

LGS: A DAD'S GUIDE

A PROGRAM BY LGSTOGETHER.COM

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The Dads:



Mark, father of adult daughter, Micaela



Jeff, father of adult son, Dan



Alex, father of teenage son, Theo



David, father of young daughter, Spencer

LIVING WITH LGS: FROM ONE DAD TO ANOTHER



THE CRUSHING BLOW OF AN LGS DIAGNOSIS

Nothing could have prepared Jeff for the overwhelming emotions he felt when his only son Dan was diagnosed with the severe form of epilepsy known as Lennox-Gastaut syndrome, or LGS, at the age of 5.

"I was crushed," Jeff recalls. "I thought about what we were going to do. Are we going to be able to play golf together, go fishing, or go hunting—you know, do all those things that a father and son do?" he said.

In spite of this, Jeff and his wife Karen vowed to do everything they could to make sure Dan's childhood was as happy, healthy, and safe as possible. However, as a father, Jeff wanted to do more.

Like Jeff, Alex says that he too was devastated when his son Theo was diagnosed with LGS. Not only did he struggle to come to terms with Theo's unknown prognosis, but also with his feelings of powerlessness.

"You always think you can protect your children and that you could do anything for them," he says. "But in that situation, you realize that you are helpless."

Mark, whose 29-year-old daughter Micaela also has LGS, can certainly relate. "Being her dad, you know, I want to be the protector," he said.



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FINDING STRENGTH

Although no two fathers react to their child's LGS diagnosis in the same way, one thing is certain: their emotions—be they denial, anger, grief, or others—are powerful. In fact, research suggests that fathers may be affected even more deeply than mothers.¹

However, with time and understanding, some fathers have been able to regain a sense of control. Both Alex and Jeff ultimately found comfort in their sons' LGS diagnosis because it provided a reference point in knowing how best to help.

"Any information you get gives you better understanding of where you can go for resources, what you can think about for his future, and then prepare, you know, for what might be ahead," said Alex.

As for Jeff, "With the LGS diagnosis, now we had a goal that we were going to work toward—to try to make Dan happy and safe and keep our family together as a whole," he said.

Getting an official LGS diagnosis also allows fathers to connect with other families who share their experiences—both the struggles and the joys of raising a child with LGS.

David who has a 9-year-old daughter with LGS shared this: "Prior to our daughter's LGS diagnosis, we sought support from other families in our community who had children with autism, Down syndrome, and other special needs—but no one who had actually walked in our shoes."

Although connecting with these families provided much-needed support, they never quite understood the challenges of an LGS diagnosis. "Now that we have the LGS Foundation and the community it provides, I think we found that direct connection we had been looking for," David said.



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A SHARED EXPERIENCE

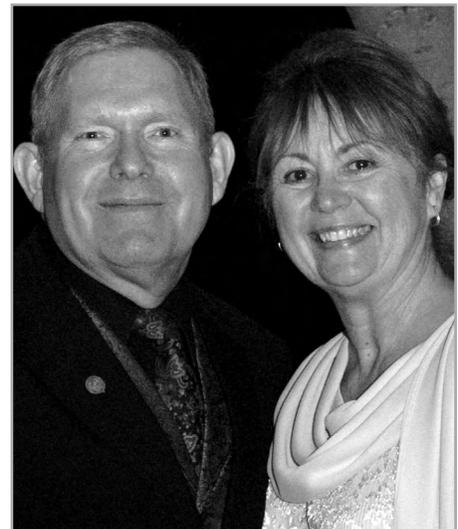
Like most chronic illnesses, LGS not only shapes the lives of those living with the disease, but that of the entire family.

Jeff acknowledges that his daughter Jess, who is only two years younger than Dan, has felt the effects of living as a sibling to a brother with LGS. So, for Jeff and his wife, making Jess feel as loved and special as her brother is a priority.

"We really try to make a special time for her, whether it's just the three of us or sometimes family time all together to make sure that she feels just as much as part of the family as Dan is," Jeff said.

Equally important for fathers, adds Mark, is making an effort to nurture his marriage. "You don't have a lot of moments other than late at night when you can get together with your wife to talk or visit because you always have to be there for someone else," he said. "Sometimes taking just a few minutes each morning or before bed to check in and talk about each other's days can keep the connection strong."

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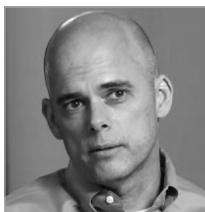
Mark, father of adult daughter, Micaela



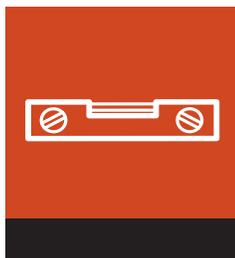
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THE NEW NORMAL

When Alex begins to make his way across the room and lets out a playful growl, a smile spreads across Theo's face. He may not be able to speak, but his eruption of giggles can only mean one thing—he's ready to rumble. Their special form of roughhousing is a sort of father-son bonding Alex had feared might

be impossible.

"He may be limited, but he's still a boy, and he loves that kind of thing," says Alex.

Adjusting to life with LGS can be difficult. However, most fathers say that as they learn to let go of expectations they had for themselves or their children, it does get easier.

For David that meant letting go of the "white-picket-fence version of what we thought parenthood would be."

"It took awhile for us to come to grips with the fact that it's not going to reverse itself and that it's not going to be like a positive turn of events where something would magically clear it up," he said.

One coping strategy many of the dad's have found particularly empowering is focusing on the little things. For Jeff, that's taking Dan for a car ride with the window down. For David, it's watching Spencer do her "happy dance" and celebrating her achievements, no matter how small they may seem.

"There's a time as a father where you have to realize that there are things you're not going to be able to do," says Jeff. "It doesn't mean that you can't try to do new things—whether it's ride a bike or play basketball or go for a ride or go for a hike, whatever it might be—but you need to let your son or your daughter with LGS show you the way."



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TIPS FOR DADS

How do other fathers cope and move forward? Here are a few things we've heard:

 <p>ACCEPT HOW YOU FEEL You can't just pretend everything is OK. Anger. Fear. Frustration. They're all normal feelings to have. Accepting and working through them is an important part of coping.</p>	 <p>TALK IT OUT Whether in person or online, talk to other fathers or families who have a child with LGS. LGSTogether.com is a great way to get connected!</p>
 <p>DIVIDE AND CONQUER You don't have to go it alone. Caring for a child with LGS takes a team effort. Look for ways that friends, family, neighbors, and community members can support you and your child—most people will lend a hand if you suggest specific things they can do to help.</p>	 <p>KEEP THE LOVE ALIVE It's not always easy to find time, but make the extra effort to take your spouse to dinner or get together with your friends. You'll be amazed at how recharged you feel when you connect with other people you love and who support you.</p>
 <p>FIND AN OUTLET Remember to take some time for yourself, too. No matter how rewarding it is to care for a child with LGS, it can also be exhausting, stressful, and emotionally depleting. Making time to rest, relax, and recharge is a necessity, not a luxury. If you're able, physical activities are an especially good way to blow off steam and clear your head.</p>	

REFERENCE:

1. Lamb M.E., Laumann Billings M.A., 1997. Fathers of children with special needs. In M.E. Lamb (Ed.), *The role of the father in child development*, 3rd edition. New York: Wiley.



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