Lennox-Gastaut syndrome (LGS)
key facts

Inspired by patients. Driven by science.

LGS is a rare and severe form of epilepsy that usually starts in childhood[1]

Seizures in early childhood are often the first sign of LGS, with symptoms developing progressively over time.[2]

LGS is more common in males than females[3,4]

LGS affects an estimated

2 in 10,000 people

in the European Union[5]

In ~65%-75% of patients living with LGS, the cause is known and can include:[3,6,7]

- Underlying structural brain abnormality (e.g., head trauma, injury from childbirth complications, tuberous sclerosis, infection such as encephalitis and meningitis, brain malformations, or tumours)
- Genetic disorders
- Metabolic causes

Diagnosis is based on:[8-10]

- Clinical history (e.g., seizure types and intellectual impairment)
- Clinical evaluation (e.g., EEG and neuroimaging studies such as MRI, CT or SPECT)
- Genetic testing
- Lab testing

Key characteristics:[11,12]

- Seizure onset in childhood (below the age of 18 years)
- More than one type of drug resistant seizure
- Electroencephalogram (EEG) shows generalized slow spike-and-wave (SSW) complexes (≤2.5 Hz), and generalized paroxysmal fast activity (GPFA) during sleep
- Cognitive and often behavioral impairments*

The incidence of LGS is estimated at 0.1 to 0.28 per 100,000 population[7,13]

75%

of patients may experience daily seizures[14]

80%-90%

of children with LGS will continue to have seizures into adulthood[15]

Children and adults with LGS share similar features, primarily suffering from multiple types of seizures that do not respond well to treatments (drug-resistant seizures)[10,11]

The most common seizure types are:[2,11,16–18]

Tonic:
Stiffness in the arms and legs

Atonic seizures:
Sudden relaxing of muscles, usually causing the person to fall

Generalised tonic-clonic:
Begins with stiffness in the arms and legs, followed by jerky movements in the arms, legs, and head with a loss of consciousness

Atypical absence
Brief altered consciousness with prolonged staring and subtle movements

Non-convulsive status epilepticus:
Prolonged seizure activity without convulsions

Myoclonic:
Involuntary, brief, jerk-like movements that cause a sudden muscle contraction

Focal impaired awareness
Affects a limited area of the brain and the affected person remains conscious. These may remain focal or evolve to bilateral tonic-clonic seizures

Epileptic spasm
Brief events of arm, leg, head flexion or extension

Burden of LGS on patients' lives:

- Impact on sleep for both patients and caregivers[11]
- Complete seizure freedom is unusual[9]
- Significant impact on quality of life (QoL) for both patients and their families[19]
- Poor long-term outcomes for patients[9]
- Cognitive delay and behavioral issues[11]
- Patients almost always suffer from lifelong motor, cognitive, and behavioral abnormalities[9,19]
- Increased risk of sudden unexpected death in epilepsy (SUDEP) due to uncontrolled seizures[20–22]

Key challenges for caregivers:[23,24]

- Logistics around providing care
- Transitioning from pediatric to adult care
- Fear, anxiety, stress and depression
- Emotional burden and isolation
- Family dynamics and impact on siblings
- Financial strain
- Lack of understanding of LGS by healthcare providers

*Developmental delay is not required to make the LGS diagnosis and 30% of children are typically developing at diagnosis.

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