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**
- **Seizures are frequent—OCCURRING DAILY—and difficult to manage**
- **LGS is characterized by a “TRIAD” of symptoms**
- **The types of seizures seen in LGS CHANGE OVER TIME**
- **LGS affects people of ALL RACES AND ETHNICITIES**
- **LGS is a LIFELONG CONDITION for which there is currently no cure**
- **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**
- **Some people are not diagnosed until ADULTHOOD**

Please see Use and Important Safety Information on page 6.
WHAT CAUSES LGS?

The cause of LGS is unknown in about 25% of people diagnosed with LGS—that’s 1 out of 4 diagnosed cases. You may have heard of these cases being referred to as “idiopathic” or “cryptogenic.” However, in the remaining 75% of cases, LGS has an identified cause.

### Known causes of LGS

- Trauma before or during birth
- Infection
- Seizures as an infant (infantile spasms)
- Abnormal brain formation
- Head trauma
- Genetic factors

### 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.

Please see Use and Important Safety Information on page 6.
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.

Please see Use and Important Safety Information on page 6.
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 family member’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

1. An EEG is a snapshot of the brain’s “electrical” activity, but instead of taking a photo of the brain, the EEG records a series of waves.
2. The shape of the waves change based on the activity of the brain when the EEG is taken.

SLOW SPIKE-AND-WAVE PATTERN

3. Unlike normal brain activity that produces a constant flow of very small and consistent waves, spikes are sharp and fast.
4. The dips and waves are much slower than normal waves and repeat with less frequency than a normal EEG.

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

Please see Use and Important Safety Information 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 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

• Do not take ONFI if you have a known allergy to ONFI or its ingredients.

• ONFI can make you sleepy or dizzy, slow your thinking, and make you clumsy which may get better over time. Do not drive, operate heavy machinery, or do other dangerous activities until you know how ONFI affects you. 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 with ONFI 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 of 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 should take ONFI or breast feed. 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 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 seen in patients taking 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.

Please see the full Prescribing Information, Medication Guide, and Instructions for Use, or go to ONFI.com for more information.

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

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