

# Lennox-Gastaut Syndrome: *A Guide for Caregivers*

## FACTS ABOUT LGS

Lennox-Gastaut syndrome (LGS) is a complex, rare, and severe type of epilepsy. While doctors don't yet know everything about this condition, they do know a lot—and you can too. Let's begin with some facts about LGS.

**LGS**  
is a severe type  
of epilepsy

It is estimated that  
LGS makes up  
**1% to 2%**  
of all epilepsies

Symptoms are typically  
first seen in children  
between the ages of  
**2** and **8**

Seizures are frequent—  
**OCCURRING  
DAILY**  
—and difficult to manage

The types of seizures  
seen in LGS  
**CHANGE  
OVER TIME**

Some people are not  
diagnosed until  
**ADULTHOOD**

**LGS**  
is characterized by a  
**"TRIAD"**  
of symptoms

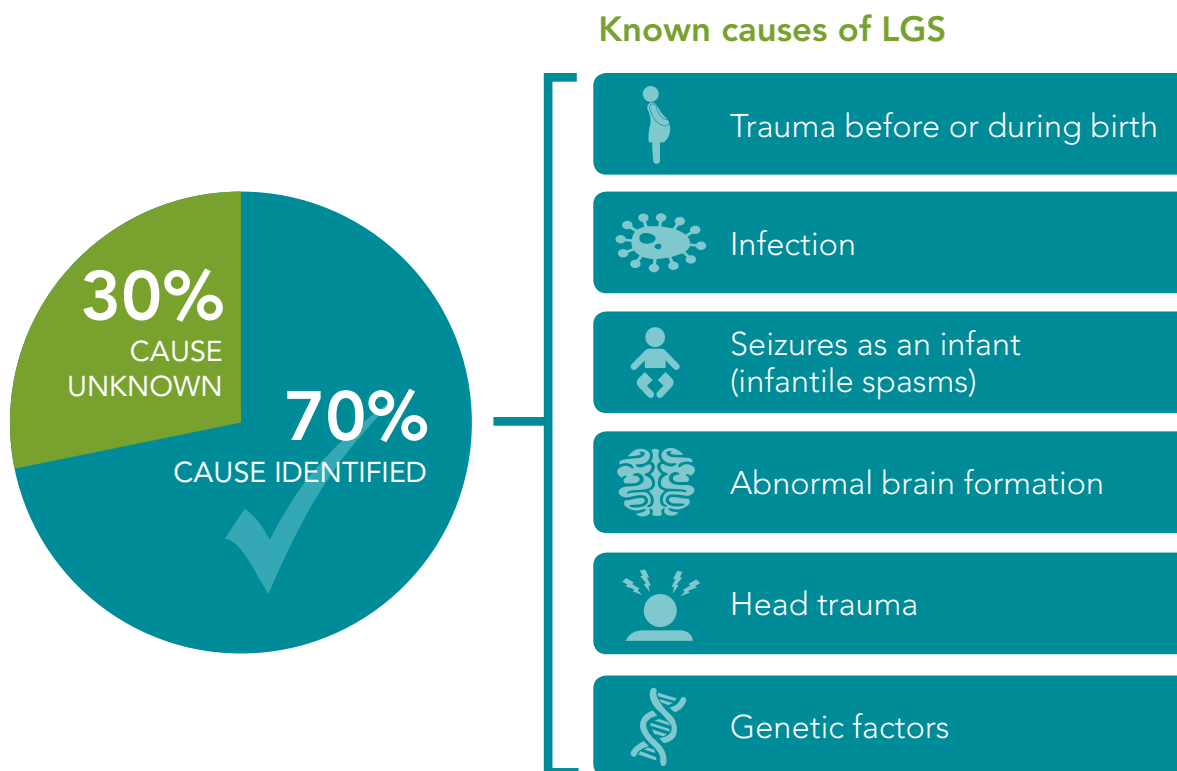
LGS affects people of  
**ALL  
RACES AND  
ETHNICITIES**

LGS is a  
**LIFELONG  
CONDITION**  
for which there is  
currently no cure

Please see Use and Important Safety Information,  
including Boxed Warning for risks from concomitant use with opioids, on page 6.

## WHAT CAUSES LGS?

The cause of LGS is unknown in about 30% of people diagnosed with LGS—that's about 1 out of 3 diagnosed cases. You may have heard of these cases being referred to as "idiopathic" or "cryptogenic." However, in the remaining 70% of cases, LGS has an identified cause.



## 3 SIGNS THAT IT MAY BE LGS

A diagnosis of LGS is based on more than just seizures, although having different types of seizures is an important part of the diagnosis.

### Sign #1

#### TYPES OF SEIZURES

People with LGS may experience many different types of seizures.

### Sign #2

#### DEVELOPMENTAL DELAYS

Developmental delays appear in nearly all patients with LGS.

### Sign #3

#### DISTINCTIVE EEG

Electroencephalograms (EEGs) in people with LGS usually show a specific pattern of activity.

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## **SIGN #1: KNOW THE LGS SEIZURE TYPES**

With LGS, people may have many different types of difficult-to-treat seizures. Knowing which type—or types—of seizures you may be seeing can help you talk with your doctor and help guide better treatment decisions.

Learn more about the different types of seizures and how they differ from one another. What you will see are general descriptions of seizure activity. You may see similar or different types of movements in your own situation. It's important to always talk with your doctor about the types of seizures your family member is experiencing.

### **Atonic**

During an atonic seizure, muscles go limp.

### **Atypical absence**

During atypical absence seizures, a person may stare blankly, appear to be daydreaming, and/or may not respond to what's going on around him or her.

### **Myoclonic**

During a myoclonic seizure, a person's muscles may quickly alternate between stiffening and relaxing, which makes it look like he or she is twitching.

### **Tonic**

This is the most common seizure type in people with LGS. It causes muscles in the arms or legs to stiffen. This type of seizure can happen when asleep or awake. Losing consciousness is possible.

### **Tonic-clonic**

This is the "classic" seizure. It has 2 successive phases—a tonic phase, where a person's muscles stiffen, followed by a clonic phase, where a person's muscles spasm and jerk. Losing consciousness is also possible.



## **TRACKING CAN HELP WITH DIAGNOSIS AND TREATMENT**

By recording seizure types and frequency, you can provide your doctor with important pieces of information that can help in diagnosis and in making a treatment plan.

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## SIGN #2: UNDERSTAND THE DEVELOPMENTAL DELAYS

In addition to different types of seizures, the diagnosis of LGS is based on whether a person shows signs of developmental delays and cognitive impairment. (Some of the most common are listed below.) If you have concerns about your loved one's progress or abilities, be sure to talk to his or her doctor.

Infants may have developmental delays

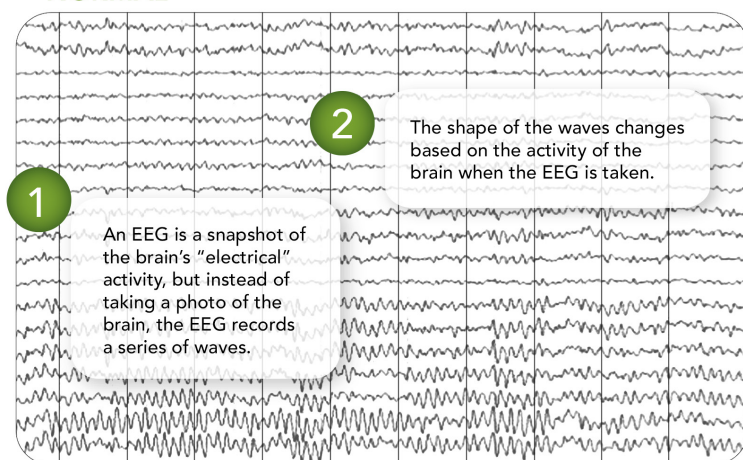
Children may develop normally but then begin to lose ground

People with LGS may have cognitive impairment

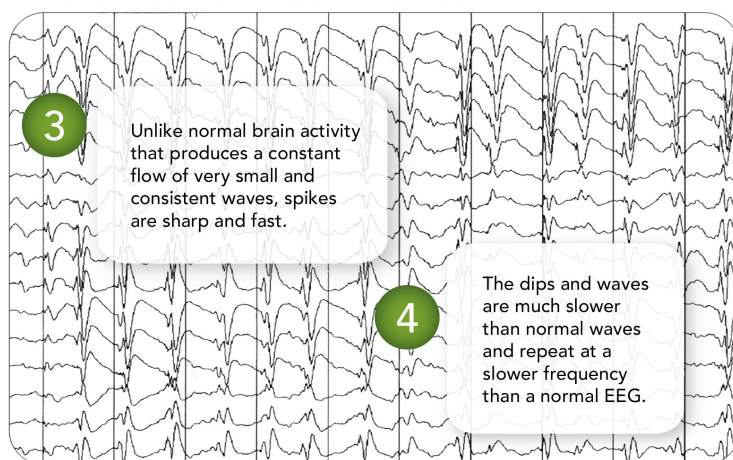
## SIGN #3: LOOKING AT AN EEG

In children with LGS, the EEG can show a specific pattern of activity called a slow spike-and-wave pattern. Take a look at the EEG below to see what a neurologist may be looking at when he or she is diagnosing LGS.

### NORMAL



### SLOW SPIKE-AND-WAVE PATTERN



*A slow spike-and-wave pattern EEG changes in adults with LGS.*

**Please see Use and Important Safety Information, including Boxed Warning for risks from concomitant use with opioids, on page 6.**



## WHAT DOES AN LGS DIAGNOSIS MEAN?

Living with LGS is challenging, and everyone's journey will be different.

By learning all you can, understanding what to expect, and working with your healthcare team, there's a lot you can do to provide the best possible care for your loved one.



## START THE CONVERSATION

Use the information you're reading to help you discuss LGS at your next doctor's visit.

**Please see Use and Important Safety Information, including Boxed Warning for risks from concomitant use with opioids, on page 6.**

## Use

ONFI (clobazam) CIV is a prescription medicine used along with other medicines to treat seizures associated with Lennox-Gastaut syndrome in people 2 years of age or older.

## Important Safety Information

### **WARNING: RISKS FROM CONCOMITANT USE WITH OPIOIDS**

**See Medication Guide and full Prescribing Information for complete information.**

ONFI is a benzodiazepine medicine. Benzodiazepines can cause severe drowsiness, breathing problems (respiratory depression), coma, and death when taken with opioid medicines.

- **Do not take ONFI if you have a known allergy to ONFI or its ingredients.**
- **ONFI can make you sleepy or dizzy and slow your thinking and motor skills. This may get better over time.** Do not drive, operate heavy machinery, or do other dangerous activities until you know how ONFI affects you. ONFI may cause problems with your coordination, especially when you are walking or picking things up.
- **Do not drink alcohol or take other drugs that may make you sleepy or dizzy while taking ONFI without first talking to your healthcare provider.** ONFI may make your sleepiness or dizziness much worse.
- **ONFI can cause withdrawal symptoms. Do not suddenly stop taking ONFI without first talking to a healthcare provider.** Stopping ONFI suddenly can cause seizures that will not stop (status epilepticus), hearing or seeing things that are not there (hallucinations), shaking, nervousness, and stomach and muscle cramps.
- **ONFI can be abused and cause dependence.** Physical dependence is not the same as drug addiction. Talk to your healthcare provider about the differences. **ONFI is a federally controlled substance (CIV) because it can be abused or lead to dependence.**
- **Serious skin reactions have been seen when ONFI is taken with other medicines and may require stopping its use.** A serious skin reaction can happen at any time during your treatment with ONFI. Call your healthcare provider immediately if you have skin blisters, rash, sores in the mouth, hives or any other allergic reaction.

- **Like other antiepileptic drugs, ONFI may cause suicidal thoughts or actions in a very small number of people, about 1 in 500.** Call your healthcare provider right away if you have any symptoms of depression, especially sudden changes in mood, behaviors, thoughts, or feelings, and especially if they are new, worse, or worry you.
- **Tell your healthcare provider about all your medical conditions,** including liver or kidney problems, lung problems (respiratory disease), depression, mood problems, or suicidal thoughts or behavior.
- If you are pregnant or plan to become pregnant, **ONFI may harm your unborn baby.** You and your healthcare provider will have to decide if you should take ONFI while you are pregnant.
- ONFI can pass into breast milk. You and your healthcare provider should decide if you will take ONFI or breastfeed. You should not do both.
- **Tell your healthcare provider about all the medicines you take,** including prescription and over-the-counter medicines, vitamins, and herbal supplements. Taking ONFI with certain other medicines can cause side effects or affect how well they work. ONFI may make your birth control medicine less effective. Talk to your healthcare provider about the best birth control method to use. Do not start or stop ONFI or other medicines without talking to your healthcare provider.
- ONFI oral suspension should be kept in its original bottle in an upright position and used within 90 days of first opening the bottle. After 90 days, safely throw away any unused ONFI oral suspension.
- The most common side effects of ONFI include: sleepiness; drooling; constipation; cough; pain with urination; fever; acting aggressive, being angry or violent; difficulty sleeping; slurred speech; tiredness; and problems with breathing.

**For more information, please see the [Medication Guide; full Prescribing Information, including Boxed Warning for risks from concomitant use with opioids; and Instructions for Use.](#)**

You are encouraged to report negative side effects of prescription drugs to the FDA. Visit [www.fda.gov/medwatch](http://www.fda.gov/medwatch), or call 1-800-FDA-1088.

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