



My Child Had a Seizure. Now what do I do?



**NATIONWIDE
CHILDREN'S**

When your child needs a hospital, everything matters.SM

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Seizures



Introduction

You were given this booklet because your child had his first seizure or has been diagnosed with epilepsy. This book was written for you, to help answer your questions. While this may not answer all of your questions it will give you a basic understanding of your child's condition. After reading these materials, be sure to ask your doctor or nurse practitioner any questions you have at your next appointment or call and talk with a nurse in the office

What is a seizure and what is epilepsy?

A seizure occurs when the nerve cells in the brain send out sudden, excessive, uncontrolled electrical signals. Everyone's brain has continuous electrical activity. When something goes wrong with this activity, your child may have a seizure. Seizures can produce a variety of symptoms depending on what part of the brain is involved. Seizures can range from something as simple as a strange feeling in your stomach to uncontrolled rhythmic movements of your entire body, called a convulsion.

About ten percent (10%) of people will have a seizure at some time in their life. Some of those people will develop epilepsy. Epilepsy is characterized by two (2) or more unprovoked seizures. Once a person has had two (2) seizures which were not provoked by something such as fever, illness, or withdrawal from drugs or alcohol he will be diagnosed with epilepsy.

Epilepsy is common. You may not know someone has epilepsy unless you see them have a seizure. Seizures occur in 1.5% of people. More people are living with epilepsy than cerebral palsy, multiple sclerosis, and Parkinson's disease combined. Each year in the U.S., 45,000 children under the age of 15 will develop epilepsy. Epilepsy is more common in children under the age of five (5) and adults over the age of 65, but can occur in anyone at any time in their life.

Once someone has one seizure, there is about a 50% chance that they will go on to have another seizure. Fifty percent (50%) of those people will have their second seizure within six (6) months and 80% within two (2) years. After having two (2) seizures, most children (80%) will have another seizure within four (4) years. If a child has an abnormal Electroencephalogram (E-LEK-tro-en-SEF-ah-lo-gram),

neurological exam, delayed development, or a structural problem with their brain, they are more likely to have further seizures after their first seizure.



How do we know if it was a seizure?

When a child has an unusual event or episode, a seizure may be suspected. A detailed description of what the event looked like is the most important information to help the healthcare team decide if your child had a seizure. Your medical team will probably not see your child have a seizure. However, they usually know what happens in the beginning, middle and end of a seizure. Your description will help your doctor or nurse practitioner determine if the episode is a seizure, and if so, what kind of seizure it is. We understand that seeing your child have a seizure is very scary and you may not remember many details. Write down the details of the seizure as soon as possible after it occurs. It is also important to keep a seizure calendar or record of all of your child's seizures. Always bring this information with you to your child's neurology appointments.

The most useful medical test used to diagnose seizures is an Electroencephalogram (E-LEK-tro-en-SEF-ah-lo-gram) or EEG. An EEG records the electrical activity in the brain. An EEG cannot tell us for sure if your child has had a seizure unless he/she has an actual seizure during the test. This rarely occurs. However, if your child has abnormalities in electrical activity even when he is not having a seizure, this tells us that your child may be at increased risk for seizures. This information, along with how you describe the event, can usually help us to determine if your child had a seizure

If a child has an abnormal EEG it does not indicate they had a seizure or ever will have a seizure. Likewise, if a child has a normal EEG, it does not mean they will never have a seizure. An EEG is just a snapshot of the electrical activity in the brain at that moment in time. Abnormal electrical activity may not show up when the EEG is performed.

What do seizures look like?

There are many different types of seizures. Not everyone falls and shakes when they have a seizure. But not everyone who does fall on the ground and starts shaking is having a seizure. There are many other kinds of problems that can look like seizures. Some things that can be confused for seizures in children include syncope (fainting), breath holding, reflux (spitting up) in babies, and anxiety attacks.

There are two main types of seizures: generalized and partial. One type is not better to have than the other; they are just different. It is helpful to figure out what type of seizure your child has in order to choose the most effective medication.

If your child's EEG is abnormal it may be able to tell us if the seizures are partial or generalized. Sometimes we can tell what type of seizure your child is having by how you describe the event. Generalized seizures are those that start from both sides of the brain. Partial seizures start in just one part of the brain but may spread to involve the whole brain. This can happen so fast that it is hard to tell they are coming from just one area. Simple partial seizures involve such a small area of the brain that the child may be aware they are having a seizure and can respond and possibly even talk during the seizure. A complex partial seizure involves a larger area of the brain and the child cannot respond and is not aware they are having a seizure. Please refer to the Helping Hand™ about these different types of seizures for a full description of how seizures are classified.

What causes seizures and epilepsy?

Seizures that are provoked (such as the case with seizures caused by fever) are not considered epilepsy. Brains of children between six (6) months and five (5) years of age are sensitive to illness and fever. When a young child has a fever, he may have a seizure. It is not usually epilepsy if it is just fever related.

When seizures are not brought on by fever or another event, it is an epileptic seizure. In most (about 70%) children who have epilepsy, the cause for the epilepsy is either unknown or genetic. We do not know very much about the genetics of epilepsy but we are learning more about it every day. There are a few genetic tests that can be done for epilepsy but a specific genetic cause cannot be found for most children. The genetics of epilepsy are very complex and there may not be anyone else in the family who has ever had epilepsy.

One of the most common causes of epilepsy in children is a developmental disorder or birth defect. This is the case in about 20% of children with epilepsy. Other causes for epilepsy include head injuries (5%); infection of the brain such as meningitis or encephalitis (4%); stroke (1.5%), and brain tumors (1.5%). Many children get minor bumps to the head and these minor injuries rarely result in epilepsy. Most children who have epilepsy due to a brain injury have had a major head injury and have been in the hospital. Many parents worry when their child has a seizure that he may have a brain tumor. Brain tumors are rarely a cause for seizures in children. They are a much more common cause of seizures in adults.

How do you determine what is causing the epilepsy?

Sometimes an EEG will show us a specific pattern of electrical activity in the brain that can give us clues as to what is causing the epilepsy. We know that some patterns are always associated with genetic causes and occur in children who are otherwise healthy and have no other neurological problems. In those children we often do not need to do any other testing because we know the epilepsy is genetic. There is no blood test for most genetic forms of epilepsy. Other times the EEG may show unusual activity in one area of the brain. If so, we will likely do an MRI (Magnetic Resonance Imaging) of the brain to see if there is any structural problem in that area of the brain. The most common type of structural problem is cortical dysplasia. This is an area in the brain that did not develop correctly and now may be causing seizures. This problem may not cause any other problems until a child has a seizure. These abnormalities do not grow like brain tumors. They have been there since birth and do not change over time. If we are worried that your child has other neurological problems in addition to seizures or has developmental problems for an unknown reason we may order other blood and urine tests.

What is an epilepsy syndrome?

Some children have a very specific pattern on their EEG and a specific type of seizure which may tell us that the child has an epilepsy syndrome. If your child has an epilepsy syndrome this means that we know more about what to expect in relation to your child's epilepsy. We may be able to tell you what type of seizures we expect your child will have, the age at which seizures usually start, when they might outgrow their seizures, and what medications work the best. Two common epilepsy syndromes in children are Benign Rolandic Epilepsy and Childhood Absence Epilepsy.

Seizure Safety

How are seizures harmful?

We know that occasional brief seizures do not hurt the brain. However, the biggest concern with seizures is that a child will be physically injured when he has a seizure. Most children are not aware they are having a seizure and cannot protect themselves. Injury is the #1 risk with seizures. Seizures may interfere with school work and other activities. If a seizure lasts longer than 30 to 60 minutes it may cause scarring of the brain but this is very rare.

What precautions can I take to keep my child from being hurt during a seizure?

Drowning is the #1 cause of injury from seizures. Never leave your child alone in a bathtub or near ANY water. A child can drown in less than an inch of water.

Older children usually prefer to shower and can be unsupervised but they need to:

- Remove the drain stop if they are showering in a tub.
- Leave the bathroom door unlocked.
- Make sure someone is in the house when they are showering.



No child or teen should ever swim unsupervised:

- Parents should watch all young children and be within reaching distance of them in the water.
- Older children and teens may swim with a buddy with a life guard present. The buddy should know how to recognize a seizure and be able to call for help if needed.
- Extra caution should be taken in water that is not clear. Life preservers should be worn when swimming or boating in oceans, lakes, and ponds because you may not be able to find a child who goes under in murky water.

Other safety precautions include:

- When children are riding bikes, skateboarding, or rollerblading, they should always wear a protective helmet.

- Children should avoid heights. They should not play on high playground equipment or climb trees, and they should not sleep on the top bunk of a bunk bed.
- Water heaters should be set to no more than 120 degrees F. to prevent a burn.
- Older children should not cook using the stovetop without an adult watching.

If a child's seizures are not well controlled and are occurring on a daily or weekly basis, greater precautions may be necessary such as not allowing any water activities and bike riding. Some children who have frequent seizures resulting in falls and frequent injuries may benefit from wearing a protective helmet during any physical activity. Talk to your child's neurology provider about what precautions they recommend for your child.

What do I do if my child has a seizure?

Try not to panic! Seizures are very scary but you need to stay calm. It is your job to protect your child during the seizure to keep them from being hurt.

As soon as you know your child is starting to have a seizure:

- Gently try to get them into a position where they are safe. If they are standing or sitting, get them to the floor or a soft surface where you can lay them on their side.
- Stay with your child. Use a watch or clock to time the seizure. Observe your child's behavior and movements.
- Do not put anything in your child's mouth. They cannot swallow their tongue and often they clench their teeth together. If you try to put something in their mouth you are likely to hurt them or yourself.
- Do not try to stop or restrain their movements.
- Children often foam at the mouth or drool during a seizure. If they are turned on their side, this will run out of their mouth rather than pooling in the back of their throat.

Some children do not have convulsing types of seizures, but may just stare or act unusual. If your child has this type of seizure, you just need to stay with them and keep them safe. You may not need to have them lie down on their side. Refer to the Helping Hand™ "Seizure Care" for more details.

What do I do when the seizure is over?

After a seizure, especially a convulsion, children often are very confused and tired. Sometimes they fall into a deep sleep and sleep for several hours. It is okay to let them sleep. Check on your child frequently until he returns to his normal self. Unless told otherwise, call your neurology provider the next business day and tell them about your child's seizures. Your child may need his medication adjusted.



When do I need to call for help?

Call 911 if:

- Your child's seizure lasts more than five (5) minutes.
- Several seizures occur in a short period of time without the child recovering in between the seizures.
- Your child was hurt during the seizure.
- Your child will not respond in any way to you 30 minutes after the seizure.
- Your child is having trouble breathing.
- Or if you are concerned something is wrong.

Most seizures last less than two (2) minutes. If a seizure is continuing after five (5) minutes it may not stop on its own. Most children do not have any serious problems with breathing during a seizure. Often children will be pale or blue around the mouth during a seizure. This is common during a seizure and not a sign of a problem. During a seizure the brain is working hard and needs plenty of oxygen. The human body naturally takes some oxygen away from the area around the mouth to send to the brain causing the blue look around the mouth. This does not mean your child is not getting enough oxygen to the brain.

Can I stop a seizure?

Most seizures last less than two (2) minutes. If a seizure lasts longer than five (5) minutes then you need help to stop the seizure. The only way to stop a seizure is with medicine. There is nothing else you can do to stop a seizure. You cannot stop the seizure by holding or talking to your child.

During a seizure your child cannot take medicine by mouth. It must be given through an intravenous line (IV) or in the rectum or nose where it will be absorbed through the mucous membranes. Common rescue medications used to stop seizures are diazepam (Valium®), lorazepam (Ativan®), and midazolam (Versed®). Sometimes

when a child has seizures that last longer than a few minutes, we give parents one of these rescue medications to have at home. When a child has a long seizure at home, parents can give a rescue medication through the rectum or nose to stop a seizure. This can prevent extra 911 calls and visits to the emergency room. All of these medicines will make your child more sleepy than usual after a seizure.

If your child has a seizure that lasts longer than five (5) minutes, call 911. The emergency squad may be able to give one of these medicines or they will take your child to a hospital where the staff will be able to give the medicine.

Can my child die from epilepsy?

Most children who have epilepsy will live a very full and long life. However, very rarely a child may die from an injury or drowning during a seizure, a very long seizure (60 minutes or longer), or from Sudden Unexplained Death in Epilepsy (SUDEP).

SUDEP is not well understood but we do know some factors increase the risk for SUDEP. People who have convulsive type seizures, have uncontrolled seizures, are on multiple seizure medications, stop medications suddenly, don't take their medications regularly, or have developmental disorders, are at greatest risk for SUDEP.

The best way to keep your child safe from injuries and SUDEP is to use seizure precautions, make sure your child takes his medication regularly, and work closely with your neurology provider to control your child's seizures as well as possible.

Treatment

How is epilepsy treated?

The primary treatment for seizures is antiepileptic medicine. Seizure medications do not cure seizures, they control seizures. Unlike antibiotics, you cannot take seizure medicines for 10 days and be cured.

Your child needs to take the medicine on a regular basis every day to keep an even level of medication in their body. Most medications are taken two (2) times each day but some may be taken only once a day and some may need to be taken three (3) or four (4) times a day. The type of medicine used for your child will depend on the type of seizures, your child's age and health, and possible side effects of the medications. For example, one medicine can cause an increase in hunger and weight gain so if possible we avoid using this medication in children who are already overweight.

There are many medications available to help children with epilepsy. Medications used most often include:

levetiracetam (Keppra®) valproic acid (Depakene®, Depakote®).
topiramate (Topamax®) lamotrigine (Lamictal®)
oxcarbazepine (Trileptal®)

The amount of medication prescribed is based first on your child's weight but then may be adjusted up or down based upon seizure control and/or side effects. **Our goal is to prevent all seizures without causing any intolerable side effects.**

Will seizure medications cause side effects?

All medications (even over the counter medicines such as acetaminophen) have the risk of side effects. All seizure medications have some risk of side effects. Most side effects are not serious but occasionally they can be more severe.

The most common side effect of seizure medications is feeling sleepy. When first starting a medication or when the dose is increased some children may feel a little drowsy for the first few days. Most children adjust to the medication and are back to feeling normal within a week. We often start with a very low dose of medicine and slowly increase the dose to help control the sleepy feeling. Sometimes we have

to increase the dose more quickly if a child is having frequent seizures and sleepiness may be more of a problem for the child.

Other side effects may include dizziness, upset stomach, and skin rash. A few medications can affect appetite. All seizure medications carry some risk of change in mood and behavior, including a very small risk of thoughts of suicide. Your doctor or nurse practitioner will always discuss side effects of your child's medication with you.

Can I use the generic form of a seizure medication?

Most children can use the generic form of seizure medications. Sometimes a child will be sensitive to even slight changes in their medication. These children may need to use the brand name medication. When starting a medication it is usually okay to start with the generic. If problems arise the healthcare team can change the prescription to the brand name.

What other medications can my child take?

Your child's response to seizure medications may change when other medications are started. This could increase your child's risk of having seizures or increase the risk of side effects from the medications.

If your child has a runny nose, cough or other cold symptoms, avoid use of over the counter medications if possible. Acetaminophen and ibuprofen are generally safe to use for treating pain and fever. Medications containing pseudoephedrine should be avoided as they may increase the risk of seizures but if necessary they can be used sparingly.

Some birth control medications may interact with seizure medications and cause either the birth control or the seizure medicine to be less effective. Talk with your doctor or nurse practitioner before starting any form of birth control.

To minimize the risk of drug interactions, keep a list of all medications your child is taking, including the dose, to share with your doctor or nurse practitioner at each appointment. It is important to talk to your doctor, nurse practitioner or pharmacist before giving your child any other medications. This includes prescription medications, over-the-counter medications, vitamins and herbal supplements.

What if my child vomits his medicine?

If your child vomits within 15 minutes of taking his medicine, you can repeat the dose one time.

If he vomits again, do not give him any more medication. Wait until the next scheduled dose and try again.

If he vomits and it has been at least 15 minutes since he took his medicine, do not give any more medication. The medicine has already been absorbed into his body.

What if my child misses a dose of medication?

It is important to take all seizure medications on a regular basis as prescribed by your child's doctor or nurse practitioner.

- Missing one or more doses of medication will increase the risk of a seizure.
- If you forget to give a dose of medicine, give it as soon as you remember and give the next dose later if possible.
- Do not give two (2) doses of medication closer than about six (6) hours apart.
- Missing one (1) dose of medication or giving it late every once in awhile will not cause a seizure in most children, but some children may be more sensitive to this.
- Missing several doses is likely to cause a seizure.

What if the medicine does not control my child's seizures?

When we first start a medication your child receives the lowest dose we think will work. This may not be the right dose and we may need to increase the dose several times to get to the right level of medication for your child. We can often increase a dose of medication three or four (3 or 4) times the starting dose before it is too much medicine for your child. If we reach the maximum dose for the medication and your child is still having seizures we may need to try a different medication or add another medication. Unfortunately, there is no magic bullet for seizures. The first seizure medication chosen has about 60% chance of controlling seizures. If that medication fails, the chance of seizure control drops to 10%. If two medications fail, then there's only a 1-2% chance of controlling seizures. Therefore, if two (2) medications have not worked for your child we may consider other treatments. These therapies are described briefly below. Your neurology provider can give you more information if these therapies are appropriate for your child:

- **Diet Therapies** – The Ketogenic Diet and Modified Atkins Diet are very restrictive low carbohydrate diets that may be used to treat epilepsy. These diets must be started and monitored closely by a team of specialists, including a dietician.
- **Vagal Nerve Stimulator** – This treatment involves placing a device that looks like a pacemaker in the chest. The device has a wire attached that leads to the vagus nerve in the neck. The device regularly stimulates the vagus nerve which then stimulates the brain resulting in a decrease in seizures. This treatment usually does not result in complete control of seizures and is not a substitute for medication. It requires surgery so it is not offered as a first line treatment for seizures. It is not brain surgery. It is usually added to medications when they are not working to completely control seizures but does not replace medication.
- **Epilepsy surgery** – If a child has partial seizures which come from one area of the brain, surgery can sometimes be performed to remove the affected area. This type of surgery may “cure” epilepsy and the child may be able to stop all of their seizure medication over time. This is not an option for all children with epilepsy. An extensive evaluation is done before offering this treatment. This option is not usually considered unless a child’s seizures are not controlled by the first or second medication tried.

Living with Seizures

Will my child outgrow seizures?

Many children outgrow their seizures. A child is more likely to outgrow his seizures if he has a normal EEG, normal MRI, normal development, no other neurological problems, and the seizures are controlled easily with medication.

After a child begins taking medicine and has no seizures for two (2) years, many children are slowly taken off the seizure medication. You should never stop medication on your own. If you stop medication suddenly it may cause your child to have a seizure. Many (60 to 75%) of children who are slowly weaned off medication will remain seizure free.

Will flashing lights from TV's, computers or video games trigger a seizure in my child?

Flashing lights can trigger seizures in some children. For most children with epilepsy, TV's, computers and video games are safe. We usually learn if your child is sensitive to flashing lights during an EEG. If this is the case he may be at increased risk for a seizure when he is exposed to flashing lights from a TV, computer or video game, or strobe lights. Hopefully, medication will decrease the risk so that no specific modifications are needed. However, some precautions may be necessary when watching TV or playing video or computer games. Your child should not sit too close to the TV, take a 10 or 15 minute break if playing computer games longer than one (1) hour, avoid these activities when overtired, and lights in the room should stay on. Wearing sunglasses with blue lenses when driving or riding in a car will decrease the risk of seizures triggered by flashing sunlight on bright days.

What else can trigger a seizure?

There are a few factors which may trigger someone to have a seizure when they are otherwise well controlled. These are often called breakthrough seizures. Factors which may trigger seizures are lack of sleep, illness and fever, missed medications, alcohol use, and significant mental or physical stress.

Can my child play sports?

If seizures are well controlled most children can play most sports. Some precautions may be needed. Sports and strenuous activities very rarely trigger seizures in children. There is even some evidence that physical activity may actually help decrease the risk of seizures. We encourage all children to be physically active but to use extra precautions as needed.

What should I tell my child's school?

Anyone who is responsible for the care or supervision of your child should know that your child has epilepsy and is at risk for seizures. They should know what to do if your child has a seizure. This may include teachers, grandparents, childcare providers, coaches, babysitters, nannies, friends and parents of friends who may be responsible for your child's care. If the school has questions about epilepsy and what to do if your child has a seizure, the Epilepsy Foundation of Central Ohio (EFCO), may be able to go to the school or daycare center to provide seizure training. Information about EFCO is listed at the end of this booklet.

My child is struggling in school. What can I do to help?

Children who have epilepsy are at risk for having learning problems in school. However not all children will have problems. Some children will have problems with memory, processing information, and paying attention in school. Some children with epilepsy also have Attention Deficit Disorder (ADD) or Attention Deficit Hyperactivity Disorder (ADHD).

Learning problems may occur because the seizure activity or the medications interfere with learning. However, most often a child's learning problems are due to the same underlying problem in the brain that causes the seizures. Often we cannot identify exactly what this problem is, but know there is a difference in how the brain is working which causes both the epilepsy and the learning difficulties. If your child is having problems in school, talk with your neurology provider. Public schools in Ohio are required by law to provide an evaluation for learning disabilities and to provide special education services. A neuropsychological evaluation done at the hospital may help to understand the learning problem.

My child seems depressed or worried. What can I do to help my child?

Just as there is an increased risk for learning problems in children with epilepsy, there is also an increased risk for depression and anxiety. This may be a result of learning they have epilepsy and dealing with the changes this has on their life. This may have been present even before they began having seizures and may be related to the underlying problem that is causing seizures and learning problems. In addition, all seizure medications have some risk for causing changes in mood and behavior.

Common signs of depression and anxiety include: withdrawing from friends and family, eating less, problems sleeping, excessive worries, crying easily or more often than usual, negative statements about themselves, increased fears, or not wanting to attend school or activities. If you have any concerns about your child, please talk to your neurology provider or call and talk with a nurse in the office. If your child ever has thoughts of harming himself or others, call the neurology office immediately.

Will my teenager be able to drive?

Most teenagers are able to drive if they take their medicine regularly and have not had a seizure for at least six (6) to twelve (12) months. When applying for a driver's license, they will be given a form that they need to bring to their neurology provider to complete and return to the Bureau of Motor Vehicles. Laws vary from state to state so it is important to check your state laws if you live or move outside of Ohio.

I am a teenager, what can I do to manage my epilepsy?

It is important for you to take an active role in managing your epilepsy. You need to find out everything you can about your seizures, your medication, and epilepsy in general.

To prevent seizures you should:

- Take your medicine every day at the same time.
- Get at least eight (8) to nine (9) hours of sleep each day.
- Not use any alcohol, tobacco or other drugs that can interact with your medications and/or trigger seizures.
- Talk to your neurology provider. Don't let your parents do all of the talking at your appointments!

Tell your parents and/or your neurology provider if you think you have had a seizure, are having any side effects to your medicine, problems with school, or feeling sad or worried.

What about birth control and pregnancy?

All available birth controls methods can be used by women with epilepsy. However, some methods may interact with seizure medications and cause either the birth control or the seizure medicine to be less effective. Even if your daughter is using birth control for regulation of periods or other reasons, these may interfere with her seizure medications. Talk to your neurology provider before starting any form of birth control.

Most women with epilepsy have normal, healthy babies. However there is a slightly increased risk of birth defects in babies born to women who take seizure medicine. Fifty percent (50%) of all pregnancies in the U.S. are unplanned. Therefore, as a precaution we recommend that all teenage girls take 1 mg of folic acid on a daily basis if they are taking seizure medicines once they start having periods. Folic acid may decrease the risk of some birth defects.

It is important to talk to your healthcare team before, during, and after pregnancy.

Where can I learn more about epilepsy?

These are some organizations and websites that you might find helpful.

Epilepsy Foundation of America: www.epilepsyfoundation.org

Epilepsy Foundation of Central Ohio: www.epilepsy-ohio.org

The Anita Kaufmann Foundation: www.akfus.org

Epilepsy Information Services: Phone: 1-800-642-0500

Epilepsy information website: epilepsy.com

How do I Contact my Neurologist or Nurse Practitioner?

Our office is open Monday through Friday, 8 a.m to 4:30 p.m. The phone number is (614) 722-4625. We have several prompts depending on the reason for your call. Please follow the prompts and be sure to leave a detailed message, and your child's name with the correct spelling and his/her birth date.

For after hours urgent questions, we always have a child neurology resident and attending doctor on call. Their responsibility is to address urgent questions you might have. When calling after hours call the hospital operator at (614) 722-2000 and ask for the neurologist on call. Please be aware that the on call doctor is not in the hospital and does not have access to your child's record.

Unless your concern is urgent it is always best to wait until the next business day when your neurologist or nurse practitioner who knows your child best is available to answer your question.

Department of Neurology
700 Children's Drive
Columbus, OH 43205-2696
NationwideChildrens.org

