

# Transitioning from Pediatric to Adult Health Care:

## A Journey with Lennox-Gastaut Syndrome

This year, an estimated 18 million youth aged 18-21 will be moving from the child to adult health care system.<sup>[i]</sup> When it comes to neurological disorders like Lennox-Gastaut syndrome (LGS) – a rare and often debilitating form of childhood-onset epilepsy<sup>[ii]</sup> – gaps in care often exist during this transition process. In fact, only about 40 percent of patients and their caregivers discuss transitioning with their health care teams.<sup>[iii]</sup>

While transitioning care can be a complicated process for many LGS patients and their caregivers, there are steps to ensure appropriate and consistent care during the transition period. Loretta Boileau, who has had epilepsy most of her life, and is a caregiver for her son, Daniel, who is living with LGS, explains that while the initial journey to find the right pediatric specialists for Daniel wasn't easy. Strong relationships, good communication and advanced preparation helped her make Daniel's transition to adult care a successful one. Loretta recalls her experiences during that critical time and offers tips and advice to help patients and caregivers who are going through the process.

### The Challenges

After Daniel's initial seizures, I had hoped that they would go away. However, as his seizures worsened, I realized that I needed to focus on getting him the best care possible. Once we explored almost all of our options with Daniel's neurologist, we hit a dead end. From this experience, I learned one of my most valuable lessons: it is important to have not only the right kind of health care provider but one that is the right fit for you and your family. Once I realized Daniel needed the attention of a specialist, we met with an epileptologist who referred Daniel to a clinic where he was finally diagnosed with LGS at the age of 10 years old.

One of the challenges that we faced had nothing to do with Daniel's condition at all – it had to do with proximity to appropriate care. In [rural] Minnesota, finding specialists can be challenging. For us that meant a 120 mile journey to the neurologist. Fortunately, Daniel's pediatric and adult neurologist work in the same building.

### My Concerns

My biggest fear was whether or not the adult team would know Daniel's history – if they would have all of his records and review them thoroughly. Daniel's epilepsy is very complex and I was afraid the new team would want to try things we had already ruled out due to inadequate records. I was also concerned about establishing a good relationship with the new health care providers – one based on mutual respect, honesty, good communication and shared goals for Daniel.

### Our Approach

Once Daniel got older and required the attention of an adult health care provider, we worked together to secure an adult team in the same clinic where Daniel was seeing his child neurologist. By doing so, most of Daniel's history was in their records and he was already familiar with the health care providers. In turn, they effectively shared his history and medical case during his transition. While staying within the same clinic isn't an option for all patients, we were grateful it was for us. Either way, it is important to have conversations about transitioning with your child neurologist early on. Addressing the transition in advance allows time for planning and getting to know your new adult health care provider so that you will feel more organized and emotionally prepared when the time comes.

### My Role

I think my principal roles were as information gatherer and advocate. It was essential for me to provide accurate information about all aspects of Daniel's condition, specifically his changing seizure patterns and how he was feeling on a day-to-day basis. As advocate, I found myself learning how to speak up for him to ensure optimal care. While the medical transition process can be difficult, I learned to accept the process as being invaluable to our family because it also represented the potential Daniel has in his life despite living with LGS.

### My Advice

- **Find the right adult health care provider:** Besides a qualified adult health care provider who understands the complexity of the condition, it's imperative to find one that you and your family are comfortable with. Partnering with your child neurologist





and communicating effectively will help ensure you find the appropriate adult health care provider.

- **Plan ahead:** Start looking for your new health care provider well ahead of time and enlist the help of others involved: your current child neurologist, school registered nurse, social worker and other providers may know a good referral. By planning in advance, you will be able to physically and emotionally prepare for and accept the transition.
- **Prepare the paperwork:** Before your first visit, work with your child neurologist and their office staff to compile all of the records you have, including appropriate paperwork, medical summaries and history. It will also be helpful to compile notes from your child's school as well as notes you've taken on your own.
- **Don't tackle it alone:** Through national and local support groups, you can find others who have gone through the process before or who are facing it now. Accepting change can be difficult but know you're not alone; you can help one another through mutual encouragement and sharing advice.
- **Keep current:** Part of being an advocate for the best possible care for your loved one means staying up-to-date on his or her situation. From exactly where in the transitions process you both are, to keeping track of the necessary paperwork and even staying current with the latest in epilepsy and LGS research and care, the advocate role blends knowledge, vigilance and love all into one.

### Transitional Care Across All Forms of Epilepsy

Loretta and Daniel's story has helped many families living with LGS with their journey through the transitions process. But transitional care is not exclusive to LGS. Those living with epilepsy of all forms need to plan for the same transition as they move from pediatric to adult care.

The Child Neurology Foundation (CNF) and Eisai have created new resources aimed at helping those living with epilepsy navigate and simplify the transition from their pediatric neurology team to their adult neurology team. This key transitional phase is responsible for a documented decline in health and health care, and until now people living with epilepsy had little guidance for a successful transition.

The resources, which will be available [later this year], include videos of patients, caregivers and doctors who have experienced a successful transition, infographics that provide actionable steps and other helpful tools that educate patients and caregivers while guiding them through a clear and predictable transition process.

"We've heard from so many neurologists that they see a need for better guidance on how to optimally transition their young patients to adult care," said Amy Brin Miller, Executive Director, CNF. "Now with these new practical resources, designed to help initiate and guide the process early, adolescents, their families and their health care teams can work together for success."

The resources are part of a partnership between CNF and Eisai, which started in 2014 with the development of a consensus statement addressing the role of the neurologist in transitioning adolescents into the adult

**Loretta Boileau** of Brainerd, Minnesota, is both an epilepsy patient and caregiver. While battling her



own epilepsy diagnosis for most of her life, Loretta's son Daniel was diagnosed with Lennox-Gastaut Syndrome (LGS) – a rare and often debilitating form of childhood-onset epilepsy – at the age of 10.

Familiar with the challenges that came with Daniel's diagnosis, Loretta started applying learnings from her personal experience with epilepsy. When it was time for Daniel to transition from pediatric to adult health care, Loretta worked closely with his health care team to ensure a successful conversion. Throughout the process, she learned the importance of anticipating the transition, starting early and partnering closely with Daniel's child neurologist to find the appropriate adult health care specialist.

For Loretta, life has always been a journey. She believes that the challenges one encounters on this journey allow people to grow and make new discoveries about themselves. Through her experiences as both patient and caregiver, she believes these challenges will inspire positive change.

To learn more about Loretta and the transitions of care process, please visit [www.childneurologyfoundation.org](http://www.childneurologyfoundation.org), [www.advancingepilepsycare.com](http://www.advancingepilepsycare.com) or [www.livingwithLGS.com](http://www.livingwithLGS.com)

*DISCLAIMER: Loretta Boileau is a paid spokesperson of Eisai, Inc.*

healthcare system, which was published in *Neurology* last summer. The statement includes eight common principles that define expectations, advise on timing and assign roles to plan for and enable a successful transition.

For additional tools, more information about the epilepsy-specific resources and the transition of care consensus statement, please visit [www.childneurologyfoundation.org/transitions](http://www.childneurologyfoundation.org/transitions) or [www.advancingepilepsycare.com](http://www.advancingepilepsycare.com).

[i] McPheeters M, Davis AM, Taylor JL, Brown RF, Potter SA, Epstein RA. Transition Care for Children with Special Health Needs. Technical Brief No. 15. AHRQ Publication No.14-EHC027-EF. Rockville, MD: Agency for Healthcare Research and Quality. June 2014. [www.effectivehealthcare.ahrq.gov/reports/final.cfm](http://www.effectivehealthcare.ahrq.gov/reports/final.cfm).

[ii] LGS: Epilepsy.com <http://www.epilepsy.com/information/lennox-gastaut-syndrome>

[iii] The National Survey of Children with Special Health Care Needs Chartbook 2005–2006: Core outcomes. Available at: [www.mchb.hrsa.gov/cshcn05/MI/cokmp.pdf](http://www.mchb.hrsa.gov/cshcn05/MI/cokmp.pdf)

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