

# Importance of Patient Advocacy and Caregiver Support Groups for Patients Living With LGS in Shortening Diagnosis Time and Addressing Evolving Needs As Patients Transition Into Adulthood

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## Introduction

- Lennox-Gastaut syndrome (LGS) is a rare, chronic, severe form of childhood-onset epilepsy that persists into adulthood<sup>1,2</sup>
- LGS is characterized by<sup>3</sup>
  - Onset of seizures prior to 18 years, between 1 and 8 years of age, with a peak age of onset of 3-5 years<sup>4-6</sup>
  - Multiple types of drug-resistant seizures including intractable tonic and atypical absence, followed by myoclonic, tonic/atonic "drops," generalized tonic-clonic, and focal seizures<sup>5</sup>
  - Specific EEG abnormalities and cognitive/behavioral impairments
- Cause is sometimes unknown<sup>7</sup>
- Diagnosis may be delayed for decades<sup>3,5</sup>
  - Diagnosis is based on clinical presentation<sup>2</sup>
  - The rarity and variability in LGS clinical presentation may result in under- and mis-diagnoses<sup>5,8</sup>
- LGS is treatment resistant<sup>5</sup>
  - Successful treatment strategies require trial and error<sup>2</sup>
- The elements above contribute to increased caregiver burden, which may be described as overwhelming and can lead to<sup>2,7</sup>:
  - High healthcare costs
  - Increased stress for caregivers and their families
  - Uncertain future

## Methods

- A live, US-based LGS caregiver advisory board was conducted on December 17, 2022, to discuss the LGS patient journey from the caregivers' perspectives
- Eight Caregivers of children and adult people living with LGS were recruited through the LGS Foundation (LGSF) community, health care professionals (HCPs), and Medical Science Liaisons
  - People living with LGS ages ranged from 4 to 25 years
  - Age at diagnosis ranged between 1 and 21 years of age (**Table 1**)

**Table 1. LGS Caregivers Demographics**

	CG1	CG2	CG3	CG4	CG5	CG6	CG7	CG8
<b>U.S. region</b>	SE	W	MW	NW	SE	NE	W	SW
<b>Caregivers' gender</b>	F	F	F	F	F	M	F	F
<b>Age (year), patients' gender</b>	8, M	17, M	8, M	21, F	9, F	7, M	12, M	4, M
<b>Age (year) of diagnosis</b>	2	4-5	3	Within the last year	1	3-4	11	3

CG, caregiver; F, female; M, male; MW, Midwest; NE, Northeast; NW, Northwest; SE, Southeast; SW, Southwest; W, West.

- A discussion guide, supporting visual assets, and supplemental activities including surveys (**Figure 1**), puzzles, and breakout groups were used to facilitate the meeting while key learnings from caregivers were documented
- Caregivers signed a plain language consent as legal guardians of their diagnosed children and adults
- The goals of this advisory board were:
  - To better understand the caregiver experience during LGS diagnosis journey
  - To understand evolving needs of caregivers as their patients age into adulthood
  - To identify treatment decision factors that may address unmet needs of caregivers and their loved ones
  - To solicit insights from the caregivers about patient advocacy and caregiver support group needs

**Figure 1. Caregivers Were Asked to Use One Word to Describe Their Loved Ones**



### Overview

#### QUESTION

How do we help alleviate burden among caregivers of patients living with LGS and provide lay information resources that address barriers to try new therapeutic options?

#### INVESTIGATION

To better identify key issues affecting the needs of caregivers and their loved ones as they progress through the journey of diagnosis, management, and treatment, an advisory board of caregivers was convened

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#### RESULTS

##### Caregiver's Quotes on Their Child's Journey to Diagnosis

**BEFORE**

- Scared
- In denial
- In crisis mode and in the dark
- Overwhelmed and unsure of the future

*"Doctors don't always know what is going on in the beginning and often things can change drastically."*

**AFTER**

- Relief of feelings of stress
- Provided a direction for treatment
- Helped shift expectations
- It's a diagnosis of many
- At diagnosis, no resources or next steps were provided

*"[T]he diagnosis, can feel like a deep rabbit hole, thrown into the deep end."*

#### CONCLUSION

Learning from other caregivers' success stories regarding loved ones' improved quality of life may encourage other caregivers who are afraid to make treatment change decisions to have an open mind in trying new therapeutic options as they continue to advocate for their loved one.

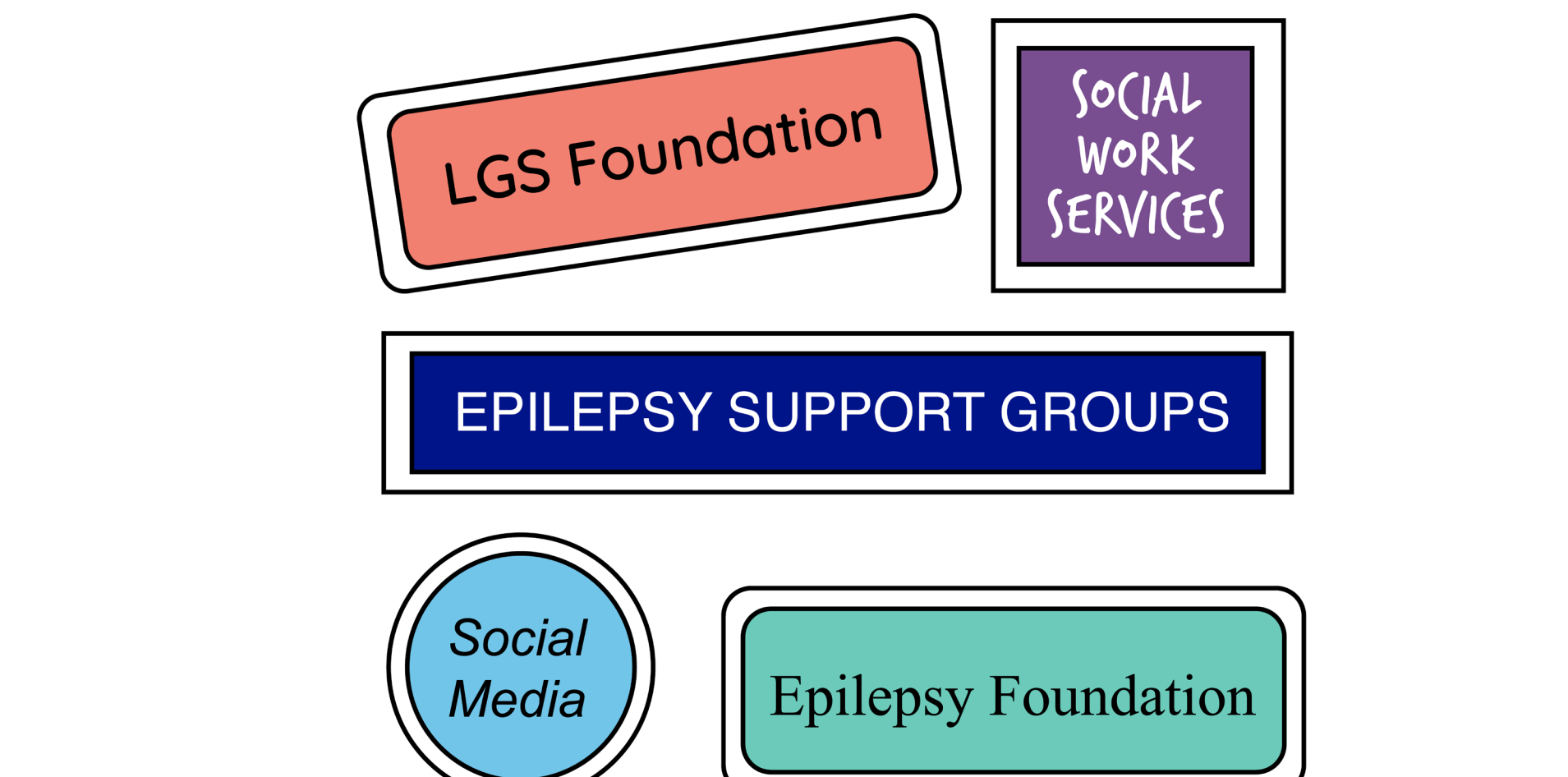
#### Caregivers Described Challenging Interactions With Healthcare Professionals

- Doctors don't always know what is going on in the beginning and often things can change drastically
- It is challenging to find a medical team, putting trust in the medical team is hard
- Doctors often don't know which treatment is going to be the best
- It is difficult to find a doctor that is constantly going to be looking at new research and thinking about how to do better
- Many doctors they see do not seem to understand LGS and think that when they do not see a seizure for a while, the patient is in remission and may remove/want to remove some anti-seizure medications
- Treatment from the healthcare team and the challenges differ based on spoken language, location, race, and economic status
- Doctor turnover is high in the healthcare system--each time, the caregiver must retell the child's story and open old wounds

## Results

- Finding a trustworthy and knowledgeable care team is both a common challenge and essential to improving quality of life
  - Caregivers indicated that they spent time visiting various physicians
  - Physicians frequently adjust children's treatment plans
  - Caregivers navigated multiple misdiagnoses over time
- Caregivers described feeling overwhelmed and uncertain of the future, pending diagnosis
  - A confirmed LGS diagnosis often relieves caregivers' stress, provides a treatment direction, and may address support needs
  - Finding a pediatric neurologist or epileptologist with experience in developmental and epileptic encephalopathies or an epilepsy center of excellence early may shorten time to diagnosis
- Even after diagnosis and therapeutic care, there remains a lack of LGS knowledge among caregivers and often a misalignment of manageable treatment goals between HCPs and caregivers until the right healthcare team with LGS experience is identified
  - Caregivers expressed feeling a great deal of pressure when making treatment change decisions because of the unknowns

**Caregivers expressed their need to contact other parents to share their experiences. CG7 indicated that a matrix of parents with special needs and a place to talk about challenges, solutions, and resources specific to LGS can be comforting/reassuring.**



### A Majority of Caregiver's Loved Ones Take Between 2 and 7 Epilepsy Medications Daily

- Treatment goals vary greatly between pediatric & adult caregivers from initial diagnosis to transitioning to adult care
- Navigating transitional care can be difficult; the healthcare team evolves over time, but trusting instincts is important in finding the best care team
- Considering long-term needs and developing a care plan is overwhelming. Adult caregivers worry about their other children having to take over the primary needs of their LGS loved one
- The healthcare team tries to educate the caregiver, but the amount of new information upon LGS diagnosis may be overwhelming to some (**Figure 2 and 3**)

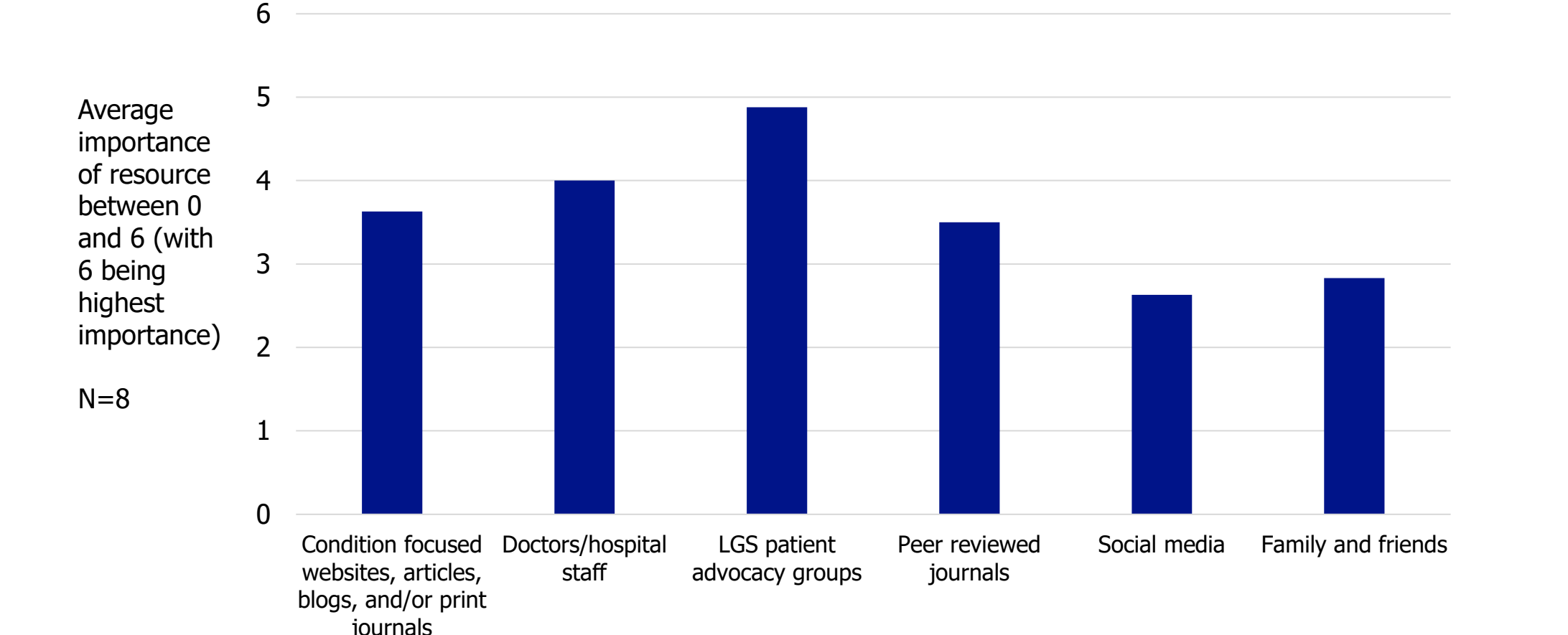
**Figure 2. Caregivers Make Their Own Attempts to Fill the Knowledge Gap and Learn From Various Resources**

#### CAREGIVERS:

- Are frustrated about the **quantity and appropriateness** of LGS information
- Seek information and **advice from the LGS Foundation** ([www.lgsfoundation.org](http://www.lgsfoundation.org)) and Epilepsy Foundation ([www.epilepsy.com/](http://www.epilepsy.com/)), social work services, social media, and Epilepsy support groups
- Express concern about a **lack of Caregiver community** to seek advice and discuss challenges, emotions, impact to quality of life, identify solutions and build helpful resources
- Require a **personalized experience** to bridge the gap in trusted resources
- Articulate how Patient and Caregiver **needs evolve over time** as children grow into adulthood
- Report that developing a **long-term care plan is overwhelming**
- Suggest a **protocol needed for new caregivers** to help navigate finding a care team
- Express **frustration over lack of state resources**, including respite care, to help deal with burnout and medical equipment needs
- Indicate that it is **challenging to adequately care for themselves** because of the constant focus on their children
- One Caregiver shared that she started seeing therapists for **panic attacks and anxiety** which helped shift the blame from themselves and accept reality

- Learning from other caregivers' success stories regarding loved ones' improved quality of life may encourage other caregivers who are afraid to make treatment change decisions to have an open mind in trying new therapeutic options as they continue to advocate for their loved one

**Figure 3. Caregivers Primarily Use LGS Patient Advocacy Groups, Doctors/Hospital Staff, and Condition Focused Websites to Educate Themselves**



**Upon diagnosis, the healthcare team tries to educate the caregiver, but many times the caregiver is overwhelmed by the information. After the initial "data dump", caregivers make their own attempts to fill the knowledge gap and learn as much as possible from every resource.**

## Conclusions

- The totality of the caregiver feedback can be summarized as follows:
  - Caregivers often wait years for a correct diagnosis of their children because of the complexity of an LGS clinical diagnosis
  - Finding a trustworthy and knowledgeable care team is a challenge, yet essential to improving quality of life
  - Earlier diagnosis is significant for patients because earlier intervention and the right medicine can improve outcomes<sup>8</sup>
  - An early diagnosis can reduce caregiver stress and uncertainty through access to LGS support programs and groups, which is critical in the journey
  - Caregivers feel pressure when making treatment change decisions because of the unknowns associated with medication effectiveness and tradeoffs between seizure reduction and side effects
  - A general lack of LGS knowledge and a misalignment of treatment goals between HCPs and caregivers can add additional stress
- LGSF ([www.lgsfoundation.org](http://www.lgsfoundation.org)) provides support, plain language information resources, tips, programs, and research updates that caregivers heavily relied on by caregivers. Shine Forward with LGS ([www.shineforwardwithLGS.com](http://www.shineforwardwithLGS.com)), funded by UCB, is an additional resource that celebrates the strength of the LGS community to support families living with LGS, built by caregivers, for caregivers.
  - HCPs should continue to refer and strongly encourage caregivers to connect with LGSF to support diagnosis education and family well-being
  - Efforts should be made to find peer-to-peer caregiver support groups that supplement the health team with additional support that addresses caregivers and patients' changing needs throughout their lifetime
  - Families living with an LGS diagnosis may benefit from mental health services to help guide the journey and manage stress<sup>9</sup>
- Caregivers & HCPs learn to live with status quo, however, being open to try new therapeutic options may improve seizure and non-seizure outcomes and alleviate the burden for the caregivers

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## DISCLOSURES

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