

SEIZURES AND TEENS: The Impact of Seizures and Epilepsy on Families

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When a teenager or child of any age develops seizures, the impact on the family can be enormous. Worries and fears may affect everyone, and left untreated, crises can occur too easily. This article will explore the way that epilepsy can affect family dynamics. Common factors that may contribute to family stress and patterns of coping will be discussed as well as opportunities for families to promote successful strategies for living with seizures.

Personal Experience

When my daughter Liz was two-years-old, she had her first seizure. As her six-year-old sister, Alice, stood by her side and watched, a swing hit Liz in the chest. Liz cried, was unable to catch her breath, dropped, and had a seizure that lasted five minutes. A babysitter carried her to me. I did not witness the initial trigger, but Liz turned blue, had a five-minute grand mal (tonic-clonic) seizure, and rode for the first time in an ambulance. Once the seizure stopped, Liz was unconscious for 20 minutes.

A year later, Liz had her second seizure after running into a wall. She once again cried, wasn't able to catch her breath, and had a five-minute tonic-clonic seizure. Her older sister Alice was again with her, and their dad came to the rescue. Liz was taken to the hospital where she remained unconscious for 20 minutes. That was the last seizure Liz had, yet the fear and anxiety remained with my family for years.

When my eldest daughter Alice was eight years old, her teacher reported that she complained of stomachaches during class. A year later, I received a frantic call from the school when Alice fell off a jungle gym and began to shake. She was afraid she would have a seizure like her sister. When my daughter Liz was seven, she began to play soccer. During one game, she was hit in the chest with a ball and ran out tearfully because she was afraid she would have another seizure. Her dad sent her back into the game and reassured her that the seizures were over.

Two seizures and five years later, my daughter screamed from the opposite end of the house. I came running into the room, worried that something serious had happened, only to find them fighting. I yelled at both girls to stop fighting and returned to the kitchen. After a few moments, I came back to apologize. I explained to them that when I heard the scream, I was afraid that perhaps Liz had another seizure. Alice, my older daughter, turned to me crying hysterically, "You were afraid. I am the one who

found Liz every time she had a seizure. I was there alone." Liz watched her sister crying hysterically and blamed herself for her sister's sadness. She too began to cry. So with both girls in tears, I joined in and held them both closely. In spite of family discussions and education about seizures, that was the moment of catharsis we all needed to share the worries of the past five years.

“Life is so daily. Parenthood is an endless series of small events, periodic conflicts and sudden crises, which calls for a response. The response is not without consequence.”

—(From Holt, Rinehard, and Winston. *The Disabled and their Parents: A Counseling Challenge*. New York: Ginnot, 1983, p.631)

The Impact of Epilepsy on the Family

What makes seizures such a frightening and overwhelming experience for the child, siblings, parents, and family? How do children and families make sense out of this condition and incorporate their experience? Epilepsy enters the family system. The child's development is impacted. The family is affected by the child's condition and responds to the challenges. Continuous challenges tend to stress the family. Over time, patterns of responses emerge, and the family develops a style of functioning to respond to their stress.

The worries of epilepsy begin early, commonly after the first seizure, and often continue to exist beyond the cessation of seizures. Results from 113 questionnaires, distributed during seizure clinics for those newly diagnosed, demonstrated that the majority of parents worry when their child has seizures. Sixty percent of mothers rated their level of worry between 7 to 10 on a scale from 1 (least) to 10 (most), and 30 percent of parents rated their worry as a 10. All the parents worried about their child having a seizure without adult supervision and that seizures would

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hurt the brain. The majority worried about how seizures would affect their child's ability to learn (74 percent), how family members would adjust to their child's condition (55 percent), and the need to restrict their child's activities (67 percent). The most common responses to open-ended questions about parent concerns included: short and long-term effects of medications, the possibility of outgrowing seizures, effects of seizures on self-esteem, dealing with schools and teachers, and factors that may increase seizures. Children worried about death, feeling different from their peers, when and where seizures would occur, how to tell others, being picked on by other kids, needles and blood tests, if they could stop breathing during a seizure, and being alone during a seizure.

As the founder and director of Camp Great Rock for children and teenagers with epilepsy, I see many children arrive feeling worried, fearful, and socially isolated. Many campers have limited knowledge and lack independence. Parents often express their worries at registration when they prepare to leave their children for the initial overnight camp experience. These worries are commonly mirrored by their children and include the anticipation of unpredictable seizures and fear of separation.

The realities of living with epilepsy often force families to maintain constant surveillance and watch for behavioral changes. Parents may feel forced to introduce medications to try to control the seizures and struggle with confusing side effects. They must learn how to partner with doctors, specialists, and extended family members to become an advocate for their child. Even sibling relationships can become an issue for parents as their attention is focused on their child with epilepsy. Over time, the increased supervision of the child with seizures can lead to unhealthy overprotection. In some cases, the lives of the primary caregiver and the child with epilepsy can become entangled, and they begin to act as one.

The Family as a System

The intrusion or invasion of epilepsy can shake up the family system and how families are organized and managed. In families, usually relationships or coalitions are established, roles develop, and members establish a social system as they join together to manage and balance everyone's needs. As part of a family, children have their first opportunity to gain a sense of self worth. The importance of the family system on an individual's development is without question. Families provide the foundation for children to learn how to behave, communicate, and interact with other people.

In order to understand the impact of epilepsy, we must first understand the function and structure of families and how the needs and developmental tasks of families may change when a child is diagnosed with epilepsy. This information can help us recognize effective coping behaviors that are present in functional and resilient families. Each family has a function. In spite of our changing society, families serve to emotionally protect members and continue important traditions and values. Over time, families nurture and socialize their children and try to pro-

vide financial security. Usually, families provide the chance for children to form attachments and identify with other people in a safe environment. Unfortunately, the financial burdens of medications and healthcare costs can make it difficult for a parent(s) to financially care for their family. Resources to protect family members from the uncertainty of seizures and burden of stigma or to help them with emotional problems may be limited. When medical demands become too great, it can be difficult to focus on the social needs of the child and family. Many traditions from the past, requiring time and effort, may be lost.

Family behavior can also be viewed in terms of roles and relationships. One person may serve in many different roles, such as a mother, wife, professional, and friend, all at the same time. Each role carries with it responsibilities and expectations. As one role begins to require more time and effort than previously expected, time is taken away from other roles, and there is the potential for stress and frustration. If two people have different expectations of their roles and responsibilities, the tension and stress will increase.

Parent Stress

Becoming a parent is a stressful experience for which few individuals are prepared. The partners or co-parents often have different customs, expectations, rules, and models for the organizational structure of the family, including support from extended family members. When children arrive and healthcare needs are great, the time requirements on parents increase significantly. A caregiver or parents may be forced to relinquish certain freedoms and redefine their roles. As the family develops, these roles are constantly revised to meet the changing needs of its members. Coalitions form between parents and children, yet at the same time, parents must maintain their own relationship and power to manage and balance the family unit. Some families have difficulty communicating and adapting to the continuous and stressful changes required and are not able to be both stable and flexible at the same time.

Many factors should be considered when looking at the effect of stress on family functioning. These include at what point the stress occurs, the duration and amount of stress, and the limit to which a family can accommodate the stress. Sometimes stressful events can become a crisis. What makes something a crisis is based on the nature of the event, the resources of the family, and how the family defines the event. The traditional view of a crisis is a stressful event in which the person or family's usual means of problem solving does not work. It commonly involves a feeling of helplessness, cognitive confusion, and a sense of just being stuck.

Crises develop when parents perceive extreme stress and generally fall into two main categories. In a "tragic" crisis, goals for the family are disrupted by uncontrollable events, usually a loss. In the more common crisis, called a "role organization crisis," the family is unable to manage the stress using their usual roles and ways of coping. For example, people may try to work harder, as if the situation is temporary instead of long term. Another approach to role

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organization crises may be to change the alliances or relationships between family members. In this case, the members begin to define their problems in terms of changed relationships and often become angry or frustrated when old patterns of relating no longer work. Family members must revise their roles and responsibilities and, at times, a parent or family member may be forced to depend on outsiders or extended family members to help perform roles they are no longer able to do themselves.

When a child or teenager lives with a chronic health condition like epilepsy, the stress often attacks the parent's relationship by exciting powerful emotions or creating feelings of failure. Even in the best of relationships, it is natural to confuse the health of the children with the health of a caregiver, partnership, or marriage. The family may become more vulnerable to the involvement of extended family members, which can reshape the way the family is organized and relates to each other. Taking care of the needs of the child and seeing a number of specialists may leave little time to address the social needs of the other children, caregiver, or partner. Fear, worry, financial pressures, and fatigue can result in a parent feeling alienated from others, and increased tension can develop within the family.

Coping with Epilepsy—What Works?

To effectively cope with epilepsy, families must navigate through three stressful phases. These include the initial crisis period, the chronic phase, and long-term maintenance of the disorder. In the initial phase, parents begin to recognize symptoms, explore evaluations and testing, obtain an initial diagnosis, begin medications, and increase their knowledge of the condition. This phase usually takes around six months to two years. In the chronic phase, children and parents will need to establish a relationship with health-care professionals; understand and accept the seizures; disclose and educate peers and family members about epilepsy; manage medications; learn about treatment options and side effects; watch for other conditions such as learning disabilities and mood disorders; search for appropriate schools and programs; and deal with bullying, teasing, and stigma. The third group of tasks will address longer-term effects of seizures. These tasks include coming to terms with one's strengths and weaknesses; understanding what is reality versus perception; establishing long-term goals; gaining independence; and maintaining flexibility in spite of the unpredictability of seizures. The growth and independence of the family members and stability of the family will ultimately depend on the parent and family's successful adaptation to the stressors and ability to address these tasks.

In strong resilient families, the members are honest and feelings are acknowledged. These families are capable of balancing the needs of the child with epilepsy with the needs of the other siblings and spouse. Parents are able to spend quality time with

all their children regardless of epilepsy. In effective family systems, the parent(s) are able to maintain boundaries between themselves and their children, utilize appropriate power, and develop strong supportive relationships. Also, effective families have consistent rules for all children, although accommodations may need to be implemented for the child with epilepsy to achieve success. All feelings are acknowledged, and members join together during crises to solve problems.

In spite of the intrusion of epilepsy, when families work well together, clear roles are promoted and independence is encouraged; for example, children are allowed to attend sleepovers and camps. The family communicates with honesty and acceptance and tries to find positive meaning for their struggles. As a result, families who cope successfully often become stronger from their experience. In these resilient families, support networks and peer relationships are encouraged within and outside of the family. In time, parents and their children learn to establish relationships with doctors and professionals and become strong self-advocates.

For More Help

While much information is available on the medical aspects of seizures, help for families and teens on coping with epilepsy can be difficult to find. Professional resources may be available from epilepsy centers or mental health clinics. Support networks geared to teens, young children, and parents may be offered by the Epilepsy Foundation and provide social support, mentoring, and self-advocacy skills. Camps designed for children and teens with epilepsy or other chronic health conditions can help campers build self-confidence, develop healthy coping behaviors, and provide much needed respite for parents.

Opportunities for support and learning can be increasingly obtained without leaving home. Children's National Medical Center in Washington, D.C. developed a DVD program for families of children with epilepsy (*Coping with Epilepsy: From Seizures to Success*, Cushner Weintein, 2006, mail to: scushwei@cnmc.org). Online support and networking for families and teens can also be found at www.epilepsy.com, including information for parents, teens, and children of all ages.

Conclusion: It has been 13 years since Liz had her first seizure with Alice at her side. Liz is a well-rounded tenth grader with dreams of becoming a neurologist. She is presently a goalie for her high school soccer team. Alice is an honor student with plans to become an elementary school teacher for third-grade students. If we look closely, all of these goals and achievements make sense within the context of the family dynamics and history. As parents, it is important to remember that when we organize and manage our family and support our children and spouses in response to the stressful events of daily life, our responses always have consequences. •