

Epilepsy & My Child Toolkit

A Resource for Parents with a Newly Diagnosed Child



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"Obstacles are the things we see
when we take our eyes off our goals."
-Zig Ziglar

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Dear Parent:

It is estimated that nearly 2.2 million Americans are currently diagnosed with epilepsy; 316,000 are children and youth ages 14 and younger. Of the 150,000 new cases of epilepsy diagnosed each year, approximately 50,000 of these cases will be diagnosed in children and adolescents under the age of 18. About two-thirds of all children with epilepsy outgrow their seizures by the time they are teenagers. The goal of eliminating seizures while preventing side effects is achievable for most children and youth, but it requires an organized system of care to ensure uniformity in the provision of services and support. As a parent, you want to help your child maintain a healthy lifestyle and ensure he/she has regular medical visits.

We hope you find the **Epilepsy & My Child Toolkit: A Resource for Parents with a Newly Diagnosed Child** useful as you take on the responsibility of managing your child's epilepsy. The Toolkit is designed to be a resource guide and information referral source. It includes forms to help you organize medical and educational information, take notes, and facilitate communication between all parties involved in your child's care. We advise you to take the Toolkit with you to medical appointments, emergency room visits, and other appointments related to your child's epilepsy.

Best Regards,



EPILEPSY & MY CHILD TOOLKIT

INTRODUCTION



This toolkit is intended as a resource for parents or caregivers whose child has recently been diagnosed with epilepsy. For many families this can be an overwhelming, emotional and stressful time. It's likely your days are suddenly filled with doctor visits, medical tests and a lot of worrying. You might feel depressed or even angry and ask, "Why did this happen to us?" While these feelings are completely normal, it's important to know that **you are not alone**. Epilepsy is much more common than many people realize.

How to Use This Toolkit

The toolkit is organized into six sections—*About Epilepsy, Managing Epilepsy, Daily Life with Epilepsy, Life Stages with Epilepsy, Resources and Forms*. Each section includes information and helpful tips with links to downloadable tools. You can either check the *Table of Contents* at the front of this document for specific information, or see the reference sections on the front of each tab. Use the Forms as indicated, to help you start managing your child's epilepsy right away. This will not only help your doctor, but also make you feel more organized and in control. Finally, be sure to review the **Resources** section to find additional information and support specific to your child's and family's needs, including listings for common epilepsy terms and Epilepsy Foundation Affiliates.

You will also want to visit the "Parents and Caregivers" section of the Epilepsy Foundation's Web, <http://www.epilepsy.com/node/2003131> site which provides additional information and online discussion groups where you can communicate with other parents, access an online version of this toolkit or order copies. If you would like to find out about all the resources available from the Epilepsy Foundation, visit www.epilepsy.com or call 1-800-332-1000.

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About Epilepsy

What is Epilepsy?

Epilepsy is a neurological condition characterized by recurrent seizures. Clusters of nerve cells, or neurons, in the brain sometimes signal abnormally and cause a person to have seizures. Epilepsy is one of the most common neurological disorders worldwide, affecting 50 million persons, including an estimated 2.2 million persons in the United States.¹ Of the 2.2 million, 316,000 are children and youth aged 14 and younger. Every year, approximately 50,000 new cases of epilepsy are diagnosed in children and adolescents under the age of 18.² To be diagnosed with epilepsy, a child must have had more than one seizure that was not caused by another treatable condition.

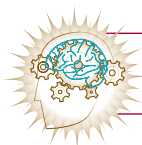


Epilepsy affects every child differently depending on age, types of seizures, response to treatment and whether or not the child has other health issues, etc. For some, the seizures are easily controlled with medicine and eventually outgrown. For others, epilepsy can create difficult challenges throughout their lives.

Epilepsy affects people from all communities, many of whom do not have any family history of seizures. Seventy percent of cases are classified as idiopathic epilepsy, a term used when an identifiable cause cannot be found. Among the rest, the cause can be related to brain malformations, tumors, or hemorrhage, metabolic/genetic conditions, infectious diseases such as meningitis or encephalitis, birth trauma and high-risk pregnancies.³

In recent years, there have been many improvements in treating epilepsy, making it a manageable condition for most. Many medications are available and more are being tested all the time. In addition to medication, there are also alternative treatments for children who continue to have seizures while on medication. Additional general information about epilepsy can be found on the following Web sites:

- Epilepsy Foundation: www.epilepsy.com
- National Library of Medicine: www.nlm.nih.gov/medlineplus/epilepsy.html
- Centers for Disease Control and Prevention: www.cdc.gov/epilepsy



Epilepsy?—two or more seizures not caused by another treatable condition.

What is a Seizure?

A child's brain has billions of nerve cells that "talk" or communicate with each other through tiny electrical charges. If too many of these cells suddenly fire together, a wave of electrical energy sweeps through the brain and causes a seizure. During a seizure, a child might stare blankly, lose consciousness or make jerky, uncontrolled movements called convulsions. Most seizures last less than two minutes, but afterward a child might feel sick, weak or confused.

While all epileptic seizures are caused by electrical disturbances in the brain, there are many different kinds of seizures. The kind of seizure a child has depends on whether the whole brain is affected—generalized seizures—or just a certain part of it—focal seizures. Some children have just one type; others may have a combination of seizure types. Children's behavior, risk of injury and treatment depend upon the type of seizures they have.

It is important to help your doctor identify what type of seizures your child is having. Use the ***Seizure Recognition and First Aid*** table and ***Seizure Record*** form included in the ***Forms*** section to help you. You might want to give teachers and other caregivers copies as well.

Myths & Facts

Despite progress in educating the public about epilepsy, some myths about epilepsy still exist. It helps to know what they are, so you can let others know that they are not true. Here are some of the most common myths:

Myth: A child having a seizure can swallow his tongue.

Fact: No one can swallow their tongue. Any efforts to hold the tongue down or put something in the mouth of a child having a seizure can hurt the teeth or jaw.

Myth: People with epilepsy are possessed by the devil, cursed and/or "spirited".

Fact: Epilepsy is simply a neurological (brain) disorder.

Myth: You should hold down a child who is having a seizure.

Fact: You should not hold down a child, just make sure the area near the child is safe by moving aside any hard or sharp objects or furniture.

Myth: You should perform artificial respiration on someone having a seizure.

Fact: Artificial respiration is only needed if the person does not start breathing after the seizure has stopped.

Myth: People with epilepsy and seizures are mentally ill or intellectually or developmentally disabled.

Fact: Epilepsy and mental illness and/or intellectual or developmental disabilities are all different conditions that can affect the brain. People with epilepsy and seizures are just like the rest of us.

Myth: You can tell that a person has epilepsy by the way he or she looks.

Fact: There's no way to tell that someone has epilepsy and seizures just by looking at them.

Myth: If someone in the family has epilepsy, the children will too.

Fact: Epilepsy can happen when there's no family history at all. Sometimes children of a parent with epilepsy will have seizures, but it's far more likely that they will not.

Myth: People with epilepsy may hurt other people during seizures.

Fact: People are most often unconscious during seizures meaning they can't hurt someone. The person may struggle if held down, but could not deliberately hurt anyone.

How is Epilepsy Diagnosed?

In children, approximately twenty-five through thirty percent of seizures are caused by a sudden illness or injury such as a fever, brain trauma or brain or spinal fluid infection.⁴ An epilepsy diagnosis is generally made when seizures occur more than once without an identifiable reason, such as fever or injury.

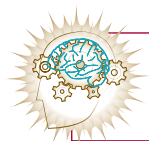
It is recommended that all children who have an unprovoked seizure seek emergency medical attention immediately following the initial seizure and then follow up with their primary care physician soon thereafter. If seizures reoccur, children should be seen as soon as possible by a specialist who manages seizures and epilepsy to ensure precise and early diagnosis and initiation of appropriate therapy.

During the diagnostic process, doctors will try to determine what caused the seizure and will begin to check for signs of epilepsy along with other treatable conditions. While every child's diagnostic process will vary, the major steps in the process should include:

- **Detailed medical history** – may include questions regarding the mother's pregnancy and delivery, any relatives with epilepsy, and if the child had a high fever, serious head injury and/or periods of staring, inattention or breath-holding.
- **Detailed account of the seizure** – it's advised that the person who was present at the time of your child's seizure communicate with the doctor.
- **Physical examination** – including assessment of cardiac, neurological and mental status.
- **Blood test** – to identify potential causes and/or to identify other significant illness.
- **CAT (Computerized Axial Tomography) or CT Scan** – can help determine whether seizures are caused by an acute or chronic brain lesion.
- **EEG (Electroencephalogram)** – shows brain wave activity that can be used to assess the risk of seizure recurrence, and it may also help determine seizure type and epilepsy syndrome (See Glossary of Common Epilepsy Terms on pg. 36). EEG also helps determine where seizures are coming from in the brain.
- **MRI (Magnetic Resonance Image)** – preferred brain picture when evaluating children with new onset seizures or seizures that may have started in a particular part of the brain.

After the exam, tests and a period of observation, your doctor will determine whether your child's seizures are being caused by epilepsy or another condition. If the doctor does diagnose your child with epilepsy, work with him/her to classify what type(s) of seizures your child is having and then discuss different treatment options. Since seizures often don't happen in the doctor's office, it is extremely important that parents and caregivers observe any unusual behavior and report them to their doctors. Again, the *Seizure Recognition and First Aid* table and *Seizure Record* form will help you keep track of that information.

You should ask your doctor whether your child's symptoms and characteristics (age, seizure frequency, family history and other factors) fit a certain kind of epilepsy syndrome or pattern. When doctors classify epilepsy into syndromes, they consider the types of seizures, test results, the child's behavior during a seizure and how they expect the child to respond to treatment.



It may not always be possible to make a definite diagnosis of epilepsy. If the diagnosis cannot be clearly established, referral to a specialty epilepsy center should be considered.

How is Epilepsy Treated?

Treatment may be the most important factor in successfully managing the condition and therefore requires close attention. There are different types of seizures, with many treatment options to consider. The goal of all epilepsy treatment is to stop the seizures with as few side effects as possible. The most common treatment is medication. If medication does not work, other options may include surgery, a medical device or a highly specialized diet.

Epilepsy is often treated by family doctors, pediatricians or internists, but your child may be referred to a neurologist or epileptologist. Doctors and parents should work together to determine the best treatment (or combination of treatments) for a child. Most children are initially treated with medication. There are currently more than 20 medications available. The doctor will choose the best one depending on your child's seizure type and syndrome, as well as possible side effects or other medications your child might be taking. Sometimes children have to try a number of different medications before finding one that works, or they may need to take multiple medications or a combination of drugs, so it is important to stay optimistic and patient during this time. If your child's seizures continue while on medication, you and your doctor may want to consider:

- **Ketogenic Diet** – an extremely strict diet that helps stop or control seizures for some children. It should be treated like serious medicine and must be closely supervised. Other more easily tolerated diets may be used in some children such as modified Atkins diet or low glycemic index diet.
- **Vagus Nerve Stimulation (VNS)** – a small battery implanted under the skin in the chest wall that sends small, regular bursts of electrical energy to the vagus nerve, a large nerve in the neck that leads directly to the brain. It is currently only approved for children 12 and over.
- **Surgery** – this option is most commonly used when the brain tissue causing seizures is confined to a small focal area of the brain, which can be safely removed without damaging function.

More information on epilepsy treatment can be found at:

- Mayo Clinic: www.mayoclinic.org/epilepsy

Depending upon how epilepsy is affecting your child, your health care coverage and what is available in your community, there are many different providers who may be part of your child's medical team and the treatment process. These may include:

- **Pediatrician** – a doctor who specializes in treating children. Some insurance plans call them a “primary care provider”. Though he/she will likely refer your child to a doctor who specializes in epilepsy or brain disorders, it is important to keep your pediatrician involved in your child’s care.
- **Neurologist** – a doctor who specializes in treating brain disorders, including epilepsy. A pediatric neurologist specializes in children’s brain disorders.
- **Epileptologist** – a neurologist who specializes in epilepsy treatment. This is usually only recommended if standard treatment isn’t working or if diagnosis remains unclear.
- **Nurse Practitioner (NP)/Advanced Practice Nurse** – a registered nurse with advanced nursing training who usually works with a pediatrician, neurologist or epileptologist.

The following providers may also be recommended for behavioral and/or learning issues sometimes associated with epilepsy:

- **Neuropsychologist** – a psychologist who specializes in the assessment of the brain’s cognitive functioning and academic achievement. (*see definition of ‘cognition’ in Common Epilepsy Terms on page 36*)
- **Mental Health Counselor** – a psychologist, social worker or psychiatric nurse who has specialized training to help children and their families with mental health issues, such as anxiety, depression and behavioral problems.
- **Physician Assistant (PA)** – a health care professional who is trained to practice medicine as part of a team with a physician.
- **Psychiatrist** – a doctor who specializes in treating psychiatric and mental health problems.
- **Psychologist** – A licensed mental health practitioner (PhD or PsyD) who specializes in evaluation and treatment of children with behavioral and learning problems.

An epilepsy diagnosis can be a frightening, unwelcome interruption in any family’s life. But with education, support and perseverance, parents can ensure that their child has a happy and meaningful life.

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Managing Epilepsy

How Can You Help Manage Your Child's Care?

After receiving a child's epilepsy diagnosis, most parents spend a lot of time juggling doctor appointments and medication schedules, researching treatment options and worrying about another seizure. It can be a busy and stressful experience. Many families find that the best way to handle these challenges is with a team approach. Like any successful team, each member has a different role or position to play, but everyone works together to accomplish the same goal—your child's well-being. Anyone who interacts with your child on a regular basis and has a role in managing their epilepsy should be considered part of this team, including family members, medical providers and staff, teachers, school nurses, coaches/instructors, babysitters, and others.



The American Academy of Pediatrics and the US Maternal and Child Health Bureau recommend that all children with special health care needs have access to a *medical home*, where health care services are accessible, family-centered, continuous, comprehensive, coordinated, compassionate and culturally-competent.⁵ A *medical home* provides high-quality health care in partnership with families and staff working together to set priorities, plan the child's care, identify community resources, and provide support in the home. Additional information on *medical homes* can be found at:

- National Center for Medical Home Implementation: www.medicalhomeinfo.org

As the day-to-day manager of your child's care, your job is to recruit the best people you can find and make sure they are doing everything they can to help your child. Before your doctor visits, write down questions you want to ask. Don't be afraid to tell your doctor about your concerns or ask if there are other treatments to consider. Use the **Medical Visit** form included in the Forms section to help you.

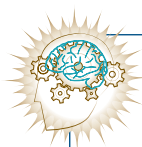
There are several tools available to help you document, organize and manage your child's care. A popular method includes maintaining a Care Notebook or Organizer, which houses all the forms included in this toolkit, along with copies of your child's various tests/reports, notes and any other information related to your child's care. You can create your own or choose from several versions available here:

- American Academy of Pediatrics: http://www.medicalhomeinfo.org/for_families/care_notebook
- Epilepsy Foundation: <http://www.epilepsy.com/get-help/toolbox/medication-and-communication-tools>

You also need to make sure your child gets the right amount of medicine and sleep, and follows recommendations made by the doctor. If your child needs to take medicine at school, you'll need to make arrangements with the teacher or school nurse and also complete the **Seizure Action Plan** form included in the Forms section of this toolkit.

If your child is taking medication, here are some important tips to remember:

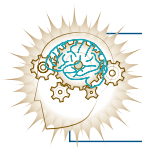
- Make sure your child takes the proper dosage and does so on time.
- Watch for any side effects, such as rash, fatigue or tiredness, nausea, loss of balance, vision changes and weight gain.
- Talk to doctors about other options if your child continues to have seizures or trouble with side effects.
- **Always talk to your doctor before making any changes in your child's medication.** Medication often works so well that parents are tempted to take their child off it or reduce the dosage. (Doing so without consulting your doctor could cause a serious increase in seizures.) Children usually need to stay on their medication for a few years before trying to stop.



Here are some tips that can help manage medication schedules:

- Keep medicine in a convenient spot so it becomes part of other daily activities. For example, near your child's toothbrush, in the kitchen, etc.
- Use a watch with a beeper to remind you or your child when it's time to take the medicine.
- Get a pillbox and count out the right amount of pills for each day.
- Make sure to refill prescriptions on time so you don't run out of medicine.

Making sure your child takes medicine exactly as the doctor prescribes is the most important thing you can do to prevent seizures. Most seizures happen randomly, with no obvious pattern. However, for some children certain activities or foods seem to trigger seizures. Whether or not a child gets enough sleep can also affect seizures. Talk to your doctor if you notice any patterns or have questions.



Common Seizure Triggers: Illness or fever, poor nutrition, stress, flickering light patterns including computer or TV screen, strobe lights, fighting/accidents, lack of sleep and menses.

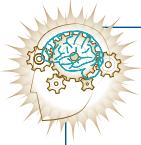
The more you know about epilepsy and the more you talk to your doctors about your child's needs, the better chance your "team" will reach its goal—to make sure your child's life is as healthy and fulfilling as possible. Follow the advice in this toolkit and use the forms included to help you achieve this goal.

What Should You Do if Your Child Has a Seizure?

Watching your child have a seizure can be frightening. You will feel much better if you and others who are with your child know what to do. Refer to the ***Seizure Recognition and First Aid*** table for how to respond, based on your child's type of seizure. This Toolkit also contains a ***Seizure Action Plan*** form to complete with your family and your child's school, so that everyone knows how best to respond if your child has a seizure.

Most seizures in children with epilepsy are not medical emergencies. They end after a minute or two without harm and usually do not require a trip to the emergency room.

The most important thing to do when your child has a seizure is **keep him/her safe**.



However, you should get immediate medical care if:

- The seizure lasts more than five minutes, the child has a series of cluster seizures or if another seizure occurs before your child returns to normal
- The seizure happened in water that the child may have swallowed
- The child has diabetes or a high fever
- The child has a head or other injury
- The child is having trouble breathing after the seizure

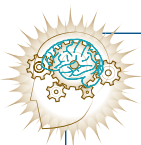
How Can You Help Keep Your Child Safe?

Wanting to do everything you can to protect your child is part of being a parent. When your child has epilepsy even everyday things, such as climbing steps, riding bicycles and swimming in the local pool can be dangerous. Each family has to make their own decisions about what is safe for their child. This will depend a lot upon your child's age, interests, type of seizures and how well your child responds to treatment. When in doubt, talk to your doctor.

In general, the more active and involved your child is, the better. However, for the child with epilepsy there are some extra safety precautions you should take. This is especially true around water. You should always:

- Supervise young children during baths and have older children take showers. Adjust the water temperature in your house to low in order to avoid serious injury if a child has a seizure when hot water is running. Make sure the drain works well and won't clog.
- Never let your child swim without an adult watching who knows your child has epilepsy and what to do in case of a seizure.

All children, especially those with epilepsy, should wear helmets when bicycling, skateboarding, etc. If your child has seizures that cause sudden falls, your doctor might also recommend wearing a helmet when playing outdoors around steps, and/or other areas that may impact the severity of a fall. Children with epilepsy can participate in many organized sports. Your physician or allied health professional should be consulted regarding any questions you may have. For the older child, be aware of the potential risks related to cooking such as injuries from hot water and stove tops.



Every day, the two most important things you can do to protect your child are to make sure that:

- Your child takes medication as directed.
- There is always someone with your child who knows what to do if your child has a seizure.

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Daily Life with Epilepsy

How Can Parents Help?

As a parent, there are many things you can do to provide support and encouragement to your child. Here are ten tips to remember:

- Learn as much as you can about epilepsy.
- Discuss epilepsy openly and honestly with your child.
- Avoid saying things that could make your child feel like a problem or burden.
- Be positive.
- Praise your child's success.
- Encourage sports, hobbies and other interests.
- Help your child make friends.
- Work with your child to explain epilepsy to friends, relatives, teachers and others.
- Continue family activities and traditions.
- Make time for yourself without feeling guilty.



How Does Epilepsy Affect Family Life?

When a child has epilepsy, it affects the whole family. As a parent you want to do everything you can to help your child. However, if you have other children you may be concerned that you are not giving them enough attention. You may be uncomfortable telling relatives because you don't want them to worry. If your child has numerous doctor appointments or is hospitalized, it can mean time away from work, adding to your stress and possible financial concerns.

Do not try to do it all alone. **One of the most important things you can do for your family is to build a support network.** Your local Epilepsy Foundation is a great place to start. See *Where to Find Support?* at the end of this section for other tips.

Take a break for your health. Respite allows you to take care of yourself so that you are physically and mentally better able to care for your child.

It is also helpful to establish routines. Routines, schedules and structure are what keep all busy families going. This is especially important for children with epilepsy. Here are some ideas:

- Have your child take medication at the same time every day.
- Make sure your child gets enough sleep to lower the risk of seizures.

- Schedule a regular time for homework.
- Give your child chores such as setting the table, picking up toys or getting water for a pet. Giving your child responsibilities will make him/her feel like a fully contributing member of the family.

If you have other children, try to understand their concerns. Having a sister or brother with epilepsy often means they get less time with their parents. Seeing their sibling have a seizure could be frightening or even embarrassing for them. Encourage them to talk about their feelings and let them know that it is okay to have them. As soon as they are old enough to understand, explain to them what epilepsy is and teach them how they can help if their sister or brother has a seizure. When you can, plan special outings or activities with them. Just ten minutes reading a book, a walk to get ice cream or watching a movie together can help children feel special. It is also important to continue to make time for traditions and celebrations (holidays, birthdays, vacations, etc.) that are so important to family life.

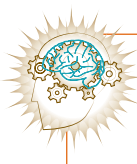
How Can You Help Your Child at School?

Most children with epilepsy can attend school and participate in everyday activities. Some may need to take medicine at school and require help with certain subjects, or extra time on tests. With more than 300,000 school-age children in the United States with epilepsy, none of this is unusual. Most children with epilepsy do not have learning problems and do well in school. However, for a variety of reasons, there is a higher rate of school performance difficulties in children with seizures. Seizures themselves rarely cause these problems, but many factors related to seizures can affect learning. For this reason, all children with epilepsy should have their school progress monitored. If your child appears to be having trouble learning, it is important to:

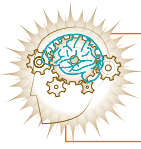
- Test the child to determine the type and severity of the learning problem.
- Look for any treatable, seizure-related factors that may be part of the learning problem.
- Create a tailored learning plan to help your child.

Start each school year by scheduling a meeting with your child's teacher and school nurse. Discuss your child's condition, any learning issues and how to respond if your child has a seizure. Complete the ***Seizure Action Plan*** form with them and assure that everyone has a copy. Keep in touch throughout the school year about your child's progress and make sure that other adults who supervise your child at school—bus drivers, student teachers, etc.—know what to do if your child has a seizure.

If epilepsy affects your child's ability to learn, you are probably entitled to special education services through the Individuals with Disabilities Education Act (IDEA). IDEA is a federal law that states that every child with a disability is entitled to free, appropriate education in the least restrictive setting possible and will have an Individualized Education Plan (IEP).⁶ An IEP describes the educational goals and accommodations, modifications and supports the school is required to provide. Under IDEA, parents are assured an active role in their child's IEP process. Your local Epilepsy Foundation can help you find out about laws and services in your state.



Who qualifies for services under IDEA? Children between the ages of 3 and through completion of 22nd birthday, who meet the eligibility criteria in one of thirteen qualifying disabilities and who require special education services because of the disability.



The IEP is a written plan/program developed by the school's special education team with input from parents. It specifies the student's academic goals and methods to obtain these goals.

There's a good chance that many of your child's teachers and classmates won't know much about epilepsy. **Educating them is one of the most important things you can do to help your child at school.** The next topic in this section *What Should You Tell Others about Your Child's Epilepsy?* can help you with this. Also, use the ***What Everyone Should Know*** fact sheet in the ***Forms*** section and provide copies to others.

Ask the teacher to discuss epilepsy with the class in a way that is age appropriate and comfortable for your child. Having a seizure at school can be embarrassing for a child and frightening for others. It is better if everyone knows about seizures in advance. Contact your local Epilepsy Foundation for assistance and to see if they can conduct a classroom presentation. To see if one is in your area, go to www.Epilepsy.com.

What Should You Tell Others About Your Child's Epilepsy?

For many kids, the most difficult part of having epilepsy is not worrying about seizures, taking medicine or frequent doctor visits. It's feeling different from everyone else. Children with epilepsy often feel as if they have to constantly explain what epilepsy is. They also might face stigma or discrimination because of the condition. Helping the people in your child's world understand epilepsy will allow them to be more comfortable with it.

When talking to children, try to keep your explanation as easy-to-understand and positive as possible. Encourage children to ask questions and be honest about their concerns or fears. If they say something that seems cruel or insensitive, try not to criticize them, but explain why it is important to think of other's feelings.

For example, if a child said, *"Tommy is weird. Yesterday he fell down and started shaking all over."* You could say, *"I'm sure it was frightening for everyone, but it's important for us to think about how Tommy felt and to try to understand what happened. Tommy had a seizure. For just a couple of minutes his brain was not able to control what he was doing. Your teacher knows how to make sure Tommy doesn't get hurt when he has a seizure and what to do to make sure that he is OK afterwards. There are two important things you can do to help Tommy."*

- 1) *If Tommy ever has a seizure and your teacher isn't there, get an adult as quickly as you can.*
- 2) *Be nice to Tommy and help others understand his condition. Tell them that just like some kids need glasses to see better and others sometimes have trouble breathing because of asthma, Tommy sometimes has seizures. His doctors are helping him find the right medicine so he doesn't have seizures too often."*

With adults, you can start by giving them a copy of ***What Everyone Should Know*** included in the ***Forms*** section to provide them with a basic overview of epilepsy. Use the ***Seizure Action Plan*** form to make sure that teachers, coaches, babysitters and others who are with your child know what to do if your child has a seizure.

Where to Find Support

Knowing that any child can get epilepsy does not make it easier to accept that your child has been diagnosed with it. Having epilepsy often creates many challenges. It's normal to ask "why us?"

Learning that you're not alone, how other families are living with epilepsy and where you can find support can help. Building these connections is not only important for you, but for your child. While every family's situation is different and each child's condition unique, after awhile just about all parents recommend the same thing: **build a support network. Do not try to do it alone!**

The school nurse, your local Epilepsy Foundation, government organizations and an online forum are all examples of where you can find support, information and other resources. However, most of the time, you will need to seek out this support. This is sometimes the hardest thing for people to do, but they are usually glad they did.

Remember, if you don't take care of yourself, you won't be able to take care of your child. You should try to go out once in a while and do something special for yourself, such as go to a movie, exercise class or dinner with friends. If you use a babysitter, talk to him/her beforehand about your child's epilepsy. Make sure the babysitter is comfortable with your child's condition before you leave him/her alone. If your child has frequent seizures, have the babysitter spend time with you and your child so he/she can see how you handle the seizures.

Epilepsy may always be a part of your child's life. But understanding the condition and knowing about the many resources to support people with epilepsy will help your child live as happy and fulfilling a life as possible. To begin building your support network, look for a mix of online and local resources. To find support groups and services available in your area, contact your nearest Epilepsy Foundation affiliate office listed in the **Resources** section. Also check with your local hospital and/or Epilepsy Center to see if they hold parent support groups. For online support, visit www.epilepsy.com/connect. You'll find online discussion groups, articles about other families with epilepsy and much more.

Specific online support networks you can visit include:

- Epilepsy.com Community: www.epilepsy.com/connect
- Facebook and Twitter: the national Epilepsy Foundation office and several of the local affiliates host pages for announcements, information, and discussion: www.facebook.com & www.twitter.com (search for epilepsy)

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Life Stages with Epilepsy

What Should I Be Concerned About as a Parent?

Epilepsy affects children of all ages and stages. Each stage has its own issues and challenges.⁶ Explaining epilepsy to your child will differ depending upon your child's age and ability to understand.

Communication is key. As soon as your child is able to understand, talk to him or her about epilepsy and answer questions openly and honestly. If you need help, talk to your doctor or ask your local Epilepsy Foundation for recommendations. Help your child feel comfortable talking to others about epilepsy. Meet with your child's teachers to discuss your child's progress and needs. Many children and families benefit from talking to professional therapists and psychologists about their concerns.



Consider sending your child to an Epilepsy Foundation-sponsored summer camp. It's not only fun, but a chance for your child to build self-confidence and find support by meeting other kids with the condition. There are camps throughout the country and financial assistance is available. To find out more about summer camp, contact your local Epilepsy Foundation.

Infants and Toddlers

Seizures occur most frequently during the first few years of life, during a time when the brain is going through its most dramatic growth and changes. Recognizing and treating seizures as early as possible can help avoid learning and developmental delays. However, diagnosing seizures in infants can be difficult, as they cannot communicate what they are feeling after a seizure or during medical tests. The more you can observe and tell your doctor, the better.

One of the biggest challenges parents of infants or toddlers with epilepsy can face is childcare. Some daycare centers may not admit children with epilepsy. Some refuse to give them emergency antiseizure medication, even though they may be required to do so by the Americans with Disabilities Act. Your local Epilepsy Foundation can provide information about laws and resources in your area.

For more information about infants and toddlers visit:

- Epilepsy.com: <http://www.epilepsy.com/get-help/services-and-support/training-programs/child-care-personnel>

Children

When children are older, having epilepsy can impact many parts of their lives, including how well they do in school, what sports they can play and how they are treated by friends. The more you can help your child lead an active, normal life, the better.

As with all children, it is best to establish routines and set clear rules and limits. Sometimes, parents worry that upsetting a child with epilepsy can lead to a seizure. Usually, if you stay calm and your child is old enough to understand why you are stopping a certain behavior, it shouldn't increase the risk of a seizure. However, if this is a concern, talk to your doctor about the best way to discipline your child.

For more information about children visit:

- WebMD: www.webmd.com/epilepsy/epilepsy-guide-8/default.htm
- Epilepsy.com: <http://www.epilepsy.com/learn/seizures-youth>

Adolescents

The pre-teen and early teen years are difficult for everyone. It's a time of great change, new challenges and some dangerous temptations. When a child develops epilepsy, the risks and insecurities that go along with this period are increased. **Talk as openly as possible with your child about epilepsy and other concerns.** Help your child find others to talk to through your local Epilepsy Foundation, the Foundation's online discussion groups and other resources. Here are some other things to consider:

- **Puberty** – Changing bodies affect how children look, feel and think. The changes in hormones can also affect seizures and medication needs, especially for girls. Talk to your doctor about whether your child might need a change in the amount or type of medication and any behavioral changes that you should be watching for.
- **Social Life** – This is the time of life when having friends and fitting in may seem to be all a child is thinking about. Being “different” in any way, such as having epilepsy, is not easy. While you can't make your child popular, you can help him/her understand that having a few good friends is actually more important than having lots of casual acquaintances. Encourage your child to talk to his/her friends about epilepsy.
- **Pregnancy** – If your teen girl is sexually active, there is a possibility that she may get pregnant. Most women with epilepsy can become pregnant, carry a child successfully through pregnancy, breastfeed and have normal healthy babies. It is important for you to know, however, that pregnancies may be higher risk for women with epilepsy, because of the possibility of seizures during pregnancy, the effects of antiepileptic drugs (AEDs) on the fetus, and the effectiveness of contraceptives in combination with AEDs. In no case should anti-seizure medications be abruptly stopped if a woman becomes pregnant. Among other recommendations, women and teens with epilepsy should be taking folic acid, and your teen's physician needs to know if she is taking birth control pills. All these issues should be discussed with the doctor and the teen so that everyone is aware of certain issues and making informed decisions and behavior choices.
- **Substance Abuse** – Alcohol and drugs are dangerous for all children, but even more so for children who are prone to seizures and may be taking medication for epilepsy. Talk to your child about the risks. Then talk some more. Ask your doctor and other people your child respects to talk to him/her, too. Studies show that even if it seems as if your child is not paying attention, it may eventually sink in. Discuss not only the risks, but also ways to get out of uncomfortable situations. For help with talking to your child about possible drug or alcohol use, visit <http://www.timetoact.org/>

- **Driving** – Every state regulates driver's license eligibility of persons with certain medical conditions. The most common requirement for people with epilepsy is that they be seizure free for a specific period of time and submit a physician's evaluation of their ability to drive safely. Another common requirement is the periodic submission of medical reports, in some states for a specified period of time and in others for as long as the person remains licensed. Discuss this with your child's neurologist and find out what you need to do to comply with your state's rules regarding driving <http://www.epilepsy.com/driving-laws>

- **Responsibility** – This is the time when teens are learning to be more independent and that their actions have consequences. If they get epilepsy at this age, it could affect their independence for awhile. As they begin to spend more time away from home, they will need to start taking some responsibilities. Work with your child and doctor to figure out the best way to organize and monitor this. See *How Can You Help Manage Your Child's Care?* in the **Managing Epilepsy** section for ideas.



Transition in health care for young adults is a process that seeks to meet their needs as they move from childhood to adulthood. Parents and the child should create a written health care transition plan in the early teen years to ensure the provision of on-going, developmentally appropriate health care services that continue uninterrupted as the child moves from adolescence to adulthood.

For more information about teens with epilepsy visit:

- Epilepsy.com: <http://www.epilepsy.com/learn/age-groups/youth/young-adults>

Sudden Unexplained Death in Epilepsy (SUDEP)

Most people with epilepsy live a full life span. However, there are potential factors associated with living with epilepsy and seizures that may increase the risk of early death. Sudden Unexplained Death in Epilepsy (SUDEP) occurs when a seemingly healthy person with epilepsy dies unexpectedly and no reason for the death can be found. Although it is not well understood, SUDEP is suspected to sometimes be related to heart rhythm problems during a seizure. SUDEP occurs more often among people with convulsive seizures, especially generalized tonic-clonic seizures that are poorly controlled. More research is needed to fully understand what causes SUDEP.

For more information about SUDEP:

- Epilepsy Foundation: <http://www.epilepsy.com/get-help/sudep-institute/getting-involved-sudep-institute>
- SUDEP Aware: www.sudepaware.org
- Epilepsy Bereaved: www.sudep.org

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Resources

Finding out that your child has epilepsy can be overwhelming at first. The good news is that there are many resources available to help support you, your child and family. The type of information and support you need may change over time and will depend on your family's unique situation. The availability of support also may differ depending on where you live. The resources listed in this section are the ones families with newly diagnosed children typically find most helpful. They will also help lead you to more specific information and support based on your family's unique needs.

Web Sites

Epilepsy Foundation

www.Epilepsy.com

The national voluntary agency dedicated to the welfare of people with epilepsy in the U.S. and their families. Every newly diagnosed parent should contact their local Epilepsy Foundation affiliate to find out what services are available in your area. The Web site also has the most comprehensive, reliable information on epilepsy available online. There are also many Epilepsy Foundation sub-Web sites to visit:

- **eCommunities:** A place for all people affected by epilepsy to share their stories – www.epilepsy.com/connect
- **Talk About It:** A site where TV and movie stars share information about epilepsy and encourage kids to talk about living with epilepsy – www.talkaboutit.org

Centers for Disease Control and Prevention - Epilepsy Programs

www.cdc.gov/epilepsy

Government agency responsible for addressing public health issues related to epilepsy to improve health, quality of life, and decrease the stigma associated with this condition.

SeizureTracker

www.seizuretracker.com

Developed by a family who has a son with epilepsy. This site has easy-to-use tools that allow patients and parents to create personalized reports of seizure activity and medication history to share with their medical team. Forms and reports can be used online or printed out.



EpilepsyClassroomwww.epilepsyclassroom.com

Developed to provide parents and teachers with tools to help change the perception of epilepsy in a child's school. The program works to educate your child's teachers and classmates, but also to empower your child to go to school confidently each day.

American Academy of Pediatrics Build Your Own Care Notebookwww.medicalhomeinfo.org/for_families/care_notebook

A tool to help parents/caregivers maintain an ongoing record of their child's care, services, and providers, along with other notes. This notebook empowers families to become experts on their child's care and is also a way to maintain the lines of communication between the many providers and services that help care for a child and their family.

Family Voices & Family-to-Family Health Information Centers (F2F HICs)www.familyvoices.org

Organization focused on family-centered care and support for all children and youth with special health care needs. F2F HICs are nonprofit, family run organizations that assist families of children and youth with special health care needs by providing support, information, resources, and training.

Parent-to-Parent USAwww.p2pusa.org

A national organization providing parent-to-parent programs that offer emotional and informational support to families of children who have special needs, most notably by matching parents seeking support with an experienced, trained support parent.

Pacer Centerwww.pacer.org

PACER Center was created by parents of children and youth with disabilities to help other parents and families facing similar challenges. The Center provides assistance to individual families, workshops, and materials for parents and professionals.

Parent Training & Information Centers and Community Parent Resource Centerswww.taalliance.org

This resource serves families of children and young adults from birth to age 22 with all disabilities—physical, cognitive, emotional, and learning—obtain appropriate education and services; connects children with disabilities to community resources that address their needs. Each state is home to at least one parent center.

Exceptional Parent Magazinewww.eparent.com

This resource provides information, support, ideas, encouragement and outreach for parents and families of children with disabilities and the professionals who work with them. **Available online and in print.**

National Information Center for Children and Youth with Disabilities (NICHCY)

www.nichcy.org

NICHCY provides information on disabilities and disability-related issues for families, educators and other professionals; focuses specifically on children and youth up to age 22.

Community Services Locator

www.mchlibrary.info/KnowledgePaths/kp_community.html

An online directory for finding services for children and families in the communities in which they live, such as health (physical and mental), family support, parenting, child care and other services.

National 211

www.211.org

2-1-1 is an easy to remember telephone number that connects people with important community services and volunteer opportunities. While services vary from community to community, 2-1-1 provides callers with information and referrals to human services agencies for everyday needs and in times of crisis.

Books**For Parents:****Epilepsy: Patient and Family Guide (2008)**

by Orrin Devinsky, M.D.

Brainstorms: Epilepsy on Our Terms - Stories by Children with Seizures and Their Parents (2008)

by Steven Schachter, M.D.; Georgia Montouris, M.D.; John M. Pellock, M.D.

Brainstorms: Epilepsy in Our View-Stories from Friends & Families of People Living with Epilepsy (2008)

by Steven C. Schachter, M.D.

Epilepsy: 199 Answers (2008)

by Andrew N. Wilner, M.D., FACP, FAAN

Missing Michael - A Mother's Story of Love, Epilepsy, and Perseverance (2005)

by Mary Lou Connolly

Growing up with Epilepsy (2003)

by Lynn Bennett Blackburn, Ph.D.

Seizures and Epilepsy in Childhood (2002)

by John Freeman, M.D., Eileen P.G. Vining, M.D., and Diana J. Pillas

The Spirit Catches You and You Fall Down (2007)

by Anne Fadiman

Brothers & Sisters (1994)

by Epilepsy Foundation

The Music Room (2009)

by William Fiennes

Children with Seizures (2006)

by Martin Kutscher

Brainstorms: Epilepsy in Our Words- Personal Accounts of Living with Seizures (2008)

by Steven C. Schachter, M.D.

The Ketogenic Diet: A Treatment for Children and Others with Epilepsy, Fourth Edition (2007)

by Jennifer Freeman, John Freeman, M.D., Eric Kossoff, M.D., Millicent Kelly, RD, LD

Epilepsy and Your Child - The 'At Your Fingertips' Guide (2004)

by Richard Appleton, Brian Chappell, Margaret Beirne

For Children & Teens:

Mommy, I Feel Funny (2009)

by Danielle M. Rocheford

Being Sara (2009)

by Chris Passudetti

Let's Learn with Teddy about Epilepsy (2008)

by Yvonne Zelenka, Ph.D.

Koko The Service Dog (2008)

by Lisa Mink, M.S.

Through His Eyes (2009)

by Lisa M. Loiodice

Epilepsy: The Ultimate Teen Guide (2007)

by Kathlyn Gay

Straight Talk on Epilepsy: What Kids Need to Know (2006)

by Epilepsy Foundation & Abbott Neurosciences

My Friend Matty: A Story About Living with Epilepsy (2005)

by Debra & Richard Siravo

Taking Seizure Disorders to School (1996)

by Kim Gosselin

Becky the Brave: A Story about Epilepsy (2002)

by Laurie Lears

Taking Seizure Disorders to School: A Story about Epilepsy (2001)

by Kim Gosselin

Special People, Special Ways (2000)

by Arlene Maguire

Karen's Epilepsy (2010)

by Elizabeth Baltaro

Frequently Asked Questions (FAQ'S)

Epilepsy

What is epilepsy?

Epilepsy is a medical condition that produces seizures that can affect mental and physical functions. It is also called a seizure disorder. Many illnesses or severe injuries can affect the brain enough to produce a single seizure. When seizures continue to occur for unknown reasons or because of a problem that cannot be corrected, the condition is known as epilepsy. *(see page 7 for more information)*

What is a seizure?

Seizures occur due to brief disturbances in the normal electrical functions of the brain. Millions of tiny electrical charges pass between nerve cells in the brain and connect to all parts of the body. When someone has epilepsy, this normal pattern may occasionally be interrupted by short bursts of electrical energy that are much stronger than usual. This can cause muscle spasms or uncontrollable body movements, loss of consciousness or confusion. These physical changes are called epileptic seizures. Normal brain function cannot return until the electrical bursts stop. Seizures can occur in just one area of the brain (partial/focal seizures) or may affect nerve cells throughout the brain (generalized seizures). Most last a few seconds or minutes. *(see page 8 for more information)*

What causes epilepsy?

In about seven out of ten people with epilepsy, no cause can be found. This is called idiopathic epilepsy. Idiopathic is a Latin word meaning “of unknown cause”. Among the rest of the people with epilepsy, the cause may be any one of a number of things that can make a difference in the way the brain works. For example, head injuries or lack of oxygen during birth may damage the delicate electrical system in the brain. Other causes include brain tumors, lead poisoning, problems in development of the brain before birth and infections like meningitis or encephalitis. Epilepsy can run in families but usually does not—you cannot catch epilepsy from someone else and nobody can catch it from you.

How common is epilepsy?

Epilepsy is the fourth most common neurological disorder in the United States after migraine, Alzheimer's disease and stroke. Its prevalence is greater than that of cerebral palsy, multiple sclerosis, and autism and Parkinson's disease combined. This year another 150,000 people in the U.S. will be diagnosed with epilepsy. Some 30 percent of people with epilepsy are severely affected and continue to have seizures despite treatment. About 316,000 American children under the age of 14 have epilepsy.

Treatment and First Aid

Which doctors treat epilepsy?

In addition to their main doctor, usually a pediatrician, most children with epilepsy will at times need to see a doctor who specializes in epilepsy treatment, such as a neurologist, pediatric neurologist, neurosurgeon, epileptologist or a neuropsychologist. Specialized care for people whose seizures are difficult to control is available in large medical centers, neurological clinics at universities and other hospitals and epilepsy centers. *(see pages 10 & 11 for more information)*

How is epilepsy treated?

Epilepsy is most often treated with medication. There are many seizure-prevention drugs (also known as antiepileptic, anticonvulsant or antiseizure drugs) available and it can sometimes take awhile to find the one or combination of drugs that works best for each child. It is important to follow your doctor's instructions about when and how much medication to give your child. The medication won't work properly until it reaches a certain level in the body, and that level has to be maintained. The goal is to keep the blood level high enough to prevent seizures, but not so high that it causes excessive sleepiness or other unpleasant side effects. If medication doesn't work, other options include surgery, a medical device or a very specialized, high-fat diet (ketogenic). *(see page 10 for more information)*

Will my child always need to take medication for epilepsy?

If a child does not have a seizure for a few years while taking medication, it may be possible to stop taking it. This is different for every child. A child should never stop taking medication unless it is recommended and closely supervised by a doctor.

Are children with epilepsy more likely to have other medical issues?

Epilepsy can increase children's chances of having a mood or learning disorder. Headaches, ulcers and other physical conditions are also more common. Such conditions that can occur along with epilepsy are called co-morbidities. It is important for parents to know about possible co-morbidities and talk to their doctors about any concerns.

What should I do or tell others to do if my child has a seizure? *(see page 19 for more information)*

The most important things to remember are:

1. Stay calm. There is very little you can do when someone is having a seizure. Don't try to stop any movements or tongue biting.
2. Move anything that could hurt the child. Put a pillow or something soft under the child's head. If you can, gently turn the child to one side to prevent choking.
3. Call an ambulance if the seizure lasts more than five minutes, the child has diabetes or is seriously hurt. If the child takes longer than usual to wake up after the seizure, call your treating physician or call 911 if the physician is not available. If the child is not breathing after the seizure, have someone call 911 and begin artificial respiration or CPR.

Raising Children with Epilepsy

This is all so new and frightening; how can I help my child get through it?

As a parent, there are many things you can do to support your child:

- Learn as much as you can about epilepsy
- Discuss epilepsy openly and honestly with your child
- Avoid saying things that could make your child feel like a problem or burden
- Be positive

- Praise your child's success
- Encourage sports, hobbies and other interests
- Help your child make friends
- Work with your child to explain epilepsy to friends, relatives, teachers and others
- Continue family activities and traditions
- Make time for yourself without feeling guilty

What should I tell teachers and friends?

Even though nearly 3 million Americans are affected by epilepsy, most people still know little about it. Help others in your child's life understand what epilepsy is and make sure they know what to do if your child has a seizure. This will not only help keep your child safe, but it will help your child feel more comfortable and do better at school. By talking openly and honestly about epilepsy, you can help decrease some of the stigma and fear about it. *(see pages 18 & 19 for more information)*

Will my child be able to live a normal life?

Most children with epilepsy live full, active lives that include school, friends, sports, and other activities. How much epilepsy interrupts a child's life depends upon the kind of epilepsy, success of treatment and many other factors. Talk to your child's doctor about what activities your child can do and encourage your child to participate. As your child grows, help him/her become more independent. Driving, college, career, marriage and raising a family are possible for the vast majority of people with epilepsy.

How can I help my child accept this and not feel so different?

- Help your child talk openly and honestly with others about epilepsy
- Encourage your child to go online and visit various epilepsy-related child and teen-tailored Web sites
- Consider sending your child to an Epilepsy Foundation camp
- If your child is facing teasing or bullying, visit the Stop Bullying Web site www.StopBullying.gov

Where can I find help?

That's one of the most important questions you can ask! Almost all parents of children with epilepsy recommend the same thing: "Build a support network. Do not try to do it alone!" Here are some great places to start:

- Local and National Epilepsy Foundation
- *eCommunities*
- Parent to Parent-USA (P2P-USA)
- Family Voices: Family-to-Family Health Information Centers

Additional information on these organizations can be found in the **Resources** section on page 25.

Common Epilepsy Terms

Absence seizure: (formerly called *petit mal*) generalized seizure which occurs most commonly in children; a lapse in consciousness with a blank stare that begins and ends within a few seconds and may be accompanied by rapid eye blinking or chewing movements.

Adjunct therapy: add-on therapy or treatment administered in addition to another.

Affect: mood, level of emotional responsiveness.

American Epilepsy Society (AES): the professional society for professionals specializing in epilepsy and closely related fields that focuses on treatment of biological, clinical and social aspects of epilepsy.

Amygdala: part of the brain's limbic system. Seizures arising in this area include a rising sensation in the stomach, nausea, mouth movements, chewing, fear, panic, flushed face and other autonomic symptoms.

Aneurysm: a bulge in a blood vessel caused by weakness in the vessel wall; can be a cause of seizures when it occurs in the brain.

Angelman syndrome: a genetic disorder marked by severe intellectual and development disability, speaking difficulties, inappropriate laughter and hyperactivity; most children with this syndrome also have epilepsy.

Anticonvulsant: an agent that halts or prevents convulsions.

Antiepileptic: an agent that halts or prevents seizures (there is no agent that prevents epilepsy).

Antiepileptic drug (AED): a seizure-preventing drug carried to the brain through the bloodstream.

Aphasia: inability to use or understand language (spoken or written) as a result of injury or disease in the brain's speech centers.

Apnea: cessation of breathing.

Ataxia: inability to coordinate muscle movement.

Atonic seizure: (or drop attack) generalized seizure where sudden complete loss of muscle control and balance results in collapse.

Aura: a sensation that precedes the onset of a seizure, which may include uneasiness, déjà vu, sensory illusions (odors, visual illusions or misconceptions, sounds), stomach discomfort, and/or dizziness.

Automatism: involuntary, undirected movements which can occur during focal or absence seizures.

Bioavailability: the amount of a drug in a capsule or tablet that actually enters the blood stream.

Bioequivalency: equal performance of two or more substances used as therapy.

Blood level monitoring: the monitoring of antiepileptic drugs levels in the bloodstream to ensure the proper amount is being metabolized.

Breakthrough seizures: seizures that occur despite treatment/medication therapy.

Catamenial epilepsy: a tendency for a woman's seizures to occur primarily at the time of menstruation.

Cavernous angioma: an abnormal tangle of blood vessels that can cause seizures when it occurs in the brain.

Cerebellum: a brain structure involved in the control and coordination of voluntary muscle movements and balance.

Cerebral cortex: the outermost layer of the cerebral hemispheres of the brain responsible for all forms of conscious experience, including perception, emotion, thought and planning. This is often called the grey matter of the brain.

Chronic: affecting a person for a long period of time; a slowly progressing and continuing disorder.

Clonic: seizure involving muscle contractions and relaxations.

Clustering: involves repeated seizures in a short span of time following long periods of no seizure activity.

Cognition: the process by which knowledge is acquired; awareness, thinking, learning and memory.

Complex partial seizure: A focal seizure (also called psychomotor or temporal lobe) during which there is impairment of consciousness (awareness) with onset within one hemisphere of the brain, often beginning with a blank stare and/or aura.

Compliance: refers to patient adherence to physician directions for taking antiepileptic drugs.

Computerized axial tomography scan (CAT or CT): imaging technique that creates three-dimensional images of the brain and shows possible abnormalities.

Convulsion: involuntary muscle contractions common in generalized tonic-clonic seizures.

Corpus callosotomy: a surgical procedure to sever the nerve fibers connecting the two hemispheres of the brain in order to interrupt the spread of seizures from one side of the brain to the other (*also see: surgery for epilepsy*).

Cortical dysplasia: abnormal development of the cortex that can cause seizures.

Craniotomy: an opening made into the skull for brain mapping and epilepsy surgery.

Cryptogenic: of unknown origin.

Depth electrodes: thin wires placed deep in the brain to detect seizure activity that cannot be recorded from the surface of the brain.

EEG (electroencephalogram): a type of noninvasive, painless and safe test performed to measure the electrical activity of the brain, often used in diagnosing or managing epilepsy.

Encephalitis: inflammation of the brain from an infection or other disease that can cause epilepsy.

Epilepsy: chronic neurological disorder characterized by recurrent seizures, estimated to affect 2.2 million Americans.

Epilepsy Foundation: the voluntary, non-profit organization that provides local and national services for people with epilepsy and funds research into causes and cures for the disorder.

Epileptologist: a physician (neurologist) expert in the diagnosis and treatment of epilepsy.

Etiology: cause of a disease or medical condition.

Febrile seizure: seizure related to high fever in babies and children, usually under age five. Most children who have a febrile seizure do not develop epilepsy.

Focal seizure: an epileptic seizure that involves one part or area of the brain (*partial seizure*).

Focus: identified area of the brain from which partial seizures arise.

Frontal lobe: located in upper region of the head, behind the forehead; frontal lobe controls decision-making, problem-solving or planning and motor movement.

Gamma knife surgery (radio surgery): a form of radiation therapy that uses gamma rays to destroy seizure-causing tissue in the brain.

Generalized seizure: main classification of seizure that involves the whole brain (see also: types of generalized seizures: tonic-clonic and absence).

Hemispherectomy: surgical removal of one hemisphere of the brain; with epilepsy, performed almost exclusively in children for whom severely damaged tissue spanning one hemisphere produces uncontrollable seizures (*see also: surgery for epilepsy*).

Hippocampal sclerosis: cell loss and hardening of the hippocampus.

Hippocampus: part of the brain's limbic system that is partly responsible for memory.

Hyperventilation: rapid, deep breathing.

Ictal: pertaining to, characterized by, or caused by an epileptic seizure.

Ictus: a seizure or stroke.

Idiopathic: of unknown origin or cause.

Incidence: the frequency in which something occurs over a specified time period (e.g. 50,000 children will be diagnosed with epilepsy each year).

Infantile spasms: a specific type of seizure seen in infancy and childhood (onset typically between 4-8 months of age) known as West Syndrome. The seizures primarily consist of a sudden bending forward of the body with stiffening of the arms and legs.

Interictal: the period of time between one seizure and another.

International Bureau for Epilepsy (IBE): the international lay organization concerned with medical, social and scientific aspects of epilepsy that exchanges information and experience on care of patients with seizures.

International classification: a periodically updated classification of seizure types, behaviors and causes used to characterize seizure disorders and epileptic syndromes.

International League Against Epilepsy (ILAE): the international professional organization for physicians which encourages scientific research on epilepsy and the exchange of information.

Intractable: not responding to treatment.

Ketogenic diet: stringent, high fat, low carbohydrate diet that can control seizures in some children. Less stringent similar diets can be used at times, a modified Atkins diet or low glycemic index diet

Lafora disease: a rare form of myoclonic epilepsy leading to progressive disability, dementia and a shortened lifespan.

Landau-Kleffner syndrome: a rare, childhood condition producing seizures and progressive loss of the ability to speak.

Lennox-Gastaut syndrome: debilitating epileptic syndrome in children characterized by myoclonic, absence and tonic-clonic seizures.

Lesion: wound or injury that results in pathological change in tissue (e.g. head injury which results in seizure-causing lesions in the brain). Lesions are sometimes surgically removed to reduce or prevent recurring seizures.

Limbic system: comprised of the brain's hippocampus, amygdala, septum, and parts of the cortex to influence the body's unconscious movement and hormonal activity.

Lissencephaly: refers to an abnormal smooth brain without folds.

Lobe: any rounded, projecting part of the anatomy; the brain has four lobes: frontal, parietal, temporal and occipital.

Lobectomy: surgical removal of all or part of the lobe of the brain bearing abnormal seizure-causing tissue (*see also: surgery for epilepsy*).

Magnetic resonance imaging (MRI): an imaging method using magnets instead of x-rays that produces detailed pictures of the internal structure of the brain and is the preferred method for evaluating new onset seizures.

Magnetoencephalography–(MEG): records magnetic activity generated by the brain's electrical activity; helps identify brain areas where seizures begin.

March: progression of muscular convulsions from one muscle or muscle group to another.

Meningitis: inflammation of the membranes of the brain and spinal cord; sometimes causes epilepsy.

Monotherapy: treatment with a single drug.

Multifocal epilepsy: epilepsy in which the seizures come from a number of locations in the brain.

Multiple subpial transsection (MST): surgery in which shallow parallel cuts are made in the cortex; used to reduce or eliminate seizures that come from critical brain areas that cannot be removed.

Myoclonic seizures: a type of generalized seizure causing massive, rapid clonic spasms of muscle(s).

Neurocysticercosis: a parasitic brain infection from eating bad pork; a common cause of seizures in some U.S. immigrants.

Neurologist: a specialist in the diagnosis and treatment of nervous system diseases and disorders such as epilepsy.

Neurons (or nerve cells): the cells that form the brain and send and receive messages to and from the rest of the body.

Nocturnal seizures: seizures that occur routinely in the evening hours and, especially, during sleep.

Nonepileptic seizures: seizures with a psychological cause or which are due to a sudden drop in blood pressure, low blood sugar or other temporary condition.

Occipital lobe: brain lobe at the rear of the head identified with vision.

Parietal lobe: brain lobe that interprets sensory input and the body's relation to space.

Partial seizure: main classification of seizure involving only one part of the brain, categorized as either simple partial or complex partial in the older classification of seizures (*see also: focal seizure*).

Perinatal: the fetal development period from the 28th week of gestation to seven days after delivery. Complications such as prolonged lack of oxygen or other trauma may result in epilepsy in the newborn.

Pharmacotherapy: medication therapy.

Photosensitivity: when seizures are triggered by flashing lights or patterns (e.g. strobe lights, video games or flipping and rolling of a television screen). An estimated three percent of people with epilepsy are photosensitive. (*see also: reflex epilepsy*)

Polytherapy: (or polypharmacy) the use of two or more antiepileptic medications for control of seizures.

Post-ictal confusion: temporary incoherence, inability to respond, and/or unfamiliarity with environment which commonly follows tonic-clonic, complex partial and atonic seizures.

Prodromal: indicating the onset of a disease. In epilepsy, indicating the onset of a seizure.

Pseudoseizure: more appropriately referred to as non-epileptic spells. A sudden disruptive change in a person's behavior which resembles epileptic seizures but has no electrophysiological changes in the brain; may be related to physical illness, psychiatric or emotional disorder.

Reflex epilepsy: rare epilepsy that occurs in response to specific sensory stimulus, including flickering light or patterns, sounds, tastes, smells, movements or sensations of touch.

Refractory: difficult to treat, unresponsive or of limited response to medication.

Seizure: abnormal electrical discharge in the brain. Seizures can be related to injury, high fever, substance abuse, metabolic disorders and other health conditions such as diabetes, and are not always a sign of epilepsy.

Seizure prediction: complex automated brainwave analysis that can predict an oncoming seizure up to 30 minutes or more before it is clinically apparent.

Seizure semiology: the clinical symptoms of a seizure.

Seizure threshold: the point at which a person can no longer tolerate a seizure-provoking stimulus (e.g., babies have a lower seizure threshold for high body temperature than do adults. High fever can trigger febrile [fever-related] seizures in babies.

Simple partial seizure: most common type of seizure activity in one part of the brain where person remains conscious but often displays jerking in one area of the body, arm, leg or face and/or distorted environments, sensory illusion or gastric discomfort (*see focal seizures*).

Single-Photon Emission Computerized Tomography (SPECT): an imaging technique to measure blood flow in the brain.

Status epilepticus: severe, potentially life-threatening non-stop seizures, not always related to epilepsy; status epilepticus can result from acute brain injury.

Stereotactic surgery: brain surgery performed with the head held in an immovable position by a special positioning device.

Subdural: referring to the area beneath the tough membrane (dura) which forms the outer envelope of the brain.

SUDEP (sudden unexplained death in epilepsy): a rare condition in which death occurs without an apparent cause but which is presumed to be related to the person's epilepsy.

Surgery for epilepsy: removal of the part(s) of the brain determined to cause seizures in a patient for whom medications prove ineffective. Surgery candidates must undergo a battery of tests and evaluations to ensure all alternatives have been exhausted, pinpoint the area of the brain where seizures begin, and map areas which must be preserved. (*see also: lobectomy, hemispherectomy, corpus callosotomy*).

Syncope: fainting due to a loss of blood flow to the brain; sometimes misdiagnosed as seizures.

Syndrome: a set of symptoms characterizing a disease, disorder or condition. An epilepsy syndrome is the complete set of seizure types and symptoms experienced by a patient. Currently, there are more than 11 widely accepted epileptic syndromes.

Temporal lobes: the areas of the brain that lie at the side of the head behind the temples and which are involved in hearing, memory, emotion, language, illusions, tastes, and smells. (*see also: lobe, anterior lobe, occipital lobe, parietal lobe*).

Temporal lobe seizure: a partial seizure involving the temporal lobe. Symptoms vary but may include visual and auditory hallucinations or distortions, déjà vu, feelings of detachment from surroundings and automatisms. Consciousness may be impaired or lost.

Tonic-clonic: a generalized seizure that usually begin with a sudden cry, fall and rigidity (tonic phase) followed by muscle jerks, shallow breathing or temporarily suspended breathing and change in skin color (clonic phase), possible loss of bladder or bowel control; seizure usually lasts a couple of minutes, followed by confusion and fatigue.

Trans-cranial magnetic stimulation: an unproven experimental procedure that exposes the brain to a strong magnetic field as a potential treatment for epilepsy.

Vagus nerve: a nerve which begins at the brain stem and passes through the cranial cavity past the jugular to the throat, larynx, lungs, heart, esophagus, stomach and abdomen.

Vagus nerve stimulator (VNS): a device to reduce severity of seizures through electrical stimulation of the vagus nerve. The device is implanted in the upper left chest with electrodes encircling the vagus nerve.

Wada test: (or intracarotid sodium amobarbital procedure) a test commonly performed in patients considering surgery to locate the dominant side of the brain's speech and memory centers.

Local Epilepsy Foundation Affiliates

Alabama

Epilepsy Foundation Alabama

Mobile, AL

800-626-1582 or 251-341-0170

www.epilepsyfoundationalabama.org

Alaska

Epilepsy Foundation Northwest

Seattle, WA

800-752-3509 or 206-547-4551

www.epilepsynw.org

Arizona

Epilepsy Foundation Arizona

Phoenix, AZ

888-768-2690

www.epilepsyfoundation.org/arizona

California

Epilepsy Foundation Greater Los Angeles

800-564-0445 or 310-670-2870

www.epilepsyfoundationgla.org

Epilepsy Foundation Northern California

San Francisco, CA

800-632-3532

www.epilepsynorcal.org

Epilepsy Foundation San Diego County

San Diego, CA

619-296-0161

www.epilepsysandiego.org

Colorado

Epilepsy Foundation Colorado

Greenwood Village, CO

888-378-9779 or 303-377-9774

www.epilepsycolorado.org

Connecticut

Epilepsy Foundation Connecticut

Middletown, CT

800-899-3745 or 860-346-1924

www.epilepsyct.com

Delaware

Epilepsy Foundation Delaware

Newport, DE

877-369-2266 or 302-999-9313

www.efde.org

District of Columbia

Epilepsy Foundation Metropolitan Washington

Landover, MD

800-332-1000 or 301-918-2117

[www.epilepsyfoundation.org/local/
MetropolitanWashington](http://www.epilepsyfoundation.org/local/MetropolitanWashington)

Florida

Epilepsy Foundation Florida

Miami, FL

877-553-7453 or 305-670-4949

www.epilepsyfla.org

Georgia

Epilepsy Foundation Georgia

Atlanta, GA

800-527-7105 or 404-527-7155

www.epilepsyga.org

Epilepsy Foundation Southeast Tennessee

Chattanooga, TN

866-570-1789 or 423-634-1771

www.epilepsy-setn.org

Hawaii

Epilepsy Foundation Hawaii

Honolulu, HI
866-528-3058 or 808-528-3058
www.epilepsyhawaii.org

Idaho

Epilepsy Foundation Idaho

Boise, ID
800-237-6676 or 208-344-4340
www.epilepsyidaho.org

Illinois

Epilepsy Foundation Greater Chicago

800-273-6027 or 312-939-8622
www.epilepsyichicago.org

Epilepsy Foundation Greater Southern Illinois

Belleville, IL
866-848-0472 or 618-236-2181
www.efgreatersil.org/

Epilepsy Foundation North/Central Illinois, Iowa & Nebraska

Rockford, IL
800-221-2689 or 815-964-2689
www.epilepsyheartland.org/

Indiana

Epilepsy Foundation Indiana

Indianapolis, IN
800-526-6618 or 317-876-0600
www.indianaepilepsyfoundation.org

Epilepsy Foundation Kentuckiana

Louisville, KY
866-275-1078 or 502-637-4440
www.epilepsyfoundation.org/kentuckiana

Epilepsy Foundation Greater Cincinnati & Columbus

Cincinnati, OH
877-804-2241 or 513-721-2905
www.cincinnatiepilepsy.org

Iowa

Epilepsy Foundation North/Central Illinois, Iowa & Nebraska

Rockford, IL
800-221-2689 or 815-964-2689
www.epilepsyheartland.org/

Kansas

Epilepsy Foundation Missouri & Kansas

Saint Louis, MO
800-264-6970 or 314-781-4949
www.efmk.org

Kentucky

Epilepsy Foundation Greater Cincinnati & Columbus

Cincinnati, OH
877-804-2241 or 513-721-2905
www.cincinnatiepilepsy.org

Epilepsy Foundation Kentuckiana

Louisville, KY
866-275-1078 or 502-637-4440
www.efky.org

Louisiana

Epilepsy Foundation Louisiana

Baton Rouge, LA
800-960-0587 or 225-298-5499
www.epilepsylouisiana.org/

Maine

Epilepsy Foundation New England

Boston, MA
888-576-9996 or 617-506-6041
www.epilepsynewengland.org

Maryland

Epilepsy Foundation Chesapeake Region

Towson, MD
800-492-2523 or 410-828-7700
www.abilitiesnetwork.org

Massachusetts

Epilepsy Foundation New England

Boston, MA
888-576-9996 or 617-506-6041
www.epilepsynewengland.org

Michigan

Epilepsy Foundation Michigan

Southfield, MI
800-377-6226 or 248-351-7979
www.epilepsymichigan.org

Minnesota

Epilepsy Foundation Minnesota

Saint Paul, MN
800-779-0777 or 651-287-2300
www.efmn.org

Mississippi

Epilepsy Foundation Mississippi

Flowood, MS
800-264-6970 or 601-936-5222
www.epilepsy-ms.org

Missouri

Epilepsy Foundation Missouri & Kansas

Saint Louis, MO
800-264-6970 or 314-781-4949
www.efmk.org

Nebraska

Epilepsy Foundation North/Central Illinois, Iowa & Nebraska

Rockford, IL
800-221-2689 or 815-964-2689
www.epilepsyheartland.org/

New Hampshire

Epilepsy Foundation New England

Boston, MA
888-576-9996 or 617-506-6041
www.epilepsynewengland.org

New Jersey

Epilepsy Foundation New Jersey

Trenton, NJ
800-336-5843
www.efnj.com

New York

Epilepsy Foundation Long Island

Garden City, NY
888-672-7154 or 516-739-7733
www.efli.org

Epilepsy Foundation Metropolitan New York

New York, NY
212-677-8550
www.efmny.org

Epilepsy Foundation Northeastern New York

Albany, NY
800-894-3223 or 518-456-7501
www.epilepsyfoundation.org/efneny

Epilepsy Foundation Rochester-Syracuse-Binghamton

Rochester, NY
800-724-7930 or 585-442-4430
www.epiny.org

North Carolina

Epilepsy Foundation North Carolina

Winston Salem, NC
800-451-0694 or 336-716-2320
www.epilepsync.org

North Dakota

Epilepsy Foundation Minnesota

Saint Paul, MN
800-779-0777 or 651-287-2300
www.efmn.org

Ohio

Epilepsy Foundation Greater Cincinnati & Columbus

Cincinnati, OH
877-804-2241 or 513-721-2905
www.cincinnatiepilepsy.org

Epilepsy Foundation Western Ohio

Dayton, OH
800-360-3296 or 937-233-2500
www.epilepsyfoundation.org/westernohio

Oregon

Epilepsy Foundation Northwest

Seattle, WA
800-752-3509 or 206-547-4551
www.epilepsynw.org

Pennsylvania

Epilepsy Foundation Eastern Pennsylvania

Philadelphia, PA
800-887-7165 or 215-629-5003
www.efepa.org

Epilepsy Foundation Western/Central Pennsylvania

Pittsburgh, PA
800-361-5885 or 412-322-5880
www.efwp.org

Puerto Rico

Sociedad Puertorriquena De Epilepsia

Bayamón, PR
787-782-6200
www.sociedadepilepsiapr.org

Rhode Island

Epilepsy Foundation New England

Boston, MA
888-576-9996 or 617-506-6041
www.epilepsynewengland.org

Tennessee

Epilepsy Foundation East Tennessee

Knoxville, TN
800-951-4991 or 865-522-4991
www.efeasttn.org/

Epilepsy Foundation Middle & West Tennessee

Nashville, TN
800-244-0768 or 615-269-7091
www.epilepsytn.pmhclients.com/index.php

Epilepsy Foundation Southeast Tennessee

Chattanooga, TN
866-570-1789 or 423-634-1771
www.epilepsy-setn.org

Texas

Epilepsy Foundation Central & South Texas

San Antonio, TX
888-606-5353 or 210-653-5353
www.efcst.org

Epilepsy Foundation Texas - Houston/Dallas/Fort Worth

Houston, TX
888-548-9716 or 713-789-6295
www.eftx.org

Vermont

Epilepsy Foundation Vermont

Rutland, VT
800-565-0972 or 802-775-1686
www.epilepsyvt.org

Virginia

Epilepsy Foundation Virginia

Charlottesville, VA
434-924-8669
www.efva.org

Washington

Epilepsy Foundation Northwest

Seattle, WA
800-752-3509 or 206-547-4551
www.epilepsynw.org

Wisconsin

Epilepsy Foundation Heart of Wisconsin

Madison, WI
800-693-2287 or 608-442-5555
www.epilepsywisconsin.org

Epilepsy Foundation Southeast Wisconsin

Milwaukee, WI
877-271-1994 or 414-271-0110
www.epilepsyfoundationsewi.org

Epilepsy Foundation Western Wisconsin

Eau Claire, WI
800-924-2105 or 715-834-4455
www.epilepsywesternwi.org

Some states may have additional local offices/branches throughout the state. Please call closest office to confirm locations.

Endnotes

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Seizure Recognition and First Aid

Seizure Type	What it Looks Like	What it is Not	What to Do
Generalized Tonic-Clonic (Also called Grand Mal)	Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control, usually lasts a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue, followed by return to full consciousness.	Heart attack. Stroke.	Look for medical identification. Protect from nearby hazards. Loosen shirt collars. Protect head from injury. Turn on side to keep airway clear unless injury exists. Reassure as consciousness returns. If single seizure lasted less than 5 minutes, ask if hospital evaluation wanted.
Absence (Also called Petit Mal)	A blank stare, beginning and ending abruptly, lasting only a few seconds, most common in children. May be accompanied by rapid blinking, some chewing movements of the mouth. Child or adult is unaware of what's going on during the seizure, but quickly returns to full awareness once it has stopped. May result in learning difficulties if not recognized and treated.	Daydreaming. Lack of attention. Deliberate ignoring of adult instructions.	No first aid necessary, but if this is the first observation of the seizure(s), medical evaluation should be recommended.
Simple Partial (Also called Focal)	Jerking may begin in one area of body, arm, leg, or face. Can't be stopped, but patient stays awake and aware. Jerking may proceed from one area of the body to another, and sometimes spreads to become a convulsive seizure. Partial sensory seizures may not be obvious to an onlooker. Patient experiences a distorted environment. May see or hear things that aren't there, may feel unexplained fear, sadness, anger, or joy. May have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.	Acting out, bizarre behavior. Hysteria. Mental illness. Psychosomatic illness. Parapsychological or mystical experience.	No first aid necessary unless seizure becomes convulsive, then first aid as above. No immediate action needed other than reassurance and emotional support. Medical evaluation should be recommended.
Complex Partial (Also called Psychomotor or Temporal Lobe, a Focal seizure with alteration of consciousness)	Usually starts with blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed and mumble. Unresponsive. Actions clumsy, not directed. May pick at clothing, pick up objects, try to take clothes off. May run, appear afraid. May struggle or flail at restraint. Once pattern is established, same set of actions usually occur with each seizure. Lasts a few minutes, but post-seizure confusion can last substantially longer. No memory of what happened during seizure period.	Drunkenness. Intoxication on drugs. Mental illness. Disorderly conduct.	Speak calmly and reassuringly to patient and others. Guide gently away from obvious hazards. Stay with person until completely aware of environment. Offer to help get person home.
Atonic Seizures (Also called Drop Attacks)	A child or adult suddenly collapses and falls. After 10 seconds to a minute he recovers, regains consciousness, and can stand and walk again. This is not a sleep disorder.	Clumsiness. Normal childhood "stage." In a child, lack of good walking skills. In an adult, drunkenness, acute illness.	No first aid needed (unless he hurt himself as he fell), but the child should be given a thorough medical evaluation. The child may need a helmet.
Myoclonic Seizures	Sudden brief, massive muscle jerks that may involve the whole body or parts of the body. May cause person to spill what they were holding or fall off a chair.	Clumsiness. Poor coordination.	No first aid needed, but should be given a thorough medical evaluation.
Infantile Spasms	These are clusters of quick, sudden movements that start between three months and two years. If a child is sitting up, the head will fall forward, and the arms will flex forward. If lying down, the knees will be drawn up, with arms and head flexed forward as if the baby is reaching for support.	Normal movements of the baby. Colic.	No first aid, but doctor should be consulted.

First Aid for Seizures

(Complex partial, psychomotor, temporal lobe)

1. Recognize common symptoms



2. Follow first-aid steps



People who've had this type of seizure should be fully conscious and aware before being left on their own. Make sure they know the date, where they are, and where

they're going next. Confusion may last longer than the seizure itself and may be hazardous. If full awareness does not return, call for medical assistance.



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Managing Your Child's Epilepsy: A Checklist

The time around your child's diagnosis can be overwhelming. On top of maintaining your family's daily schedule, there can be a lot of appointments to manage, people to talk to and reading to do. Many parents fear that if they don't get it all figured out overnight, their child might have another seizure. Try your best to take everything in stride. Your doctor will tell you the immediate and most urgent next steps you should take. In addition, use this checklist to help guide you in the process from diagnosis to management. Since each child and family's situation is different, this list may not include everything, but offers a starting point for general care and management of your child's epilepsy.

Managing Epilepsy

Medical Visit

- ☐ Find out from your doctor what your immediate next steps should be.
- ☐ Ask questions and use the **Medical Visit** form included in this toolkit to record important information from the visit.
- ☐ Get copies of all your child's test results and any other documents for your records.
- ☐ Find out if and when you need to schedule follow-up appointments with any other providers (specialists, primary care physician, psychologist, school nurse, etc.)
- ☐ Develop a care plan with your doctor.
- ☐ Make sure your child has the opportunity to ask questions.

Medication

- ☐ Follow all instructions provided by the doctor
- ☐ Have your child's prescription filled exactly as prescribed (make sure the pharmacist has not switched manufacturer) and begin giving your child the medicine exactly as the doctor instructed.
- ☐ Keep careful watch for any side effects and/or changes you see in your child and record them in the **Medication Record** form in this toolkit to tell the doctor during the next visit.
- ☐ If medication is to be taken at school, ask your pharmacist to prepare a labeled prescription bottle for school nurse.

Seizure Control:

If your child has a seizure:

- ☐ Follow the instructions the doctor gave you for how to respond. You may also refer to the **Seizure Recognition & First Aid** table in this toolkit.
- ☐ Begin using the **Seizure Record** forms in this toolkit to record a detailed description of the seizure to tell your doctor.
- ☐ If the seizure lasts longer than five minutes, call 911.
- ☐ Educate your family, school staff and others who spend time alone with your child on what to do if your child has a seizure.
- ☐ Meet with your child's school teacher and/or nurse to complete the **Seizure Action Plan** form in this toolkit.
- ☐ Take the necessary steps to reduce any seizure triggers.
- ☐ Take the necessary steps to ensure that adequate safety precautions are in place.
- ☐ Avoid overprotecting and limiting your child's activities.

Managing Life with Epilepsy

Educating Yourself, Your Child and Others

- ☐ Understand your child's diagnosis. Your doctor should have provided you with the following information during your medical visit:
 - o Background information about epilepsy
 - o Your child's specific epilepsy syndrome and seizure type
 - o Prognosis
 - o Diagnosis and treatment options
 - o Medication side effects & management
 - o Managing seizures – triggers, first aid, emergencies
 - o Epilepsy management and self-care
 - o Safety – risks and precautions
 - o Learning and/or psychological issues
 - o School issues
 - o Resources – information, support programs/services

If the doctor did not provide you with this information, follow up with him/her accordingly. You can also do your own research. There is a wealth of information available online and through the Epilepsy Foundation.

- ☐ Gather and organize information and resources. It's important to keep careful track of your child's medical documentation, care management forms (such as the ones provided in this toolkit) and other important information so that you have it when you need it.
- ☐ Educate your child on his/her epilepsy diagnosis in an appropriate age-manner and encourage independent learning.
- ☐ Educate your family.
- ☐ Educate your child's school teachers, staff, classmates and others in your child's life.
- ☐ Pay extra attention to educating and talking openly about epilepsy with your child and his/her friends.

School

- ☐ Schedule an appointment with your child's teacher(s), school nurse, coaches, etc. to make them aware of your child's epilepsy and the role each of them will have to ensure proper management.
- ☐ Complete the ***Seizure Action Plan*** with the school nurse.
- ☐ Discuss the need for close observation regarding medication side effects and/or learning/behavioral problems.
- ☐ If your child has a learning disorder, work with the teachers to develop an Individual Education Plan (IEP).
- ☐ Follow-up with your child's teacher and school staff regularly to monitor progress.

Support/Coping

- ☐ Do not try to do it alone.
- ☐ Take care of yourself.
- ☐ Find out what resources are available in your local area by calling your local Epilepsy Foundation affiliate or asking your doctor and utilize them.
- ☐ Look to other parents and seek out local or online support groups.
- ☐ Encourage your child and the rest of the family to be open and honest about their feelings.
- ☐ Continue family traditions and activities.
- ☐ Carve out special time to spend with your other children.
- ☐ Schedule an appointment with a therapist or counselor for yourself, your child, and/or family if you think it will help.



What Everyone Should Know About Epilepsy

Epilepsy affects over 2.2 million Americans. It is prevalent or common enough that everyone should know about it. Here is some very basic information that you can copy and share with others:

What is epilepsy?

Epilepsy is a chronic neurological condition characterized by recurrent seizures. A seizure happens when abnormal electrical activity in the brain causes an involuntary change in body movement or function, sensation, awareness or behavior. A person can have a seizure due to a number of other treatable conditions. Epilepsy is diagnosed when a person has two or more seizures that cannot be attributed to another condition. It is a physical condition and not a mental illness or sign of low intelligence.

What is a seizure?

A seizure is a brief electrical disturbance in the brain that often causes sudden, uncontrolled changes in movement, behavior and consciousness. There are many types of seizures, but they are generally classified into two main categories by what part of the brain is involved. Generalized seizures affect the whole brain. Partial seizures only affect part of the brain. If you know someone with epilepsy, you should become familiar with what type(s) of seizure they have and how best to respond.

Who has epilepsy?

It is estimated that nearly 2.2 million Americans are currently diagnosed with epilepsy; 316,000 are children and youth ages 14 and younger. Most people develop epilepsy in early childhood or later in life. Of the 150,000 new cases of epilepsy diagnosed each year, approximately 50,000 of these cases will be diagnosed in children and adolescents under the age of 18. About two-thirds of all children with epilepsy outgrow their seizures by the time they are teenagers. While epilepsy can present many challenges, most people who have it live full, active lives.

Why do people develop epilepsy?

Anyone can get epilepsy. It affects people of every age, race/ethnicity, nationality, background, etc. In 70 percent of the cases, there is no known cause. Among the rest, there can be a number of different causes, such as brain tumors, serious head injuries and brain infections. In most cases epilepsy is not inherited, although people with a close family member with epilepsy are at a slightly greater risk. Epilepsy is not contagious.

How can you help someone who is having a seizure?

The most important things to remember are:

- Stay calm. There is very little you can do when someone is having a seizure. Don't try to stop any movements or tongue biting.
- Move anything that could hurt the person. Put a pillow or something soft under the person's head. If you can, gently turn the person to one side to prevent choking.
- Call an ambulance if the seizure lasts more than five minutes, the person has diabetes or is pregnant, or if the person is seriously hurt. If the person is not breathing after the seizure, have someone call 911 and begin artificial respiration or CPR.
- If someone has a seizure in water, keep the person's head tilted above the water and get medical attention immediately after.
- Do not force any object in the person's mouth.

How is epilepsy treated?

The most common treatment for epilepsy is medication. If that doesn't work, other options may include surgery, a medical device, or for children, a highly specialized diet. The goal of all treatment is to stop the seizures with as few side effects as possible.

Where can you learn more about epilepsy?

Visit or www.epilepsy.com or contact your local Epilepsy Foundation affiliate office.



Seizure Record

The following form will help you keep a record of when your child's seizures occur. You should find it useful for giving the doctor an accurate report. It will be particularly helpful during the early visits when the doctor is developing the proper medication program for your child. The form below allows for your own description and notes, while the ***Seizure Observation Record*** provides a more guided, detailed format to keep track of the seizures.

Date/ Time	Length of Seizure	Description of Seizure	Other Details/Information

Seizure Observation Record

The *Seizure Observation Record* provides a guided, detailed format to keep track of a person's seizures. This form can be used by any observer including parents, family members, caregivers, teachers, coaches, etc.

Name:					
	Seizure #1		Seizure #2		Seizure #3
Date & Time:					
PRE-SEIZURE OBSERVATIONS:					
List & describe behaviors, triggers, activities, etc.					
Awake when seizure started? (yes/no/altered)					
Injuries sustained during seizure: (briefly describe)					
SENSATIONS EXPERIENCED BY PERSON:	Please Circle Yes or No				
Feeling that something has already happened	Yes	No	Yes	No	Yes No
"Funny" taste in the mouth	Yes	No	Yes	No	Yes No
"Funny" feeling in the stomach	Yes	No	Yes	No	Yes No
Changes in vision (blurriness, etc.)	Yes	No	Yes	No	Yes No
Changes in hearing	Yes	No	Yes	No	Yes No
Strange or surprising smells	Yes	No	Yes	No	Yes No
MUSCLETONE/BODY MOVEMENT:	Please Circle Yes or No				
Rigid/Clenching	Yes	No	Yes	No	Yes No
Limp	Yes	No	Yes	No	Yes No
Fell Down	Yes	No	Yes	No	Yes No
Rocking	Yes	No	Yes	No	Yes No
Wandering Around	Yes	No	Yes	No	Yes No
Whole Body Jerking	Yes	No	Yes	No	Yes No
EXTREMITY MOVEMENTS:	Please Circle Yes or No				
Right Arm Jerking	YesNo	Yes	No	Yes	No
Left Arm Jerking	YesNo	Yes	No	Yes	No
Right Leg Jerking	YesNo	Yes	No	Yes	No
Left Leg Jerking	YesNo	Yes	No	Yes	No
Random Arm/Leg Movement	YesNo	Yes	No	Yes	No
COLOR:	Please Circle Yes or No				
Bluish	YesNo	Yes	No	Yes	No
Pale	YesNo	Yes	No	Yes	No
Flushed	YesNo	Yes	No	Yes	No

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Seizure Observation Record

continued from previous page

Name:					
	Seizure #1		Seizure #2		Seizure #3
Date & Time:					
EYES:	Please Circle Yes or No				
Pupil Dilated	Yes	No	Yes	No	Yes No
Turned to One Side (R or L)	Yes	No	Yes	No	Yes No
Rolled up/Not Visible	Yes	No	Yes	No	Yes No
Staring or Blinking	Yes	No	Yes	No	Yes No
Closed	Yes	No	Yes	No	Yes No
MOUTH:	Please Circle Yes or No				
Salivating	Yes	No	Yes	No	Yes No
Chewing	Yes	No	Yes	No	Yes No
Lip-Smacking	Yes	No	Yes	No	Yes No
OTHER SYMPTOMS (PLEASE DESCRIBE):	Please Circle Yes or No				
Verbal Sounds: (Gagging, talking, throat clearing, etc.)	Yes	No	Yes	No	Yes No
Breathing: (Normal, heavy, stopped, noisy, etc.)	Yes	No	Yes	No	Yes No
Incontinence: (Urine or feces)	YesNo	Yes	No	Yes	No
POST-SEIZURE OBSERVATION:	Please Circle Yes or No				
Confused	YesNo	Yes	No	Yes	No
Sleepy/Tired	YesNo	Yes	No	Yes	No
Headache	YesNo	Yes	No	Yes	No
Slurred Speech	YesNo	Yes	No	Yes	No
Other (please describe)					
Seizure Length?					
How long to full awareness?					
Parents/Guardian Notified? (Time of call)					
EMS called? (Time of call & arrival time)					
Observer's name					
ADDITIONAL COMMENTS:					

What is a Seizure Action Plan?

A Seizure Action Plan (SAP) is a document that provides detailed health and medical information about a student and his/her epilepsy or seizure disorder. More explanation is provided on page 18 in the section, 'How Can You Help Your Child at School?'. Usually, the SAP provides guidelines as to how to respond when a student is experiencing a seizure. This document will include input from the student's guardian, physician and/or neurology specialist.

Who uses it?

Every individual who interacts with a student who has a seizure disorder will benefit from this information. Specifically, school teachers, school nurses, coaches and other individuals with supervisory roles, should receive and review the SAP.

Where is it kept?

Typically, school nurses serve as the "gatekeeper" of the SAP. It is advisable for a school nurse to have the SAP in the student's file; and, the classroom teacher(s) should have a copy. Parents and physicians usually keep a copy as well.

Why is it necessary?

If a student has been diagnosed with epilepsy the child and his/her family will likely not consider a seizure an emergency. Unfortunately, most of the time seizures are treated as an emergency. Often, 911 is dialed. This creates unnecessary medical expenses and is embarrassing for the student. The SAP provides student specific information that will enable the most appropriate response for the student. It also provides information to explain when a seizure is an emergency and 911 should be dialed.

Who will benefit?

Everyone benefits from a SAP. Students are more likely to receive an appropriate response, school teachers and school nurses have the necessary information to respond and provide first aid, and parents are more at ease knowing that a written plan is in place.

Is there a cost involved?

No, a SAP is free provided that the student has access to, and visits, a physician treating their seizure disorder. The only cost involved is related to the time it takes to write and read the document.

How often is the SAP updated?

It will depend on the needs of each student and changes in his/her medical condition. Most students will have the SAP for the entire school year and maybe as long as they attend a given school. Students with more complex conditions may have their plan updated more frequently by their physician or medical specialist.

Seizure Action Plan

This student is being treated for a seizure disorder. The information below should assist you if a seizure occurs during school hours.

Student's Name	Date of Birth	
Parent/Guardian	Phone	Cell
Other Emergency Contact	Phone	Cell
Treating Physician	Phone	
Significant Medical History		

Seizure Information

Seizure Type	Length	Frequency	Description

Seizure triggers or warning signs:

Students's response after a seizure:

Basic First Aid Care & Comfort

Please describe basic first aid procedures:

Does student need to leave the classroom after a seizure? ☐ Yes ☐ No

If YES, describe process for returning student to classroom:

Basic Seizure First Aid

- Stay calm & track time
 - Keep child safe
 - Do not restrain
 - Do not put anything in mouth
 - Stay with child until fully conscious
 - Record seizure in log
- For tonic-clonic seizure:**
- Protect head
 - Keep airway open/watch breathing
 - Turn child on side

Emergency Response

A "seizure emergency" for this student is defined as:

Seizure Emergency Protocol (Check all that apply and clarify below)

- ☐ Contact school nurse at _____
- ☐ Call 911 for transport to _____
- ☐ Notify parent or emergency contact
- ☐ Administer emergency medications as indicated below
- ☐ Notify doctor
- ☐ Other _____

A seizure is generally considered an emergency when:

- Convulsive (tonic-clonic) seizure lasts longer than 5 minutes
- Student has repeat seizures without regaining consciousness
- Student is injured or has diabetes
- Student has a first-time seizure
- Student has breathing difficulties
- Student has a seizure in water

Treatment Protocol During School Hours (include daily and emergency medications)

Emerg. Med.	Medication	Dosage & Time of Day Given	Common Side Effects & Special Instructions

Does student have a Vagus Nerve Stimulator? ☐ Yes ☐ No If YES, describe magnet use:

Special Considerations and Precautions (regarding school activities, sports, trips, etc.)

Describe any special considerations or precautions:

Physician Signature_____

Date_____

Parent/Guardian/Signature_____

Date_____



Medications Record

This form will serve as a permanent record of drugs that have been prescribed for your child and the effect each has had. Keep it updated every time there is a change in the type of medication, the amount prescribed, and/or how often it is to be taken. Use the last column to make notes and reminders on special doctor's instructions and any changes you notice in your child's health or mood that you think may be related to the drug. Be sure to discuss this information the next time you see the doctor. If your child develops a rash, is very fatigued, or shows any health signs that concern you, call the doctor at once.

Medication	Dose	Start/Stop Date	Comments/Notes

Medical Visit

Use this form to get the most out of your visits with the doctor. It can help to remind you of the important questions you should ask and record the doctor's answers and any other instructions or comments.

Appointment Date: _____

Doctor's Name: _____

Before the Visit

1. Reason for today's visit:	
2. How long has this been going on?	
3. What makes it better/worse?	
4. What have you tried so far?	

During the Visit

1. What is the diagnosis?	
2. Does my child need a prescription? If yes, what is the medication and dosage?	
3. What should the medication do and when?	
4. Is there anything I should watch out for / side effects?	
5. If no medication is needed, what should I do for my child to resolve the issue?	
6. What should I do if my child gets sick or has more symptoms?	
7. Where can I get more information?	
Other Notes/Comments: (Follow-up visit, Other things discussed, etc...)	

Other Questions to Ask During Your Medical Visit

Seizure Management

- What's the best first aid for my child's epilepsy or type(s) of seizures?
- What would qualify as an emergency for my child?
- Should the paramedics or an ambulance be called every time?
- How long should I wait before calling an ambulance if the seizure goes on longer than usual?
- Should I let my doctor or nurses know when my child has a seizure or just at check-ups?
- Should my child see a neurologist/specialist or go to a special center for more testing?
- In addition to medication, what else can I do to help avoid and/or manage seizures?

Treatment

- Is there anything I can do to help manage potential side effects from the medication?
- Are there any in-home treatments for clusters of seizures or seizures that last longer than usual that I should know about?
- If the medicine is causing a lot of side effects at home and/or school, is there another medicine that we could try?
- Could the medicine be making my child act up? Or is this all part of what's causing the seizures?
- Would the ketogenic diet work for my child? Is there a dietitian who has experience with the ketogenic diet associated with this plan?
- Does my child have the kind of epilepsy that might be treated by surgery?
- Would the VNS (vagus nerve stimulation) device help my child?
- What are the risks and benefits of other treatment options (ketogenic diet, surgery, VNS)?

Other

- Are there any activities my child should avoid or take extra precaution when doing?
- Should I have my child tested for learning or attention problems and where would I get this done?
- If my child is not doing well at school could it be caused by the medicine he or she is taking, or is it more likely due to the seizures or a learning disability?
- Who else should I schedule appointments or follow-up with?
- Are there any special services or activities my child or our family might benefit from?
- Who else should I tell about my child's epilepsy and what should I tell them?

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