# Identifying and Managing Seizures

Lennox-Gastaut syndrome (LGS) is a complex, rare, and severe type of epilepsy. Learning more about the brain, what happens in the body during a seizure, and the different options for seizure management can help you better understand what's best for your loved one with LGS.

A **seizure** is a physical sign or set of signs of abnormal electrical activity in the brain. To understand what happens during a seizure, it helps to first learn the basic parts of the brain and what each part controls.

# WHAT ARE THE STRUCTURES AND FUNCTIONS OF THE BRAIN?

The brain is one of the largest and most complex organs in the body. Getting to know the structures of the brain and its functions may help you better understand why you see certain types of movements and reactions during a seizure.

- 1 The **frontal lobe** is most often associated with personality/moods, motor function, and decision-making
- 2 The **parietal lobe** plays a role in spatial orientation (knowing where the body is) and in sensing temperature, touch, and taste
- 3 The occipital lobe handles visual information

4 The **cerebellum** is responsible for coordination and balance

- 5 The **brain stem** controls activities like breathing and sleep
- 6 The **temporal lobe** is involved in memory, speech, hearing, and smell

Seizures can happen in any lobe of the brain. Sometimes the seizure activity can spread from one lobe to another, leading to a seizure that involves the whole brain.



Please see Use and Important Safety Information, including Boxed Warning for risks from concomitant use with opioids, on page 4.

#### WHAT HAPPENS IN THE BRAIN DURING A SEIZURE?

Typically, the nerve cells in the brain carry chemical and electrical messages from one part of the body to another in a very orderly and controlled way. But if any number of these nerve cells misfire, the chemical and electrical messages become jumbled and uncontrolled—and this causes seizure symptoms.

The **beginning phase** is called aura, and it's a lot like a warning sign that a seizure is about to start. Some common auras include feeling anxious; getting a headache; or seeing or hearing things that are not really there (hallucinating).

The **middle phase** is called ictal, and this is the actual seizure. The activity you will see depends on the type of seizure your family member has. The different types of seizures are:

- 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

The **last phase**, called post-ictal, is the end of the seizure and the time when the person recovers from the seizure activity. Recovery can be quick, or it may take some time. It's possible for a person to feel confused, agitated, and tired and need to sleep.



As a parent, if you let LGS control your life, it will consume you. You can empower yourself by learning more about LGS and asking questions like, 'What triggers seizures in my child? What helps or decreases them?'

—Dale, father of Adam, who has LGS

#### WHAT ARE SEIZURE TRIGGERS?

For some people with epilepsy, certain situations or activities can make having a seizure more likely. These are called **seizure triggers**. Not everyone with epilepsy has seizure triggers. Yet, for those who do, triggers can vary widely. What triggers a seizure in one person may not affect another.

Some of these triggers impact or reflect what's going on inside the body and may include:

- Lack of sleep or being tired
- Not eating well or missing meals
- Having a fever or being sick
- Feeling stressed or anxious
- Changes in hormone levels (such as during a woman's menstrual cycle)

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#### WHAT ARE SEIZURE TRIGGERS? (Continued)

Other triggers may be situations or activities that are happening outside of the body, in the environment. These types of triggers include:

- Flashing, bright lights or patterns such as from the TV or video games
- Smells or odors
- Certain sounds and loud noises
- Heat and humidity

Some people have also reported that activities such as reading, thinking, writing, consuming caffeine, or drinking alcohol, can also trigger seizures.

# SEIZURE MANAGEMENT: MEDICATION AND BEYOND

From medication to surgery and diet, people with LGS often try a combination of treatments to reduce seizures. It's normal to feel discouraged by ongoing adjustments to the management plan, but it is important to keep striving for the best results possible.

### Medication is often the first step

The first goal in seizure management is often to reduce the number of seizures by using antiepileptic drugs (AEDs). Because people with LGS have many different types of seizures, most people take several different AEDs.

Because medications can cause side effects, it's important to find the balance between seizure reduction and as few side effects as possible.

#### Surgery may be an appropriate option

Surgery may be an option for some people who do not respond to AEDs. One procedure that may be used is a **corpus callosotomy**, which disconnects pathways between parts of the brain to keep seizure activity from spreading. However, this type of surgery does not work on all types of seizures and its effects may not last.

Seizures may also be reduced by implanting a device that sends electrical pulses into or near the brain:

- Vagus nerve stimulation (VNS) uses a device implanted under the skin in the chest to send signals to the vagus nerve, which controls activity between the brain and major internal organs
- **Responsive neurostimulation** uses wires (electrodes) placed in the brain near where the seizures are happening to sense unusual brain activity and send out signals to stop symptoms before they start

Some patients may have seen a decrease in the frequency of their seizures with surgery. There is also the possibility of side effects. Please talk with your doctor to see if surgery may be an appropriate option for your loved one.

### Dietary changes may help

The **ketogenic diet** changes the body's main source of energy from sugar (glucose) to fat. The exact way this diet reduces seizures is unknown, but it is believed to increase the brain's ability to resist seizure activity.

The effect that this diet will have on reducing seizures varies from person to person. To learn more about the ketogenic diet, please speak with your physician or a registered dietitian.



To learn more about LGS and a treatment option, visit ONFI.com.

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#### 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 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 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 <u>Medication Guide</u>; <u>full Prescribing</u> <u>Information, including Boxed Warning for</u> <u>risks from concomitant use with opioids</u>; and <u>Instructions for Use</u>.

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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