CONDITION

Lennox-gastaut syndrome

Lennox-Gastaut syndrome is a severe childhood-onset epilepsy with several seizure types and learning or developmental difficulties.

WHAT IT IS
Childhood-onset epilepsy syndrome with multiple seizure types

BODY SYSTEM
Nervous system

MAIN SYMPTOMS
Drop attacks, stiffening seizures, staring spells, learning difficulties

WHAT CAUSES IT
Brain injury, genetic conditions, or no identified cause

HOW IT IS DIAGNOSED
Seizure history and characteristic EEG findings

MAIN TREATMENT
Antiseizure medicines, dietary therapy, devices, or surgery

CAN IT BE CURED?
No - usually a lifelong epilepsy

IS IT AN EMERGENCY?
Sometimes - seizure lasts five minutes or breathing stops

LONG-TERM OUTLOOK
Usually lifelong seizures with ongoing learning and support needs

Overview

Lennox-Gastaut syndrome, or LGS, is a type of epilepsy that usually begins in childhood. Epilepsy causes repeated seizures because of sudden bursts of abnormal electrical activity in the brain.

LGS is called a syndrome because it is defined by a pattern of features rather than one single cause. These features include several types of seizure, particular changes on an electroencephalogram, and difficulties with learning, development, or behavior. An electroencephalogram, usually called an EEG, records the brain's electrical activity.

LGS matters because its seizures are often difficult to control and may cause sudden falls or injuries. The condition can also affect communication, memory, movement, sleep, and independence. Some children already have developmental difficulties before seizures begin. In

others, difficulties become clearer over time.

Care usually involves a specialist epilepsy team. Treatment aims to reduce the number and severity of seizures, limit injuries and medicine side effects, and support development and quality of life.

Symptoms

LGS can cause several seizure types. Their appearance and frequency may change as a child grows.

Common seizure types include:

Some seizures are subtle. A brief head nod, repeated eyelid movement, sudden loss of balance, or unexplained nighttime waking may be related to seizure activity.

Learning and developmental difficulties are also part of LGS. These may affect speech, attention, memory, movement, or problem-solving. Behavior changes such as irritability, restlessness, aggression, or withdrawal can occur. Sleep disturbance is common and may be related to nighttime seizures, medicines, or the underlying brain condition.

- Tonic seizures: The body, arms, or legs suddenly become stiff. These often happen during sleep and may cause a fall if the person is awake.
- Atonic seizures: Muscle tone is suddenly lost, causing the head to drop or the person to collapse. These are often called drop attacks.
- Atypical absence seizures: The person stares, becomes less responsive, or appears confused. These spells may begin and end gradually.
- Other seizures: Myoclonic jerks, focal seizures, or generalized convulsive seizures can also occur.

Causes and risk factors

LGS can result from many conditions that affect how the brain develops or functions. In some people, no cause is identified even after detailed testing.

Known causes include:

A genetic cause does not always mean the condition was inherited from a parent. Some genetic changes happen for the first time in the affected child.

Some children have another epilepsy syndrome, such as infantile spasms, before developing

the LGS pattern. However, most children with seizures or developmental difficulties do not develop LGS.

- Changes in brain development before birth
- A genetic condition or a new genetic change
- Brain injury caused by a lack of oxygen
- Previous infection or inflammation involving the brain
- Stroke, head injury, or another structural brain problem
- Certain metabolic conditions that affect how cells produce or use energy

Diagnosis

LGS is diagnosed from the overall pattern of seizures, development, and EEG findings. There is no single blood test that confirms it.

An EEG is central to diagnosis. It may show a slow spike-and-wave pattern while the person is awake and bursts of rapid electrical activity during sleep. Because sleep findings are important, the test may include a nap, an overnight recording, or longer video-EEG monitoring.

Video-EEG records behavior and brain activity at the same time. This can help distinguish different seizure types from movements, sleep events, or behavior that is not caused by a seizure.

The assessment may also include:

MRI and genetic testing may identify the underlying cause, but they do not by themselves establish the LGS diagnosis. The pattern can also become clearer over time, so the diagnosis may require repeated assessment.

- A detailed description or video of suspected seizures
- A review of development, learning, and behavior
- MRI to look for differences or damage in the brain
- Genetic testing
- Blood, urine, or spinal fluid tests for selected metabolic conditions

Treatment and management

LGS often requires more than one treatment. Complete seizure control may not be possible,

but reducing drop attacks, prolonged seizures, and medicine side effects can make a meaningful difference.

Several antiseizure medicines are used for LGS. Options may include valproate, lamotrigine, clobazam, rufinamide, topiramate, cannabidiol, fenfluramine, or felbamate. Availability and approval differ between countries. Each medicine has possible interactions and side effects, and some require blood tests or other monitoring.

The choice depends on seizure types, age, other health conditions, previous treatments, and pregnancy considerations. Medicines should not be stopped suddenly unless emergency medical advice says otherwise, because abrupt withdrawal can trigger more seizures.

If medicines do not provide enough control, other options may include:

A written seizure action plan should explain usual first aid, when to use prescribed rescue medicine, and when to call emergency services. Helmets or other protective equipment may be considered when frequent drop attacks create a high risk of head injury.

Management also includes speech and language therapy, physiotherapy, occupational therapy, educational support, sleep care, and help with behavior or mental health. These supports remain important even when seizures improve.

- Ketogenic dietary therapy: A high-fat, carefully controlled diet that changes how the body produces energy. It requires specialist supervision because it can affect nutrition, growth, digestion, and body chemistry.
- Vagus nerve stimulation: A device placed under the skin that sends regular electrical signals through a nerve in the neck.
- Corpus callosotomy: An operation that separates some nerve connections between the brain's two halves. It is mainly used to reduce dangerous drop attacks.
- Cause-directed surgery: An option for selected people when seizures arise from a removable area of abnormal brain tissue.

Complications

Sudden falls can cause cuts, broken bones, dental injuries, or concussion. Repeated stiffening seizures during sleep may also disturb rest and affect daytime attention.

A seizure lasting longer than expected, or repeated seizures without recovery, can become status epilepticus. This requires urgent treatment. In LGS, status epilepticus is not always strongly convulsive; it may appear as prolonged confusion, reduced responsiveness, or repeated subtle seizures.

Eating and swallowing difficulties can increase the risk of poor nutrition or food entering the airway. Limited mobility may contribute to muscle tightness, reduced bone strength, or constipation.

Antiseizure medicines can cause sleepiness, unsteadiness, appetite changes, mood changes, or problems with concentration. Effects differ between medicines, so new symptoms should be reviewed rather than assumed to be part of LGS.

People with epilepsy also have a risk of sudden unexpected death in epilepsy, known as SUDEP. The risk is higher when generalized convulsive seizures remain uncontrolled. Following the treatment plan, reporting seizure changes, and discussing nighttime safety with the epilepsy team can help address known risks.

Prevention

LGS usually cannot be prevented. Many causes arise from genetic changes, differences in brain development, or an earlier brain injury that cannot be reversed.

General measures that reduce the risk of serious head injury or some brain infections may prevent a small number of underlying causes, but they cannot guarantee that LGS will not occur.

When testing finds an inherited condition, genetic counseling can explain how it may affect other family members or future pregnancies. Counseling provides information and choices; it does not mean that anyone caused the condition.

Living with it and what to expect

LGS is usually long term. Seizure types may change through adolescence and adulthood, and the classic childhood EEG pattern may become less obvious. This does not necessarily mean the epilepsy has gone away.

Some people have meaningful reductions in seizures with medicines, dietary therapy, a device, or surgery. Others continue to have frequent seizures despite several treatments. Development can continue, but progress may be slower and skills may be uneven. Some people lose skills during periods of frequent seizures or illness, while others remain stable or gain abilities over time.

Support needs range widely. Some adults can take part in work, education, or community activities with limited help. Others need lifelong assistance with communication, personal care, mobility, and safety. Families may need respite care, accessible education, transport support,

and help planning the move from child to adult services.

Regular follow-up usually includes reviewing seizure records, injuries, sleep, development, medicine effects, nutrition, and emotional well-being. Treatment goals may change over time. For example, preventing falls or improving alertness may become more important than reducing every brief seizure.

When to get medical help

Call emergency services if:

During a convulsive seizure, protect the head, move nearby hazards, and time the seizure. Do not restrain the person or put anything in their mouth. When it is safe, turn them onto their side to help keep the airway clear. Follow the individual action plan and use rescue medicine only as instructed.

Arrange prompt, non-emergency review if seizures become more frequent, a new seizure type appears, recovery changes, or medicines cause concerning side effects. Developmental regression, new swallowing problems, repeated falls, worsening sleep, or major behavior changes also need assessment.

Routine follow-up is used to review treatment, growth, learning, safety equipment, and support needs. Pregnancy planning should be discussed in advance because some antiseizure medicines can affect pregnancy and must not be changed without specialist guidance.

- A seizure lasts five minutes or longer, unless the action plan gives another threshold
- Seizures repeat without the person returning to their usual level of awareness
- Breathing is difficult, the lips turn blue or grey, or recovery is unusually slow
- A seizure happens in water
- There is a serious head injury or other major injury
- It is the person's first known seizure

Common questions

Can a child outgrow Lennox-Gastaut syndrome?

LGS usually continues into adulthood, although its seizure types and EEG pattern may change. Some people gain much better seizure control, but ongoing medical and developmental support is often needed.

Is Lennox-Gastaut syndrome genetic?

Sometimes. LGS may be linked to an inherited condition or a new genetic change, but it can also result from brain injury or have no identified cause. Genetic testing may help explain the cause without predicting the exact future course.

Does LGS always cause intellectual disability?

Learning or developmental impairment is part of the usual LGS pattern, but its severity is not the same for everyone. Abilities may also be affected by the underlying cause, seizure burden, sleep disruption, and medicine side effects.

Can the ketogenic diet stop LGS seizures?

It can reduce seizures for some people, but it does not work for everyone and is not a cure. Because the diet is medically restrictive, it should be planned and monitored by an experienced epilepsy and dietetic team.

Can someone with LGS live independently?

Some people achieve a degree of independence, while others need lifelong daily care. Communication, mobility, seizure control, learning ability, and safety all influence the level of support required.

Does Lennox-Gastaut syndrome affect life expectancy?

Many people with LGS live into adulthood. Life expectancy can be affected by the underlying brain condition, severe injuries, prolonged seizures, swallowing problems, and SUDEP. An individual outlook cannot be predicted from the diagnosis alone.

Sources

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