Unlock Better Sleep for LGS Families: Insights & Practical Tips From More Than 500 Survey Participants

Understanding Sleep Challenges in Lennox-Gastaut Syndrome

for Parents and Caregivers

LGS FOUNDATION
LENNOX GASTAUT SYNDROME

Patient Journeys.

Understanding Sleep Challenges in Lennox-Gastaut Syndrome

Sleep is essential for health, and disruptions can severely impact well-being. For individuals with Lennox-Gastaut Syndrome (LGS), sleep problems are often intensified by frequent nocturnal seizures, medication side effects, and the syndrome's unpredictable nature. These sleep challenges also extend to caregivers, who often face their own sleep deprivation, heightened stress, and anxiety due to the demands of caregiving responsibilities.

To better understand these issues, the LGS Foundation and PatientJourneys.org conducted a comprehensive survey with more than 500 participants, primarily parents of children with LGS. The survey aimed to capture the types and frequency of sleep issues experienced within the community and to shed light on the personal toll on individuals with LGS and their caregivers. Additionally, it gathered valuable insights into the strategies and adjustments caregivers use to improve sleep quality, revealing practical approaches that some families find helpful.

This report provides a summary of the survey results, highlighting the significant impact of LGS on sleep health for both individuals with LGS and their caregivers. It also offers practical tips and suggestions from participants, aiming to support others in managing these persistent challenges and to foster a shared sense of community.

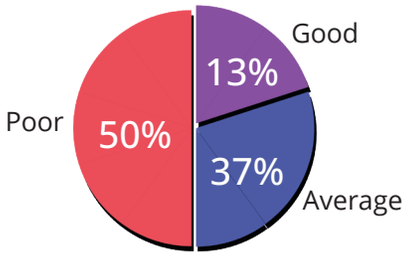
> We're all doing our best. It's heartening to know others are working through the same struggles and finding ways to manage."
>
> **— Survey Participant**

Understanding Sleep Challenges in Lennox-Gastaut Syndrome

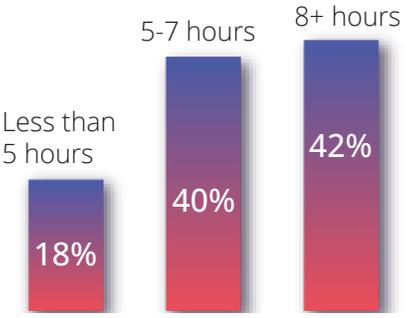
Key Findings: Sleep Quality for Individuals With LGS

87% of respondents state the person with LGS experiences poor to average quality of sleep; approximately half state that the quality of sleep is poor.

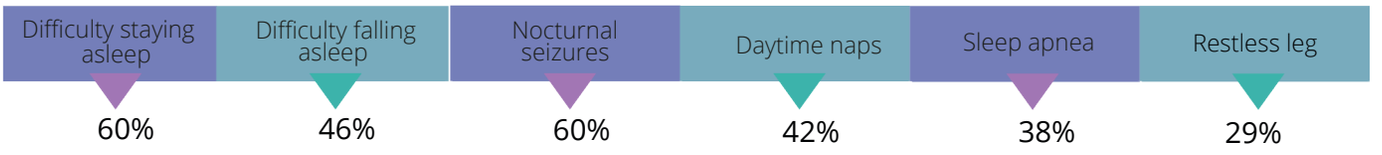
Sleep Quality



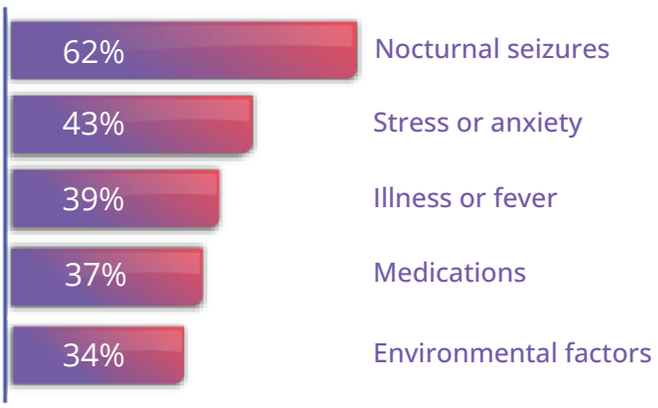
Hours of Sleep per Night



Individuals with LGS face multiple sleep issues



Factors that worsen sleep-related issues



Poor Seizure Control Is Linked to Greater Sleep Issues

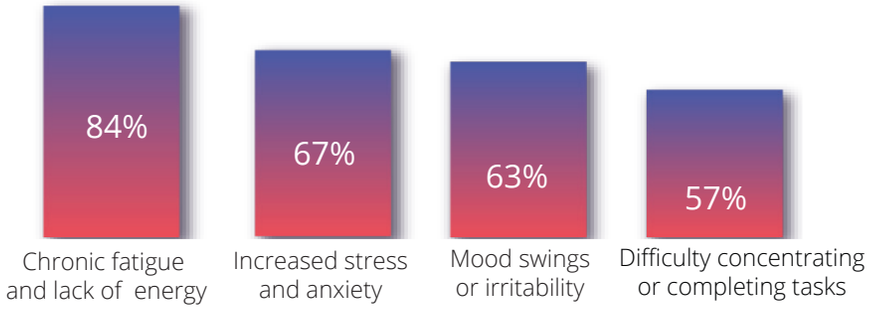
Those experiencing more than 20 seizures per month report increased sleep-related issues, including:

- Difficulty falling/staying asleep
- Sleep apnea
- Nocturnal seizures
- Bedwetting
- Restless leg
- Daytime napping

Key Findings: Caregivers' Sleep Quality

90% state that their own sleep is disturbed; for approximately **40%**, this occurs on a nightly basis.

Sleep disruptions impact overall well-being



43% of respondents report co-sleeping to monitor their loved one. The majority do so 5 or more times a week.

Practical Tips for Improving Sleep

While the survey highlighted numerous challenges, it also provided valuable suggestions from participants on managing sleep issues. Here are a few practical tips and strategies that caregivers and patients have found helpful.

Ideas to Improve Your Loved One's Sleep

Implement a Pre-Sleep Routine

Practice relaxation techniques like deep breathing, meditation, or gentle yoga before bed. Include calming activities and maintain a consistent pre-sleep routine.

Create a Comforting Sleep Environment

Beyond the obvious dark and quiet room, use weighted blankets, sleep music, mood lighting, blackout curtains, and adjust room temperature. Control sounds with white noise or natural sounds using smart devices.

Make Nutritional Adjustments

Adjust meal times and contents, reducing sugar intake in the evening and increasing foods that promote sleep, such as those high in magnesium or tryptophan.

Ideas to Improve Your Sleep

Utilize Respite Care and Night Nurses

Utilize respite care providers or night nurses to take over caregiving duties during the night.

Take Short Naps During the Day

Take short naps when possible during the day to make up for lost sleep at night.

Embrace Technology

Consider video monitors or seizure alarms to reduce the need for constant physical presence.

Reflections on Sleep Challenges: Insights and Lessons for LGS Families

Sleep is fundamental to health and well-being, providing essential support for physical, emotional, and cognitive functions. For individuals with seizure disorders like Lennox-Gastaut Syndrome (LGS), sleep plays an especially critical role, as poor sleep health can exacerbate seizure activity and hinder effective daily functioning. The importance of sleep health extends to caregivers as well, who often shoulder significant nighttime responsibilities to ensure their loved one's safety. Understanding the unique sleep challenges for both individuals with LGS and their caregivers is crucial for enhancing quality of life in this community.

Findings from our survey indicate that sleep health for individuals with LGS is profoundly impacted by nocturnal seizures, difficulty falling and staying asleep, and other factors related to their condition. Nearly 87% of caregivers report that their loved one with LGS experiences poor to average sleep quality, with about half rating it as "poor." These sleep disturbances are exacerbated by high seizure frequencies, with many individuals experiencing more than 20 seizures per month, which in turn disrupts any sleep patterns that might be established. Such frequent interruptions can hinder overall health, daily activities, and seizure management for those with LGS.

> Sleep feels like a constant battle. Even when my loved one with LGS finally rests, I'm awake, wondering if a seizure will disrupt the night."
>
> **— Survey Participant**

For caregivers, sleep health is also a major concern. Roughly 40% report nightly sleep disruptions, often from the need to monitor or respond to seizures, which leads to chronic fatigue and stress. Many caregivers resort to co-sleeping with their loved ones to be readily available for nighttime care, but this arrangement often compromises their own rest. The emotional toll of disrupted sleep is considerable, with common symptoms like anxiety, irritability, and difficulty concentrating that affect not only personal health but also the ability to effectively support their loved ones with LGS.

To address these challenges, caregivers have shared strategies that provide some relief. Establishing a consistent bedtime routine, optimizing the sleep environment with tools like white noise machines and blackout curtains, and managing nighttime caregiving with respite support where possible are common approaches. Despite their efforts, many caregivers express a need for additional resources, support, and research to better understand and manage the complex relationship between sleep and seizures in the LGS community.

> We're trying new routines and tools each day. It's a journey, but small improvements in sleep make a big difference—for both of us."
>
> **— Survey Participant**

Voices of Resilience: Insights and Experience

We extend our heartfelt gratitude to the more than 500 caregivers who shared their personal experiences and insights in this survey. Your voices help paint a clearer picture of the unique sleep challenges faced by individuals with LGS and their loved ones who dedicate their lives to caring for these very special people. By sharing your struggles, strategies, and hopes, you're not only fostering understanding within the LGS community but also helping others know they're not alone in this journey. We hope these quotes offer connection, strength, and practical ideas to support better sleep health for all.

"Knowing that others in the **LGS community** struggle with similar sleep issues has helped me feel less alone"

"**Sleep** is an ongoing challenge for us, but I find comfort knowing I'm not the only one up at night, doing the best I can."

"I never thought **small changes** like adjusting room temperature would help, but it made a ***difference.***"

"We've tried a **bedtime routine**, sensory-friendly sheets, and even calming music. Each effort shows we're doing everything we can."

"**Co-sleeping** with my child isn't easy, but it helps me rest a little easier knowing I'm close if they need me."

"Some nights feel impossible, but seeing others **find solutions** gives me hope that we can too."

"We tried **white noise machines** and blackout curtains. It's not a perfect solution, but it's given us a few extra hours of rest."

"It's hard to balance sleep and **seizure control**, but each small step we take feels like a victory."

"It's a journey. I'm grateful for every bit of advice that helps us get through the night."

We wish to thank Jazz Pharmaceuticals for sponsoring this important survey.

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