

Epilepsy and Family

Children are born into families; the family nurtures the child from the beginning of life and helps the child learn how to develop roots and wings. Families are somewhat alike in structure (parents and children), but can be very different in how they deal with major parenting tasks. From about the age of 2, when a child becomes very mobile and learns the word “No,” a major task of parenting is how to balance discipline with encouragement. Major styles of parenting have been categorized as: **authoritarian**, **authoritative** and **permissive**.

The **authoritarian** parent is very strict and forbids many activities without including the child’s point of view. The **permissive** parent does not set many rules and often tries to be the child’s friend. Both of these parenting styles can lead to difficulty later. The **authoritative** parent sets limits but discusses them with the child, and balances strong praise with punishments or consequences that are tied to how the child is expected to behave.

Parenting a child with a chronic health condition can make it difficult to find the middle ground between holding the line and allowing the child to do what he or she can do. It takes some adjusting by everyone in the family. It is also important to set expectations, though these will be based on what the child will be able to achieve. Chronic health conditions can also create stress between parents, and between parents and extended family. Seeking support is vital for parents of children and youth with epilepsy.

For all of the activities that are discussed in this and the next section, the parents have to take part and lead. As such, it is important to do what you need to do to

take care of yourself. That may mean finding support groups or hotlines, lining up professionals to address particular needs, and meeting parents who have had experience with children and youth with epilepsy. Try to stay positive and hopeful; if you feel that you are slipping, see a case manager or other appropriate person who may be able to listen to your concerns and direct you to services as needed. Help is available!

Patient and Family Advocacy: The key role of the family is being the champion for your child, since nobody knows your child better. It is important for the family to promote the patient’s needs with the physician. In the case of children and youth with epilepsy, many of the medications have side effects that can seriously affect quality of life. The family should note all of the side effects and communicate them effectively to the physician, so the family, the patient and the physician can make the best decision for the patient. There are many family- and patient-centered groups focused on advocating for the different needs of patients with epilepsy:

medicalhomeinfo.org/tools.care_notebook.html

Family-centered self-assessment tool

familyvoices.org/

Family Voices

nami.org/

NAMI – The National Alliance on Mental Illness

epilepsyandmychild.com/epilepsyfoundation.org/ecommunities