Being a Strong Advocate

One of your biggest responsibilities as a parent or caregiver of a loved one with Lennox-Gastaut syndrome (LGS) is to be a strong advocate. The dictionary defines an advocate as one who supports or promotes the interest of another.¹

We’ve learned from caregivers with families like yours that being an effective advocate takes preparation and can be the foundation of a close partnership with the healthcare team supporting your loved one. Read on to learn how some LGS families achieved this goal.

Teaming up

Building an open, trusting relationship with your loved one’s healthcare team can help ensure that he or she gets the best care possible. Research studies have shown that patients can benefit when healthcare providers closely partner with patients and their families.²

Your loved one’s healthcare team may include:

• Pediatric or adult neurologist
• Epileptologist
• Pediatrician or family practice doctor
• Speech therapist, occupational therapist, physical therapist
• Special education teachers, aides, and possibly others

Your job is to head up this team so they can support your loved one and your whole family.

Your “home” team needs to be all on the same page in order to help your family have meaningful communication with your healthcare team. LGS caregivers shared this advice, which we hope will help you.

• Be honest and talk about how each member of your family feels—share your fears and frustrations.
• Don’t give up hope. Keep trying to improve seizure management.
• Take time to care for your own health by eating right, exercising, and doing things that can help you relax.
• Don’t be shy about finding people to talk to and asking for help.

Strengthening Your Team

Caregivers have shared that it takes some work to build a true partnership with your loved one’s healthcare team, but it’s well worth the effort. Here are some things you can do to team up more effectively. Remember, your involvement can help all of you benefit from better communication.² Good communication is important to your healthcare team too.³

1. Get well informed

• Show that you are involved and interested in learning more about LGS.
• Ask about additional treatment options. Then start researching them so that you can have an informed discussion with your loved one’s healthcare provider.
• Ask about the pros and cons and specific side effects of each treatment option and what to do if they occur.

2. Do your homework for every healthcare provider’s visit

• Bring questions about medications and your loved one’s health.
• Write down the answers that the healthcare provider gives you so you can review what was said later.
• Track seizure activity in a journal and take it with you to discuss with your healthcare provider. You can use a paper journal or one that you have downloaded from the computer. Bring video clips too if you can.
• Bring other family members with you to appointments with the neurologist to show that the whole family is in this together.
• Prepare your loved one for each visit. Talk about where you are going. Be positive and make it something to look forward to.

3. Speak up
• Ask direct questions but be respectful.
• Be clear and specific. Avoid asking “why” questions that may put healthcare professionals on the defensive. Ask collaborative questions instead such as, “What do you suggest?” or “What would you do if this were your loved one?”
• Plan what you and your spouse want to say or ask ahead of time. Also agree on who is going to ask which questions. That way you can get through them all during your visit.
• Say what’s on your mind. It’s OK to say you’re confused or that you don’t agree with a treatment plan. If you don’t understand what’s been said, say so. Ask if there’s a video, brochure, or website that could provide helpful information for you.

4. Put yourself in your healthcare provider’s shoes
• Focus on the main reason for the visit and make your point quickly in order to make good use of your healthcare provider’s time.
• Healthcare providers appreciate it when parents make suggestions. But, like any of us, they don’t appreciate demands. Share any research you’ve found, and politely ask for your healthcare provider’s opinion about it.
• Ask follow-up questions. Let your healthcare provider know that you appreciate his or her efforts to help your loved one. But also let your healthcare provider know that you are open to trying other options.
• It’s your right to ask your healthcare provider for a referral to get a second opinion. Once you receive a referral, be sure to request that reports and records be provided back to your primary healthcare provider.

By asking good questions—and sharing your concerns and observations—you can help your healthcare team take better care of your loved one, and this will help your whole family too.

Sharing in the Decision-Making
Being an active partner on your loved one’s healthcare team is one way you can help address the challenges of LGS. Talk to your healthcare provider about the treatment plan for your loved one. Be sure you understand the plan so you can agree on it together. This process is called shared medical decision-making.4
• Your job is to listen closely to the treatment plan your healthcare provider suggests, ask all your questions, and share any concerns you have.
• The healthcare provider needs to explain the treatment plan in words that you can understand while making you feel respected, listened to, and comfortable.

Research has shown that helping healthcare providers, patients, and caregivers communicate more clearly is one of the keys to better healthcare.2 Here are a few tools that can help make that happen:

1. Ask Me 3 is a patient education program created by the National Patient Safety Foundation that encourages patients/caregivers to ask and understand the answers to 3 questions at every visit. Healthcare providers should make sure the answers to these questions are discussed in clear, simple language.5
   • What is my main problem?
   • What do I need to do?
   • Why is it important for me to do this?

Go to http://www.npsf.org/?page=askme3 to learn more.

2. Be proactive and prepared by asking “The 10 Questions You Should Know,” created by the US Department of Health & Human Services’ Agency for Healthcare Research and Quality.3

Go to http://www.ahrq.gov/patients-consumers/patient-involvement/ask-your-doctor/videos/index.html to watch videos of healthcare providers and nurses talking about how these simple questions can help them take better care of you and your loved one. Patient videos describe how asking these questions can help patients be active members of their own healthcare team while preparing them to take better care of themselves too.

Taking care of yourself
Look for opportunities to connect with other LGS caregivers. You can learn from their experiences and gain insights on how to care for yourself while being a strong advocate for your loved one.
**Why is it important for me to do this?**

By building your knowledge and keeping yourself healthy in body and mind, you can be a better advocate for your loved one with LGS. Visit the Helpful Resources section on ONFI.com for more caregiver resources, plus links to social, emotional and financial services you or your loved one may find useful. See the Glossary section of the site to get comfortable with LGS terms and definitions.

**IMPORTANT SAFETY INFORMATION**

**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 your 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.

  Please see the Medication Guide; full Prescribing Information, including Boxed Warning for risks from concomitant use with opioids; 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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To learn more, visit ONFI.com