

Transitions in Care for Lennox-Gastaut Syndrome

BEST PRACTICES

Transition is the process of preparing children with chronic illnesses and their families for adult care. For patients with Lennox-Gastaut syndrome (LGS), transition from pediatric to adult care can be particularly challenging. This is due to several factors, including a lack of adult providers, the intellectual disabilities associated with LGS, and the number of financial and legal safeguards that must be in place before the patient reaches adulthood.¹ Transition of care involves a large multidisciplinary team to attend to the varied needs of the patient and their family. At minimum this should include the pediatric neurologist, an experienced social worker, a nursing team, and any health care professionals necessary to care for patient comorbidities or chronic illnesses. Adult nurses and adult neurologists should be added to the team later in the transition process. If placement in a long-term care home, a group home, or a day program is a goal for the patient, then a representative from that program should also be included.²

Figure 1. Best practices for transitions in care in LGS^{1,3,4}

Initiate Transition Process

- Conversations about transition with patients and caregivers should begin early, ideally around 13 years of age
- At this time, set expectations for what long-term care will look like for the patient
- Identify a potential adult provider early in the transition process

Review Testing

- Assess the patient's history of testing and determine if any additional tests are needed
- Testing results should be included in the transition packet along with any additional recommendations for testing

Routine Conversations With Patient and Caregiver

- Check in with the patient and caregiver regularly during the transition process
- Discuss issues of long-term care, education, sexuality, and work and living placements
- Connect families with established support groups where they may find additional support and resources

Discussions with Family and Social Worker

- Conversations about guardianship, health insurance, Social Security, and long-term care should include the family and an experienced social worker
- Decisions about where the patient will live in adulthood need to be made at this time
- If the patient will live in a long-term care facility, identifying this facility and making contact with the staff is important

Managing Long-Term Care and Comorbidities

- Patient should be regularly assessed for comorbidities
- Identify adult providers for any comorbidities to ensure continuity of care
- Providers for routine care, including gynecologists, should be identified

Transition of Care

- The pediatric neurology provider must create a succinct transition document that includes the following: diagnostic summary, seizure types, testing results, medication history, current therapies, and seizure action plan
- This document should be provided to the adult neurology provider prior to transition

RESOURCE FOR YOUR PATIENTS

The C.A.R.E. Guide

The C.A.R.E. Guide is a guidebook to help families when planning long-term care for individuals with rare epilepsies, including LGS: lgsfoundation.org/adult-care-binder

References

1. Camfield PR, Gibson AP, Douglass LM. Strategies for transitioning to adult care for youth with Lennox-Gastaut syndrome and related disorders. *Epilepsia*. 2011;52(Suppl 5):21-27.
2. Auvin S, Arzimanoglou A, Falip M, et al. Refining management strategies for Lennox-Gastaut syndrome: updated algorithms and practical approaches. *Epilepsia Open*. 2025;10(1):85-106.
3. Nabbout R, Molimard A, Scorrano G, et al. Transition from pediatric to adult care system in patients with complex epilepsies: Necker model for transition evaluated on 70 consecutive patients. *Epilepsia*. 2025;66(1):134-147.
4. Childhood Neurology Foundation. *8 Common Principles to Assist with the Transition of Care*. Childhood Neurology Foundation Website. https://www.childneurologyfoundation.org/wp-content/uploads/2020/10/TransInfoGraphicTools_2020-updates.pdf. Accessed March 5, 2025.