



Dear Friends & Family Members of LGS Caregivers,

The life of a caregiver can be complex and lonely. Friends and family are often at a loss for how they can best support us, as our main role is that of caregiver. To that end, we would like to share a bit about what caring for someone with LGS looks like. While it's not easy to explain in depth, we believe it's important for you to understand some key things so you can offer your support, compassion, and patience in ways that are truly helpful.

Caregivers often face a lot of social isolation. It's hard to be apart from the person we care for, and even harder to feel like a support system outside of our immediate family can exist. One way to help us stay connected without overwhelming us is to visit our home instead of asking us to travel to yours. This can make a huge difference, offering our family a chance to be a part of our community of friends and family members, even if only for a short time. Simply visiting, talking, and being together can be incredibly meaningful.

Another important thing to consider is taking the time to learn about LGS, from the various seizure types to the challenges that families face beyond just the seizures, such as behavioral and sleep issues. Knowing what the seizures of an individual with LGS look like or what other challenges may exist can allow you to assist in a crisis and respond safely and appropriately. If assistance is ever needed, it would be such a relief to know that others are equipped to help when needed. This knowledge can ease a lot of worries and provide comfort.

It's also helpful to know that the caregiver may frequently cancel plans or step back from commitments. Seizures and other health challenges can arise unpredictably, and often nothing can be done to prevent them. These moments can be exhausting and overwhelming, but they are part of the reality faced every day. We hope you understand if the need to back out of something at the last minute occurs. If you sense the caregiver feels frustrated or guilty about this, please be understanding and reassure them that you support their decision.

Lastly, we would ask you to please respect any dietary needs of the person with LGS. Many individuals with LGS are on strict, medically supervised diets, such as a ketogenic or modified Atkins diet. These diets are crucial in helping to manage seizures. Sometimes, it may be inconvenient, but it's important to follow these guidelines. When you're hosting meals or events, it can be a great comfort to the caregiver to know that their loved one's dietary restrictions are being respected.

Caring for someone with LGS can feel incredibly isolating and challenging, but having supportive, understanding friends and family can make all the difference. The hope is these suggestions will provide a glimpse into what we're managing daily and how you can be a positive force in making life a little easier for both the caregiver and the person living with LGS.

Thank you for taking the time to read this. Your understanding and support mean the world to us.

With Love,

Our LGS Family

