



Epilepsy affects the whole family. However, the effects of epilepsy on the life of the family and child are extremely variable. For example, children who experience mild, infrequent seizures that are easily controlled by medication will likely lead lives with few restrictions on their social and physical functioning. At the same time, children and their families may be frightened by the diagnosis of epilepsy and continue to feel worried and uncertain about the possibility of another seizure. Indeed, good seizure control with few accompanying medical problems does not necessarily reduce parental anxiety.

Even if epilepsy is eventually well managed, there will be several key stages in the life of your child that will be more stressful for you and your child, for example:

- at the time of the first seizure and diagnosis
- when there are changes in the frequency or type of seizures (the latter may change over time)
- withdrawal of medication

- recurrence of seizures after a seizure-free period
- starting school
- transition through adolescence
- transition into young adulthood and leaving home

During these stages, parents may struggle with feelings about how best to parent their child.

Feelings you may experience, together with some coping strategies, are discussed in detail on the "Looking After Yourself" page in this section.

Your child's response to epilepsy

The child's response to epilepsy depends on his age and stage of development:

- School age children, who tend to be concrete in their thinking, may be frustrated by the limitations imposed on their physical activities and how closely they are monitored by parents and others.
- During adolescence, youth typically spend more time with peers and become increasingly independent. Epilepsy can potentially increase social isolation because of self-esteem issues related to the seizures; "rejection" by peers (bullying, teasing); or because of seizure-related safety concerns that result in limits on the adolescent's independence. The adolescent's desire "not be different" from peers and to be liked by others may be compromised if he is having seizures that are visible to his peers. He may feel resentful, or he may feel anxious about

his own safety and the limitations (decreased independence) that are imposed on him because of his seizures.

Suggestions to help your child cope with epilepsy are discussed in detail on the "Your Child with Epilepsy" page in this section.

The response of siblings

It may be difficult to pay attention to the response of brothers and sisters when so much of your energy is being focused on your child with epilepsy and his needs. Siblings may feel as though their concerns are being ignored, minimized, or overshadowed by the seizures.

Sibling response to epilepsy depends on many variables, including the age of the sibling and her understanding of seizures and epilepsy. It is possible that siblings may feel resentful of having less time with their parents, responsible for the care of their brother or sister with epilepsy, or overwhelmed by worry about their brother or sister's well-being. Siblings may also be interested in finding ways to support their brother or sister with epilepsy. Many families have told us that having a child with epilepsy has resulted in more empathetic and caring siblings. Most likely, siblings will have mixed feelings.

Suggestions to help your other children cope are discussed in detail on the "Your Other Children" page in this section.

Your relationship with your spouse or partner

A chronic condition such as epilepsy can also affect a couple's relationship. Epilepsy can often feel like the third person in a relationship. For some parents, epilepsy is the impetus that forces them to work more closely together as a couple. In other cases, epilepsy causes a great deal of strain in the relationship. One thing for certain is that parenting a child with a chronic conditions requires open communication between caregivers.

Often the "jobs" in families are divided between the adults. This division is sometimes clearly negotiated and at other times assumed. For example, in a two-parent family where the mother expects the father to participate in school meetings and clinic appointments and the father assumes this will be the mother's role, there is the potential for conflict until this issue is openly discussed and resolved.

Another challenge that couples often describe occurs when the emotional energy of one parent becomes so tied up in monitoring the child with seizures that there is little attention available for their own relationship. For some couples this situation seems to be acceptable and manageable to both partners. However, for other couples, this situation can create distance in the relationship or even resentment from one or both partners.

Suggestions to help you and your partner cope together are discussed on the "You and Your Spouse or Partner" page in this section.

Single-parent families

The responsibility in single-parent families can be immense because the one parent must oversee all aspects of the child's care, including monitoring the child's seizures. Exclusive responsibility for parenting a child with epilepsy may limit the parent's opportunities to engage with friends and extended family. Social outings may be difficult to plan because of the unpredictable nature of seizures. Feelings of

isolation and loneliness may be challenging at times. The pages on "Looking After Yourself" and "Coping as a Family" offer some suggestions on managing as the single parent of a child with epilepsy.

Coping as a family

Coping with epilepsy as a family is discussed in detail on the "Coping as a Family" page in this section.

