

LENNOX-GASTAUT SYNDROME (LGS) OVER TIME

Seizures and symptoms typically associated with LGS in childhood change over time; therefore, LGS in adults can be hard to recognize.

LGS IN CHILDHOOD

Diagnosis is typically based on 3 things—known as the “triad”:

1 Multiple seizure types, including atonic seizures, also called “drop seizures”

2 Slowed development—delays in intellectual ability and/or physical motor skills

3 Abnormal electroencephalogram (EEG) or brain wave pattern called a slow spike-wave pattern



LGS IN ADULTHOOD

Triad of features seen during childhood evolves as each individual transitions into adulthood.

Change in seizure type and frequency

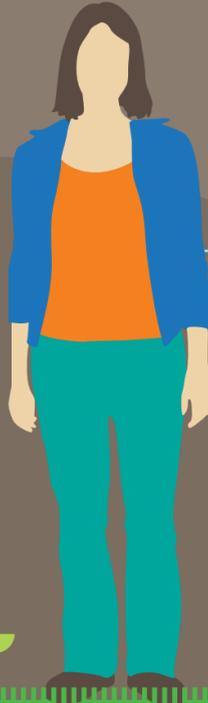
- Over time, seizure type and frequency can change
- “Drop seizures” usually become less frequent and may disappear
- Tonic seizures tend to persist, especially during sleep

Changes in cognitive development and behavior

- Over time, there is a general slowing of intellectual function
- Adults with LGS may experience complex behavioral problems ranging from autistic features to aggressiveness

Changes in EEG

- By adulthood, 50% to 70% of people no longer have the slow spike-wave pattern EEG that is typically used to diagnose the syndrome



A MISSED DIAGNOSIS—EVEN IN CHILDHOOD

Even when the triad presents at a young age, it may not be diagnosed as LGS, but instead labeled as difficult-to-control epilepsy. It's not uncommon for a person to live with LGS for many years before being accurately diagnosed.



WHY HAVEN'T WE HEARD ABOUT THIS?

LGS was first described in the late 1950s and early 1960s. Before 1989, children would likely not have been diagnosed with LGS because it was not yet recognized as a syndrome.

WHY THE DIAGNOSIS MATTERS

IF YOUR LOVED ONE'S EPILEPSY IS LGS, A PROPER DIAGNOSIS CAN HELP YOU:

Find the answers you need and new sources of ongoing support

Connect with a special community of families living with LGS and the knowledgeable professionals who care for them



“Parents who have children with disabilities are a great source of strength for one another because they have that shared experience.”

Jennifer, mother of teenage son Theo

“With a diagnosis of LGS, we were finally able to look at the signs and symptoms and it all clicked. Now we better understand why she's having these problems.”

Mark, father of adult daughter Micaela



TALK TO YOUR DOCTOR

ABOUT YOUR LOVED ONE'S MEDICAL HISTORY. IF LGS IS THE UNDERLYING DIAGNOSIS, OPTIONS DO EXIST.



Find us on Facebook
Facebook.com/LGSTogether

Learn more at:
LGSFoundation.org • LGSTogether.com
Epilepsy.com

NAVIGATING LENNOX-GASTAUT SYNDROME (LGS)

As you begin your LGS journey, there is a lot to learn. Caregivers have shared that while they felt overwhelmed and alone in the beginning, they soon realized an LGS diagnosis can bring new opportunities for answers, support, and seizure management options.

Get started on your journey by learning about LGS and what you can expect over time.

WHAT IS EPILEPSY?

Epilepsy is a medical condition in which a person has had two or more unprovoked seizures. There are many types of epilepsy, each with different causes and symptoms.

LGS: A RARE DISORDER

LGS can be challenging to diagnose because it varies from person to person and everyone's journey is different.

LGS characteristics

- Multiple types of seizures
- Slow development—delays in mental and/or physical motor skills
- An abnormal electroencephalogram (EEG) or brain wave pattern

A unique journey from childhood to adulthood

80% of children diagnosed with LGS will continue having seizures into their adult years

LGS typically occurs between

2 and 8

years of age

LGS makes up

1 to 2%

of all epilepsies, although figures of 3% to as high as 10.7% have been reported

"To me, it's important to connect with others, especially other parents who have kids with LGS, so that I can have someone understand me, so that I can have someone know what I go through every day."

Kelly, mother of young daughter Isabela

Find strength and support from each other

The cause of LGS is unknown in over 30% of children

Known causes include:

- Genetic disorders
- Brain injury or infections
- Trauma before or during birth

1 out of 5 children have a prior history of infantile spasms

"When we first connected with another family with LGS, we could ask questions, share stories, share advice. It was astounding!"

Karen, mother of adult son Dan

"We decided to take control of the chaos, and that was an attitude change. We continue to talk with our doctor, and it has really helped us along the way. It has put us in a much better place."

Jane, mother of adult daughter Micaela

HOPE FOR THE FUTURE

Tap into LGS resources and get connected with a supportive community.