

Family Strategies for Understanding and Coping with the Impact of Epilepsy

by Linda Landreth-Harris, MSW



I am the mother of a young adult who has lived with the daily challenges of generalized epilepsy since the age of six. Despite multiple combinations of anticonvulsant medications, the vagus nerve stimulator, and the ketogenic diet, her epilepsy remains difficult to control. No one understands the quest for knowledge better than other parents when their child receives the diagnosis of epilepsy. Because there is no way to prepare families for living with and caring for a child with epilepsy, the purpose of this article is to share the knowledge and experience I have acquired over the course of my daughter's journey from a variety of caring epilepsy professionals, young persons with epilepsy, and their families; moreover, to encourage others and to offer hope.

Life Goes On for Your Child

One of the challenges facing the family of a child who has difficult-to-control epilepsy is going on with everyday life. Moving forward is not an easy task. It may be hardest during times of stress: when you learn that your child has epilepsy, when your child is in the hospital, during an episode of breakthrough seizures, or when your child is experiencing the side effects of treatment. Even when treatment is going well, epilepsy can still affect each and every member of your family. When your child enters the hospital or goes for treatments, each member has to adjust in some way, family members may be apart, days of work may be missed, siblings may feel left out; everyone may be worried and tense.

One of the challenges facing the family of a child who has difficult-to-control epilepsy is going on with everyday life. Moving forward is not an easy task.

Despite all this, family life does go on; brothers and sisters have school and activities; parents have jobs. Juggling everyday activities and responsibilities can sometimes be overwhelming. Remember that you are not alone! Help can be gained from many sources, such as the treatment team, which sometimes includes a social worker who can help you in dealing with your child's unique needs, other parents of children with epilepsy, epilepsy symposiums, children's summer camps, and family weekend retreats. The information within this article may be helpful for you, your child, other children in your family, your extended family, and friends.

Before and after the first seizure, your child has the same needs as other youngsters; going to school, having friends, and enjoying everyday activities of life. You can help meet these needs by letting your child live as normal a life as possible. Some activities, however, may need to be adjusted due to safety concerns; help your child explore new hobbies and interests.

School and Friends

Encourage your child to stay in touch with friends; keeping contact is easier if your child can continue to go to school while being diagnosed and treated, but staying in

school is sometimes not possible. If time off from school is needed, it is often best for your child to return to school as soon as possible. Children need and like to be with others their own age; keeping up with schoolwork empowers them and helps them to feel good about themselves. Some epilepsy agencies and foundations offer back-to-school programs, which may help children and classmates understand seizures and know what to expect. Ask them to help your child. Such programs send trained individuals to the child's classroom to talk about the child's seizures and treatment with classmates and teachers. Children with epilepsy often worry about how their friends and classmates will behave towards them; while many students are accepting, they may still have questions. Help your child to think of ways to answer questions and to tell friends and classmates that they cannot "catch" epilepsy. Your child needs to know that many people, including children, are uneasy about seizures; these people may act differently or say hurtful or wrong things that can have long-lasting impact.

You may want to talk with your child's teachers and school nurse about your child's seizure type, treatment, days missed, and any needed changes in accommodations for

school lessons, medications needed during school hours, or emergency seizure plans. You and your family, the doctor, or members of the treatment team can explain your child's medical condition and answer questions. Focus on finding solutions; not highlighting problems. Teachers and other school staff may want to use this information to talk with the other students about what to expect. If your child cannot return to school for a temporary period of time, a home tutor may be available through the school system to help your child keep up with studies, making it easier to return to school.

Family Coping Strategies

To help your child and his or her siblings deal with fears and feelings, you may consider:

- Say "I love you" often.
- Assure your children that seizures and treatment are not punishments.
- Encourage your child or children to talk about seizures.
- Ask your children questions to get the conversation started. Family talks can help everyone feel less worried; talking helps the whole family cope with seizures together.
- Tell your child that it is okay sometimes to feel sad or angry. Help them put their feelings into perspective; look for healthy alternatives to express feelings of anger and sadness, then let it go.
- Encourage activities to help your child feel more relaxed. Drawing, playing with puppets, and role-playing may help younger children feel better. For older kids: yoga,

journaling, painting, music, positive self talk, and deep breathing techniques.



In addition, setting limits for behavior and activities is important and even comforting to your child; it is helpful to remember that children, like adults, have good days and bad days. Help your child feel part of normal life:

- Allow your child to make choices as long as they do not cause interference with their treatment.
- Help your children take responsibility for taking their medications; learn their correct doses, names of meds, and seizure types (age appropriate). During doctor visits is a great time to practice this skill with the medical team; most of them will be supportive in this initiative. Create a "seizure fact sheet" together with your child to present to their babysitter, coach, teacher, school nurse, or medical provider when you are not present.
- Watch your child take daily meds; praise them for it. The peace of mind this provides is priceless.

- Maintain consistent rules and level of discipline.
- Ask your child to continue doing regular chores around the house.

Supporting Your Child

Like you, your child is likely to feel uncertain, worried, and afraid at times, but he or she may find it hard to talk about these fears and may behave differently than usual. For example, your child may become loud or bossy, be quieter than usual, have nightmares, have changes in eating habits, not do as well in school, or revert to earlier behaviors. These common behavior changes are just a few of the ones you may see. You may want to talk about such changes with the doctor, nurse, social worker, teachers, and school counselor, who have had similar experiences—in order to both learn from them and to sensitize them to your child's specific needs.



Teenagers have special concerns. They frequently complain that their parents try to

protect them too much. Teenagers are at a stage in their lives when they are naturally trying to be in control and do things for themselves; having seizures sometimes forces them to depend on you, especially if driving is an issue. At times they may blame everything on their epilepsy or rely too much upon their parents, which can create feelings of helplessness. Giving teenagers opportunities to make their own decisions and choices, allowing them to learn from their experiences when possible, will help foster independence and boost their self-esteem.

You

Epilepsy can bring many changes to your life. To help you cope with these changes, you may want to consider the following suggestions:

- Make time for yourself. Do not feel guilty that you need some time for yourself. Also, make a special effort to find private times to talk with your partner or those who are close to you. Do not let all your conversations revolve round your child's medical issues.
- Prepare yourself for a lot of waiting. Find ways to make waiting during clinic visits or while in the hospital less frustrating. Take something to read or do while your child is asleep or does not need your attention. Try to take care of insurance issues while you have access to individuals who may be able to explain billing codes and procedures to your insurance company.
- Turn to treatment staff or other resourc-

es for support. Treatment centers have trained staff who can talk with you about your concerns. Make use of these people for support.

- Contact support groups. Your treatment center can provide names of support groups at which you can meet with other parents of children who have epilepsy. Community resources can provide support and information. They can tell you how other parents have dealt, or are dealing with the same types of situations you are facing.
- Share the care of your child with your partner and/or others close to the family. Sharing responsibilities with partners, family, and friends will not only give each of you a break, but it will help keep you and your partner from growing apart should one become more involved than the other in your child's treatment.

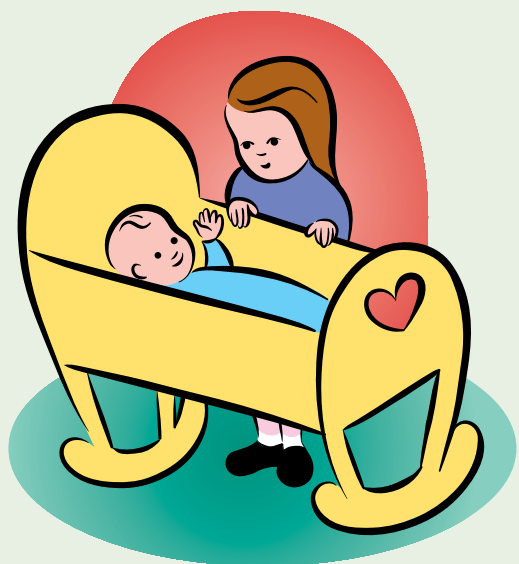
Siblings

The lives of children who have a brother or sister with epilepsy can change a great deal. Siblings may have many different feelings about the brother or sister who has seizures and the extra attention the child receives. They may feel sorry for their sibling. Younger children may feel that they caused the seizures; or more commonly, they may believe that their own needs are being ignored.

When a child receives a diagnosis of a chronic illness, the focus is on that child. As a parent, you may not be able to devote as much attention to your other children

Helping Siblings Cope with Epilepsy

- Talk with them about their feelings
- Talk with them about seizures, treatment, and care
- Spend time with your other children
- Encourage them to take part in outside activities
- Involve them in their brother's or sister's treatment
- Talk with them about questions others may ask them
- Ask other family members and friends for support



as you did before. You may even have to miss some of their special school or sports events. You may also use up all your energy and patience caring for the child with seizures and not have enough energy or time to talk with your other children, play with them, or help them with their homework. It is natural, then, for siblings to be annoyed at the attention your child who has seizures is receiving.

As a result, siblings' behavior may change. They may become depressed, have headaches, or begin to have problems in school. School counselors and support groups may be able to offer you helpful advice for dealing with these issues. In addition, here are some things you can do to help your other children:

- Talk with them about their feelings. Talk with them about the special attention their sibling is getting. Let them know that feeling mad is natural. Try to explain what is happening and why you may not be as available as you were before.
- Talk with them about seizures, the treatment, and care. Younger children's fears can be helped by knowing they couldn't have caused epilepsy by wishing or by spreading germs. Treatment and procedures should be explained as being helpful things and not punishments.
- Spend time with your other children. Try to spend some time with them doing the things they like.
- Encourage them to take part in outside activities. Make a point of noticing and praising what they do in these activities.

- Involve them in their brother's or sister's treatment. Let them come along with you to the clinic or hospital. Having them along will allow them to see for themselves what the hospital, clinic, and treatment are like. Their knowledge and participation increases opportunities for becoming future epilepsy advocates.
- Talk with them about questions their schoolmates and friends may ask. Help them think of possible questions and answers so that they will feel comfortable talking about their brother's or sister's seizures.
- Ask other family members and friends to spend time with the other children in the family. For example, an aunt or uncle might go to school events or attend important games or performances. A neighbor might help them with homework or take them on outings.

Family and Friends

Sometimes epilepsy affects not only the child, parents, and siblings, but also grandparents, other relatives, and friends. These people can support and assist you during this time. Your employers also may need to be told about your child's condition, so they will know why you are asking for extra time off from work. If needed, your child's doctor can write your employer to explain the situation.

You may need to tell people how to help you. Here are some ideas on how to tell them:

- Be open and honest.

**Sometimes epilepsy also affects
grandparents, other relatives, and friends.
These people can support and assist you
during this time.**

- Take the lead to show others how you and your child want to be treated.
 - If they are giving you too much attention, gently point it out.
 - You may find it tiring to have to repeat details about your child's medical issues to many family members and friends. Ask one person to handle calls and questions. You can leave short messages on a home answering machine, or send email updates to the relevant group of people.
 - It can be helpful to ask one friend or family member to be the "point person" to share with people your needs, e.g., laundry or grocery shopping.
- sources available to families of children with special health care needs.
 - Get help if you need it to understand the policy or how to file claims if you need to. Do not be afraid to ask friends, family members, or a social worker for help. Private companies and some community organizations also offer help to deal with insurance. Some insurance companies provide case managers for children with co-occurring diagnoses and complex medical needs.
 - Keep careful records of all expenses and claims. Store bills and insurance forms together to make it easier at tax time.

Financial and Insurance Related Issues

Many parents of children who have ongoing chronic conditions are concerned about the costs of treatment, continuing care, and how these costs will be met. You may not have health insurance or insurance may not cover all costs. Some insurers will not cover certain costs when a new treatment is under study. You will need to understand the coverage that your policies offer. Here are some tips for making the most of your insurance:

- Get copies of your insurance policies and find out exactly what is covered.
- If you do not have insurance, check with your local department of health for re-



Learning to implement the right coping strategies can help your child lead a rich and rewarding life.

- File claims for all covered costs. Sometimes, people do not take full advantage of their insurance, either because they do not know about a benefit or are put off by the paperwork.

If your claim is turned down, file again. Ask your doctor to explain to the company why the services should be covered under your policy. If you are turned down again, find out if the company has an appeals process. Never give up!

Conclusion

Families need support from specialists, nurses, rehabilitation experts, and social workers to help them cope with the many adjustments and uncertainties that accompany the diagnosis of epilepsy. Children and their families need a normal life. Because knowledge leads to understanding, the goal is to provide insight into assisting families in identifying and mobilizing the appropriate resources available to them. Knowledge is critical to how parents manage their child; knowledge can make a huge difference in the lives of their entire family and community. For children with epilepsy and their families, knowledge is important, but creating healthy relationships in the context of a normal life is even more important. Understanding and coping with the impact of liv-

ing with epilepsy and learning to implement the right coping strategies can help your child lead a rich and rewarding life. This article may help families navigate through the daily challenges for you, your child, and your community—to help all concerned to achieve a sense of encouragement and an attitude of optimism.

Linda Landreth-Harris is the mother of a young adult who has lived with the daily challenges of generalized, idiopathic epilepsy since the age of six. At the time of diagnosis, there was little information available, the Internet was relatively new and there was no support group available in her community. In her search for information and answers, Linda became knowledgeable about special education, accommodations for persons with disabilities, and the complexities of healthcare systems. She made the decision to return to school and pursue an education in the field of clinical social work to help other families understand those systems, find solutions, and guide others to achieve their highest quality of life. She has worked with children, adults, and families in hospice facilities, medical outpatient clinics, medical inpatient facilities, and community-based settings.