could see”

or even experience temporary blindness. I recently met a nine-year-old pupil who had experienced this for years before getting a diagnosis – she didn't realise that she was seeing things that no one else could see.

If bright, articulate pupils find it difficult to identify seizures and get us to take them seriously, how do very young children or those with additional learning needs or communication difficulties cope? That is why it's so important that all the adults around them observe and record behaviours that may indicate something is amiss.

Generalised seizures

Generalised seizures may involve the whole brain. A key characteristic is a loss of consciousness, sometimes brief. In the case of absence seizures, the effect lasts for seconds.

Unlike daydreams, you cannot rouse children by calling their name. In extreme cases, a child may have several hundred absence seizures a day, which can easily be missed because they are over so quickly. The impact of repeatedly missing little bits of information can have a dramatic effect on a child's learning and quality of life.

Tonic clonic and atonic seizures

The more recognisable seizures are usually generalised seizures too. In a generalised tonic clonic seizure, the child's muscles contract and become stiff (the tonic phase) followed by rhythmical jerking movements of the body, which mimic the synchronous firing of the neurons in the brain (the clonic phase).

The first indication may be that the child cries out, not because they are in pain or distress, but because air is being forced out of their lungs as the muscles around them contract. Reassuring people that the child is OK is important.

You may also notice some blueness around the lips as the contracting muscles inhibit the normal flow of oxygen around the body, then the person will pull a contorted shape, lose balance and topple over, often backwards.

As the tonic phase passes and the clonic phase begins, the muscles relax and breathing resumes, although it may be laboured. Most seizures stop within five minutes without the need for any treatment. However, five minutes can

feel endless, so it is important that you time the seizure. Tonic seizures can occur without the subsequent convulsive clonic phase and vice versa.

Another generalised seizure – the atonic seizure – stops all messages to the muscles, making the child lose all muscle tone and drop to the floor, usually forwards.

The impact of epilepsy

Independent research carried out on behalf of Young Epilepsy found that 51 per cent of parents believe the condition has a 'significant' impact on their child's education. Of those questioned, 46 per cent said their child had missed classes. Only 40 per cent were aware of staff at their child's school receiving epilepsy training. One in five people with epilepsy will have a learning difficulty.

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Children with epilepsy are four times more likely than their peers to have an emotional disorder, and some reports indicate that 20-30 per cent of children with epilepsy will also have ADHD. Children with an autism spectrum disorder have a significantly increased risk of having epilepsy, which can be as high as 50 per cent when coupled with a diagnosis of severe learning difficulties.

Being vigilant for epilepsy in these vulnerable groups of children is important because focal and absence seizures are so hard to spot.

The impact on learning

It may seem obvious that a condition affecting the brain will have an impact on learning, but children with epilepsy often get little additional support; their diagnosis is usually recognised only as a medical condition.

Seizure control is possible for many children once epilepsy has been correctly diagnosed from accurate eyewitness accounts (there is no definitive test), and the correct dose of medication has been



CHAS PARKER aged nine, says: 'Last year I started I seizures and it was very scary. I was at school when first began and I remember my teacher looking quite He didn't know what was happening.'

'My mum had meetings with the headmistress who kind and understanding. She spoke to the children in and explained that sometimes I may not be well and anyone I was not feeling too good to fetch an adult s away. There is a photograph of me up in the staffroom remind all staff about my condition.'

'My teacher is nice and always takes extra time to I am OK. My headteacher read all about my condition arranged for some teachers to attend an epilepsy aw session. In January I started swimming lessons with school and I have a swim buddy. I feel safe at school knowing that everyone is supportive and caring.'

achieved through trial and error (there is no simple way of identifying what work for which child). However, the may then have to cope with the side of epilepsy medication, which includes tiredness, mood swings, aggression, dizziness, nausea and headaches. The child may need extra support while the body adjusts to drugs when these are prescribed and then whenever the dose is adjusted as the child grows.

Confidence

The worry of not knowing when the seizures might occur, and how people react, can also have a significant impact on self-esteem and confidence. When this is coupled with low expectations of achievement, often shared by parent teachers, it is not surprising that some studies report that almost 50 per cent of children with epilepsy underachieve at school compared with their potential IQ scores.

What can teachers do?

Find out as much as you can about each child from the parents and pupils themselves and keep a record.

- Type of seizure (what it looks like just the name).
- Frequency (how often and any particular time of day).
- Factors that make a seizure more

- such as tiredness, fever, flashing lights.
- Up-to-date medication details including any side effects.
- Learning and behavioural difficulties and which interventions work.

A good night's sleep

Set up a communication system between home and school so that any concerns or information on seizures can be shared. Ensure learning and behaviour tracking is in place to identify when the condition is fluctuating and more support is needed.

For example, if seizures have happened at night, the child's normal memory processing, which usually happens in different phases of sleep, may have been disrupted so the child will need more support than on the previous day.

Making provision

Identifying the particular needs of an individual is key to providing the correct level of support.

The main learning difficulties experienced by children with epilepsy are with processing information, memory, language and communication, and maintaining attention.

Schools have lots of strategies to support all these difficulties. However, they need to ensure age-appropriate support continues where necessary as the child moves up through the school, because development may be delayed in specific areas of the brain as a result of seizures, even once seizure control has been established.

Meanwhile, seizures are less likely to occur if the child is engaged in mentally and physically satisfying activities. It is also vital for children and young people's self-esteem that they take part in the same kinds of activity as their peers if possible. To facilitate inclusion, risk assessments need to be carried out on activities to ensure the right support is in place.

School-wide education

All pupils will come across children with epilepsy during their school years (secondary schools will have on average five children with epilepsy) and many will have friends or relatives with the condition. So it is worth teaching all children about epilepsy as part of a wider disability awareness and inclusion programme.

Ensuring everyone is confident about what it is and what to do will help peers to include a child with epilepsy in their social circles and remove the stigma that currently makes talking about the condition difficult.

THOMAS MORLEY, now seven, is sitting in a fire engine. He was diagnosed with epilepsy when he was 14 months old. His father Andy writes: 'He started having absence seizures but these progressed on to tonic clonic and atonic seizures, with a few seizures every month.'

'When Tom started nursery school, it became apparent that his seizures were getting worse – he could have 40 to 50 a day. His school were really good: they provided him with a bed where he could recover after seizures and even employed a special needs carer to work with him one-to-one. As Tom grew older he was given a seizure helmet to protect his head from bangs that might result from atonic seizures. He was also fitted with a VNS device to help control his seizures. The school staff were trained how to operate this and his teacher and his special needs carer were trained by the epilepsy nurse at the hospital in Nottingham.'

'Tom's school have been really supportive and helped in every way they could in obtaining his written statement of special needs. Without the support from his special needs carer, Tom's school life would have been very different.'



Support in the classroom

- Visual, auditory, kinaesthetic support for learning.
- Small manageable tasks, clearly explained objectives and success criteria, prompted regularly and concluded with a plenary to reinforce the learning.
- Group work to encourage independence from adults.
- More time to complete tasks while providing support for memory.
- Memory aids: mnemonics, key words/pictures, and visual timetables.
- Role-play, computers and art to encourage communication.

The Young Epilepsy website has lots of downloadable resources for schools to use in lessons and assemblies to raise awareness and understanding among pupils. www.youngepilepsy.org.uk

Managing seizures

Taking care of a child who is having a seizure involves some simple steps.

- Remain calm.
- Make sure that they are safe – remove any objects that could cause them to injure themselves.
- Don't move the child unless there is a danger that cannot be removed, such as fire.
- If they are conscious but in a confused state, guide them to a safe place and stay with them until they recover.
- Put something soft under their head to protect them from further injury.
- Time the seizure so you can record how long it lasts.
- Let the seizure run its course.
- Put them in the recovery position after any convulsions have stopped.
- Once they have regained consciousness, give them time to rest.
- It is important that you do not restrain their movements or put anything in their mouth.

Although most seizures stop without the need for medical treatment, call an ambulance when:

- a seizure lasts for more than five minutes (or two minutes longer than is usual for that child)
- the child has repeated seizures without fully regaining consciousness in between each one
- the child is injured
- this is the child's first seizure.

Young Epilepsy mobile app

Keeping a record of seizures and symptoms is crucial for diagnosis and management of the condition. Young Epilepsy has developed a free app for young people and parents to record and share information with GPs and other healthcare professionals. Available on iOS and Android: search Young Epilepsy in your app store.

Editor's note: Non-epileptic attacks

Confusingly, some young people may seem to have 'blackouts' or 'fits' but may not be suffering from epilepsy. Dissociative (non-epileptic) attacks, also called dissociative seizures or functional seizures/attacks, are one of the most common functional/dissociative symptoms seen in neurology (although they are rare in children under 12). One specialist consultant reports that nearly half of all patients brought into hospital with suspected serious epilepsy have them. Find out more: bit.ly/SC211-02