Epilepsy in children

Summary

- Epilepsy is commonly diagnosed in children and can be confused with other conditions. An accurate diagnosis is essential.
- Seizures usually respond well to medication and most children with epilepsy will enjoy a normal and active childhood.
- The impact of epilepsy will vary for each child. Try to keep epilepsy in perspective for your child and your family.
- Remember to keep a balance between protecting your child and encouraging their independence.

About epilepsy in children

Epilepsy can begin at any time of life, but it's most commonly diagnosed in children, and people over the age of 65.

Some children with epilepsy will outgrow their seizures as they mature, while others may have seizures that continue into adulthood.

Although epilepsy varies from person to person, many children with epilepsy have seizures that respond well to medication, and they enjoy a normal and active childhood.

Recognising epilepsy in children

Seizures may not always be recognised in children when they first occur, depending on the seizure type.

People often think of seizures as convulsive, but some seizures can be subtle and very brief, such as an 'absence seizure', in which the child has brief episodes of loss of awareness and responsiveness.

Furthermore, there are many 'non-epileptic' episodes that can mimic seizures, and epileptic seizures often don't look the way people expect them to. This can sometimes make diagnosis complicated.

Some childhood events that may be confused with seizures are:

- fainting spells
- breath-holding spells
- normal sleep jerks
- daydreaming
- night terrors
- migraine
- heart and stomach problems
- mental health issues.

Febrile convulsions

Febrile convulsions are seizures brought on by fever during times of illness. They tend to occur in families. About 1 in 25 children has a febrile convulsion at some time, most commonly between the ages of 6 months and 6 years.

Up to one third of children will have further febrile convulsions with consecutive fevers. Having febrile convulsions does not mean the child has epilepsy and their risk of developing epilepsy is no higher than anyone else. There is a slightly higher risk of developing epilepsy if there is a family history of epilepsy, or the child has a neurodevelopmental impairment (such as cerebral palsy). Or the child has a complex febrile convulsion.

A complex febrile convulsion is when the convulsion:

- lasts more than 15 minutes
- may involve a part or side of the body
- happens more than once in 24 hours.

Understanding the diagnosis of epilepsy

If your child has had a seizure it is most likely you will have received a referral for an EEG and a neurologist or paediatrician appointment.

An important part of epilepsy diagnosis is a good description of the seizure(s) and symptoms surrounding it. Sometimes a video of a seizure can be helpful.
Tests can often return normal, but this is common and does not necessarily mean a seizure didn't happen.

Epilepsy syndromes

There are many different seizure types. Broadly, seizures are classified as either 'focal' or 'generalised' (see the **Epilepsy** page for more information).

An epilepsy syndrome can be diagnosed when a group of signs and symptoms occur together. For example, when particular types of seizures begin at a certain age and are associated with other conditions or characteristics. Some of the specific signs and symptoms in epilepsy syndromes that doctors look for include:

- the type of seizures
- the age at which they start
- the specific pattern they show on **EEG (electroencephalogram)** (a medical test used to measure the electrical activity of the brain).

If the epilepsy fits a particular syndrome, this can help the doctor to select the best medication for that syndrome. It can also help to predict whether the seizures are likely to be easily controlled, limited to childhood, or whether the condition may be more persistent.

Some of the more common types or epilepsy or epilepsy syndromes in childhood include:

- **childhood absence epilepsy (CAE)** – these seizures usually start between ages 2 to 12. Absence seizures are very brief: the child will suddenly stop what they are doing and stare blankly, like they are daydreaming. Just as suddenly they stop and continue with the previous activity. Absence seizures can happen numerous times a day. They are usually well controlled with medication, and stop by puberty
- **juvenile absence epilepsy (JAE)** – these seizures usually start between ages 8 to 20. The seizures are like childhood absence seizures but may be longer and can include movements such as eyelid fluttering or chewing. They occur less often than childhood absence epilepsy seizures. Up to 80% of children with this type of epilepsy will also have tonic-clonic seizures. The seizures can be well controlled with medication, but the syndrome is considered lifelong
- **benign rolandic epilepsy/benign epilepsy with centrotemporal spikes (BECTS)** – onset age is usually 1 to 14 years. Seizures are often focal and include twitching, numbness or tingling of the child's face or tongue, and may interfere with speech and cause drooling. Sometimes they can progress into a tonic-clonic seizure. Seizures usually happen in early stages of sleep. Medication is not always needed. This type of epilepsy resolves by about age 15 years.
- **juvenile myoclonic epilepsy (JME)** – this syndrome can be diagnosed anywhere between 8 and 25 years and tends to run in families. It typically starts with myoclonic seizures that occur soon after waking either in the morning or from a nap. They are sudden, single muscle jerks of both arms. Sometimes these movements are not obvious, and make the person seem clumsy or prone to dropping things. Tonic-clonic seizures can also occur, and this usually leads to diagnosis. Seizures can be well controlled with medication and lifestyle changes.
- **temporal lobe epilepsy (TLE)** – this type of epilepsy can start at any age. It involves focal onset seizures with or without impairment of awareness. Seizures are often unusual and involve confusion and changed behaviours or emotions. Sometimes seizures may progress to tonic-clonic seizures.
- **frontal lobe epilepsy (FLE)** – this type of focal epilepsy can start at any age. It involves focal onset seizures with or without impairment of awareness. Seizures are often unusual and may include vigorous motor (physical) activity or emotions. FLE can be confused with behaviours, psychiatric disorders or sleep disorders

such as parasomnias or night terrors, and the child may need prolonged monitoring to make a diagnosis

- **West syndrome or infantile spasms** – onset of this syndrome is typically seen during the first year of life. The very brief spasms (seizures called infantile spasms) cause the baby to stiffen suddenly. Often the arms are flung out as the knees are pulled up and the body bends forward ('jack-knife seizures'). The baby will cry. The spasms usually occur in clusters. Sometimes they are mistaken for colic, but the cramps of colic don't occur in clusters. Most children develop other kinds of seizures in later childhood, including an epilepsy syndrome called Lennox-Gastaut Syndrome. Intellectual disability is usually seen.
- **Lennox-Gastaut syndrome (LGS)** – this syndrome has the onset of seizures from age 3 to 5 years. It can include multiple seizure types and seizures are resistant to medication. Intellectual disability is seen in up to 90% of people with this syndrome.

Some other, less common, forms of epilepsy include:

- **generalised epilepsy febrile seizures plus (GEFS+)**
- **severe myoclonic epilepsy of infancy (Dravet syndrome)**
- **myoclonic epilepsy of infancy (Doose syndome)**
- **Landau-Kleffner syndrome (LKS)**
- **Rasmussen's syndrome**.

Treatment of epilepsy

Medications used to control seizures are called antiepileptic drugs (AEDs). The decision whether to treat a child with AEDs after they have been diagnosed with epilepsy is made depending on the risk of further seizures against the potential risks and benefits of AEDs. This decision also incorporates the family's values and preferences.

Medication is the first line of treatment for epilepsy. Medications are not a cure, but they lessen or stop the seizures, preferably with few or no side-effects. Medications are not always prescribed for every child who has a seizure.

Starting a child on medication can be a difficult choice. Most parents worry about side effects and any long-term effects of taking medications. The doctor will consider the risks of having seizures versus the risks and benefits of taking medication for the child.

Whether or not to prescribe medication, and what type of medication, will depend on:

- the likelihood of further seizures
- the type of seizures the child has, and how often they occur
- the risks the seizures may pose
- the age of the child
- the presence of developmental or behavioural problems
- the wishes or willingness of the child and family to start medication.

Treatment is not recommended lightly and the decision to treat is usually based on sound clinical evidence. AEDs are effective for approximately 70% of people with epilepsy (although it may take time to find the right medication or combination of medications). If several medications fail to control seizures, other options for treatment may be considered such as:

- surgery
- vagus nerve stimulation
- dietary management.

General information about medications

Most AEDs are started at a low dose and slowly increased until seizures no longer occur or if there are troublesome side effects. The dose may need to be adjusted as the child grows and their weight increases, or if new medications are added.

A second AED may be added or substituted if the first was not fully effective in stopping seizures, or if it caused unwanted side effects.

Many AEDs interact with other medications, causing unwanted reactions or reducing their effectiveness. Speak to your doctor or pharmacist before giving your child any other medication or supplement, even over-the-counter medicines for coughs and colds.

Never stop AEDs suddenly. This can cause seizures – sometimes seizures that are more severe than usual. Instead, under the guidance of your doctor, wean your child off these medications slowly to avoid withdrawal side effects.

AEDs are not prescribed long term for seizures that aren't considered epilepsy, such as febrile convulsions.

Epilepsy and the family

Epilepsy can sometimes be inherited, or passed down, in a family. If you're planning a baby and concerned about the potential risks of epilepsy in the family, ask your doctor to explain any risks in your case. Genetic risks don't apply to all epilepsies and, in most cases, are low.

The unpredictable nature of epilepsy can result in significant worry for children as well as their parents. People with epilepsy have a higher risk of experiencing depression and anxiety. Parents of children with epilepsy can sometimes experience isolation, stigma and the financial strain of increased medical appointments and time off work. They also report higher levels of anxiety and depression compared to parents of children without a chronic illness. In these cases, it's important that parents also feel supported, which may include professional psychological support or financial assistance.

Parents with epilepsy may worry about the impact that their condition has on their role as a parent. You may decide to have a discussion with your child about your epilepsy and what to do in the event of a seizure. If you would like further support as a parent with epilepsy, the Epilepsy Foundation's Information Line (Tel. **1300 761 487**) is a free service for supporting people living with epilepsy.

Siblings can also feel overlooked when one child has additional needs (this is not only the case with epilepsy). **Siblings Australia** has a range of resources for supporting siblings of children and adults with chronic illness or disability.

Epilepsy and learning

Most children with epilepsy have the same range of intelligence and abilities as other children. However, some children with epilepsy will have learning difficulties. This may be due to epilepsy-related factors such as an underlying brain abnormality, how often seizures happen, or due to a coexisting condition such as attention deficit hyperactivity disorder (ADHD) or autism spectrum disorder (ASD). Night-time seizures can cause daytime drowsiness, which can impact on learning and educational participation.

Sometimes medication also contributes to drowsiness, moods or behaviours. When a learning difficulty is identified in a child, there are strategies available – both medical and educational – that can be applied.

The Epilepsy Foundation has also developed a program called **Epilepsy Smart Schools**. This national program provides a range of information and classroom supports for families, teachers and children living with epilepsy.

If you feel like there have been significant changes in your child's learning, thinking skills, concentration or memory, then your child may need a full neuropsychological assessment. A neuropsychologist has specific training in understanding the relationship between the physical brain and behaviour, cognition (thinking skills) and how this can be affected by factors such as epilepsy, medication and mood.

Epilepsy – sport and play

Children with epilepsy should be encouraged to participate in and enjoy a full school and social life. They should be given the opportunity to engage in recreational activities where possible with the appropriate risk management strategies in place to support the child.

To manage the risk in schools, the **Victorian Department of Education and Training Epilepsy and Seizure policy** states that schools are required to ensure appropriate health and management plans are in place for students with epilepsy. It also states that staff are trained by a recognised epilepsy provider to provide medical assistance in cases where emergency medication is required. The same approach can be applied to all recreational activities in the community.

Exercise can lead to improved physical and emotional health, including positive effects on seizure control. Striking a

safe balance between epilepsy, its treatment, and appropriate exercise recommendations can bring children important health benefits.

It's uncommon for seizures to be triggered by exercise or sports. Most sporting activities are suitable if the child avoids overexertion, dehydration and low blood sugar (hypoglycaemia). Take special care with activities such as water sports, or activities from heights.

Where an activity carries risk, general restrictions are sometimes unnecessarily imposed on children with epilepsy. Risks are best assessed for each child. Other safety precautions or adapting various activities may lower risks to an acceptable level. There are some activities that require closer supervision than others, for example:

- swimming – supervision by a competent adult is good practice for all children in and around water, whether that is a pool, beach or bath
- cycling – all children should wear a bike helmet and cycle away from busy roads
- climbing – trees and rocks present risks if the child's seizures are not well controlled.

Epilepsy and genetics

Some types of epilepsy can run in families. Even if your family has a genetic form of epilepsy, the chances of passing it on are relatively low. For instance:

- A sibling of a child with epilepsy may have a slightly higher risk of developing epilepsy if there is a genetic tendency in the family for seizures and epilepsy. Even so, most siblings will not develop epilepsy.
- The risk for children whose father has epilepsy is only slightly higher.
- If the mother has epilepsy and the father does not, the risk is still less than 5 in 100.
- If both parents have epilepsy, the risk is a bit higher. Most children will not inherit epilepsy from a parent, but the chance of inheriting some types of epilepsy is higher.

If you're planning on having a baby in the future and you are concerned about the potential risks of epilepsy, ask your doctor to explain the risks or refer you to a genetic counsellor for genetic testing. Genetic risks do not apply to all epilepsies.

Epilepsy support and information

If your child is diagnosed with epilepsy, it's a good idea to learn as much as you can. Some suggestions that may help include:

- There are many types of epilepsy. Get a clear diagnosis if you can and seek out the information that is specific to your child.
- Your child will have questions – answer these clearly. There are some great animations to help explain to your child such as **Understanding epilepsy digital comic** and **Understanding epilepsy digital comic with narrative**.
- Make sure that anyone who cares for your child knows how to help your child if a seizure occurs.
- A good **first aid seizure animation for children** is also available. Or a **first aid seizure animation for adults**.
- The Epilepsy Foundation webinar **Epilepsy During the School Years** provides families with information and insights around the impact of epilepsy during the school years from the perspectives of a clinical neuropsychologist, a social worker and a parent of a child with epilepsy.
- As your child gets older, it's important to help them take responsibility for their epilepsy – for example, remembering to take their medication at the right times without you prompting them.

Remember to keep a balance between protecting your child and fostering independence.

Epilepsy Parents Australia is an active Facebook support group for parents of children with epilepsy.

Where to get help

- Your **GP (doctor)**
- Your **paediatrician**
- Your **paediatric neurologist**

- **NURSE-ON-CALL** Tel. **1300 60 60 24**
- **Epilepsy Action Australia** Tel. **1300 37 45 37**
- Epilepsy Action Australia have produced **animated seizure first-aid videos aimed at both adults and children**.
- The **Epilepsy Nurse Line** is a phone and email service to support people living with epilepsy and their families. The Epilepsy Nurse Line is available from 9am to 5pm, seven days a week in all Australian states and territories. Tel. **1300 EPILEPSY (37 45 37)** or email **epilepsy@epilepsy.org.au**
- **Paediatric Epilepsy Network**
- **Epilepsy Foundation Victoria** Information Line Tel. **1300 761 487** or **(03) 8809 0600**
- Children's Epilepsy Program, The Royal Children's Hospital Melbourne Tel. **(03) 9345 5661**

This page has been produced in consultation with and approved by:

Epilepsy Action Australia