

# What Helps Parents Help Kids?

## One Mom Reflects on Caregiving for Children with Epilepsy

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When Lynn Szkoda posted her very first message about her daughter Ally to the Epilepsy Foundation's "Parents Helping Parents" online forum, she had no idea what kind of response she would get.

"I didn't find the forum until a year after Ally's diagnosis, when I was beside myself looking for certain foods to start the ketogenic diet. To post and walk away and then go back and find 10 responses was overwhelming! I was no longer alone!"

The need to feel that you are not alone is commonly expressed by parents and other caregivers of children with epilepsy. The Epilepsy Foundation estimates that there are more than 3 million people with epilepsy in the United States, 300,000 of whom are children under the age of 14. Twenty-five percent of them experience persistent seizures despite the treatments they receive, and therefore usually require some kind of regular assistance from a parent or other caregiver. If each one of those 25 percent had only one caregiver—and most have two parents and a host of other relatives providing care—

that's at least 75,000 caregivers, many of whom feel that they're in it alone.

But they're not. Caregiving is becoming more and more common in the United States. According to the National Family Caregivers Association (NFCA), one in five adults in America serves as a family caregiver. These 50 million Americans provide a vast array of nursing, transportation, chore assistance, financial help, homemaking and other services to loved ones who have a chronic disorder or disability, are elderly or have other special needs. The value of these "free" services is conservatively estimated to be \$306 billion annually.

Of course, Lynn Szkoda doesn't even think of herself as a caregiver. "I'm just a parent and parents do what needs to be done."



Allyse Lynn Szkoda, of East Hampton, Conn., had the honor of meeting Representative Rosa L. DeLauro (D-Conn.) at the 12th annual Public Policy Institute.

### Doing What Needs To Be Done

Just what does a caregiver for a child with epilepsy do? There's no set job description because there are many different kinds of seizures and every child is unique. The job involves the usual exhausting litany of daily parenting tasks, from cooking dinner and supervising math homework to buying last-minute birthday presents and driving to baseball practice. Plus, it involves a variety of special responsibilities related to the child's epilepsy.

Some of the typical tasks include:

- providing seizure management and basic first aid to keep a child safe during his or her seizures
- giving medication, often several different types that must be given several times per day at precise dosages
- tracking medications and their side effects to find a combination that achieves the greatest level of control, which is often a lengthy, trial-and-error process that can take years
- keeping accurate and lengthy medical records
- serving as the primary liaison with the child's doctor
- navigating complex and often confusing medical insurance systems
- providing transportation to and from medical appointments
- working with the child's teacher, school nurse, principal and others to ensure that the school is properly prepared to respond to the child's epilepsy
- educating friends, classmates, family members and others about epilepsy
- helping the child maintain a positive sense of self-esteem

For parents whose children are on the ketogenic diet, the responsibilities are even greater. Parents must be careful not to allow the child to eat anything—even cookie crumbs or toothpaste—that isn't on the diet or hasn't been pre-measured or pre-weighed.

### All This and A Job, Too?

Many parents of children with epilepsy work outside the home, but have to adjust their work schedules to care for their children. In fact, the NFCA notes that 6 out of 10 family caregivers who are employed alter their work life (and consequently their family's financial status) by cutting their hours or taking unpaid leave to meet their caregiving responsibilities. In 2000, the typical working family caregiver lost \$109 per day in wages and health benefits due to the need to provide full-time care to a loved one at home.

Lynn, who formerly worked full time as an engineer for a construction company, now works 10 to 20 hours per week with no benefits. "I'm lucky enough to have a flexible work place and a husband with good health insurance," she explains. "I literally have had to call into work and say that I can't come in because Ally is seizing and I honestly have no idea when it will stop for me to get into the office. I can check my work e-mail from home and they know that they can call me. My husband also uses Family Medical Leave Act time to attend all of Ally's doctor's appointments and to be there for scary things like sedated MRIs and blood draws. We would love for me to be able to work full time now that our kids are older, but Ally can't really be left alone yet."

### Care for the Caregiver

When asked what helps her help Ally, Lynn can't say enough about the support the other parents in the online forum have given her. "The forum is always open—you'd be surprised at the 3 a.m. posts—and you don't need a babysitter to access it!" Lack of child care, she noted, is a major barrier to joining support groups in her local community. She wouldn't be able to leave Ally with anyone in order to attend the meetings. The online forum solves this problem for her.

She also finds that local support groups don't offer enough people whose issues are similar to her own. "At our local support group, there was a nice couple whose daughter just found out she had epilepsy as she was leaving for college. Her experiences are very different from Ally's. That's not much of a support system. Online, there is such a large pool of people in all different circumstances who can tell you what has worked for them. It's a family."

The support of these online friends has made a world of difference to her. "I can't believe that I didn't have that support system for the first year after Ally's diagnosis," Lynn reflected. "I had to completely rely on my husband for support that first year and that was too much pressure on both of us. My mom loves Ally very much, but she's like any grandmother. She would just cry. That wasn't that helpful! Now, I'll post a message to the forum about a medication we're thinking about trying and get feedback from other parents who have been there. Each child is like

its own personal chemistry lab; there are no two cases that are alike. You have to try different options to see what will work. You can benchmark what you're doing against what other parents in the forum have tried," she explained. "Plus, other parents have different skills and talents. Some are excellent researchers. They will find and share articles. Others will just give you a hug when you need one."

Parents of other children with epilepsy can be more of a support network than lifelong friends who just don't "get it." "My friends will ask, 'How's Ally?'" Lynn noted, "and we have to say, 'The same,' or 'Only three seizures last night.' They're impatient. They want to know when this is going to go away."

"Recently, some friends and I took our children swimming at a lake," she recounted. "My friends wanted to stand around and talk. I was thinking, 'I'm going to talk to you, but I can't look at you. I've got to keep my eyes on Ally in the water.' I couldn't concentrate on what they were saying because I was so focused on Ally. I thought, 'Gee, couldn't you get your kids to swim closer so that Ally's not up to her nose in the water?'"

Other things separate both Ally and Lynn from their old friends. Sleepovers are out. Fireworks are out. "When Ally was on the ketogenic diet, we dropped off the face of the earth. My husband and son could go out places, but Ally and I stayed home for a year. After a while, people don't call you anymore.

They don't mean anything by it, but that's just the way it is."

### Leaving the House

Lynn believes that most parents of kids with epilepsy need occasional respite care, but it's rarely available. Now that her daughter's no longer on the ketogenic diet, her own need for a break has somewhat diminished; it's easier for her to leave the house for short periods of time. "Ally's fairly well managed now, and her older brother likes to babysit, so if my husband and I both need to leave the house, we can. But one of us always comes home to give Ally her medication. She absolutely has to take it at the proper time and that's too much responsibility to leave on my son."

Lynn has also found a great deal of support from her new church community. "The last time we went through a bad time with Ally's medication, I had very little support. Now, if I went through a bad time, I wouldn't have to cook. People would be there for us. Next time, I'll be smarter about asking for help."

Visit the Foundation's online forums at [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org).

The Lifespan Respite Care Act recently passed the House and Senate and is expected to be signed by the president before the end of the calendar year. The bill authorizes competitive grants to states to make quality respite available and accessible to family caregivers, regardless of age, disability, or family situation. Respite can help provide the relief necessary for caregivers to maintain their own health, strengthen families and avoid out-of-home placements. The Foundation worked diligently to ensure passage of this bill.