

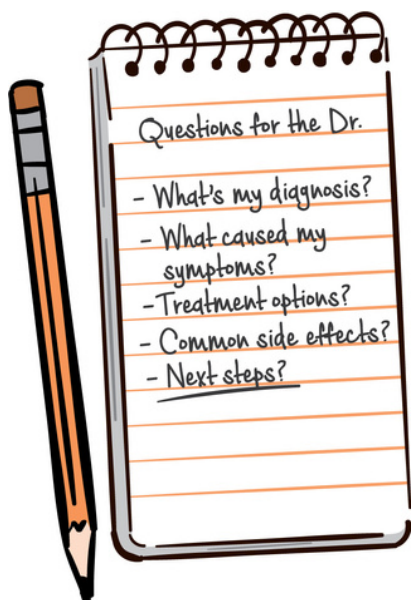
# MAKING THE MOST OF YOUR DOCTOR VISIT

## Preparing for Your Doctor's Visit

You may feel overwhelmed by concern, fear, and anxiety at a doctor's appointment. This is normal. Caregivers are often unable to recall much of what the doctor said. However, it is important to understand the specifics of your loved one's diagnosis.

### Keep these tips in mind:

- Don't be afraid to ask questions to learn about the needs of your loved one. Bring a list of questions with you.
- Bring photos or videos of your loved one's symptoms.
- Take another family member or support person with you.
- If you need translation, interpretation, or other communication support, make this known when scheduling your appointment.
- Ask for any written information about the diagnosis (including medical details). Read this when you get home.
- Ask the doctor to explain the information to other family members. This will allow you to talk about it more at home.
- Ask for information about how the diagnosis will affect your loved one and your day-to-day lives. Ask about services that can help.
- Arrange for the next appointment with your loved one's neurologist. This will allow you to ask further questions once you have digested the information.
- Take time to process the information given to you.



## 5 WAYS to Make the Most of Your DOCTOR VISIT

Being able to **talk with your doctor** is important, especially if you have **health problems** or **concerns**.



**Use these TIPS** to make the most of your doctor visit.

- 1 Prepare for your visit.**  
Be ready to ask three or four questions. Share your symptoms, medicines or vitamins, health habits, and any major life changes.



- 2 Take notes or ask for written materials.**  
Don't be afraid to ask the doctor to repeat or clarify important information.



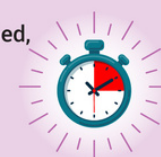
- 3 Make decisions with your doctor that meet your needs.**  
Discuss risks, benefits, and costs of tests and treatments. Ask about other options and preventive things you can do.



- 4 Be sure you are getting the message.**  
If you have trouble hearing, ask your doctor to face you when talking and to speak louder and more clearly.



- 5 Tell the doctor if you feel rushed, worried, or uncomfortable.**  
You can offer to return for a second visit or follow up by phone or email.



Learn more about communicating with your doctor:

<https://www.nia.nih.gov/health/doctor-patient-communication>

**NIH** National Institute on Aging

# FIND A DOCTOR OR LGS COMPREHENSIVE CARE CENTER

## What is a Neurologist?

Neurologists are doctors who specialize in treating diseases of the brain and spinal cord. To become a neurologist in the United States, one must graduate from medical school, then complete a neurology residency for four years.

## What is an Epileptologist?

Epileptologists are neurologists who specialize in caring for those with epilepsy. To become an Epileptologist, one must first become a neurologist and then complete an additional one or two years of epilepsy subspecialty training.

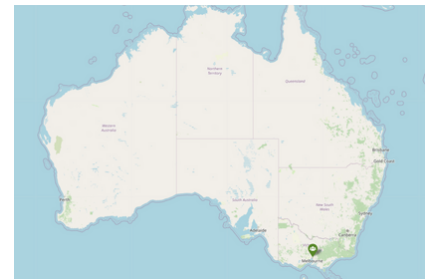
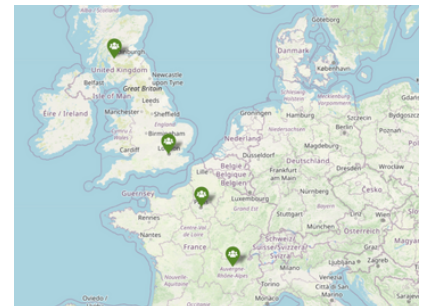
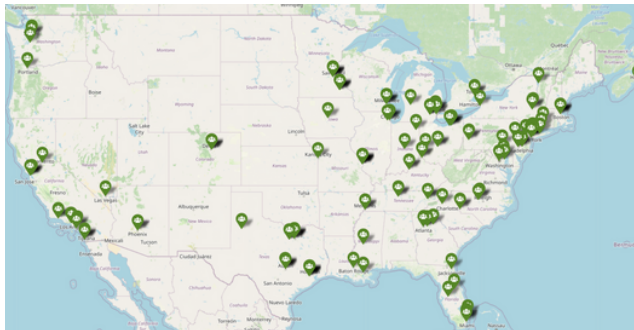
## Find a Doctor

Are you looking for a doctor who knows about LGS?

Check out our list.

Professionals listed on this site have treated patients with Lennox-Gastaut Syndrome and/or related disorders. Many have been recommended by LGS families in our community of support.

Find or Recommend  
a Doctor



## Find an LGS Comprehensive Care Center

Individuals with Lennox-Gastaut Syndrome have complex and lifelong neurological and medical needs that are unique. Often, a local care team is not familiar with LGS or may not have had another patient with this diagnosis. A visit to a Comprehensive Care Center will benefit the patient and family, allowing them to connect with knowledgeable experts and form a bridge to their local care provider when complex issues arise.

To qualify as an LGS Comprehensive Care Center, the center is expected to:

- Offer a multidisciplinary approach for the treatment of Lennox-Gastaut Syndrome
- Have a high concentration of expertise and related resources centered on LGS
- Demonstrate a strong knowledge base and familiarity with LGS
- Commit to furthering clinical knowledge of LGS through collaboration with others, including the LGS Foundation
- Have involvement in studies and/or clinical trials for Lennox-Gastaut Syndrome and are knowledgeable about new treatments and cutting-edge research

Find or Recommend  
a Center



None of the information herein constitutes medical advice, diagnosis, treatment, or recommendation. Always seek the advice of your doctor, or other qualified health professional, with any questions about or related to a medical condition.

# Doctor Visits

Date:		Time:		
Doctor:	Location:	Contact Info:		
Reason(s) for Visit		Questions / Symptoms		
<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>		<hr/> <hr/> <hr/> <hr/> <hr/> <hr/> <hr/>		
Doctor's Comments / Notes				
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Age:	Weight:	Height:	Blood Pressure:	Heart Rate:
Prescription(s)		Prescription(s) Instruction		
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Next Appointment:				

Download  
and Print  
More  
Doctor  
Visit  
Trackers




# MEETING A NEW NEUROLOGIST OR EPILEPTOLOGIST

Are you meeting a new doctor soon? It's important to bring the right information with you when you do.

This toolkit from our friends at the Child Neurology Foundation might help.

In English:










## Child Neurologist New Visit Toolkit

### What your new neurologist needs to know

**DIRECTIONS:** We encourage you to fill out this form prior to your first visit with a neurologist or when visiting a new neurologist. We recommend you print this form out and bring it to the visit with you as well as keep an electronic or paper copy for yourself. It will be a valuable resource to track your child's journey and ensure the best quality of care.

**SECTIONS ON THIS FORM INCLUDE:**

 New Visit Highlights	 Testing & Treatment Summary	 Medication Summary
 Symptoms Summary	 Service Summary	 Seizure Summary
 Prenatal/Birth History		

*Please note, you may not have all this information, and that is OK. Simply provide what information you can.*

Giving your neurologist essential information helps them effectively diagnose and treat your child. Often there are symptoms you do not realize are significant and may be related to your child's condition. We hope this tool helps you and your neurologist collaborate successfully during your visit.

### Additional items to bring to your visit

**IF YOU HAVE ANY OF THE FOLLOWING ITEMS, THEY MAY BE HELPFUL.**

1. A copy of visit notes from your last medical visit related to this condition.
2. Videos of any relevant seizures, movements, behaviors etc.
3. Bring a copy of related test results (labs, genetic tests, imaging etc), if you have electronic copies bring those as well.
4. Copy of most recent neuropsychologist/academic assessment.

### Tips and tricks for your visit


1. **Bring a notebook and pen** so you can take notes.
2. When describing symptoms, **be as specific as possible** and don't exaggerate or downplay symptoms.
3. If your child is able, **encourage them to share their concerns and questions during the visit.** This will help your child feel involved in the process and gives them skills to advocate for themselves.
4. **Invite another adult** to help take notes, offer support, and care for the child so you can focus on the conversation with the doctor.
5. **Don't be afraid to ask a question** if you are confused by what the doctor is saying. You may want to repeat answers back to ensure you've captured everything.
6. Be sure to ask when/if you should **schedule your next visit.**
7. If you are having tests done, if they can't give you results immediately, **ask when you should expect to get the results,** and ensure you authorize sharing results with other members of your child's care team.
8. Before you leave, **make sure you discussed your top concerns and got answers to your top 3 questions.** If the doctor does not have time to answer them during the visit, ask if a nurse can help, or if you should schedule a follow up visit or phone call.
9. **Doctors prefer summaries over specifics.** If they need more details they will ask, so having your information organized can help make answering those questions easier. Consider putting everything into a binder and group visit summaries, test results, treatment summary and medication history in separate sections. If possible, keep in chronological order, with the most recent information first.

Download Toolkit

Get the Toolkit.  
It's available in  
English and  
Spanish!



In Spanish:










## Kit de herramientas para nueva visita con el neurólogo infantil

### ¿Qué necesita conocer su nuevo neurólogo?

**INSTRUCCIONES:** Le aconsejamos que rellene este formulario antes de su primera visita con el neurólogo o cuando visite a un nuevo neurólogo. Le recomendamos que imprima este formulario y lo traiga con usted a la visita, así como también que guarde para usted una copia electrónica o en papel. Este será un recurso valioso para seguir la trayectoria de su niño y para garantizar la mejor calidad de la atención.

**LAS SECCIONES EN ESTE FORMULARIO INCLUYEN:**

 Lo más destacado de la nueva visita	 Resumen de las pruebas y el tratamiento	 Resumen de los medicamentos
 Resumen de los sistemas	 Resumen del servicio	 Resumen de la convulsión
 Historial prenatal/nacimiento		

*Por favor, tenga en cuenta que es posible que usted no tenga toda esta información, y eso está bien. Solo proporcione la información que usted pueda.*

Al suministrarle la información esencial a su neurólogo le ayuda a diagnosticar y tratar con efectividad a su niño. A menudo hay síntomas que usted no considera significativos y que pueden estar relacionados con la afección de su niño. Esperamos que esta herramienta le ayude a usted y a su neurólogo para colaborar exitosamente durante su visita.

### Materiales adicionales que debe traer a su visita

**SI TIENE CUALQUIERA DE LOS SIGUIENTES MATERIALES, PUEDEN SER DE AYUDA.**

1. Una copia de las notas de la última visita médica relacionada con esta afección.
2. Videos de las convulsiones, movimientos, conductas, etc., de importancia.
3. Traiga consigo una copia de los resultados de las pruebas relacionadas con este estado de salud (pruebas de laboratorio, genéticas, imágenes, etc.), si tiene copias electrónicas también trágalas.
4. Copia de las evaluaciones neuropsicológicas/académicas más recientes.

### Consejos y tácticas para su visita

1. Traiga consigo una libreta y un bolígrafo para que pueda tomar notas.
2. Cuando describa los síntomas, sea lo más específico posible y no exagere ni reste importancia a los mismos.
3. Si su niño puede hacerlo, **ánimelo a que comparta sus preocupaciones y preguntas durante la visita.** Esto ayudará a que su niño se sienta involucrado en el proceso y le dará habilidades para defenderse por sí mismo.
4. Invite a otro adulto a que le ayude a tomar notas, le ofrezca apoyo y cuide del niño para que usted pueda centrarse en la conversación con el médico.
5. No tenga temor de hacer preguntas si está confundido por lo que le está diciendo el doctor. Es posible que quiera repetir las respuestas para asegurarse de que ha captado todo.
6. Asegúrese de preguntar cuándo/le debe programar su próxima visita.
7. Si se hacen pruebas, y no le pueden dar los resultados inmediatamente, pregunte cuándo debe esperar recibirlos y asegúrese de dar la autorización para compartir los resultados con otros miembros del equipo de atención de su niño.
8. Antes de marcharse, asegúrese de haber hablado sobre sus principales preocupaciones y de haber obtenido respuestas a sus tres (3) preguntas principales. Si el médico no tiene tiempo para responder las preguntas durante la visita, pregúntele si una enfermera puede ayudarlo o si debe programar una visita o una llamada telefónica de seguimiento.
9. Los médicos prefieren los resúmenes en lugar de los detalles, pero si ellos necesitan más detalles se los pedirán, por lo que tener su información organizada puede facilitar las respuestas a esas preguntas. Considere la posibilidad de poner todo en una carpeta y agrupar los resúmenes de las visitas, los resultados de las pruebas, el resumen del tratamiento y la historia clínica de los medicamentos recetados en secciones separadas. Si es posible, mantenga todo en orden cronológico, con la información más reciente primero.

Download Toolkit

Works great for  
adults with LGS,  
too!



# HOW TO NAVIGATE INSURANCE DENIALS

## I just received an insurance denial. What happens now?

Receiving a coverage denial notice for yourself or your loved one can be stressful, frustrating, time-consuming, and complicated. The first step in managing the denial process is to understand the reason for the denial so you can take steps to try to appeal and resolve it. To help navigate the process, below are some tips on denials, appeals, and where to find more information.

What are some common reasons for denials?

- Review the Explanation of Benefits (EOB), a document from your insurance company that provides information about your claims, or the denial letter to identify the reasoning behind the denial. If you are unsure of the reason for denial, contact your insurance company or healthcare team for an explanation.
- Some common reasons medications are denied include:
  - There may have been a processing error: examples include a missing authorization code, the paperwork was not filed in a timely manner, or payment was not received.
  - There are limits on the amount of medication (dose, quantity, or intervals between doses) you can receive.
  - The insurance company has a medication formulary (a list of medications that it covers) that prefers you use a generic or biosimilar medication rather than the prescribed brand name medication.
  - The medication is non-formulary, meaning it is not covered by your insurance plan.
  - A pre-authorization is required by your insurance company prior to receiving the medication.
  - The insurance company requires you to try and fail another medication(s) first before providing coverage for your prescribed treatment. This is also known as step therapy or fail first.

### Appealing a Denial

- When you file an appeal, you are asking your insurance company to reconsider its decision of denying coverage for a specific medication, treatment, or service. Depending on your insurance plan, there may be a deadline for filing an appeal, so pay attention to timelines for submission. Most of the time, your doctor's office will handle submitting an appeal, but patients have the option to submit an appeal letter as well. Contact your healthcare team for support when writing your appeal letter, as they may have templates or helpful information to include. After you submit, follow up with your insurance company and confirm they received your appeal letter and that the appeal is being processed.
- Helpful tips when writing an appeal letter:
  - When writing your appeal letter, clearly state the purpose is to appeal a decision. Include the policy number, claim number, date of service, and your completed contact information (home address, best phone number, and email address). Be as concise as possible, and include only facts related to the denial reason. Check for spelling and grammar errors. You want to include a letter(s) from your healthcare team documenting your personal LGS journey and showing medical necessity for the denied medication, treatment, or service, as well as copies of any relevant medical records.
  - When sending your letter, be sure to include any of the items below as supportive documentation:
    - A copy of the denial letter or Explanation of Benefits (EOB).
    - A copy of any bills received (if applicable).
    - A copy of the completed appeal form from the insurance company.
    - If needed, an 'Appointment of Representative' Form which allows you to name someone to make medical decisions for you.
    - Letter of medical necessity from your healthcare team and any other supportive letters.
    - Relevant medical records related to the denial.
    - Supportive peer-reviewed journal articles.
- Remember:
  - File appeals in a timely fashion and pay attention to deadlines - there are often short windows during which an appeal can be filed after a claim is denied.
  - Keep all copies of correspondence from your doctor's office and the insurance company.
  - Keep a record of all names/titles of everyone you speak to and any case or authorization numbers.
  - Only send copies of documents and keep all originals on file for reference.