

PARENTS' GUIDE:
WHEN THE SEIZURES DON'T STOP...
WHY-AND WHAT TO DO NEXT



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It is always difficult for any parent to be faced with a child who is ill – even the slightest sniffle or fever can be the source of great concern. A child who experiences a seizure is even more upsetting – the parents usually have no idea what is happening or what to do. There may even be the fear of death. Nothing that the parents do usually has any effect on shortening the seizure.

The first seizure is upsetting enough, but when seizures continue, the parents may become completely overwhelmed and confused. They worry about whether they need to go to the emergency room each time there is a seizure, whether they should call the doctor, and are increasingly confused and anxious when they realize that there is little that they or anyone else can do to shorten seizures.

WHAT IS EPILEPSY?



WHAT IS A SEIZURE?

Seizures are not a mental disorder. Everyone's brain contains billions of nerve cells called neurons, which conduct nerve impulses by means of electricity. A seizure occurs when there is too much electricity in the brain and the neurons fire all at once.

WHEN DOES A SEIZURE BECOME EPILEPSY?

Epilepsy is a clinical diagnosis – it is based on the number of seizures. A child has epilepsy when he or she has two or more unprovoked seizures – that is, seizures without a known cause such as fever, head injury, drug use, alcohol use, or sleep deprivation.

DO SEIZURES CAUSE BRAIN DAMAGE?

Generally, seizures do not cause brain damage unless they last for a prolonged period of time. Controlling seizures is a way to lessen the risk of seizure-related brain damage.

DOES BRAIN DAMAGE CAUSE A SEIZURE?

Yes, brain damage caused by head trauma or tumors can be a cause of seizures.

CAN MY CHILD DIE FROM A SEIZURE?

The chance of your child dying from a seizure is very small. There is a risk of physical harm due to falls and injury associated with partial loss of consciousness. The "Seizure First Aid" section of this booklet contains suggestions for minimizing these risks.

WHY DO CHILDREN GET SEIZURES?

There are many different reasons why children get seizures:

- Seizures can occur as a result of trauma – accidents, falls, being hit in the head.
- They can also occur as a result of brain defects that are present at birth.¹ These may include bleeding in the brain, disorders of brain development or lack of oxygen at birth. Usually when there is a birth defect, there are other signs or symptoms that the parents are also aware of – such as premature birth, developmental disorders, cerebral palsy or mental retardation. However, most children who have epilepsy do not have mental retardation, cerebral palsy, or other problems. Likewise, most children who do have mental retardation or cerebral palsy do not have epilepsy.
- Seizures can also occur as a result of a brain tumor.¹ However, again, there are usually other symptoms present before the seizure.
- Some children have metabolic disorders that cause seizures¹ – again, there are usually other symptoms that occur with the seizures.
- Seizures can occur when an overwhelming infection is present¹ – fever, virus, meningitis.
- The cause of most cases of childhood seizures is unknown.

PEOPLE TALK ABOUT PARTIAL AND GENERALIZED SEIZURES. WHAT IS THE DIFFERENCE?

The type of seizure depends upon what part of the brain is affected. Some seizures cause convulsions or strange behavior. Other types of seizures are subtle and more difficult to recognize. Despite how the seizures look, it's important to know that your child is not in pain.

Some people experience a warning sign, which is a feeling of being frightened, abnormal taste or smell, or abnormal sensation. This is called the “aura.” Recognizing an aura can help people with epilepsy prepare for a seizure or at least warn others that a seizure is coming.

Generalized seizures affect both sides of the brain. The types of generalized seizures are listed below.

- **Absence seizures** (may be referred to as “petit mal”) result in a momentary loss of awareness sometimes accompanied by involuntary movements of the face, blinking, or arm movements. Children experiencing an absence seizure will generally have a glazed look and they will not respond if they are called or touched.

Children who are daydreaming will respond to such stimulation. Absence seizures usually last 15 seconds and cause no confusion afterwards. They may occur many times throughout the day.

- **Tonic-clonic seizures** (may be referred to as “grand mal”) are the most common in children with epilepsy. These seizures cause convulsions in which the body stiffens and then goes into massive jerking movements. These seizures usually last a minute or two. Breathing is shallow or even stops for a short time as the jerking movements end. The lips and face may turn blue, which resolves once the seizure is over. The child may be confused, sleepy, or appear angry as consciousness returns.

- **Atonic seizures** cause sudden, brief loss of muscle tone so the child falls without being able to react.
- **Myoclonic seizures** cause sudden, brief, and massive muscle jerks (similar to “sleep jerk” that most people experience on occasion when they are falling asleep). The force of the jerks can be mild to severe.

In contrast to generalized seizures, partial seizures involve only a part of the brain. The two types of partial seizures are called *complex* and *simple*.

- **Complex partial seizures** may begin with a blank stare as if in a dreamlike state. The child may begin making random movements, mumbling, walking around, or pulling at his/her clothing. The child is not conscious of his/her behavior and will not remember what happened during the seizure.
- **Simple partial seizures** are partial seizures in which consciousness is maintained; however, the child may not be able to control body movements. Senses may also be distorted so the child sees, hears, smells, or experiences feelings that are not real. This may cause them to be confused or frightened.

HOW DO I STOP THE SEIZURES?

Children are often taken to the emergency room when they have a seizure. This trip may prove frustrating for the parents, as generally, the child will be observed and perhaps blood tests will be done, but often no specific treatment may be given. There are some treatments that can be given at home by the parents or caregivers to stop certain types of seizures. Your doctor can provide you with additional information about these options. The doctor should always be notified of any seizures that have occurred, especially if they cannot be stopped. Emergency room personnel may call the child’s neurologist for additional information.

HOW DO I STOP THE SEIZURES FROM OCCURRING?

There are many things that can trigger seizures (or make it easier for seizures to occur). These include fevers, lack of sleep, and certain medications. All children who have a history of seizures should be on a strict bedtime schedule, both during the week and on weekends. It is important to notify the parents of friends when a sleepover is occurring to communicate the importance of the need for sleep. This point should also be emphasized with your child.

A fever also makes it easier for seizures to occur. Children who have fevers should be on a strict fever management regimen. It is very important to follow the neurologist’s and pediatrician’s instructions to avoid elevated temperatures.

Some medications may also make it easier for the seizure to occur. Be sure to check with your child’s doctor before starting any other medications, even for unrelated illnesses. The doctor will be happy to provide a list of medications to avoid.

Antiepileptic drugs are medications that work to prevent seizures. There are several different mechanisms that medications use to prevent seizures – including affecting nerve cell chemistry and changing the levels of neurotransmitters (the chemicals that transmit nerve impulses from one neuron to another). Different medications work on one or more of these mechanisms.²

WHY DIDN'T THE SEIZURES STOP AFTER THE FIRST MEDICATIONS?

Patients may continue to have seizures even though they are treated with antiepileptic drugs. The goal is to decrease the number and the frequency of the seizures. Patients may not have their seizures controlled on the first medication that is used for their seizures.³ Most neurologists will continue to increase the dose to the maximum level for the patient's size before deciding that the medication is not working. If certain side effects occur, your child's doctor may stop the medication or lower the dose. Do not stop your child's medication without consulting the doctor.

HOW DOES THE DOCTOR DECIDE WHAT MEDICATIONS TO USE?

Usually a physician begins with a medication that is known (after many clinical studies) to be safe and effective. Certain medications are indicated for certain types of seizures. Your doctor may prescribe one of these medications if there is strong evidence in the medical literature that it is beneficial.

WHAT HAPPENS WHEN THE FIRST MEDICATION FAILS?

If the first medication fails to control the seizures adequately (including increasing the dose to the highest level that can be safely tolerated), the doctor may switch to a new medication or add a second medication. The goal is always to control the seizures with as few medications as possible and with the least side effects.² More medications lead to more risk of interaction and to an increase in side effects.

Parents may become particularly concerned when more medications are added. The usual rule of thumb is that the child is started on one medication. That dose is slowly increased until the child is at a therapeutic dose – one that is appropriate for his

or her weight and age. If seizures continue, a second medication is added and slowly increased until seizures are controlled. Dose adjustments to both medications are made when seizures are controlled. There are occasions when a child may continue to need two or more medications for seizure control.

IS IT POSSIBLE FOR MEDICATIONS TO MAKE SEIZURES WORSE?

Usually, medications do not make seizures worse or more frequent. In some instances, however, certain medications can make certain seizure types worse. This is part of the reason that careful selection and monitoring of medication by your doctor is an important process.

MY CHILD HAS BEEN ON TWO MEDICATIONS AND NEITHER HAS STOPPED THE SEIZURES. NOW WHAT?

In rare instances, a child may need to try more than two medications or may require the use of more than two medications at one time. It is always important that your doctor continue to investigate the use of other medications and to consider other treatment options such as the vagal nerve stimulator, diet or surgery.

HOW DO I FIND A NEUROLOGIST?

Ask your pediatrician or your own primary care doctor. You can also ask your local Epilepsy Foundation. If your child has been hospitalized, ask the nurses who cared for your child in the hospital. Ask your friends – it is amazing how many people have seen a pediatric neurologist or who have friends and family with epilepsy.

HOW DO I KNOW WHICH DOCTOR IS THE RIGHT ONE TO TREAT MY CHILD?

Any child who is having seizures (except for fever-related) should be seen by a neurologist for evaluation. Children diagnosed with epilepsy may be referred to a pediatric neurologist – a physician who is specially trained in both pediatrics and neurology. Pediatric epileptologists are specialists who have been trained in pediatrics, neurology and epilepsy.

WHAT ABOUT MY DOCTOR'S TEAM?

Many doctors work closely with nurse practitioners and epilepsy nurses. These are people who have extra training and certification in pediatrics and neurology. These team members may also prescribe medications and may make decisions regarding treatment options in consultation with doctors. Nurses provide valuable assistance to families regarding school needs and referrals to other doctors if required. They may help set up tests, order blood work, and are also well versed in issues regarding epilepsy.

Doctors and nurse practitioners usually have staff working with them including office managers and secretaries. These staff can help with facilitating appointments, and ordering tests. Often, it is much faster to talk to the staff when there is no emergency and leave a message for the doctor or nurse practitioner.

WHAT QUESTIONS SHOULD I ASK MY DOCTOR?

Parents, at the first visit and at every subsequent visit, should have a list of prepared questions. It is important initially to ask the following questions – and many of these can be asked of the office staff before you even get into the doctor's office:

Are you board certified in neurology, child neurology, epilepsy?

What hospitals are you affiliated with – where is your epilepsy center located?

Who else is on your staff? Which doctors cover for you? Do you have nurse practitioners, nurses, and physician assistants?

How do I get in touch with you in an emergency?

How do I set up appointments?

How do I obtain prescriptions?

Where do I get blood work done?

How long have you been practicing?

Do you see only children or children and adults – if you see both, what percentage of patients are children?

What percentage of your practice is epilepsy?

Do you only treat epilepsy?

Are you involved in any clinical trials?

Do you mind if I get a second opinion?

How do you feel about me using alternative therapies in addition to the medications you prescribe?

HOW DO I CONTACT MY DOCTOR IN EMERGENCIES?

Most doctors will give you a card or a letter detailing ways to get in touch. You will be told what to do in an emergency – make sure you have a way to quickly get in touch with your doctor if necessary – you don't want to be placed on hold or routed through an answering service if your child is in the middle of a seizure.

For routine questions, or updates on a child's condition, many practices will ask you to email. Be sure to ask about this and when email should be used. Also be sure to ask the doctor how to get in touch about blood results, test results, EEG results, etc.

SHOULD I GET A SECOND OPINION?

No one should discourage you from getting a second opinion. Consider talking to someone who specializes in epilepsy.

HOW IS EPILEPSY DIAGNOSED?



WHAT TESTS MAY BE DONE ON MY CHILD?

A variety of different tests may be done. It is unlikely that any of these tests will be done on the day of your appointment with the doctor. If your child goes to the emergency room with a seizure, usually only a CT scan and blood work will be done.

WHAT IS A CT SCAN?

A CT scan or CAT scan is a way of looking quickly for obvious abnormalities in the skull – it is used to make sure that there are no abnormalities in the bones (like a skull fracture) and no obvious tumors. It is often done in the emergency room when a child comes in after a seizure.

WHAT IS AN MRI?

An MRI looks at the structure of the brain. It is often used in children who have seizures that are suspected to arise from one particular area of the brain. An MRI may be used to rule out abnormalities like tumors or vascular problems like enlarged veins or arteries. If an MRI is ordered for your child, you will receive instructions about what the test will be like, as well as any preparations that are required.

Sometimes the doctor may want an MRI with contrast – this means that during the MRI, an intravenous tube is inserted and a temporary dye is injected into your child's blood system. This allows for a better view of certain structures in the brain.

WHEN DO WE NEED TO REPEAT AN MRI?

MRIs may need to be repeated when there is a change in the type of seizures or when the child's condition changes, or to monitor an area of abnormality within the brain. Your doctor will tell you whether or not it needs to be repeated periodically.

WHAT IS AN EEG (electroencephalogram)?

This is a machine that records brain waves. Tiny wires are taped to the head and electrical signals from brain cells are recorded as wavy lines. Your child must lie still for approximately one hour. Special patterns help the doctor decide whether or not a child has epilepsy, as well as what type of seizures he or she is experiencing. Treatments for seizure disorders are partially based upon the EEG results.

Often children are scheduled for "sleep-deprived" EEGs. This means that the child is kept up later than usual the night before the EEG and is awakened earlier than usual the day of the EEG. The child should be kept awake while traveling to the laboratory for the EEG, so that he or she will fall asleep during the test. The doctor will want to see the EEG during sleep. During the EEG, the child may be asked to hyperventilate by blowing quickly and lights may be flashed in his or her eyes. This is to simulate conditions that may also bring on a seizure.

Younger children may be sedated for EEGs. You will receive instructions on how to prepare your child for this test. Heart rate and oxygen will be monitored by the appropriate staff during the procedure.

WHAT IS A VIDEO EEG?

A video EEG is an EEG that is performed continuously for 24 to 72 hours in a hospital. It is less upsetting for many young children. This time, the tiny wires are affixed to the head with a stronger adhesive and wrapped with gauze, so that they are more difficult to remove. The wires are then usually hooked up to a backpack-like device that connects to a computer. The child can move somewhat around the room, but should try to stay within range of the video camera. The entire time that the EEG is being recorded the child is on the video camera. This way, any events or episodes can be recorded and the doctor can view the event at the same time as the EEG. Parents or family members should plan on staying with the child. They are instructed to push a button on the backpack whenever they notice the child staring or seizing or doing anything unusual. While pushing the button, they should speak clearly to the speaker and record what is occurring. This allows the technicians and doctors to quickly view the events.

While the child is having the video EEG (and staying in the Epilepsy Monitoring Unit), a technician and nurses are always available, as are doctors.

In more difficult cases of epilepsy or in ones where seizures continue over many years, the physician may want to order other tests. These may include PET scans, SPECT scans, and MEG scans. These are performed in special centers to determine exactly where in the brain the seizures are beginning.

WHAT IS A PET SCAN?

A PET scan measures the local uptake of a chemical in the brain by imaging the measurement of rates of chemical reactions. It studies energy metabolism and helps to localize the area where the seizures begin.

WHAT IS A SPECT SCAN?

A SPECT scan estimates blood flow in different areas of the brain. It requires injection of a solution through an intravenous tube while a seizure is occurring. It is used to assist in the localization of seizure onset, and is sometimes done prior to surgery.

WHAT IS A MEG SCAN?

A MEG scan measures the magnetic field around different currents in the brain. It can localize the area of the brain where the seizures are starting.

HOW IS EPILEPSY TREATED?



WHAT MEDICATIONS ARE USED TO TREAT EPILEPSY?

Often, children with epilepsy are placed on medication to control their seizures. Your doctor will determine which medications are the most appropriate for your child's seizure type. One of the most important things to ask about are which side effects can be expected, which are potentially serious, and which side effects should be immediately reported to the doctor. You should also ask about drug interactions and what other medications should not be used while your child is on seizure medications. Some parents may be concerned that the medications have changed their children's mood or emotions. If this is the case, it is a good idea to contact your doctor.

It is important to understand that all medications have side effects. This does not mean that your child will have all or maybe even any of the side effects associated with the medication. It is a good idea to ask your doctor what the side effects are, what the likelihood is of your child experiencing side effects, and which side effects require immediate attention.

When your child is placed on medication, there are certain questions that you should ask.

Use this grid to keep track of the answers (tear out [A]):

What is the starting dose?	
How often will we increase the medication?	
What is the maximum dose?	
When would we discuss a change in medications?	
What are the side effects?	
What is the likelihood that my child will have side effects?	
Will blood work or other tests be required?	
What do I tell the school?	
What medications can my child not take with this medication?	
Do you have information for me regarding this medication?	

WHAT IS THE KETOGENIC DIET?

Some children who have seizures that do not respond to medications may be treated with the ketogenic diet. This is a diet that is very high in fat and low in carbohydrates. It must be started in a hospital, with a team that specializes in the use of the diet. While the child is on the diet, he or she must be closely monitored – using blood and urine tests.

WHAT IS “VNS,” OR VAGUS NERVE STIMULATION?

Vagus nerve stimulation (VNS) is a treatment that may be tried when partial seizures cannot be controlled by other methods. A small, disk-like generator about the size of a stopwatch is surgically implanted under the skin of the chest. The device is programmed to release regular energy impulses that are routed to the brain in order to regulate brain activity. If a child senses a seizure coming on, the device can be manually activated to give extra impulses of energy.

The VNS system does not promise complete freedom from seizures, and medication is usually required after the procedure. This option can be further discussed with your child’s doctor.

WHAT ELSE SHOULD I KNOW TO HELP MY CHILD?



WILL MY CHILD NEED BLOOD TESTS?

If your child takes medications to control the seizures, blood work will typically be ordered at the beginning of the treatment and periodically while your child is taking medication. This is to monitor blood levels of the medication. Some doctors check blood often, others infrequently. Check with your doctor about how often blood work will be done.

ARE THERE ANY MEDICATIONS THAT MY CHILD SHOULD NOT TAKE?

Yes, some medications may make it easier for your child to have a seizure. You should particularly avoid certain over-the-counter medications and check with your doctor or pharmacist for clarification. Some birth control medications may affect levels of antiepileptic medications. You should notify your neurologist of any medications that have been prescribed for your child by other healthcare professionals.

WHAT ABOUT VITAMINS?

Typically, patients who take medication to prevent seizures should discuss taking calcium supplements and a multivitamin with their doctor. Girls who have gone through puberty should also discuss taking folic acid with their doctor. Talk to your doctor about types and amounts of vitamins and supplements.

WHAT ABOUT HERBS AND HOMEOPATHIC MEDICATIONS?

Some herbs and traditional medications used in the US and in other countries can interact with the epilepsy medications or may contain alcohol. It is always best to bring the medication to your doctor in its original container so that he or she can decide whether its use is appropriate.

WHAT ABOUT DIET?

Check with your child's doctor about any diet restrictions or food to avoid.

CAN MY CHILD DRIVE?

No one whose seizures are uncontrolled should drive a car. Each state has specific rules for drivers with epilepsy. Usually there is a requirement that drivers should be seizure-free for at least 6 months before driving. In some states, doctors are required to report their patients with epilepsy to the Department of Motor Vehicles. Drivers are required to self-report their health history. Check with your state Department of Motor Vehicles for your state's specific rules.

WHAT ABOUT DRINKING ALCOHOL?

Alcohol lowers the seizure threshold and makes it easier for a seizure to occur. It also interacts with many medications. Discussions with your doctor are recommended.

WHAT ABOUT SLEEP?

Lack of sleep lowers the seizure threshold and makes it easier to have a seizure. Teens and children typically need nine to ten hours of sleep per night – in one solid block.

HOW DO I MANAGE MY CHILD'S EPILEPSY?



WHY DID THIS HAPPEN TO MY CHILD?

Like many parents, you may be wondering if it was something you did or didn't do that triggered epilepsy. You may be searching for a cause as a way to understand why this happened to your child. It is unlikely that you did anything to cause your child's epilepsy.

It is perfectly normal to feel overwhelmed and confused at first. But if you ask lots of questions and gather as much information as you can, you are doing the most effective thing to help your child.

IT'S TIME TO TAKE CONTROL AND GET ORGANIZED!

One of the most important things that you can do for yourself and your child is to get all the information that is coming in rapidly organized. It is very helpful if you have complete medical records available for all the treating doctors who are involved in your child's care.

Start immediately – get a large binder and divide it into sections for a running log, test results, questions, doctor information, seizure log, medication log, insurance information, therapists, and schools.

1. Running log – this should be where you jot down results of every doctor visit, every phone conversation, and lists of questions to ask the doctors. Take notes while you are in the doctor’s office – it is very common to arrive home and not remember half of what is said. Have one notebook that is only for keeping notes. You will also need to keep a seizure log – noting date and time of each seizure, what the seizure looked like and how long it lasted, as well as whether or not medications were given to stop the seizure. You’ll need to keep a medication log, as well, noting when doses were changed and medications were added or discontinued. It’s important to keep track of any side effects that occurred.

This is particularly important if your doctor manages any of your child’s care over the phone – phone calls may or may not be documented by the doctor in the chart. Don’t just rely on your memory or the doctor’s notes – keep detailed records of every telephone conversation.

2. Keep track of your child’s sleep, behavior, appetite, weight gain or loss, and menses.

HOW DO I KEEP TRACK OF ALL THE TESTS THAT MY CHILD HAS?

1. Keep track of tests: Each time that a test is done, you should ask the doctor for a written copy of the report – blood, CT scans, MRIs, EEGs, etc. Keep this in one section of your folder or binder.

2. You should also keep track of how often your child has seizures:

The following is a sample of a seizure log. It helps keep track of each time your child has a seizure and what occurs during the seizure. A tear out sample log can be found in the back of this book (tear out [B]) and includes important information to tell the doctor.

Date	Time	Length	Symptoms*	Brought on by**	Treatment***

* For example: cyanosis (turning blue), eye deviation, flexion, extension, head dropped, noises, vomiting, one-sided or both sides, general shaking, lip smacking, chewing, bizarre behaviors, loss of muscle tone, brief sudden jerk, clonic, tonic, tonic-clonic
 ** For example: lack of sleep, fever, missed medication, late medication,
 *** For example: went to ER, called doctor, tests done in ER, doctor’s orders

3. You will also need to track the medications that are used to control your child’s seizures: Keep a medication log – sample form is below. Again, a tear out sample can be found in the back of this book (tear out [C]) and contains useful information to help you keep track of what medications worked, what combinations were used and what side effects occurred.

Date	Medication	Dose	# Seizures	Blood Level	Side Effects

4. Keep a list of doctors with whom you've spoken or seen (tear out [D] in back of book):

Doctor	Specialty	Phone	Address	Referred by

5. Keep a list of therapists (tear out [E] in back of book):

Name	Type	Phone	Address	Email	Referred by

6. Keep a list of school contacts (tear out [F] in back of book):

Name	Address	Phone	Contact	Referred by

7. Insurance: Keep a separate binder for copies of bills, checks, contacts at the insurance company, etc. Get a case worker at the insurance company.

8. Questions: Have a spot to jot down the questions that occur to you in the wee hours of the morning and leave room for answers.

9. Keep a list of parent contacts: names, numbers

10. Keep a list of agencies: names, numbers, and contacts

WHERE DO I FIND INFORMATION ABOUT MY CHILD'S CONDITION?

Look in bookstores (especially medical school bookstores), the library (libraries will special order books for you), and government agencies.

Search online, but BE CAREFUL and use common sense. Do not go to chat rooms – they can be full of worst case scenarios and items written by parents dissatisfied with their child's care. Go only to reputable medical sites – some are listed at the end of this book.

Do not buy mail order "miracle treatments" without talking to your doctor. Remember, if "miracle treatments" truly performed miracles, every doctor would be using them.

Talk to other parents, go to seminars (often run by the big epilepsy centers), look in the phone book for agencies that help with your child's disease, ask your doctor for referrals to Early Intervention programs or the Committees on Special Education in your school district. Buy magazines that deal with disabilities.

WHAT ABOUT SUPPORT GROUPS?

Find support groups for yourself, your spouse and your family. You are no use to your child and your family if you are overwhelmed or become sick. Your children sense your stress and it scares them. You need a place to talk out your fears and concerns. Look in the phone book under: Disabilities; Parents for; Agencies for; League for; or under the actual disease or disability. Your doctor, nurse, Early Intervention coordinator and your local hospital will also be able to tell you what associations exist and where support groups may be available. If you go online to a chat room, be sure that there is a medical moderator on the chat room.

Your child and your family may be eligible for counseling paid for by the state or the local Epilepsy Foundation.

Meditation and yoga or exercise classes may be helpful for you and your spouse, and activities for siblings of children with epilepsy may be available for your other children.

MANAGING YOUR RELATIONSHIP WITH YOUR HEALTHCARE PROVIDER:

1. Use your doctor(s) and nurse practitioner(s) and nurse(s) as information sources. Prepare a list of questions for each visit and do not be afraid to ask them.
2. Be sure to ask, "Will the results of this procedure or test change the current treatment plan?" If they won't, ask about the purpose of the test.
3. Discuss treatment options – ask, "Why are we using this particular treatment?"
4. Ask about clinical studies – if your doctor is not involved in one, you may be referred to another center where one is going on. Also, ask if your expenses will be reimbursed if you participate in the study.
5. Remember, you are a team – you are the expert on your child, the doctor is the expert on the disease.
6. Bring logs of seizures, medications, side effects, etc., to your appointment – make copies of evaluations and logs to leave with the doctor.
7. Make sure the doctor has copies of records from previous doctors – you must request that they be sent; the doctor cannot get them without your approval.
8. Follow up on everything – call for results of tests. Remember that labs can be very busy and often test results, blood levels, etc. are not automatically sent to the doctor.

9. If your child needs to be hospitalized away from where your neurologist practices and you feel that the treatment may not be appropriate, you can ask that he or she be transferred to a different hospital.

OTHER TIPS:

1. Keep doctors' names and numbers and emergency information in several different places. Let family members and babysitters know where they are posted.
2. Get your child a Med-Alert bracelet.
3. Keep your doctor's card in your child's pocket or backpack.
4. You must be your child's advocate. Ask for what you want – nicely. Ask repeatedly. Put everything in writing. Cultivate friends at the school district, the doctor's office, and the Early Intervention program, if this service is appropriate for your child.

WHAT DO I DO ABOUT GETTING HELP FOR MY CHILD AT SCHOOL?

Special education is just that – education for people who learn differently and need to be taught in a special manner. Special education is funded by the government and begins at birth.

In most states, Early Intervention (sometimes called Birth to Three) may be funded by the state government and administered by the county or local school district. At this age, children may be eligible to receive physical therapy, occupational therapy, speech therapy and/or special instruction in the form of a teacher or play therapist that works with the child.

A separate program may provide services to children ages 3 to 5. Again, the same services may be available locally. The child may also attend a local preschool and just have additional services – like speech therapy, special instruction, etc. – provided at the school or at home.

Parents of school age children may want to explore different educational settings to fit their child's needs. These may include class size, teacher/student ratios, and special programs. Parents should discuss this with their physician and may want to involve their child's teacher.

WHAT ARE SOME OF THE THERAPIES THAT MAY BE AVAILABLE TO MY CHILD?

Discuss the following options that may be beneficial to your child with your doctor.

- Speech and language – This is not just for children who “don't speak well,” it's also for children who may have difficulty processing language and information.
- Occupational therapy – Helps with fine motor issues, like handwriting, tying shoes, etc.
- Physical therapy – Deals with gross motor issues – walking, climbing, etc.
- Play therapy – Helps act out the child's concerns, in a non-threatening manner.
- Counseling – Can be done with a psychologist or social worker.
- Social skills training – Helps children to interact appropriately in a group.
- Special instruction – An educator who works one on one with the child, either at home or in the school setting – that is, may accompany the child to a regular preschool program to teach social skills and appropriate behavior
- One-to-one aide – A person who accompanies the child to school to assist with keeping on task, writing, organizational skills – for the child who would otherwise require a more restrictive environment for education.
- Health aide – Supplied to children who may need assistance in school in terms of toileting, safety (preventing falls) and to children who have frequent poorly controlled seizures.

CAN MY CHILD PLAY SPORTS?

Your child may not have restrictions as long as the seizures are well controlled. Obviously, common sense prevails. Some common safety precautions that apply to all children are: wearing helmets when bicycling, skiing, snowboarding, skateboarding, roller-blading, ice-skating, and scootering. Children with poorly controlled seizures should not climb ropes, ride bicycles, or rock-climb. No child should be swimming alone and everyone needs to wear a life vest when water-skiing.

Sometimes, children with seizures may have difficulty participating in team sports – especially if they have any issues with fine and gross motor skills. Parents often find that it is easier for their child to participate in individual sports – yoga, karate, swimming, golf, skiing, and horseback riding.

It is important that children participate in social activities and sports – it builds self-esteem and reinforces the fact that they are normal children, who happen to have an illness. Be sure to discuss the types of team sports and activities that your child can engage in with your child's doctor.

WHAT SHOULD I TELL THE SCHOOL?

It is up to the parents and the child to decide whether or not to notify the school regarding the child's seizures. Clearly, it is imperative to do so if the child is at risk for having a seizure in school. At the end of this book is a form that can be photocopied and given to the school. Be sure to discuss this with your child's doctor.

WHAT SHOULD I TELL THE PEOPLE WHO CARE FOR MY CHILD – GRANDPARENTS, BABYSITTERS, ETC.?

Tell them that your child may have a seizure while they are caring for them. Remind them that it is important to ensure that the child gets adequate sleep, goes to bed on time, and takes their medication.

If the child is to be given medication while you are out, be sure to have it ready and clearly marked. Instruct them whether the pills are to be crushed or opened and sprinkled, or exactly how much of the liquid medication to give. Leave out the equipment for measuring the medicine or, better yet, pre-measure it. Tell them what drink to give with it. If you are leaving for a few days, it is helpful to leave pills pre-poured in a pillbox. If the pills need to be cut, provide a pill cutter or leave them already cut.

Give them the hand-out on seizure first aid that follows at the end of this book and be sure to leave your doctor's numbers, as well as ways to reach you.

WHAT SHOULD I DO ABOUT PLAYDATES?

Your child should continue to socialize with other children and play outdoors. They should be supervised. You should discreetly tell the other parents about your child's history, especially if the seizures are not well controlled. Tell them how to get in touch with you and what to do if your child has a seizure.

SEIZURE FIRST AID:



DO NOT PANIC!

DO NOT PLACE ANYTHING IN THE CHILD'S MOUTH!

Lay the person on his or her side (if he or she is on a bed or couch, lower them carefully to the floor). If they are on the floor, move away furniture that may cause injury if they bang into it.

Let the seizure run its course – if you have medicine to stop the seizure give it at the time that was specified by your doctor.

Time the seizure and take note of what is happening – shaking on one side of the body or both sides, eye deviation, incontinence of urine or stool, extension extremities, etc. (See seizure log.)

Let the child rest afterwards.

After having a seizure, the child may be sleepy, confused, etc.

EPILEPSY RESOURCES:



General information Web sites:

<http://www.epilepsyfoundation.org>

Web site of the Epilepsy Foundation, the U.S. national organization that works for people affected by seizures. A good place to get reliable information, especially on legal affairs and community services.

<http://www.naec-epilepsy.org>

The Web site of the National Association of Epilepsy Centers. Find a comprehensive epilepsy center near you!

<http://www.paceusa.org>

Parents Against Childhood Epilepsy is an organization that provides support for parents of children with epilepsy. Features information regarding fundraising efforts in support of advances in medical research of epilepsy.

<http://specialchildren.about.com/cs/epilepsy>

A list of epilepsy Web sites primarily for parents of children with epilepsy.

<http://www.cdc.gov/nccdphp/epilepsy/index.htm>

National Center for Chronic Disease Prevention and Health Promotion: A page dedicated to some general information on epilepsy.

Research Web sites:

<http://www.ninds.nih.gov/index.htm>

The site of the National Institute of Neurological Disorders and Stroke, the part of the U.S. National Institutes of Health that covers brain disorders. News about research developments and clinical trials.

<http://www.aesnet.org>

Web site of the American Epilepsy Society, which promotes research and education for healthcare professionals.

<http://www.centerwatch.com/patient/studies/CAT62.html>

Center Watch: A comprehensive list of epilepsy clinical studies going on throughout the United States.

Books for parents of children with epilepsy:

Children With Epilepsy: A Guide. Helen Reisner, Ed. Kensington, MD: Woodbine House, 1988.

Does Your Child Have Epilepsy? James E. Jan, Robert G. Ziegler, and Guiseppa Erba. Baltimore, MD: University Park Press, 1983.

Epilepsy and the Family: A New Guide. Richard Lechtenberg. Cambridge, MA: Harvard University Press, 1999.

Epilepsy: Patient and Family Guide. Philadelphia, PA: F.A. Davis Co., 2001.

Epilepsy: The Ultimate Teen Guide. Kathlyn Gay and Sean McGarahan. Lanham, MD: The Scarecrow Press, 2002. Call number: Disabilities-FAM WL 385 G285e 2002.

Seizures and Epilepsy in Childhood: A Guide. John Mark Freeman. Baltimore, MD: Johns Hopkins University Press, 2002.

Seizures and Epilepsy in Childhood: A Guide for Parents. John Mark Freeman. Baltimore, MD: Johns Hopkins University Press, 1997.

Children's books

Dotty the Dalmatian Has Epilepsy. Gladstone, NJ: T. Peters and Co., 1996.

Lee, the Rabbit with Epilepsy. Deborah M. Moss. Kensington, MD: Woodbine House, 1989.

Audiovisual resources

The child and the family (video). Epilepsy Foundation of America, 1986.

Epilepsy in children: A primary care perspective (video). Landover, MD: Epilepsy Foundation of America, 1989.

Just like you and me (video). Alexandria, VA: PBS, 1990.

References:

1. Freeman JM, Vining E, Pillas DJ. Seizures and epilepsy in childhood: a guide. 3rd ed. Baltimore, MD: The Johns Hopkins University Press, 2002.
2. Wyllie J. The treatment of epilepsy: principles and practices. 3rd ed. Philadelphia, PA: Lippincott Williams & Wilkins, 2001.
3. Kwan P, Sander JW. The natural history of epilepsy: an epidemiological view. *J Neurol Neurosurg Psychiatry*. 2004;75:1376-1381.

Biographies:

BIOGRAPHY - STEVEN WOLF, MD

Steven Wolf, MD, graduated from Albany Medical School and served his residencies in Pediatrics and Neurology at Montefiore Hospital (the teaching hospital for the Albert Einstein College of Medicine). He completed fellowships in Pediatric Neurology and Epilepsy. He is currently the Director of the Developmental Disabilities Center at Roosevelt Hospital, the Director of Pediatric Neurology at St. Luke's/Roosevelt Hospital Center, the Director of Pediatric Epilepsy at Beth Israel Medical Center, and the Co-director of the Epilepsy Monitoring Unit at Beth Israel. He is assistant professor of Neurology and Pediatrics at the Albert Einstein College of Medicine. He is in private practice with Patty McGoldrick, NP, with whom he runs several clinics. He serves on the Professional Advisory Committee and the Board of Directors of the Epilepsy Foundation of New York City. He is the author of a textbook, numerous articles, and several patient guides. He resides in New York City with his wife and two sons.

BIOGRAPHY - PATRICIA ENGEL MCGOLDRICK, NP

Patty McGoldrick received a Master's degree in Public Administration from New York University and a Master's degree in Nursing (with certification as a Pediatric Nurse Practitioner) from Columbia University. She is associate director of the Developmental Disabilities Center at Roosevelt Hospital and is in private practice with Steven Wolf, with whom she runs several clinics. She is a clinical instructor in the Nursing Departments at Columbia University and New York University. She has co-authored several articles and patient guides with Dr. Wolf. She lives in Westchester County, New York with her husband and three children.

What dose will we start at?

How often will we increase the medication?

What is the maximum dose?

When would we discuss a change in medications?

What are the side effects?

What is the likelihood that my child will have side effects?

Will blood work or other tests be required?

What do I tell the school?

What medications should my child not take with this medication?

Do you have information for me regarding this medication?

Treatment

Brought on by

Symptoms

Length

Time

Date

Date	Time	Length	Symptoms	Brought on by	Treatment

Date	Medication	Dose	# Seizures	Blood Level	Side Effects

Date	Medication	Dose	# Seizures	Blood Level	Side Effects

Doctor	Specialty	Phone	Address	Referred by

TEAR OUT (D) DOCTORS YOU HAVE SPOKEN WITH

Doctor	Specialty	Phone	Address	Referred by

Name	Type	Phone	Address	Email	Referred by

TEAR OUT (E) THERAPISTS

Name	Type	Phone	Address	Email	Referred by

Name	Address	Phone	Contact	Referred by

Name	Address	Phone	Contact	Referred by

