

What is a syndrome?

A syndrome is a group of signs or symptoms that happen together and help to identify a unique medical condition.

What is a 'childhood epilepsy syndrome'?

If your child is diagnosed with an epilepsy syndrome, it means that their epilepsy has some specific signs and symptoms. These include:

- the type of seizure or seizures they have;
- the age when the seizures start;
- a specific pattern on an electroencephalogram (EEG); and
- sometimes a pattern on a brain imaging scan.

An EEG test is painless and records patterns of electrical activity in the brain. Some epilepsy syndromes have a particular pattern, so the EEG can be helpful in finding the correct diagnosis. A magnetic resonance imaging (MRI) brain scan is also painless and looks at the structure of the brain for any underlying abnormality.

An epilepsy syndrome can only be diagnosed by looking at all the signs and symptoms together.

[See our leaflets *diagnosis and seizures* for more information.](#)

If your child is diagnosed with an epilepsy syndrome, it may help the paediatrician (a doctor who specialises in treating children) to plan their care (for example, choosing treatment options or deciding whether further tests are needed).

Different types of syndrome

Syndromes can vary greatly. Some are called 'benign' which means children become seizure-free (have no seizures) once they reach a certain age. Other syndromes are 'severe' and children have seizures which are difficult to control. Anti-epileptic drugs (AEDs) may be tried alone, or in combination with each other, and some non-drug treatments may also be tried, for example the ketogenic diet.

Many children with severe epilepsy syndromes have additional difficulties with learning and behaviour and may need extra support.

[See our leaflet *medication for epilepsy* and our factsheet *ketogenic diet* for more information.](#)

Examples of childhood syndromes

Benign rolandic epilepsy (BRE)

This syndrome affects 15% of children with epilepsy and can start any time between the ages of 3 and 10.

Children may have very few seizures and most become seizure-free by the age of 16. They may have focal motor aware seizures (previously simple partial seizures), which means they involve movement. They are often at night, and usually involve one side of the face and/or the muscles that involve speech and swallowing, causing gurgling or grunting noises, mouth movements, and dribbling. Speech can be temporarily affected and symptoms may develop into a tonic clonic seizure. AEDs may not be necessary, but can be helpful if seizures are more frequent or are mostly tonic clonic.

[See our leaflet *seizures* for more information.](#)

Childhood absence epilepsy (CAE)

This syndrome starts between the ages of four and ten, and can affect up to 12% of children with epilepsy under 16. Absence seizures happen frequently (up to 100 times a day) and are very brief, lasting only a few seconds. Because of this, they often go unnoticed.

During a seizure a child will become unconscious. They may look blank or stare, their eyelids may flutter, and they may make repetitive movements. They may not respond to what is happening around them, or be aware of what they are doing. Seizures respond well to medication. If a child is seizure-free for two years, medication is sometimes gradually reduced. Up to 90% of children with CAE will grow out of seizures by the time they are adults. Sometimes a child may also have other types of seizures.

There are many different types of epilepsy syndrome. This factsheet gives a brief overview of what childhood epilepsy syndromes are and includes details of some specific syndromes.

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Juvenile myoclonic epilepsy (JME)

This syndrome usually starts between the ages of 12 and 18. Many children have different types of seizure: myoclonic seizures (brief muscle jerks) in the upper body and tonic clonic seizures. Some children may also experience occasional brief absence seizures.

Seizures often happen as, or shortly after, the child or young person wakes up. Medication can be successful in controlling seizures, and may be needed for life.

Tiredness, stress, lack of sleep, and excess alcohol can trigger seizures. Up to 40% of children or young people with JME have seizures that are triggered by flashing or flickering lights (photosensitive epilepsy).

[See our factsheet *photosensitive epilepsy* for more information.](#)

Infantile spasms (or West syndrome)

This syndrome often begins in the first year of life and can affect children:

- who have had a previous brain injury before the age of six months;
- whose brain has not formed properly (brain malformation); or
- who have genetic abnormalities.

It is identified by brief spasms or jerks which happen in 'clusters'. Spasms can affect the whole body or just the arms and legs. Each cluster can include between 10 – 100 individual spasms, which often happen when the child is waking up. AEDs and corticosteroids (medicines to reduce inflammation) are used to treat this syndrome, although around 25% of children have spasms that do not respond well to medication. Many children develop problems with learning or behaviour. Some may go on to develop Lennox-Gastaut syndrome.

[Visit Contact a Family for more information](#)

Lennox-Gastaut syndrome

This syndrome usually begins between the ages of three and five, but can start as late as adolescence. Children may have different types of seizures, most commonly tonic (where the muscles suddenly become stiff), atonic (where the muscles suddenly relax), and atypical absences. Atypical absences are different from typical absences as they often last longer, and a child may be responsive and aware of their surroundings. Many children also develop learning difficulties and behaviour problems. This syndrome can be very difficult to treat with AEDs, and most children need a combination of different drugs. Some non-drug treatments, such as the ketogenic diet and vagus nerve

stimulation therapy (VNS), can also be helpful. Seizures often continue into adult life.

[See our factsheets *ketogenic diet* and *VNS therapy*.](#)
[Visit Contact a Family for more information.](#)

Who can I talk to?

If your child has been diagnosed with a childhood epilepsy syndrome, you may have concerns or questions. You can get information and advice from a paediatrician with an interest in epilepsy, or a paediatric neurologist. Support may also be available through an epilepsy specialist nurse, counsellor, support group, or helpline. Epilepsy Society has a confidential helpline that offers time to talk, information, and emotional support. Some people find it helpful to talk to friends or family about their child's epilepsy. You might find it helpful to speak to other parents. Support groups and online forums may be a useful way to share your experiences.

[Contact our helpline for more information on support groups.](#)

Further information

Epilepsy Society information

Diagnosis	Photosensitive epilepsy
Ketogenic diet	Seizures
Medication for epilepsy	VNS therapy

Epilepsy Society Helpline

01494 601 400

Information and emotional support.
Confidential, national call rate.

Epilepsy Society

Chesham Lane,
Chalfont St Peter,
Buckinghamshire
SL9 0RJ

Other organisations

Contact a Family

0808 808 3555

contact.org.uk

Information and links to support for many childhood conditions, including epilepsy syndromes.

NICE (National Institute for Health and Care Excellence)

NICE recommends that everyone with epilepsy has a comprehensive care plan.

[Visit epilepsysociety.org.uk/comprehensive-care-plan](http://epilepsysociety.org.uk/comprehensive-care-plan)

Every effort is made to ensure that all information is correct at the time of printing. Please note that information is intended for a UK audience. This information is not a substitute for advice from your own doctors. Epilepsy Society is not responsible for any actions taken as a result of using this information.



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