

# Coping and Resilience, Finding a Medical Home and Resources

Resilience, **being able to bounce back or cope with difficult events**, is helpful when thinking about coping with the stress of having a child with a chronic illness such as epilepsy. The stress can increase if the child also has a behavioral or mental health issue. Resilience is the idea that we develop strength in response to stress, and we can use that strength to help us get through trying situations. It can be summed up in the old adage, “Whatever doesn’t kill you makes you stronger.” It is our strengths plus the coping mechanisms we develop that help us.

Some common coping mechanisms that can help parents of children with epilepsy include:

- Having a good social support network, including good family support
- Having a ready source for answers to questions
- Using a problem-solving approach to issues that arise

## Medical Home

### What is a Medical Home?

A family-centered medical home is an approach to care that is based on the needs of the patient and the family. According to the Institute of Medicine, a *Medical Home* is “respectful and responsive to individual patient preferences, needs and values.”

### What are the important components of a Medical Home?

Accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally effective.

### What can the Medical Home provide?

**Preventive and primary care:** The patient gets all the appropriate screening according to age and needs, short-term care in the case of medical illness, and long-term management of the disease.

**Coordination with subspecialty care:** This is key for youth with epilepsy, since patients with families may visit many different specialists. Communication between the primary care doctor and each one of the subspecialties is important. Coordination can help improve the patient’s care, making sure that all of the providers know the critical issues the patient is facing, the medications he or she is taking, who is providing what care, and when the next appointment with each provider is needed. Coordination helps the family know whom to contact for specific issues.

Visit [medicalhomeinfo.org/](http://medicalhomeinfo.org/) to build your *Medical Home tool kit*.

### Coordinating Behavioral Health Care with the Medical Home

The physician who is in charge of your child’s care for epilepsy should be the primary contact. If you have a Medical Home, there may be another person (a pediatrician, family practice doctor, a care manager, or a nurse practitioner) who is also a contact. These professionals can put you in touch with behavioral health specialists, often psychologists or social workers, who can help you design a treatment plan to address mental health issues. If you have a Medical Home, the behavioral health specialists may work as part of the team or be located in the same facility.

If there is not a Medical Home, your physician or other contact person can refer you to a knowledgeable practitioner. The behavioral health specialist may work in an office building close to you, or may work in a medical facility. Some behavioral health specialists may be able to come to your home.

Your contact person should take into account how far you will have to travel to see the behavioral health specialist, since these appointments usually occur on a frequent (often weekly) basis for a period of time.

The behavioral health specialist will:

- Need a complete history of your child's epilepsy
- Want you to describe the child's behavior that concerns you. Before your appointment, think about the things that concern you. Also think about the special strengths of your child, since the description of your child should include strengths as well as needs. Write these down and take to the appointment.

Try to be as specific as possible about how you would like things to look when change has occurred. This will help the specialist work with you to set goals.

Together with the specialist, you will set goals and design a treatment plan. The treatment plan will ask you to keep track of how things are working. If you are not used to recording and charting your child's behavior, you may want to ask the specialist for tools to help you do this.

You will meet with the specialist to review how things are going. If needed, you may agree to try different things in order to achieve your goals.

**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](http://medicalhomeinfo.org/tools.care_notebook.html)

Family-centered self-assessment tool

[familyvoices.org/](http://familyvoices.org/)

Family Voices

[nami.org/](http://nami.org/)

NAMI – The National Alliance on Mental Illness

[epilepsyandmychild.com/epilepsyfoundation.org/ecommunities](http://epilepsyandmychild.com/epilepsyfoundation.org/ecommunities)

## Coordination and Community Resources

It is the role of the physician to connect the family with different resources it may need. When a child is newly diagnosed with epilepsy, it can be very overwhelming; having support from different community organizations and parents who have a child who was diagnosed with epilepsy and is now under control can make an important difference in the life of a child and the family.

[epilepsyfoundation.org/](http://epilepsyfoundation.org/)

Epilepsy Foundation

See extreme parenting video project by Elizabeth Aquino:

[youtube.com/watch?v=iZ78gHne0LM](https://www.youtube.com/watch?v=iZ78gHne0LM)

Parents are really the managers of the care for the child or youth with epilepsy. It is the parents' job to recruit the best professionals to manage the child's epilepsy and any of the other conditions associated with it. Before every medical or specialty visit, it is important to think about your goals for the visit:

1. Write all the questions that you want to ask your doctor and let the doctor know that you want these questions answered. Don't wait until the last five minutes of the appointment to ask your questions.
2. Gather all the information necessary to make informed decisions: how the patient is doing at school, if there any improvements observed by other key people in the child's life (teacher, providers, therapist).

3. If you are not happy with your child's treatment, let your doctor know. If you are concerned about side effects, discuss them. Your doctor will appreciate that you are discussing your concerns.
4. If medication has to be taken at school, have you filled out a seizure action plan for the school? Does the school nurse know that your child has epilepsy? It is very important that all the key providers are informed and ready to help your child.

Having a seizure action plan is very important – every child with epilepsy should have one. You can download this template and fill it out with your doctor in the next visit.

[epilepsyfoundation.org/livingwithepilepsy/educators/socialissues/schoolnurseprogram/upload/seizure-action-plan-pdf.pdf](http://epilepsyfoundation.org/livingwithepilepsy/educators/socialissues/schoolnurseprogram/upload/seizure-action-plan-pdf.pdf)

Resources for a parent of a newly diagnosed child:

[epilepsyfoundation.org/livingwithepilepsy/parentsandcaregivers/index.cfm](http://epilepsyfoundation.org/livingwithepilepsy/parentsandcaregivers/index.cfm)

Parent tool kit with useful school forms and seizure observation form:

[epilepsyfoundation.org/projectaccess/findaresource/forfamilies/toolkits-Care-Books.cfm](http://epilepsyfoundation.org/projectaccess/findaresource/forfamilies/toolkits-Care-Books.cfm)

Manual for parent of a child with epilepsy:

[epilepsyfoundation.org/livingwithepilepsy/parentsandcaregivers/parents](http://epilepsyfoundation.org/livingwithepilepsy/parentsandcaregivers/parents)

CDC – Epilepsy Tool kit for parents of teens:

[cdc.gov/epilepsy/toolkit/index.htm](http://cdc.gov/epilepsy/toolkit/index.htm)

It is important to track how frequent the seizures are; here are some resources for seizure diaries:

[webease.org/Overview.aspx](http://webease.org/Overview.aspx)

[seizuretracker.com/](http://seizuretracker.com/)

[epilepsy.com/seizurediary](http://epilepsy.com/seizurediary)

Some resources to learn more about medications:

[drugs.com](http://drugs.com)

[dailymed.nlm.nih.gov/dailymed](http://dailymed.nlm.nih.gov/dailymed)

[professionals.epilepsy.com/page.medications.com](http://professionals.epilepsy.com/page.medications.com)

To learn more about generic medication vs. brand name:

[nomoreseizures.org](http://nomoreseizures.org)

Some websites that offer medication assistance:

[epilepsyfoundation.org/aboutepilepsy/treatment/upload/Patient\\_Assistance\\_Programs-February-2013.pdf](http://epilepsyfoundation.org/aboutepilepsy/treatment/upload/Patient_Assistance_Programs-February-2013.pdf)

[needymeds.org](http://needymeds.org)

Standard of care for epilepsy:

[naec-epilepsy.org/spec\\_care/guidelines.htm](http://naec-epilepsy.org/spec_care/guidelines.htm)

Seizure assistance dogs:

[assistancedogsinternational.org](http://assistancedogsinternational.org)

[k94life.org](http://k94life.org)

*Canine partners for life*

[ChelseaHutchinsonFoundation.org](http://ChelseaHutchinsonFoundation.org)

*(for fundraising to get a dog)*