Understanding seizures with Lennox-Gastaut syndrome (LGS)

Theo, at age 6
Living with LGS

Jazz Pharmaceuticals

LGS FOUNDATION®
LENNOX-GASTAUT SYNDROME

Seizures, LGS, and the journey ahead

YOU ARE NOT ALONE

ABOUT
48,000
PEOPLE
LIVE WITH LGS IN THE UNITED STATES

3 TO 4%
OF CHILDREN WITH EPILEPSY HAVE LGS

Lennox-Gastaut syndrome (LGS) is a term that you may have never heard before your loved one received a diagnosis—and since then it's all you seem to think about.

Whether your loved one just received a diagnosis or has been living with seizures and LGS for some time, a million thoughts are probably running through your mind.

While the idea of seizures associated with LGS may bring a lot of fear and questions, you can take valuable action by learning how to work with your family and care team to prepare for seizures, identify them, and even reduce their occurrence.

We hope you'll find comfort in knowing there is a great deal of research, support, and guidance available to you.

Jackson, at age 10
Living with LGS

Quinn, at age 6
Living with LGS

What is LGS?

Lennox-Gastaut syndrome (noun): len'ŏks gahs-tō sin-drōm—a rare form of epilepsy characterized by multiple types of seizures. The peak onset of LGS is between the ages of 3 and 5 years. Symptoms of LGS may not be present at birth but usually appear in early childhood and evolve over time. People with LGS may have uncontrolled seizures or developmental delays before receiving a definitive diagnosis.

Possible signs and symptoms of LGS

No two people living with LGS are exactly alike. Depending on the possible underlying cause of LGS, symptoms can vary, including the types of seizures your loved one experiences. The table below contains some of the symptoms that may occur in LGS. *Your loved one may not experience all of these.*

Common signs and symptoms of LGS:

SEIZURES

- Multiple seizure types that begin in childhood
- Specific EEG patterns

DEVELOPMENTAL DELAYS

- Impaired intelligence compared with peers

BEHAVIORAL DISORDERS

- Hyperactivity
- Aggression
- Autistic traits

LGS is defined by having multiple seizure types beginning in childhood, specific EEG patterns, and intellectual impairment.

Understanding seizures with LGS

Lindsay, at age 22
Living with LGS

Seizures are a defining feature of LGS. A seizure is a sudden, uncontrolled electrical disturbance in the brain that may cause changes in your loved one's behavior, movements, and levels of awareness.

People with LGS may experience different seizure types throughout their lifetime.

Tracking the number and types of seizures each day will help your loved one's doctor in making treatment decisions. The information provided is not intended to replace a doctor's medical guidance.

AT LEAST
50% OF PEOPLE EXPERIENCE SEIZURES THAT CAUSE FALLS, ALSO KNOWN AS DROP SEIZURES

ABOUT
50% OF PEOPLE EXPERIENCE SEIZURES LASTING FOR MORE THAN 5 MINUTES

Types of seizures most common with LGS

- Tonic
- Atonic
- Generalized tonic-clonic
- Atypical absence
- Myoclonic
- Focal aware or impaired awareness (previously called partial seizures)

In LGS, it is common for many of these seizure types to last longer than 5 minutes or occur very close together without breaks. This is known as status epilepticus, which requires emergency medical intervention. It is also common for seizure clusters to occur, which is when seizures happen close together with breaks in between them.

See pages 10-11 for a list of seizure types and tips on how to identify them.

The importance of early recognition, diagnosis, and treatment

By catching seizures early on, your loved one's doctor can work with you and your family to develop the right treatment plan.

Unrecognized and/or uncontrolled seizures are linked to developmental disabilities, learning and behavioral disorders, and other negative long-term outcomes.

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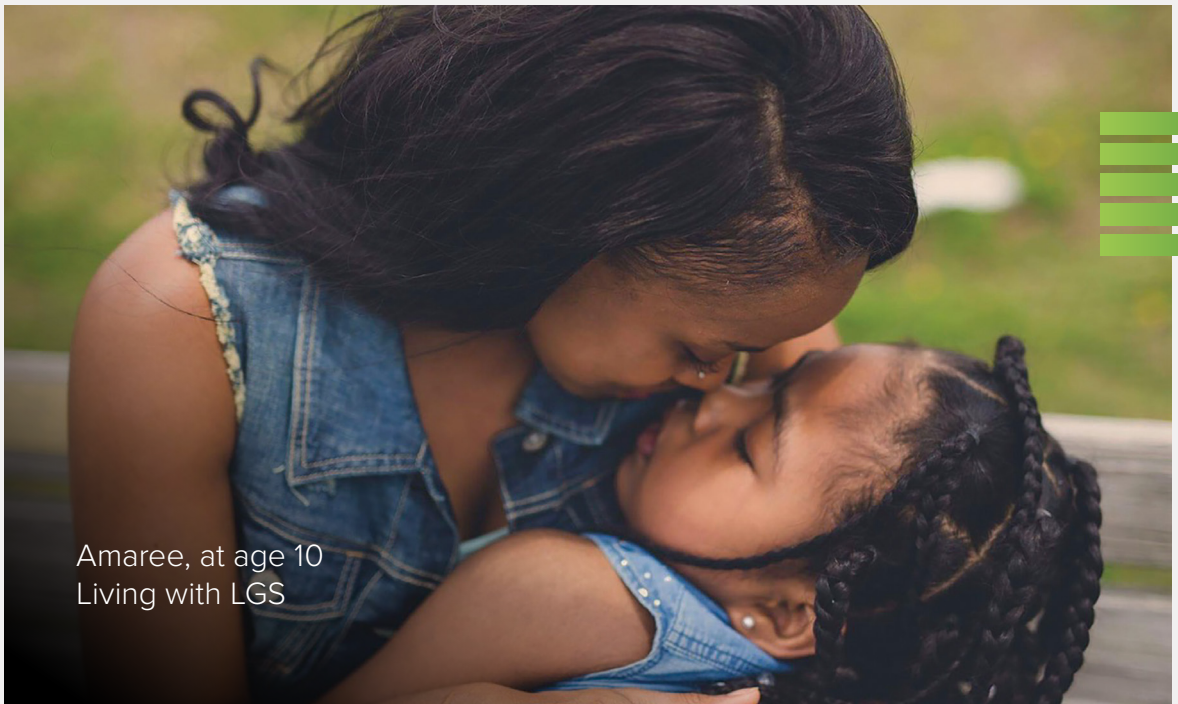

Amaree, at age 10
Living with LGS

Uncontrolled or undetected seizures can **increase** the severity of

Risk of injury due to falls

Learning and/or cognitive impairments

Developmental disabilities

A few tips to help:

Talk with your doctor as soon as you notice a seizure, or a change in seizures, in your loved one. See pages 10-11 for a list of seizure types and how to identify them.

Consider **purchasing a helmet** to prevent head injuries caused by some seizure types with LGS. Speak with your loved one's doctor to find the right helmet to keep your child safe.

According to the Epilepsy Foundation, **seek emergency medical attention** if a seizure lasts for more than 5 minutes or there is no recovery in between seizures.

While it may be difficult in the moment, **take a video** to show to your doctor if you suspect your loved one is having a seizure.

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Tips on how to identify a seizure

Seizures can vary from momentary disruptions of the senses, to short periods of unconsciousness or staring spells, or even convulsions. Typically seizures are short lived; however, they can become long-lasting, leading to status epilepticus, or can occur as clusters. Any seizure type listed below, including non-convulsive types, can lead to status epilepticus.

Types of seizures common with LGS and how to identify them:

TONIC

- Muscles in the body, arms, or legs suddenly become stiff or tense
- May happen during sleep or can cause a person to fall if standing
- Typically lasts for less than 20 seconds at a time

ATONIC

- May be referred to as a “drop attack” or “drop seizure”
- Person has a sudden loss of muscle tone and goes limp
- Mild seizures look like a head nod or drop, while severe seizures can cause a person to fall to the ground
- People with these types of seizures may wear helmets to protect from injuries

GENERALIZED TONIC-CLONIC

- Formerly known as “grand mal” seizures and is what most people think of when they hear the word seizure
- Person loses consciousness or awareness, muscles extend and become rigid, and then muscles jerk rhythmically on both sides of the body

ATYPICAL ABSENCE

- Blank staring, with eye blinking, chewing movements, or lip smacking
- Could include finger or hand rubbing, or other small hand movements
- May begin and end gradually, usually lasting for about 5-30 seconds
- May be difficult to distinguish between this seizure type and typical behavior in those with cognitive impairment

Your loved one may experience many different types of seizures. Below is information to help you identify seizures most common with LGS—so you can talk with their doctor right away.

The information provided is not intended to replace a doctor's medical guidance.

MYOCLONIC

- Sudden, brief shock-like muscle movements or jerks that usually don't last more than a second or two
- Person is alert
- May occur in clusters and may be more pronounced upon wakening

FOCAL

FOCAL AWARE

- Used to be called simple partial seizures
- Person is fully alert and able to interact
- Experiences can include
  - — Involuntary motor movements on one side of the body
  - — Intense sensory or emotional episodes, such as déjà vu or feeling unexplained emotions

FOCAL IMPAIRED AWARENESS

- Used to be called complex partial seizures
- Person loses awareness, may not respond, and has no memory of the seizure
- Can vary between people, but may start with a blank stare, followed by chewing/lip smacking
- Can also include random activity like picking at the air or clothes, attempting to pick up objects, remove clothing, repeat words or phrases, etc

Your loved one may not experience all of these seizure types.

Danny, at age 32
Living with LGS

Living with LGS

Seizures can change over time

LGS is an ever-evolving condition—the types and frequency of seizures experienced during childhood may change during adolescence and adulthood. There is also a chance that seizures may go into remission, or they may recur.

This section contains information about the changes in seizures you may witness in your loved one from childhood onward.

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YOUNG CHILDREN

- The most common initial types of seizures include
  - — Tonic, atonic, and atypical absence
  - — Tonic seizures during sleep
- Generalized tonic-clonic and focal seizures may also occur
- Seizures happen several times per week, with most people experiencing daily seizures

80 to 90% of children with LGS continue to have seizures into adulthood.

ADOLESCENTS/ADULTS

- Generalized tonic-clonic, atonic, and atypical absence seizures continue
- Tonic seizures may occur while your loved one is awake
- With age, tonic seizures may become the most characteristic seizure type, mainly during sleep

During adolescence and adulthood, the frequency of daytime seizures may decrease; however, drop seizures, which may lead to injuries, may increase.

Recognizing and tracking seizures

How to help your doctor identify the seizure type your loved one is experiencing

1. As difficult as it may seem in the moment, try to take a video to show your doctor if you suspect your loved one is having a seizure. This will help the doctor better identify the type of seizure and how to proceed with treatment.

2. Keep a diary of seizure activity in a dedicated notebook or by downloading a seizure tracking app. This can help you track to the best of your ability how often seizures happen and their possible triggers.

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Follow the seizure action plan you have created with your doctor to determine when to use rescue medication and when to visit the emergency department.

How your loved one's doctor may approach monitoring and treating seizures

There are many monitoring and treatment options for recurring seizures:

Electroencephalogram (EEG)
A test used to determine if there is abnormal brain activity that is causing seizures.

— Due to seizures or seizure patterns occurring at night, a nighttime EEG may be recommended

Magnetic resonance imaging (MRI)
An imaging technique used to look for abnormalities in the brain that could be causing the seizures.

Antiseizure medications
Therapies used to treat seizures. Certain rescue medications may be used for seizures that last longer than 5 minutes, or occur very close together without breaks.

Dietary approaches
Your loved one's doctor may prescribe a high-fat, low-carb medical diet that needs to be carefully monitored by a dietitian.

Surgical therapies
For some people, the use of implanted devices or surgical methods, including corpus callosotomy, may be recommended.

Some people with LGS may not respond to these treatment approaches. Talk with your loved one's doctor for more information about what may work for your loved one.

It may be necessary to try more than one antiseizure medication at a time to effectively reduce the number of seizures because these drugs may work through different targets in the body. These therapies may take a while to start working, and it is not uncommon for people to be on multiple therapies at a time.

Where can I find support?

Finding out that your loved one has LGS can be overwhelming, but there is hope. No two experiences with LGS are exactly alike, and you and your loved one are not alone. There's a community of support and resources to help you and your loved one navigate life with LGS. If your loved one is newly diagnosed, we encourage you to connect with the LGS community of caregivers and experts who openly share their stories and advice.

The Lennox-Gastaut Syndrome Foundation

The LGS Foundation is dedicated to improving the lives of individuals living with Lennox-Gastaut syndrome and their families through research, family support programs, and education.

Learn more about the LGS community by visiting

LGSfoundation.org

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Jazz Pharmaceuticals

At Jazz Pharmaceuticals, we are dedicated to offering innovative solutions that go beyond medicine. Our mission is to transform the lives of children, adults, and families who live with rare neurological diseases. Families are at the center of everything we do.

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