

Living with Lennox-Gastaut Syndrome



A severe childhood onset developmental and epileptic encephalopathy, characterized by multiple types of drug-resistant seizures and electroencephalography (EEG) abnormalities, as well as serious impairment of neurodevelopmental and cognitive functions, in addition to behavioral disorders.^{1,2,3,5}



What is LGS?

LGS is a rare, severe form of epilepsy characterized by the presence of tonic seizures and at least one additional seizure type. It typically starts during childhood and persists into adulthood.⁴ Approximately 50% of infants with a severe infantile epilepsy syndrome evolve over time to LGS.⁵

LGS has far-reaching effects beyond seizures; impairments with developmental delay culminating in cognitive impairment, communication, psychiatric symptoms, sleep, behavioral challenges and mobility are common.⁵

Seizures largely remain uncontrolled on currently available medications.⁸ Sudden unexpected death in epilepsy (SUDEP) is a major concern for patients and families with LGS.⁹

Safety concerns for patients with LGS

LGS is characterized by many different seizure types. Some of these seizure types—tonic, atonic, generalized tonic-clonic, atypical absence, and myoclonic—may result in frequent falls and injuries. As a result, protective equipment such as helmets are often needed.^{1,3,5,15}

Moreover, the cognitive impairment in patients with LGS may impact their use of language.¹⁰ Some patients may place themselves in potentially dangerous situations, if not properly supervised. Importantly, families and caregivers may need to take appropriate precautions to ensure their loved one diagnosed with LGS is safe.¹¹

Burden of disease

LGS has wide-ranging affects, which include:



- Behavior disorders⁵
- Intellectual disability⁵
- Persistence through childhood and adolescence to adult years⁵
- Impacted quality of life due to seizure frequency and number of seizure free days¹⁴



LGS impacts the entire family—parents, caregivers, and siblings—including:¹⁵

- Feelings of isolation, which can lead to depression¹⁵
- Restriction of social life and relationship problems between partners and other family members¹⁵
- Physical exhaustion and disrupted sleep¹⁵
- Financial concerns¹³

LGS by the numbers:

There are approximately:



~48K

LGS patients in the U.S.¹⁷

~1M

LGS patients worldwide.¹⁷



How is LGS treated?

Treatment options vary for patients with LGS.

Several ways to treat LGS include anti-seizure medicines, dietary therapy, neuromodulation and other management options.¹⁶

The information provided is not intended to be used for diagnosis, treatment, or medical advice. It should not be used as a substitute for advice from a healthcare professional.

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