

Lennox-Gastaut syndrome (LGS)

A developmental and epileptic encephalopathy (DEE) associated with a wide range of aetiologies¹



Resulting from high-frequency, synchronised activity in bilaterally distributed brain networks¹



Develops in a susceptible age period in childhood¹

LGS accounts for approximately

1–2%

of all persons with epilepsy¹

Reported incidence estimated at

0.1 to 0.28 per 100,000

population and is slightly more common in males^{1,2}

3.6%

of all children with epilepsy and

19%

of children with seizures starting in infancy evolve to LGS¹



In Europe, patients and their families wait on average, **12.3 months to receive a correct LGS diagnosis** following the first seizure at 4 years old (median age)³

75%

of patients may experience daily seizures⁴



Recognising LGS

Characterised by a triad of symptoms¹

1 Multiple types of drug-resistant seizures with onset prior to 18 years (one of which must include tonic seizures)¹

- Drop seizures,* which can pose risk of serious injuries^{5,6}
- Convulsive seizures e.g. generalised tonic-clonic seizures are commonly observed^{1,7}
- Generalised tonic-clonic seizures increase the risk of sudden unexpected death in epilepsy (SUDEP) approximately 10-fold compared to patients with other seizure types^{7†}

2 Cognitive and often behavioural impairments, which may not be present at seizure onset¹

Motor, cognitive and behavioural abnormalities are lifelong, with serious intellectual disability worsening over time^{6,8}

3 Diffuse slow spike-and-wave (<2.5Hz) and generalised paroxysmal fast activity on electroencephalogram (EEG)¹

LGS usually begins between 18 months and 8 years of age, with peak age of onset at

3–5 years

Onset after age 10 is rare¹

Abnormalities on neurological examination (for example, pyramidal signs) are often found and are related to the underlying aetiology¹

Most children have developmental impairment that predates seizure onset, but developmental stagnation or decline can occur with onset of frequent seizures. Less commonly, development and behaviour may be normal at seizure onset¹

Genetic testing cannot confirm LGS diagnosis but can be useful in excluding other potential causes of seizures⁹

Other features in LGS include:¹

- Impact on sleep
- Cognitive delay and behavioural issues
- Motor and mobility difficulties



Impact of LGS

Impact of LGS on patients:

- Significant impact on quality of life (QoL)⁵
- Often suffer from lifelong motor, cognitive, and behavioural abnormalities^{5,10}
- Poor long-term outcomes¹⁰
- Complete seizure freedom is unusual¹⁰
- Increased risk of SUDEP due to uncontrolled seizures^{11–13}

Impact of LGS on parents/caregivers:^{14,15}

- Logistics around providing care
- Family dynamics – caregiver may experience resentment when giving up career
- Transitioning from paediatric to adult care – physical difficulties from lifting and manoeuvring can lead to back and shoulder pain
- Fear, anxiety, stress and depression
- Emotional burden and isolation
- Stigma around condition, leading to negative social encounters
- Financial strain

Greater than
50%

of young siblings aged 9–17 reported experiencing feelings of irritability or grumpiness "sometimes" or "a lot" (n=41)^{†16}

47–62%

of young and adult siblings aged 9+ reported experiencing feelings of unhappiness "sometimes" or "a lot" (n=120)^{†16}



of young siblings aged 9–12 expressed fear that their sibling might die (n=19)^{†16}



of adult siblings reported a history of treatment for clinical depression (n=79)^{†16}

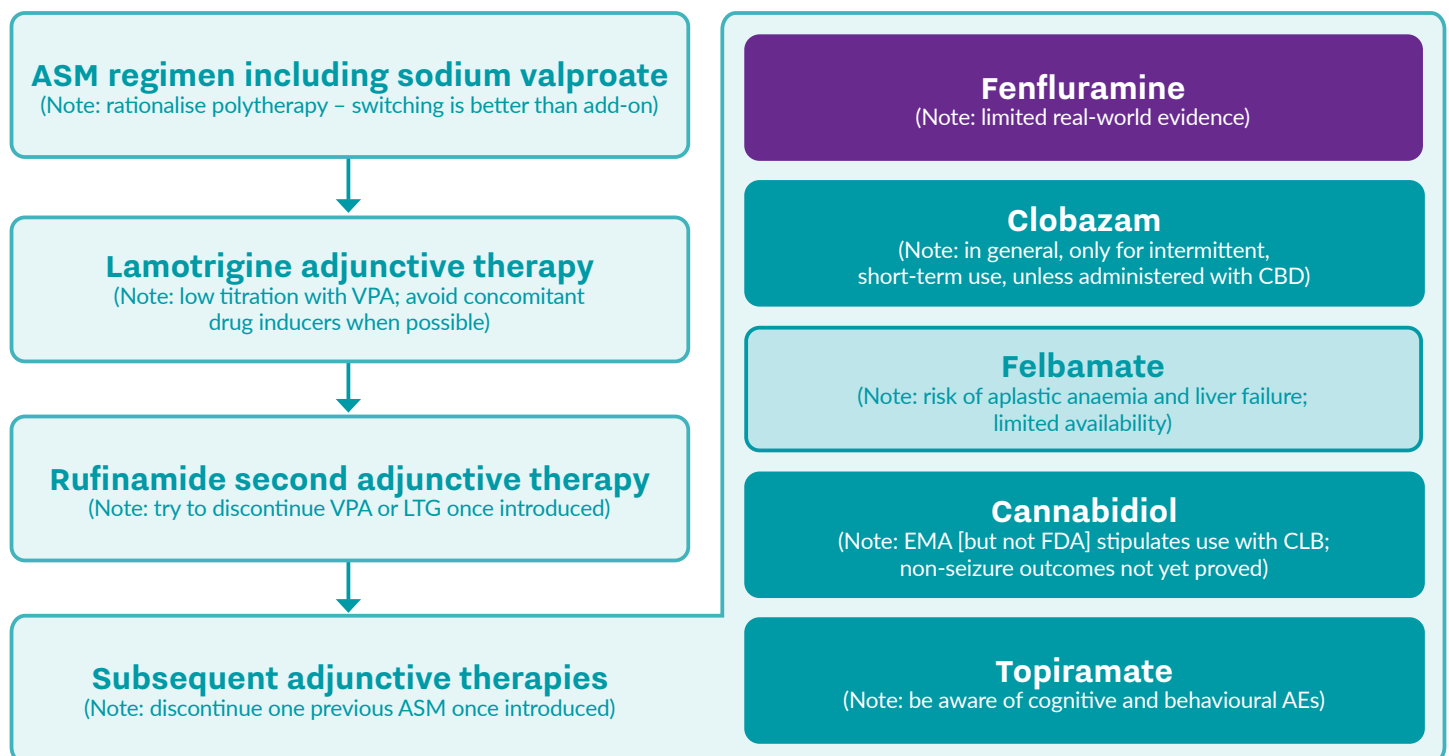
Treating LGS



Long-term seizure freedom in LGS is rare. A panel of five epileptologists reconvened to provide updated guidance and treatment algorithms for LGS, incorporating recent advancements in antiseizure medications (ASMs) and understanding of DEEs.¹⁷

Pharmacological treatment algorithm for a newly diagnosed patient with LGS or a patient with LGS already receiving ASM therapy¹⁷

Approach personalised based on aetiology



Adapted from Auvin S, et al. *Epilepsia* Open. 2025;10(1):85–106.



Treating LGS with Fintepla® (fenfluramine)

Fintepla®
now offers
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The approval of Fintepla® gives adult and paediatric neurologists an additional adjunctive treatment in LGS. Fintepla® is indicated for the treatment of seizures associated with Dravet syndrome and Lennox-Gastaut syndrome as an add-on therapy to other antiepileptic medicines for patients 2 years of age and older.¹⁹

The most commonly (≥1/10) reported adverse reactions are decreased appetite, fatigue, diarrhoea and somnolence.¹⁹ Please refer to the SmPC for further details of adverse events.

Fintepla® should be initiated and supervised by healthcare professionals with experience in the treatment of epilepsy. Fintepla® is prescribed and dispensed according to the Fintepla® Controlled Access Programme (CAP). The CAP has been created to:

- Prevent off-label use in weight management in obese patients
- Confirm that prescribing physicians have been informed of the need for periodic cardiac monitoring in patients taking Fintepla®

Please refer to the SmPC for further information.

More than
15K
Patients on Fintepla®
worldwide!²⁰

GB-FA-2600034
May 2026

¹Drop seizures are defined as seizures associated with a drop or fall: generalised tonic-clonic, secondary generalised tonic-clonic, tonic, atonic, and tonic-atonic seizures. ²Study results are not specific to LGS. ³The Sibling Voices Study included 3 subgroups of siblings: The young siblings group included cohorts of siblings aged 9–12 and 13–17, and the adult siblings group included siblings aged 18 and over. Parents were also invited to participate in the study. The Sibling Voices Study was developed to assess the emotional impact of growing up with a sibling with a DEE. Participants responded to 1 of 4 online, age- and role-specific surveys. LGS, Lennox-Gastaut syndrome; DEE, Developmental and epileptic encephalopathy; SUDEP, Sudden unexpected death in epilepsy; EEG, Electroencephalogram; QoL, Quality of life; ASM, Antiseizure medication; VPA, Sodium valproate; LTG, Lamotrigine; CBD, Cannabidiol; EMA, European Medicines Agency; FDA, Food and Drug Administration; CLB, Clobazam; AE, Adverse event; SmPC, Summary of Product Characteristics; CAP, Controlled Access Programme.

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