



Understanding Lennox-Gastaut Syndrome

Lennox-Gastaut Syndrome (LGS) is a rare epilepsy syndrome typically diagnosed in children between the ages of two and eight. LGS can be linked to many different causes, such as a brain injury or genetic mutation. Children with LGS typically have frequent seizures and many different kinds of seizures. They may also have learning and developmental delays.

When a child is diagnosed with LGS, it's important to work with an epilepsy specialist to set treatment goals and expectations for the future. In general, the goal of LGS treatment is to find a balance between seizure and medication management. In many cases, managing LGS includes minimizing the frequency and severity of seizures while reducing treatment-related side effects. The ultimate goal is to give your child the best quality of life, prioritizing their safety and wellbeing.

Children with LGS often take multiple medications to manage their seizures. It's important to work closely with your doctor and pharmacist to follow the medication instructions and minimize side effects.

As you plan for child's future, share your seizure management plan with your child's teachers, school nurse and other key people involved with your child's care and education. Communication is an important way to make sure your child receives consistent care. Every child has the right to an education, and together you can make sure that he or she has a safe learning environment. The Individuals with Disabilities Education Act (IDEA) website has information and resources that may be helpful as your child prepares for school.

www.sites.ed.gov/idea



Your Team of Health Care Professionals

Raising a child with LGS often has unique challenges. It can be beneficial to draw support from professionals who have experience managing the various aspects care. In addition to a team of epilepsy specialists, you may want to meet with people who can help with your child's developmental, pharmaceutical and nutritional needs. If your child has LGS, it's important to monitor his or her development. A formal assessment of your child's physical and mental abilities is often recommended before he or she starts school. It can be beneficial to have professional help from a physical therapist, an occupational therapist and a speech therapist.

LGS can be difficult to manage. Children with this diagnosis may be on several different medications. It's important to connect with your child's clinical pharmacist for help administering medications, managing side effects and avoiding potential drug interactions.

You may want to connect with a social worker or case manager to help you manage your child's LGS. Case managers coordinate and build bridges between medical professionals, teachers and caregivers. This is important to help ensure that everyone works together to provide the best possible care. They can also help you find resources and connect with other families who are familiar with LGS.

LGS may also affect your child's behavior. If your child is having behavioral issues, a psychologist may be able to help. Your doctor will help you decide if other medical specialists, such as a gastroenterologist or a cardiologist, could be beneficial.



A physical therapist is someone who helps people affected by injury or disease with their movement and exercise therapy.



An occupational therapist helps people learn and participate in everyday activities.



Speech therapists offer training for people with speech or language difficulties.

Helmet Use

If your child has LGS it may be a good idea to talk with your doctor about the need to wear a helmet. Seizures can be unpredictable and severe. A helmet offers protection to help keep your child safe. Children with LGS still enjoy playtime and need fun activities, but they may have additional considerations. Potential restrictions often depend on each unique case of LGS. Talk with your child's epilepsy specialist about how to keep your child safe during playtime.

Living Arrangements

Simple ways to improve home accessibility include adding shower bars and arranging your furniture to have clear walkways. Having your child's bedroom on the ground floor may be helpful for both of you, especially as he or she matures.

Keeping a Journal

Keeping a journal can be an effective tool for people managing LGS. Journals help you track your child's seizures, monitor development and remember milestones in their treatment journey. You may want to share the journal with teachers, caregivers and others to ensure your child's care remains consistent. Important information about medication, emergency contacts and your seizure response plan can all be included in a journal.

Many apps available on your smart phone or tablet can help track this information and quickly alert emergency contacts. Apps can store information about your child's treatment and other resources about the condition.

Medical Alert Bracelets

Medical alert bracelets, necklaces or other jewelry may be a good investment for your child with LGS. Having important medical information readily available can save time in an emergency and ensure that your child receives the best care. Medical alert bracelets come in many different styles, so you can choose the medical ID that works best for your child.

Medication Management

LGS often requires multiple medications to achieve the best outcomes. Keep a detailed list of your child's medications, including which medication to use, the correct dose, how to administer the medicine and other relevant information. Be sure to share this list with your child's school, local physician and other caregivers. Many medications used to treat LGS have side effects. Talk with your child's doctor or pharmacist to help reduce or manage your child's side effects.

Amber Specialty Pharmacy recommends filling all your child's prescriptions at one pharmacy. This allows you to develop a good relationship with your child's pharmacist. It also allows the pharmacist to view the full picture and watch for potential drug interactions. In addition to your child's regular seizure management medication, it's generally recommended that you have rescue medication at your home. Rescue medications are generally meant to provide immediate symptom relief. Talk to your doctor or pharmacist about when and how to properly administer rescue seizure medications.

Developing a Seizure Response Plan

Developing a seizure response plan is a fundamental part of caring for a child with LGS. Seizures are often unpredictable, so it's important to be prepared. Work with your child's epilepsy specialist to develop a seizure response plan that you can share with your local hospital and your child's school.

An epilepsy specialist may not be available to treat seizure emergencies in your hometown. Sharing your child's seizure response plan with your local physicians can help make sure your child gets consistent treatment for his or her LGS. Make sure your child's school or caregiver has a copy of the seizure response plan in case you are not around during your child's seizure event. Consider adding a brief explanation of LGS to your seizure response plan to make sure responders understand the condition.

A seizure response plan should include a detailed list of your child's medication. In a seizure event, you should be able to

Seizure Response Plan continued...

tell emergency responders and hospital staff what medicine your child has already received. Other important information to include in your seizure response plan includes your child's birthday, allergies and emergency contact information for you and your child's epilepsy medical team.



Seizure Response Checklist

- ✓ Your child's name
- ✓ Date of birth
- ✓ Name of epilepsy condition
- ✓ Detailed medication list
- ✓ Emergency contact information
- ✓ Allergies
- ✓ Other medical conditions
- ✓ Contact information for your child's epilepsy specialist
- ✓ General hospital treatment procedures



Amber Specialty Pharmacy is here to help.

We offer guidance and support through our dedicated team of healthcare experts. From the beginning, we help you with the enrollment process and review your insurance coverage. We explore financial assistance opportunities to help you lower your medication costs whenever possible. Our pharmacists review your prescriptions with you - including how to take your medication and manage any side effects. Pharmacists are available 24/7 to assist you when you have questions. Our Registered Nurse and Registered Dietitian offer personalized consultations to assist you with any medically-based questions and nutritional care. We stay in touch with you regularly to remind you when it is time to refill your prescriptions. We are always here to help.

This information is intended for educational purposes only. The material is not a substitute for professional help or medical diagnosis. It is important that you consult a medical professional if this information leads you to believe there is a concern for you or your patient(s). The diagnosis and treatment of all physical and/or psychological disorders requires a trained professional.