

Fact Sheet 35

Epilepsy and Behaviour in Children

Some children find living with epilepsy challenging and may show their unhappiness in a number of ways such as becoming irritable or angry, or by becoming disruptive. All behaviour is a form of communication and as adults our first step in understanding any challenging behaviour is to fully understand what epilepsy is and how children can be impacted by seizures and medications. Also, some children may have another comorbidity or syndrome that needs consideration. Our role is to support children in their journey with epilepsy and its impacts.

What is epilepsy?

Epilepsy is a complex neurological condition characterised by seizures. Seizures happen when the neurons misfire, causing periods of unusual behaviour, sensations, and sometimes loss of awareness. Seizures can happen either in part of the brain (focal seizures) or in the whole brain (generalised seizures). There are at least 40 different seizure types and people can have more than one type of seizure. A seizure is often seen as an episodic event but in fact seizures affect people in a number of additional ways that can endure for life. See ewct.org.nz/living-challenges-epilepsy/ for more information.

Some seizures are well identified because of what they physically look like, such as with tonic clonic, tonic, atonic, or myoclonic seizures (ewct.org.nz/epilepsy-types/). Other seizures are subtle in appearance and are not as easily identified.

All seizures can cause changes in behaviour, personality, or mood before (pre-ictal), during (ictal), and after a seizure (post-ictal). These changes may include inattentiveness, hyperactivity, irritability, or verbal or physical aggression. During this period, certain triggers may further irritate a child and thus increase their frustration or aggression. Understanding a child's seizure type (or types) and how it (or they) presents helps adults to recognise uncharacteristic behaviour in a child and how to offer support around a seizure and its aftermath.

Sometimes it is possible to witness a mood and behaviour change in a child hours or days before a seizure happens. This is called a prodrome period.

Many children have seizures in the temporal lobes and they may experience strange sensations which are often hard to describe. The sensations may include déjà vu, hallucinations, vertigo, smell and taste changes, sweating, ringing sounds, and out-of-body sensations. Such seizure events and associated sensations can be quite frightening and a child may become upset, especially if they recognise that another seizure event is imminent.

Temporal lobe epilepsy can also present with automatic behaviour (automatisms) and with decreased awareness. Children may look to be swallowing, picking at their clothes, screaming,

laughing, or crying for no known reason, undressing, or losing bladder and/or bowel control. They will slowly become aware of their surroundings and be unaware of their seizure.

Many children are diagnosed with a syndrome which affects behaviour. A syndrome is a group of signs or symptoms that share common features (ewct.org.nz/children-and-epilepsy/). Understanding a child's syndrome helps provide support for the child.

Epilepsy and other disorders

There is a link between epilepsy and other disorders such as in autism, attention deficit hyperactivity disorder (ADHD), cerebral palsy (CP), and Down Syndrome. These comorbidities can affect behaviour in a child with epilepsy.

a) **Epilepsy and autism:** Epilepsy is found to be more common in children with autism, and autism is more prevalent in children who have epilepsy. The link between the brain abnormalities that are associated with autism spectrum disorder (ASD) may also contribute to seizures occurring and affect mood. Some medications used to stop seizures may bring about severe behavioural deterioration and cause a child to feel hyperactive and irritable.

b) **Epilepsy and ADHD:** Research has shown that the symptoms of ADHD sometimes start before the first seizure and, despite good seizure control, children still struggle with ADHD.

ADHD negatively affects children's behaviour even more than the seizures.

c) **Cerebral palsy:** Epilepsy occurs in up to 50% of children with CP. Behavioural problems are common in children with CP, and even more so when epilepsy is present. Difficulty with communication seems to be a significant factor in understanding and mitigating challenging behaviors.

d) **Down Syndrome:** Seizures occur in about 5-10% of children with Down Syndrome. Challenging behaviour is a common occurrence.

Epilepsy, anxiety and depression

A good number of children living with epilepsy will experience depression or anxiety, and some of these children may have suicidal thoughts. Mood disorder symptoms may look different in children. Many will have low self-esteem and negative thinking but some will show irritability and disruptive behaviour, poor school performance, and changes in sleep patterns or appetite. Parents and teachers need to be aware of mood changes in children, especially if seizures worsen, or after a medication change.

Some behavioural issues may mask anxiety and depression (ewct.org.nz/epilepsy-and-mood-disorders/).

Anti-seizure medications

Epilepsy is largely controlled (but not cured) by the use of anti-seizure medications. Around 70% of people become seizure-free, or will have reduced numbers of seizures. For most people there are few or no side effects. Parents and carers, however, are able to notice sudden and negative changes in their child's behaviour or mood when an anti-seizure medication is introduced or increased. Some medications are known to be associated with behavioural changes for some people.

The side effects of medications may be minor or severe, short-lasting and reversible, or long lasting and potentially irreversible.

Medication side effects could cause dizziness, clumsiness, nausea, headaches, becoming fatigued or tired, and low mood. Other side effects affect the different systems of the body and are checked by regular blood tests.

Social and emotional challenges

There are many challenges affecting children living with epilepsy apart from those mentioned above. Seizures are unpredictable and can cause anxiety for a child who may already fear losing control of the body during a seizure. This embarrassment may lead to social isolation and to poor self-esteem, anxiety, depression, or suicide.

Some children experience unpleasant symptoms, including strange sensations (noted above), around their epilepsy and consequently become fearful or distressed especially if they are unable to talk about those 'strange' feelings.

Medical appointments and procedures such as blood tests, EEGs, etc interrupt normal life and can be tiring and potentially frightening.

Children will communicate their distress by becoming angry, irritable, or having tantrums etc, but many children will adjust to having epilepsy over time with the right support.

Any concerns about a child's behaviour need to be discussed with a paediatrician. In some cases, further help from a mental health professional specialising in children or adolescents may be needed.

Behaviour and cognition

Children with epilepsy (CWE) have a wide range of learning abilities but many will experience problems with cognition, memory, learning processes, concentration, or behaviour. It is suggested that at least 25% of CWE will function in the learning-disabled range as a result of the underlying cause of epilepsy and their seizures and/or medications. Consequently, many CWE, especially boys, are at risk generally of underachievement and make less progress than would be expected for their age and intelligence level. CWE have very high rates of behavioural and learning difficulties which often go unrecognised.

It is suggested that up to 70% of children with epilepsy have subclinical discharges which do not

show up as seizures. These discharges impact behaviour.

Epileptic seizures affect cognitive processes in many ways and can cause long-term learning difficulties for children in the school system.

- a) Children may find it difficult to concentrate on the task at hand. They will be unable to block out distractions and finish work on time.
- b) Children will be unable to store and retrieve new information. Following instructions is difficult.
- c) They will find it difficult to process information quickly.
- d) Children often fail to develop friendships because of their inability to modify their behaviour and behave appropriately.

The many frustrations and failures faced by CWE in the classroom can lead to behavioural issues which are associated with epilepsy. It is important therefore that there is awareness around behavioural challenges and epilepsy so that effective and appropriate management techniques and support can be given to children.

Further information

Further information about epilepsy and its management is summarised in EWCT's book entitled "[Understanding and managing epilepsy: an introductory guide](#)". It is available from your EWCT epilepsy advisor or it can be purchased via the EWCT website: ewct.org.nz/product/understanding-and-managing-epilepsy-an-introductory-guide/

Disclaimer: this fact sheet is for education purposes only. Please consult your doctor or other health professional for advice regarding your epilepsy.