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

More than half of 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, children with epilepsy generally 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 do not 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. One in 25 children has a febrile convulsion at some time, usually between the ages of three months and six years.

For children who have their first seizure before the age of one, approximately half will have another, while for those who have a febrile convulsion after the age of one, approximately a quarter will have further febrile convulsions. Having febrile convulsions does not mean that the child necessarily has epilepsy. Ninety-seven per cent of all children with simple febrile convulsions have no higher risk of developing epilepsy later on.

Febrile convulsions tend to occur in families. If a child has had a febrile convulsion, the risk for a sibling of that child to have a febrile convulsion is about 10 per cent, or almost 50 per cent if a parent has febrile convulsions as well. A child is also at higher risk of developing epilepsy if there was evidence of abnormal development prior to the convulsion, or if they experience a complex, or prolonged (longer than 15 minutes) febrile convulsion.

Understanding the diagnosis of epilepsy

When epilepsy is thought to be due to a genetic disposition to seizures, it is called idiopathic or genetic epilepsy. Where epilepsy is the result of an illness, brain lesion or brain injury, it is called symptomatic or structural–metabolic epilepsy. Sometimes, however, it is not possible to pinpoint the cause of the condition.

Understanding the pattern of epilepsy in a child can be a slow process and a frustrating time for parents. It may not be possible to know all the answers about a child's condition at the time of diagnosis. The picture may only become clear as the child grows.

Epilepsy syndromes

There are currently over 60 different types of seizures documented. Broadly, seizures are classified as either 'focal' or 'generalised' (see the [Epilepsy](#) page for more information).

When particular types of seizures begin at a particular age and are associated with other conditions (comorbidities), then this is known as an epilepsy syndrome. When looking to diagnose epilepsy, or an epilepsy syndrome, some of the specific signs and symptoms 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 pattern or 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 of epilepsy or epilepsy syndromes in childhood include:

- **childhood absence epilepsy (CAE)** – these seizures usually start between ages two 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 eight to 20. The seizures are similar to childhood absence seizures but may be longer and can include movements such as eyelid fluttering or chewing. They can occur several times a day, but are not as frequent as childhood absence epilepsy seizures. Up to 80 per cent of children with this type of epilepsy will also have tonic-clonic seizures. The seizures often are well controlled with medication but the syndrome is considered lifelong
- **benign rolandic epilepsy/benign epilepsy with centrotemporal spikes (BECTS)** – onset age is usually five to ten years. Seizures may be minor and cause drooling and speech arrest (when the child cannot speak for a while). They usually happen in sleep or first thing in the morning as the child wakes. Convulsions may also occur. Medication is not always needed. This type of epilepsy resolves with age, usually by the teenage years
- **juvenile myoclonic epilepsy (JME)** – this syndrome can be diagnosed anywhere between eight and 25 years. It typically starts with myoclonic seizures that occur on waking either in the morning or from a nap. They are sudden, irregular 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 are also seen. Seizures can be well controlled with medication and lifestyle changes. This syndrome runs in families
- **temporal lobe epilepsy (TLE)** – this type of epilepsy can start at any age. It involves focal impaired aware seizures (previously known as complex partial seizures) and focal aware seizures (previously known as simple partial seizures), with staring and confused behaviour. TLE can also include generalised seizures
- **frontal lobe epilepsy (FLE)** – this type of epilepsy can start at any age and is one of the more common types of focal epilepsy. Seizures often occur during sleep and may include vigorous motor (physical) activity.

FLE can be hard to tell apart from another type of sleep disorder known as parasomnia and the child may need to be monitored overnight in order 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) 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 do not occur in clusters. Most children with infantile spasms will have developmental disabilities later in life and develop other kinds of seizures or epilepsy
- **Lennox-Gastaut syndrome (LGS)** – this complex syndrome has the onset of seizures from age one to seven years. It can include multiple seizure types and is often difficult to manage. Developmental delay is seen in 90 per cent of people with this syndrome and often includes intellectual disability.

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 syndrome)**
- **Landau-Kleffner syndrome (LKS)**
- **Rasmussen's syndrome.**

Treatment of epilepsy

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

Medication is the first line of treatment for epilepsy. Medications are not a cure. They are intended to lessen or control 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 for parents. 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. AEMs are effective for approximately 70 per cent of people with epilepsy (although it may take some time to find the right medication or combination of medications). If several medications fail to control seizures adequately, other options for treatment may be considered such as:

- surgery
- vagus nerve stimulation
- dietary management.

General information about medications

Most AEMs are started at a low dose and slowly increased until seizures no longer occur. The dose may need to be adjusted as the child grows and their weight increases, or if new medications are added for other problems.

A second AEM may be added or substituted if the first medication was only partially effective in stopping seizures, or if it caused unwanted side effects.

Many AEMs 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 AEMs 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.

AEMs 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 are planning a baby and you are concerned about the potential risks of epilepsy in the family, ask your doctor to explain any risks in your case. Genetic risks do not apply to all epilepsies and, in most cases, are fairly low.

The unpredictable nature of epilepsy can result in significant worry for children as well as their parents. Parents of children with epilepsy can sometimes experience isolation, stigma and the financial strain of increased medical appointments and time off work. As such, they can also report elevated levels of anxiety and depression compared to parents of children without a chronic illness. In these cases, it is important that parents also feel supported, which may include professional psychological support or financial support from the government.

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 or the frequency of seizures. It may be due to a coexisting condition such as attention deficit hyperactivity disorder (ADHD) or autism spectrum disorder (ASD). Night-time seizures can result in daytime drowsiness, which can impact on learning and educational participation.

Sometimes, medication is a contributing factor as it may cause drowsiness or hyperactivity. When a learning difficulty is identified in a child, there are strategies available – both medical and educational – that can be implemented. You can find further information from **your local Epilepsy Australia member organisation**.

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 thinking skills or memory, or you need to confirm the possibility of an intellectual disability (for example, for an NDIS funding application), then your child may need a full neuropsychological assessment. A neuropsychologist is a psychologist who has specific training in understanding cognition (thinking skills) and how this can be impacted 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. Teachers and activity supervisors are often concerned about caring for a child with epilepsy. Children 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 and 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 is uncommon for seizures to be triggered by exercise or sports. Most sporting activities are suitable as long as 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. Video games, for example, will trigger seizures in less than three per cent of children with epilepsy.

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 are 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. Seek out the information that is specific to your child.
- Choose a doctor with whom you and your child can discuss your epilepsy questions freely.
- Your child will have questions. Answer these clearly. Age-appropriate material may be found on the **Epilepsy Smart Schools website** which carries a full range of information for parents, teachers and children living with epilepsy.
- Your child will sense any fear and embarrassment you may have about epilepsy. If you can adopt a positive approach to the condition, your child will have a positive model to follow.
- Make sure that anyone who cares for your child is informed and knows how to help your child if a seizure occurs. The Epilepsy Smart Schools program aims to also educate teachers and school staff about how to manage seizures and emergency medication (if necessary) through **epilepsy and emergency medication**

training as well as **educating students about what epilepsy is** through a range of classroom activities.

- 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 is 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

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