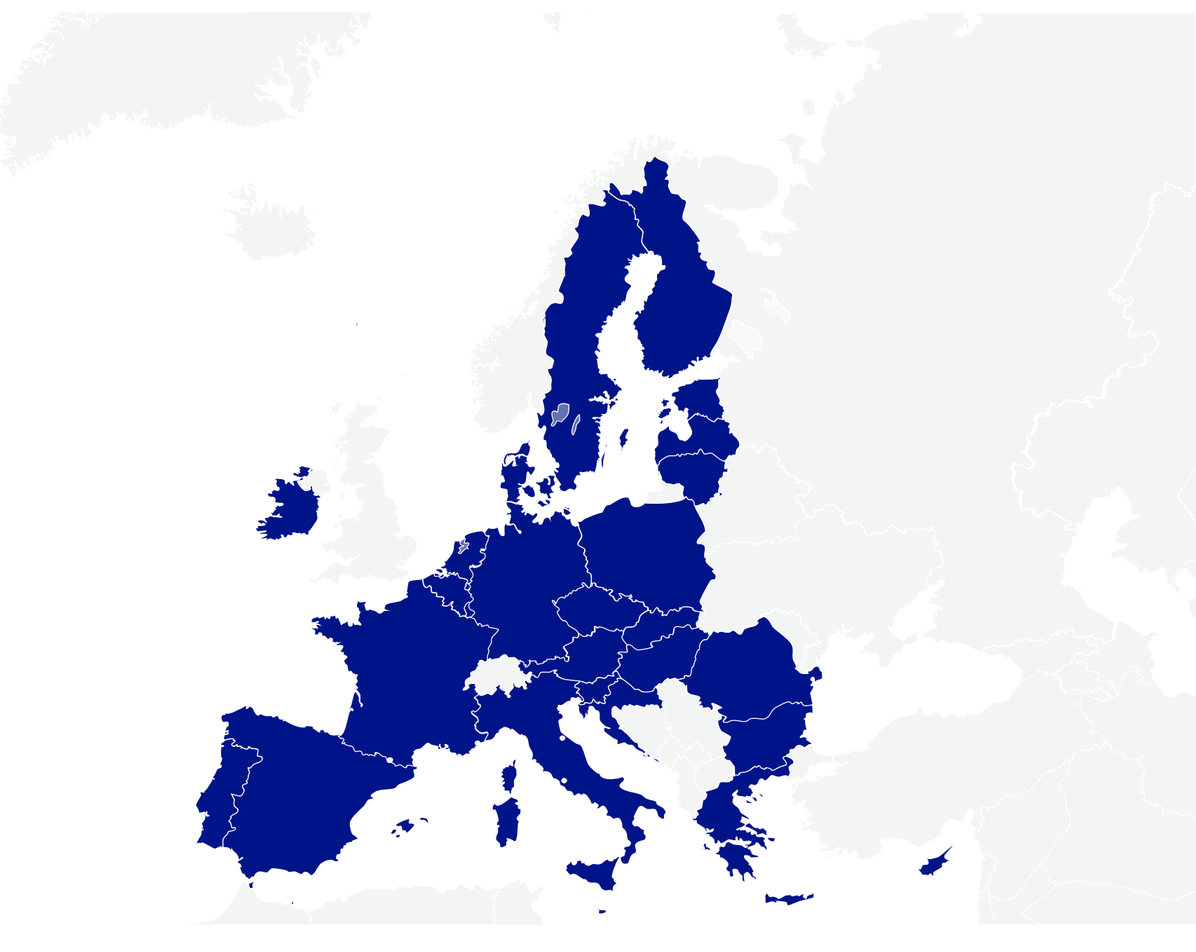
Lennox-Gastaut syndrome (LGS) key facts

Inspired by patients. Driven by science.

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

Nobody is born with LGS. However, it may develop over time from childhood seizures that remain uncontrolled by treatments[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]

- Seizure onset in childhood
- More than one type of seizure
- Abnormal brain waves on the electroencephalogram (EEG)
- Developmental delay*[12]

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

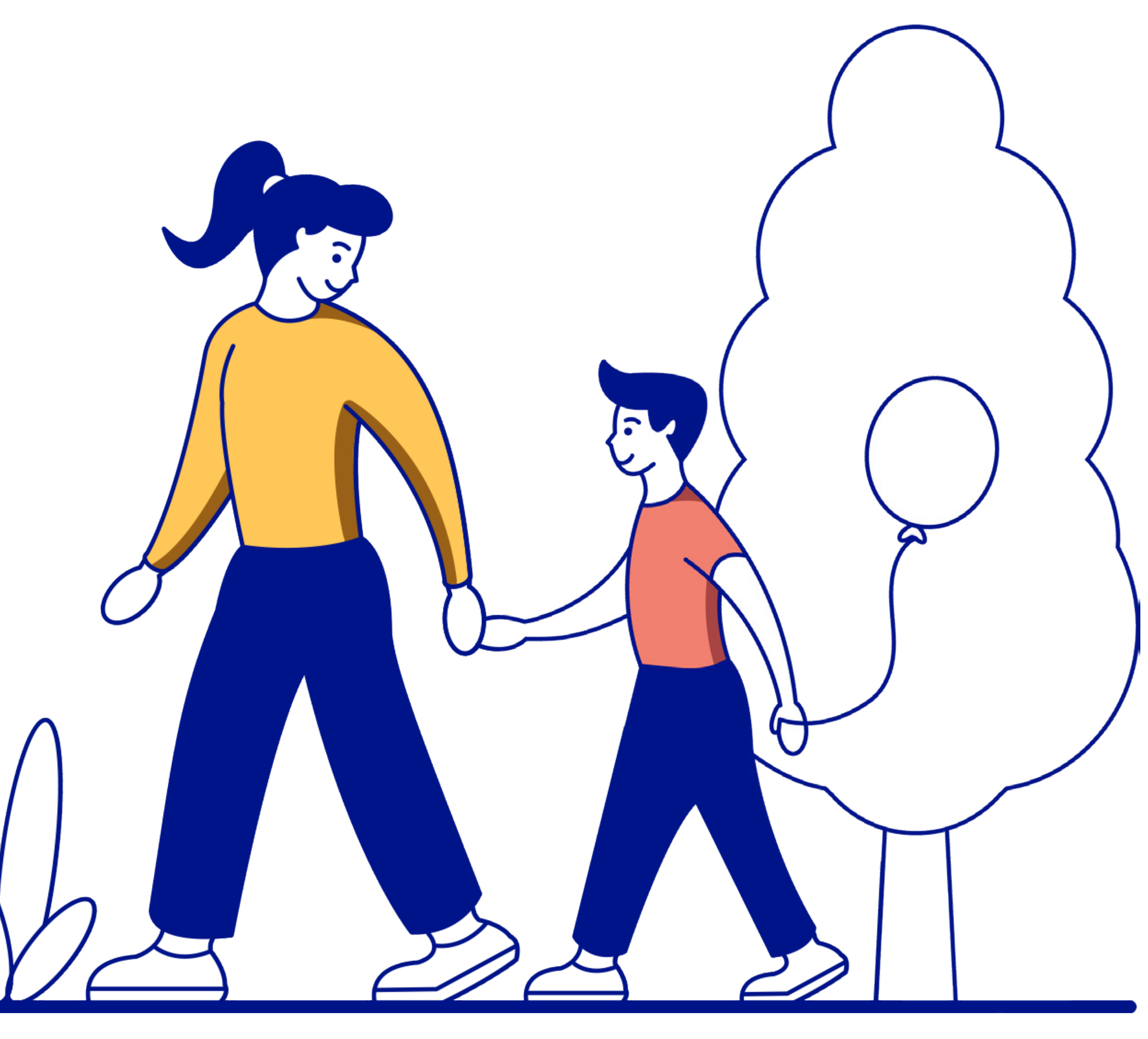
Focal impaired awareness
Affects a limited area of the brain and the affected person remains conscious. These may remain focal or evolve to bilateral tonic-clonic seizures

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

Burden of LGS on patients' lives:

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

Key challenges for caregivers:[23,24]



- Logistics around providing care
- Family dynamics
- Transitioning from paediatric to adult care
- Financial strain
- Fear, anxiety, stress and depression
- Lack of understanding of LGS
- Emotional burden and isolation

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

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Date of preparation: October 2024 | GL-DA-2400581
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