

# Cook Children's Jane and John Justin Neurosciences Center

1500 Cooper St.  
Fort Worth, TX 76104



## Seizure Booklet



## What is a seizure?

The brain sends electrical signals to all parts of the body. Each signal follows a special pathway.  
*A seizure happens when the signals mix up.*

### 1. Electrical signals mix up.

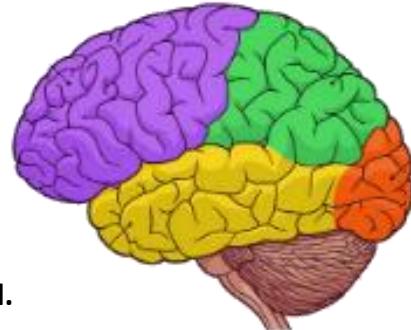
- They do not meet or do not go to the right place in the brain.
- When they stop, they give off a sudden burst of electricity.

### 2. Burst of electricity can move.

- It can stay in one area of the brain.
- It can spread to the other parts of the brain.

### 3. Burst of electricity causes body to do things it cannot control.

- The muscles may twitch, shake, or jerk.
- We call this movement a clinical seizure.



## What is epilepsy?

Epilepsy means your child has had 2 or more unprovoked seizures or has had a single seizure and the chances of additional seizures (based on history, EEG, etc.) is high.

### Different causes:

1. Brain has not developed normally.
2. Had seizures as a baby.
3. Have a family history of seizures.
4. Testing shows high possibility of seizure activity.

### Signs of seizures:

1. Uncontrollable shaking, twitching, or jerking.
2. Changes in the way child acts.
3. Changes in how awake child feels.
4. Brief staring spells.
5. Changes in breathing and heart rate.
6. Loss of bowel or bladder control.

### Seizures can :

1. Be very quick and hard to spot.
2. Cause twitching, jerking, or stiffness of any or all parts of the body.
3. Cause your child to be unresponsive or lose consciousness.

**Most children with epilepsy have normal appearing brains.**

Seizures happen without any known cause.

*Many times we never know why the brain signals get mixed up.*

## Helping Your Child's Doctor

*Telling us all about the seizure is very important.*

There are many different kinds of seizures. Different seizures need different medicines. In order to choose the right medicine, your doctor needs to know the kind of seizure your child has.

Sometimes it can be very difficult to tell seizures apart. Information from medical tests can help us identify the seizure type, but many times parents give us the best information. **The better you can describe the seizure, the easier and quicker your doctor can start controlling it.**



1. Your child may have more than one type of seizure.
2. If you see more than one kind, be sure to describe each one.
3. Write down the type you think it is.
4. You can also track your child's seizures by downloading apps to your smart phone.
5. You can send videos to the patient portal at mycookchildrens.org. You will need to download the app from google Play or AppStore.

## General and Focal Seizures

### Generalized Seizures: 6 types

Seizure Type	Your child may
<b>1. Generalized Tonic-Clonic</b> Was called "Grand Mal" seizure	<ul style="list-style-type: none"><li>• Suddenly cry, fall, or get stiff, and have muscle jerks.</li><li>• Have trouble breathing.</li><li>• Stop breathing and turn blue. Normal breathing usually starts when seizure is over.</li><li>• Lose consciousness.</li><li>• Wet their pants or have a bowel movement.</li><li>• Become confused or sleepy after seizure.</li></ul>
<b>2. Absence</b> Was called "Petit Mal" seizure	<ul style="list-style-type: none"><li>• Have a blank stare that suddenly starts and stops. This lasts only a few seconds.</li><li>• Blink really fast.</li><li>• Have some chewing movements of the mouth.</li><li>• Not know what is happening. Quickly returns to normal when seizure stops.</li></ul>
<b>3. Atonic/Drop</b>	<ul style="list-style-type: none"><li>• Suddenly fall.</li><li>• Soon return to normal and can stand or walk.</li></ul>

Seizure Type	Your child may
<b>4. Myoclonic</b>	<ul style="list-style-type: none"> <li>Have sudden jerks. This can happen in one part of your body or all over.</li> <li>Spill or drop things or fall.</li> <li>Have these seizures soon after waking up.</li> </ul>
<b>5. Infantile spasms</b> Starts between 3 months and 2 years	<p>Your baby may have several quick, sudden movements. We call these movements “<b>clusters</b>”.</p> <p><b>If baby sitting up:</b></p> <ul style="list-style-type: none"> <li>Head falls forward.</li> <li>Arms bend forward or extend backwards.</li> <li>Bends forward from the waist.</li> </ul> <p><b>If baby lying down:</b></p> <ul style="list-style-type: none"> <li>Knees draw up.</li> <li>Arms and head bend forward. It looks like the baby is reaching for something.</li> <li>Neck, arms and legs stretch out and get stiff</li> </ul>
<b>6. Tonic</b>	<ul style="list-style-type: none"> <li>Full body stiffening.</li> <li>Usually lasts less than 30 seconds, but may last longer.</li> </ul>

## Focal Seizures: May happen different ways

### Your child may:

- Remain awake and alert.
- Have jerking that starts in the one arm, leg or face.
- Have jerking that moves from one area of the body to another.



### Other children may:

Have seizures lasting a few minutes, but after the seizure, confusion can last longer. They may have no memory of what happened during seizure period.

- |   |   |
|---|---|
| <ul style="list-style-type: none"> <li>Get confused or dazed</li> <li>Mumble</li> <li>Act clumsy</li> <li>Run or appear afraid</li> </ul> | <ul style="list-style-type: none"> <li>Have blank stare, followed by chewing</li> <li>Cannot answer questions or recognize people</li> <li>Pick at clothing, pick up objects, try to take clothes off</li> <li>Struggle or fight if held</li> </ul> |
|---|---|

### Focal seizures progressing to generalized seizure activity

- Usually starts the same as above.
- Followed by whole body shaking similar to a generalized tonic-clonic seizure.

# Seizure First Aid

The brain sends out signals to all parts of our body. A seizure happens because the signals are not working right. Some seizures are easy to see. The person may fall down and start shaking all over.

## **Some seizures look different. The person may begin:**

- Staring
- Picking at an object
- Chewing, Smacking their lips
- Moving a body part over and over

**Having a seizure may seem scary. Knowing what to do helps you stay calm.**

*Following these steps helps keep the person safe.*

## **WHAT TO DO**

<b>Protect Child</b>	<ul style="list-style-type: none"><li>• Move hard or sharp objects away from area.</li><li>• If child is on ground, place something soft under the head. Pillow, towel, or rolled up jacket works well.</li><li>• Some people may start walking during a seizure. Gently stop them from going out a door or into street.</li><li>• Do not hold child down.</li></ul>
<b>Nothing in Mouth</b>	<ul style="list-style-type: none"><li>• Do not try to force anything into mouth.</li><li>• It is impossible to swallow the tongue when having a seizure.</li></ul>
<b>Time Seizure</b>	<ul style="list-style-type: none"><li>• Look at a clock or watch as soon as you see the seizure.</li><li>• Most seizures stop within 5 minutes.</li><li>• If seizure lasts longer than 5 minutes, or if several seizures happen in a row, call 911.</li></ul>
<b>If Unconscious Turn To Side</b>	<ul style="list-style-type: none"><li>• If child passes out, turn to one side.</li><li>• This prevents choking if vomiting or drooling happens and helps your child to breathe easier.</li></ul>
<b>Check Breathing</b>	<ul style="list-style-type: none"><li>• During seizures, a person may briefly stop breathing and turn blue.</li><li>• Most of the times, we do not need to do CPR.</li><li>• Breathing and color will get better after the seizure.</li><li>• When the seizure stops, if there is no breathing or no pulse, call 911 and start CPR.</li></ul>
<b>Rest after seizure</b>	<ul style="list-style-type: none"><li>• After seizure is over, let child rest.</li><li>• Stay with the child and offer comfort.</li><li>• If in a public place, offer to phone a taxi, friend, or relative to take the person home.</li></ul>

# What to Know About Seizure Medicines

## 1. Medicines do not cure epilepsy.

- Medicines only stop or lessen seizures.
- Different types of medicines work on different types of seizures.
- Sometimes one seizure medicine works well. Sometimes your child will need several different medicines.
- Sometimes doses of medicines need to be changed as your child grows.
- Often you start with a low dose of seizure medicine and slowly work up to normal dose.

## 2. Only work when you follow directions.

- DO NOT stop seizure medicines without talking to your child's doctor first.
- Seizures can start if the medication is stopped too fast.

## 3. May cause drowsiness.

- Do not drink alcohol or take illegal drugs.
- Do not take any sleeping medicine without talking to your doctor first.

## 4. Come in tablets, sprinkles, capsules or syrup.

- Shake liquids well.
- Some medicines can upset your child's stomach. Taking medicine with food can help.
- Talk to your doctor or pharmacist first to make sure food will not affect how the medicine works.
- Do not swallow chewable tablets without chewing first.

## 5. Before taking any new medicine:

*Always tell your child's doctor*

**This includes:**

- Vitamins
- Cold and fever medicines
- Herbs
- Medicines you can buy without prescriptions

You can find more information about seizure medicine on [www.epilepsy.com](http://www.epilepsy.com)

**Keep all medicine away from children.  
Never share your child's medicine with anyone.**

# Medicine Guidelines

## 1. Never guess about medicines

If you do not understand or are not sure what to do, call us or talk to your pharmacist.

## 2. Give the right dose at right time

Your child's doctor will tell you the dose of medicine to give and when to give it. Do not give your child a different dose or at a different time.

**For liquid medicine:** Always use medicine dosing cup, dosing syringe, or dosing spoon. Not a regular spoon.

## 3. If you miss a dose

If you miss a dose, give it as soon as possible. If it is more than half the time to the next dose, skip the missed dose. Do not double up on dosing.

## 4. Storage and disposing of medicines

Store your medicines in a closed container at room temperature, away from heat, moisture, and direct light. Some medicines need to be refrigerated.

Do not give expired medicines. Ask your pharmacist what to do with expired medicines

# Generic Substitution

Most medicines have 2 names

<b>1. Brand Name:</b>	<ul style="list-style-type: none"><li>The drug company gives a special brand name to each medicine they develop.</li><li>Brand names are usually short and easy to remember.</li></ul>
<b>2. Generic Name:</b>	<ul style="list-style-type: none"><li>This name has to do with the chemicals that make the medicine work.</li><li>Many chemical names are long and hard to remember.</li></ul>

## Naming New Medicines

### A drug company makes a new medicine.

- They give this medicine a Brand Name.
- At first, this is the only company that can make and sell the new medicine.

### At some point, other drug companies can make this medicine.

- They cannot use the brand name, so they call the drug by its chemical name.
- This is called the **generic medicine**.
- Example: Tylenol is the brand name. Acetaminophen is the generic name.

## Differences between Brand and Generic Medicines

### Generic medicines:

- May look different.
- Are usually cheaper.
- Some of the chemicals used to make the medicine are prepared differently.
- Sometimes pharmacies will substitute generic medicines.
- Pharmacies will substitute generic medicines unless the doctor specifies the brand name is necessary on your child's prescription.
- Please talk with your doctor if generic substitution is suitable for your child.

Always talk to your doctor first before you change from a brand name seizure medicine to a generic medicine.

## Blood Levels

The blood level is the amount of seizure medicine in the blood. Your doctor will decide the dose of seizure medicine your child needs and how often to take it.

### **To stop or lessen a seizure, your child will need:**

1. The *right* seizure medicine.
2. The *right* blood level of this seizure medicine.

**It may take several days or weeks for a medicine to reach the right blood level.**

### **The blood level can become too low to control seizures if:**

1. If your child stops taking the seizure medicine.
2. Takes the seizure medicine at different times.

*Many seizure medicines do not have blood levels that are routinely checked.* It is very important for your child to take the seizure medicine exactly as ordered.



**It is very important for your child to keep taking their medicine, even if they have not had a seizure for a long time.**

***Not having a seizure means the medicine is working.  
It does NOT mean your child no longer needs it.***

### **Doctors usually start medicine slow and increase the dose on a daily or weekly basis:**

1. We try to keep dose as low as possible to lessen side effects, but still control seizures.
2. The dose of medicine depends on your child's weight and age. Sometimes dosing also depends on how well your child's kidneys and liver are working.
3. If your child continues to have seizures, it does not mean the medicine is not working.
4. We may need to change the amount, times, or type of your child's medicine.

**Sometimes after a long period of control with medicine, a child may start having seizures again. This does not usually mean the epilepsy is getting worse.**

# Common Side Effects of Seizure Medicines

**Seizure medicines can increase the risk of having thoughts of suicide. It is very important to call your doctor if your child has any thoughts or actions of suicide.**

**All seizure medicines have possible side effects.**

Please tell your child's doctor if they have any of the following:

<b>Feelings</b>	<ul style="list-style-type: none"><li>• Thoughts of suicide.</li><li>• Sleepiness, usually goes away after 2 to 3 weeks on medicine.</li><li>• Loss of energy.</li><li>• Changes in ability to concentrate or focus on things.</li><li>• Mood changes.</li><li>• Difficulty sleeping.</li><li>• Extreme hyperactivity.</li><li>• Behavior problems.</li></ul>
<b>Head</b>	<ul style="list-style-type: none"><li>• Swollen or tender gums.</li><li>• Sore throat and/or ulcers in mouth.</li><li>• Headache that doesn't go away.</li><li>• Swollen glands in neck.</li><li>• Yellowish color noted on eyes.</li></ul>
<b>Throat</b>	
<b>Stomach</b>	<ul style="list-style-type: none"><li>• Severe nausea and vomiting.</li><li>• Appetite changes.</li><li>• Color change noted in urine or stool (usually dark color).</li></ul>
<b>General</b>	<ul style="list-style-type: none"><li>• Yellowish color noted on skin.</li><li>• Unexplained fever or chills.</li><li>• Unusual bleeding or bruising.</li><li>• Rash (may be small dots to large red patches).</li><li>• Joint pain.</li><li>• Symptoms of infection (fever, cough, etc.)</li><li>• There may be an increase in feelings of sadness, call your doctor immediately.</li></ul>

*Call your doctor immediately if your child has a skin rash or allergic reaction*

**Teens and young adults: tell your doctor if you are sexually active.**

**FDA WARNING: Some seizure medicines may cause thoughts of suicide.**

The U.S. Food and Drug Administration states companies that make some seizure medicines must include this warning as a potential side effect. Please call your neurologist immediately if you see any of the following in your child:

1. Thoughts or attempts of suicide.
2. Violent behavior.
3. New or worse irritability, anxiety, or depression.
4. Extreme changes in behavior
5. Unusual Mood

## Common Seizure Medicines

Brand Name	Generic Name
Aptiom®	Eslicarbazepine acetate
Banzel®	Rufinamide
Briviact®	Brivaracetam
Depakote®	Valproic Acid
Dilantin®	Phenytoin
Epidiolex®	Cannabidiol oral solution
Felbatol®	Felbamate
Fintepla®	Fenfluramine
Fycompa®	Perampanel
Keppra®	Levetiracetam
Lamictal®	Lamotrigine
Lyrica®	Pregabalin
Mysoline	Primidone
Neurontin®	Gabapentin
Onfi®	Clobazam
Luminal Sodium	Phenobarbital®
Sabril®	Vigabatrin
Symmetrel®	Amantadine
Tegretol® /Carbatrol®	Carbamazepine
Topamax®/Trokendi XR®	Topiramate
Tranxene®	Clorazepate
Trileptal®/Oxtellar XR®	Oxcarbazepine
Vimpat®	Lacosamide
Zarontin®	Ethosuximide
Zonegran®	Zonisamide

**NOTE:** This is general educational information. It reviews basic medicine information for seizures and epilepsy. This medicine information does not cover all possible uses, actions, precautions, side effects, or interactions of these medicines. Some of these medicines are not FDA approved to be used in children. Some are not FDA approved for certain seizure types. Please call your doctor if you have any questions or concerns about any of these medicines.

## Rescue Seizure Medicines

Brand Name	Generic Name
1. Ativan®	Lorazepam
2. Diastat®	Diazepam
3. Klonopin®	Clonazepam
4. Valium®	Diazepam
5. Versed/Nayzilam Nasal Spray®	Midazolam
6. Valtoco	Diazepam nasal spray

### Notes:

---

---

---

---

---

---

## Common Seizure Medicines

Medicine Name	Medicine used for	Possible Side effects	Possible <u>Serious</u> effects
Banzel® Rufinamide	1. For treatment of generalized seizures associated with Lennox/Gastaut syndrome. 2. Your child can take this with other medicines. 3. Comes as a tablet.	<ul style="list-style-type: none"><li>• Feeling light headed, dizzy, or sleepy.</li><li>• Blurred vision.</li><li>• Headache.</li><li>• Stomach pain or nausea. Should take with food.</li><li>• Heart problems.</li></ul>	<ul style="list-style-type: none"><li>• Changes in urination.</li><li>• Rash: Call your child's doctor immediately.</li><li>• Fever: Call your child's doctor immediately.</li></ul>
Briviact® Brivaracetam	1. Combination with other medicines for treatment of focal and generalized seizures. 2. Comes in tablets and liquid.	<ul style="list-style-type: none"><li>• Sleepiness</li><li>• Dizziness</li><li>• Nausea</li><li>• Mood changes</li></ul>	<ul style="list-style-type: none"><li>• Decreased white blood cell count</li></ul>

<b>Medicine Name</b>	<b>Medicine Used for</b>	<b>Possible Side effects</b>	<b>Possible <u>Serious</u> effects</b>
<b>Depakote®</b> Divalproex Sodium <b>Depakene®</b> Valproic Acid	<ol style="list-style-type: none"> <li>1. For treatment of generalized tonic-clonic, myoclonic, atonic, focal, and absence seizures.</li> <li>2. Your child can take it as a single medicine or with other medicines.</li> <li>3. Comes as coated tablets, sprinkle capsule, or liquid <b>Depakene®</b>.</li> </ol>	<ul style="list-style-type: none"> <li>• Stomach pain or nausea (can take with food).</li> <li>• At higher doses, you may have fine tremors or shakiness of the hands.</li> <li>• Increased appetite and weight gain.</li> <li>• Increased hair loss or thinning; usually stops after a few months and hair returns to original thickness.</li> <li>• Birth defects: Fetal malformation, including 10% risk of neural tube defects – spina bifida.</li> </ul>	<ul style="list-style-type: none"> <li>• Liver damage – Patients with pre-existing liver disease should not take the medicine.</li> <li>• Rare cases of liver failure resulted in death.</li> <li>• Easy to bleed.</li> <li>• Decreased white blood count; red blood cell count or both.</li> <li>• Pancreatitis.</li> <li>• Decreased platelet count/easy bruising.</li> <li>• Polycystic ovary disease.</li> </ul>
<b>Dilantin®</b> Phenytoin	<ol style="list-style-type: none"> <li>1. For generalized tonic-clonic, focal seizures, and focal seizures with secondarily generalized seizures.</li> <li>2. May take with other medicines.</li> <li>3. Comes as capsules, chewable tablets, or as a liquid.</li> </ol>	<ul style="list-style-type: none"> <li>• Long term use can lead to loss in bone density.</li> <li>• Changes in taste.</li> <li>• Dizziness, Loss of balance when walking</li> <li>• Nausea and vomiting</li> <li>• Headache</li> <li>• Constipation</li> <li>• Dry mouth</li> <li>• Sleeplessness</li> <li>• Decreased appetite</li> </ul>	<ul style="list-style-type: none"> <li>• Cosmetic side effects such as thickening of gums and increase in body hair are common. Thickening of gums can be reduced by good dental care with brushing and flossing and dental visits.</li> <li>• Allergic skin rash: Call your neurologist immediately.</li> </ul>
<b>Epidiolex®</b> <b>Cannabidiol oral solution</b>	1. Used with and without other seizure medicine for seizures associated with Lennox-Gastaut Syndrome, Dravet Syndrome and Tuberous Sclerosis Complex.	<ul style="list-style-type: none"> <li>• Decreased appetite</li> <li>• Sleepiness</li> </ul>	<ul style="list-style-type: none"> <li>• Allergic reaction</li> <li>• Anemia</li> <li>• Liver problems</li> </ul>
<b>Felbatol®</b> Felbamate	<ol style="list-style-type: none"> <li>1. For use with and without other seizure medicine for severe focal and generalized seizures.</li> <li>2. Comes in tablets and as a liquid.</li> </ol>	<ul style="list-style-type: none"> <li>• Increased liver enzymes</li> <li>• Muscle pain</li> <li>• Changes in vision</li> <li>• Changes in appetite</li> <li>• Changes in behavior</li> </ul>	<ul style="list-style-type: none"> <li>• Blood cell count problems. It is important to report any signs of infection (fever, sore throat) or bruising to your doctor right away.</li> <li>• Liver damage. Call us right away if you have dark urine, vomiting, or yellowing of eyes and skin.</li> <li>• Facial swelling</li> </ul>

<b>Medicine Name</b>	<b>Medicine Used for</b>	<b>Possible Side effects</b>	<b>Possible <u>Serious</u> effects</b>
<b>Fintepla®</b> Fenfluramine	1. Used with and without other seizure medicine for seizures associated with Dravet Syndrome	<ul style="list-style-type: none"> <li>Decreased appetite</li> <li>Diarrhea</li> <li>Weight loss</li> <li>Sleepiness</li> </ul>	<ul style="list-style-type: none"> <li>Allergic reaction</li> <li>High blood pressure</li> <li>Changes in eyesight, red eyes, eye pain or very bad eye irritation</li> </ul>
<b>Fycompa®</b> Perampanel	1. Used with other seizure medicines for partial and generalized seizures. 2. Comes in a tablet and may take with or without food. 3. You should take this medicine at night time. 4. This medicine interacts with several different medicines. 5. Please check with a pharmacist before starting any new medicines or herbal medicines.	<ul style="list-style-type: none"> <li>Dizziness</li> <li>Sleepiness</li> <li>Irritability</li> <li>Headache</li> <li>Blurred vision</li> <li>Nausea</li> <li>Weight gain</li> <li>Abnormal bruising</li> <li>Muscle and joint pain</li> </ul>	<ul style="list-style-type: none"> <li>Increased risk of suicidal thoughts</li> <li>Changes in mental status</li> <li>Rash and fever at the same time.</li> </ul>
<b>Keppra®</b> Levetiracetam	1. Used in combination with other medicines for focal seizures and some generalized seizures. 2. Comes in tablets and as a liquid.	<ul style="list-style-type: none"> <li>Headaches</li> <li>Drowsiness</li> <li>Dizziness</li> <li>Behavior disturbance</li> <li>Hallucinations</li> </ul>	
<b>Lamictal®</b> Lamotrigine	1. Mainly used for control of focal seizures and some generalized seizures (generalized tonic-clonic, absence, and myoclonic). 2. Comes in chewable tablets or regular tablets. May have a line down the middle to break in half easily, if needed.	<ul style="list-style-type: none"> <li>Headaches</li> <li>Nausea and vomiting</li> <li>Dizziness, sleepiness, awkward balance, double vision and blurred vision</li> <li>Skin rash may occur when taking Lamictal and you must report it to your doctor immediately.</li> <li>Severe allergic reactions including Stevens-Johnson syndrome have occurred. This is common in children who are also taking Depakote.</li> </ul>	

<b>Medicine Name</b>	<b>Medicine Used for</b>	<b>Possible Side effects</b>	<b>Possible <u>Serious</u> effects</b>
<b>Lyrica®</b> Pregabalin	<ol style="list-style-type: none"> <li>1. Mainly used with other medicines to control focal seizures.</li> <li>2. Comes as a capsule.</li> </ol>	<ul style="list-style-type: none"> <li>• Headaches</li> <li>• Nausea and vomiting</li> <li>• Feeling light-headed, sleepy, or dizzy</li> <li>• Dry mouth</li> <li>• Feelings of sadness or happiness.</li> </ul>	
<b>Onfi®</b> Clobazam	<ol style="list-style-type: none"> <li>1. Used for treatment of Lennox-Gastaut syndrome and other generalized epilepsies.</li> <li>2. Comes in tablets and liquid. You may crush tablet and give with food, if needed.</li> </ol>	<ul style="list-style-type: none"> <li>• Sleepiness</li> <li>• Aggression</li> <li>• Confusion</li> <li>• Difficulty swallowing</li> <li>• Cough</li> <li>• Constipation</li> </ul>	<ul style="list-style-type: none"> <li>• Difficult or slow breathing</li> <li>• Stevens-Johnson syndrome</li> <li>• Decreased white and red blood cells</li> <li>• Swelling of the lips or face</li> </ul>
<b>Luminal®</b> Phenobarbital  *It is not recommended to use this medicine when children are trying to learn in a school setting.  Often another medicine is used for the school-aged child.	<ol style="list-style-type: none"> <li>1. Used for generalized and focal seizures primarily in infants and very small child.</li> <li>2. Comes in tablet and liquid forms.</li> </ol>	<ul style="list-style-type: none"> <li>• Hyperactive behavior often described as fussy, irritable, or stubborn. Most children will get use to this side effect within a month.</li> <li>• Always report any rash to your neurologist.</li> <li>• Drowsiness.</li> </ul>	<ul style="list-style-type: none"> <li>• Difficult or slow breathing</li> <li>• Stevens-Johnson syndrome</li> </ul>
<b>Sabril®</b> Vigabatrin  *This is a REMS drug. Your child must be enrolled before they can start this medicine.	<ol style="list-style-type: none"> <li>1. Used for intractable complex partial seizures, most commonly infantile spasms associated with tuberous sclerosis.</li> <li>2. Comes as a tablet and as a liquid.</li> </ol>	<ul style="list-style-type: none"> <li>• Feeling light-headed, sleepy, dizzy, or nervous.</li> <li>• Rash</li> <li>• Weight gain.</li> <li>• Nausea or vomiting</li> </ul>	<ul style="list-style-type: none"> <li>• Swelling of the face, throat, or tongue. Call your doctor immediately.</li> <li>• Changes in or loss of vision, including peripheral vision. Your doctor will schedule a regular eye exam while on this medicine.</li> </ul>

<b>Medicine Name</b>	<b>Medicine Used for</b>	<b>Possible Side effects</b>	<b>Possible <u>Serious</u> effects</b>
<b>Tegretol®</b> <b>Carbatrol®</b> Carbamazepine	<ol style="list-style-type: none"> <li>1. Helpful for focal seizures. May be used alone or in a combination with other medicines.</li> <li>2. Comes in chewable tablet and an orange flavored liquid.</li> <li>3. Tegretol XR® is an extended release tablet that should not be chewed. Carbatrol® is an extended release sprinkle capsule.</li> </ol>	<ul style="list-style-type: none"> <li>• Drowsiness or sleepiness.</li> <li>• Nausea, vomiting, and stomach cramps.</li> <li>• Rash</li> <li>• Increased appetite.</li> </ul>	<ul style="list-style-type: none"> <li>• Decreased white blood count, hemoglobin and platelet may be seen.</li> <li>• Liver damage.</li> <li>• Low sodium- changes in urination and increased drowsiness.</li> <li>• Severe rash Call your doctor immediately.</li> <li>• Swelling of the face, throat, or tongue.</li> </ul>
<b>Symmetrel®</b> Amantadine	<ol style="list-style-type: none"> <li>1. Used mainly for absence seizures.</li> <li>2. Comes in tablets and liquid.</li> </ol>	<ul style="list-style-type: none"> <li>• Dizziness</li> <li>• Low blood pressure when standing</li> <li>• Dry mouth</li> <li>• Mood changes</li> <li>• Upset stomach</li> </ul>	<ul style="list-style-type: none"> <li>• Blurred vision</li> <li>• Bruising</li> <li>• Joint swelling</li> <li>• Discoloration of skin</li> </ul>
<b>Topamax®</b> Topiramate Topiramate XR Trokendi XR	<ol style="list-style-type: none"> <li>1. Used primarily to treat focal and generalized seizures.</li> <li>2. Comes in tablet and sprinkles. Tablets may have a bitter taste if crushed or chewed.</li> <li>3. It is important to drink plenty of water each day when taking this medicine, especially during the summer.</li> </ol>	<ul style="list-style-type: none"> <li>• Sleepiness, drowsiness, dizziness, incoordination may be felt</li> <li>• Some have complained of tingling</li> <li>• Watch for difficulty learning, problems in school, or problems with concentrating or memory; and alert your doctor if they become a problem.</li> <li>• Decreased appetite that can result in weight loss.</li> <li>• Decreased sweating, increased body temperature and flushing of the face have been reported. Alert your doctor if this occurs.</li> <li>• In rare instances can cause glaucoma. Call for any eye redness, tearing, pain or blurred vision.</li> </ul>	<ul style="list-style-type: none"> <li>• Very noticeable changes in mental status.</li> </ul>

<b>Medicine Name</b>	<b>Medicine Used for</b>	<b>Possible Side effects</b>	<b>Possible <u>Serious</u> effects</b>
<b>Tranxene</b> Clorazepate	<ol style="list-style-type: none"> <li>Used to treat seizures and anxiety.</li> <li>Comes in tablets that you can crush or chew, if needed.</li> </ol>	<ul style="list-style-type: none"> <li>Drowsiness, sleepy, difficulty concentrating</li> <li>Changes in appetite</li> <li>Dry mouth</li> <li>Changes in vision</li> </ul>	<ul style="list-style-type: none"> <li>Difficulty breathing</li> <li>Extreme agitation</li> </ul>
<b>Trileptal®</b> Oxcarbazepine Oxtellar XR	<ol style="list-style-type: none"> <li>Mainly used for treatment of focal seizures in patients with epilepsy.</li> <li>Comes in tablets and as a liquid.</li> </ol>	<ul style="list-style-type: none"> <li>Fatigue, headache, dizziness, abnormal walking, tremor.</li> <li>Diplopia (double vision), abnormal vision.</li> <li>Nausea, vomiting.</li> <li>Rash</li> </ul>	<ul style="list-style-type: none"> <li>Severe rash</li> <li>Changes in mental state</li> <li>Low sodium</li> <li>Changes in blood cells</li> </ul>
<b>Vimpat®</b> Lacosamide	<ol style="list-style-type: none"> <li>Used with other medicines in treatment of focal seizures for patients with epilepsy.</li> <li>Comes in tablets and as a liquid.</li> </ol>	<ul style="list-style-type: none"> <li>Dizziness, headaches.</li> <li>Diplopia (double vision), abnormal vision.</li> <li>Nausea, vomiting.</li> <li>Rash</li> <li>Behavior changes.</li> </ul>	<ul style="list-style-type: none"> <li>Severe rash</li> <li>Changes in the liver</li> <li>Extreme behavior changes.</li> </ul>
<b>Zarontin®</b> Ethosuximide	<ol style="list-style-type: none"> <li>Used mainly for treatment of absence seizures. May be used with other seizure medicines.</li> <li>Comes in a gel cap and raspberry-flavored liquid.</li> </ol>	<ul style="list-style-type: none"> <li>Nervousness, dizziness, headaches, sleepiness, lack of energy, or irritability. These may disappear with time.</li> <li>Stomach pain – may take with meals</li> <li>Rash</li> <li>Nausea, vomiting</li> </ul>	<ul style="list-style-type: none"> <li>Decreased white or red blood cell count</li> <li>Changes in liver function</li> <li>Severe rash Always report rashes to your doctor.</li> </ul>
<b>Zonegran®</b> Zonisamide	<ol style="list-style-type: none"> <li>Used with other seizures medicines for treatment of focal and generalized seizures.</li> <li>Comes in capsules.</li> <li>It is important for your child to drink plenty of water each day when taking this medicine, especially during the summer.</li> </ol>	<ul style="list-style-type: none"> <li>Headache, dizziness, difficulties in concentration or memory, mental slowing, fatigue</li> <li>Decreased appetite, kidney stones, weight loss</li> <li>Always report any rash to your neurologist, especially if allergic to sulfa drugs</li> <li>Decreased sweating, flushing of the face and increased body temperature have been reported with this medicine. Alert your child's doctor if this occurs.</li> </ul>	<ul style="list-style-type: none"> <li>Changes in speech or taste. Immediately alert your child's doctor if this occurs.</li> <li>Severe rash</li> <li>Hair loss</li> <li>Changes in breathing</li> <li>Changes in urination-less often or dark urine</li> </ul>

## Rescue Seizure Medicines

**Prescribed Time:** *Time that you give the medicine.*

For example:

1. Your child's doctor may tell you to give a rescue seizure medicine at 5 minutes.
2. If your child is having a seizure and it is now 5 minutes later, you will give rescue medicine.
3. Most children receive their rescue medicines between 3 to 5 minutes.

How to Take	Medicine Name	Medicine used for:	Possible side effects	Possible serious effects
Oral Dissolvable Tablet	Klonopin® Clonazepam	<ol style="list-style-type: none"><li>1. Mainly used for generalized myoclonic, atonic, absence, atypical absence seizures and focal seizures. It is also used for seizure flurries/clusters.</li><li>2. Comes in an orally dissolving tablet.</li><li>3. May use with other seizure medicines.</li></ol>	<ul style="list-style-type: none"><li>• Rash</li></ul>	<ul style="list-style-type: none"><li>• Shallow breathing</li><li>• Pause in breathing</li></ul>
Nasal Spray	<b>1. Versed®</b> Midazolam <b>2. Nayzilam®</b> Midazolam <b>3. Valtoco®</b> Diazepam	<ol style="list-style-type: none"><li>1. Used to stop seizure activity.</li><li>2. Comes as a spray that goes in the nose.</li><li>3. Follow doctor's instructions for giving this medicine.</li></ol>	<ul style="list-style-type: none"><li>• Dizziness</li><li>• Sleepy</li><li>• Difficulty concentrating</li><li>• Dry mouth</li><li>• Change in balance</li><li>• Rash</li></ul>	<ul style="list-style-type: none"><li>• Shallow breathing</li><li>• Pause in breathing</li><li>• Trouble breathing, call 911</li></ul>

How to Take	Medicine Name	Medicine used for	Possible side effects	Possible serious effects
Rectal	<b>Diastat®</b> Diazepam	<p>1. Rectal medicine is for both focal and generalized seizures.</p> <p>2. Give this medicine rectally for a seizure lasting more than the prescribed time or for “cluster” seizures. Your doctor will define cluster seizures for you.</p> <p>Diastat comes in a pack of 2 rectal suppositories. Follow the packet instructions for administration or ask your doctor for details.</p>	<ul style="list-style-type: none"> <li>Drowsiness and staggering while walking.</li> <li>Increased drooling.</li> <li>Behavior changes such as irritability, inattentiveness, restlessness, hyperactivity, and sleep disturbances.</li> <li>Changes in appetite.</li> </ul>	<ul style="list-style-type: none"> <li>Rash</li> <li>Shallow breathing</li> <li>Pause in breathing</li> </ul>
IV	<b>Ativan®</b> Lorazepam	<p>1. Mainly for generalized and focal seizures to stop seizure activity lasting longer than the prescribed time or used for “clusters”.</p> <p>2. Your child’s doctor will define cluster seizures for you.</p> <p>3. Comes as a tablet and liquid.</p> <p>4. Give this medicine as ordered by your child’s doctor.</p>	<ul style="list-style-type: none"> <li>Drowsiness, confusion, dizziness.</li> <li>Low blood pressure.</li> <li>Change in appetite.</li> <li>Visual disturbances such as seeing stars or odd colors.</li> </ul>	<ul style="list-style-type: none"> <li>Rash</li> <li>Shallow breathing</li> <li>Pause in breathing</li> </ul>

**Want to learn more? Here are some resources for patients and caregivers:**

- Ask your provider about a library consult.
- [www.cookchildrens.org/neurology](http://www.cookchildrens.org/neurology)
- [www.epilepsy.com](http://www.epilepsy.com)

**Mycookchildren's Patient Portal**

- |   |   |
|---|---|
| <p>1. Summary of visit<br/>2. Test results<br/>3. Appointments<br/>4. Request refills</p> | <p>5. Access and print immunization records<br/>6. Direct communication with your child’s care team<br/>7. Virtual care</p> |
|---|---|

## Seizure Safety Precautions

**Until your child's seizures are controlled, the following activities can be dangerous:**

- Horseback riding
- Rock/tree climbing
- Water/snow skiing
- Contact sports
- Football
- Wrestling
- Rugby
- Scuba diving
- Soccer
- Boxing
- Operating motorized vehicles (go-carts, 4 wheelers, scooters, etc.)

**Call your doctor or nurse before taking part in any of the above activities**

**Important for all children diagnosed with seizure disorder  
To follow these safety precautions:**

1. Have an adult close by when taking a bath.
2. Have adult present when swimming in a pool or lake.
3. Wear a life jacket when swimming.
4. Do not climb trees.
5. Only climb to heights that are protected. Wear a safety belt or harness.
6. Always wear a bicycle helmet when on a tricycle, bicycle, or rollerblades.
7. Always wear a helmet when horseback riding.

### **Please Note:**

This list does not cover every possible sport or activity.  
Parents must always use their best judgment for their child.

**Safest activities for children with a seizure disorder  
are the ones that keep both feet on the ground.**

Check with your doctor about these common activities.



## What is SUDEP?

Sudden unexpected death in epilepsy (SUDEP) is when a person with epilepsy dies suddenly and no other cause of death is found.

1. Each year 1 out of every 1000 adults with epilepsy die from SUDEP.
2. Each year 1 out of every 4000 children with epilepsy die from SUDEP.

## Exact cause of SUDEP unknown

Seizures in the brain may cause changes in a person's heart rate or breathing.

- SUDEP often happens during sleep.
- SUDEP may happen after a seizure.

## Some people with epilepsy have a higher risk of SUDEP

### This includes:

- Young adult age group
- Generalized tonic clonic seizures
- Taking many seizure medicines
- Seizures at night or during sleep
- Sudden changes in epilepsy medicine

## Chance of SUDEP increases

- If brain surgery is being considered because of uncontrolled seizures.
- If seizures are caused by brain damage or a brain tumor.

## Reduce risk of SUDEP

Have as few seizures as possible

### 1. Take seizure medicine

- Make sure your child takes seizure medicines every day.
- Avoid sudden changes in medicine.
- Do not stop seizure medicine without talking to your child's neurologist.

### 2. Keep your child healthy

- Help child get plenty of sleep each night.
- Avoid activities that will make your child too tired.

### 3. Train everyone who is around your child the following:

#### Train on a regular basis

- Safety precautions for seizures
- Seizure first aid training
- CPR (cardio-pulmonary resuscitation) training

### 4. After a seizure happens, make sure:

- Breathing returns to normal.
- Color returns to child's lips and face.

### 5. Keep appointments with your child's neurologist.

If you have any questions or concerns, please call either your:

Neurologist: 682-885-2500

Neurology educator: 682-885-2964.