

If you would like a printed copy of
the booklet, please contact the
Neurology Clinic at 720-777-6895



Seizure Safety Station

A resource guide for families.
If you have questions about the information
provided, please ask your care provider.

NEUROSCIENCE
INSTITUTE



EPILEPSY
FOUNDATION
Colorado

TABLE OF CONTENTS

Section 1

Welcome to the Neurology Department 6

Section 2

Have a Plan 18

Section 3

Safety 22

Section 4

School and Daycare Information..... 26

Section 5

Activities 32

Section 6

Emergency Medications 36

Section 7

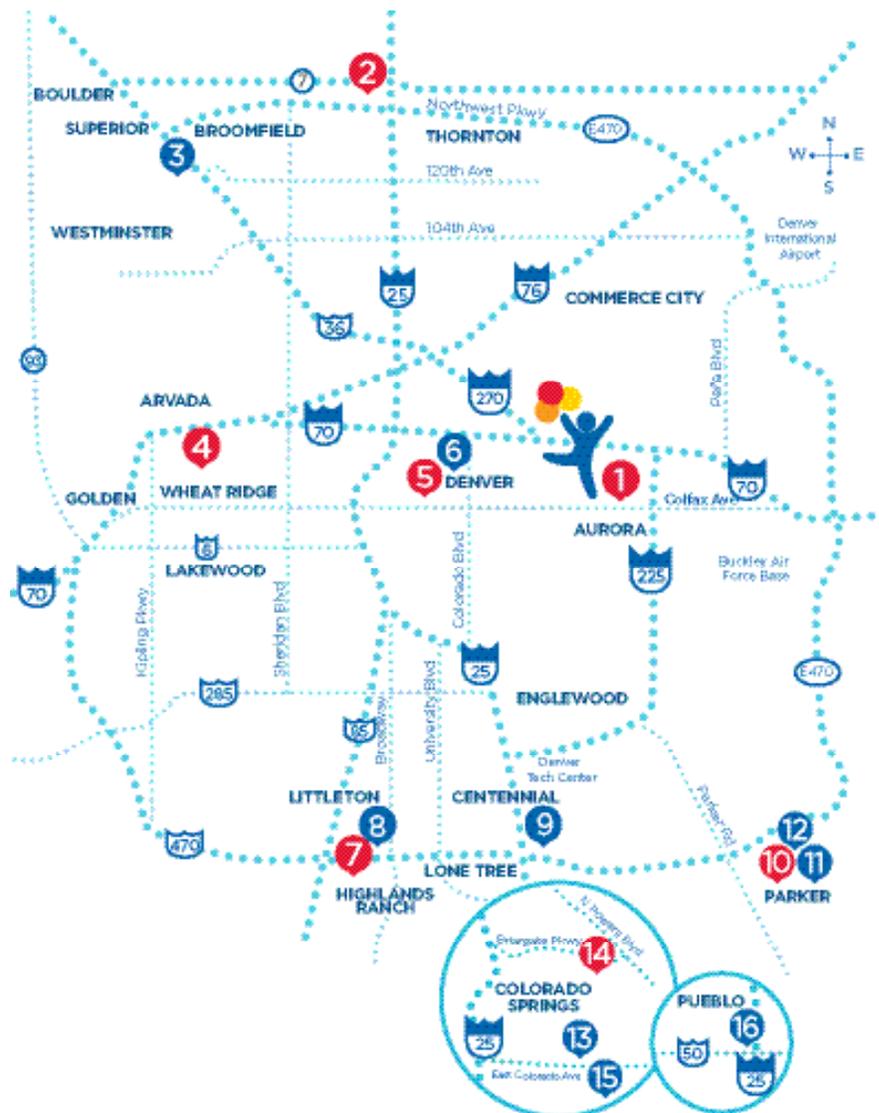
Medication 40

Section 8

Resources 46

CHILDREN'S COLORADO LOCATIONS

- 1** Children's Hospital Colorado Anschutz Medical Campus, Aurora
- 2** Children's Hospital Colorado North Campus, Broomfield
- 3** Children's Hospital Colorado Therapy Care, Broomfield
- 4** Children's Hospital Colorado Urgent and Outpatient Specialty Care, Wheat Ridge
- 5** Children's Hospital Colorado Urgent, Emergency and Outpatient Specialty Care, Uptown Denver
- 6** Children's Hospital Colorado KidStreet
- 7** Children's Hospital Colorado South Campus, Highlands Ranch
- 8** Children's Hospital Colorado Therapy Care, Highlands Ranch
- 9** Children's Hospital Colorado Orthopedic Care, Centennial
- 10** Children's Hospital Colorado at Parker Adventist Hospital Emergency Care, Parker
- 11** Children's Hospital Colorado Outpatient Specialty Care, Parker
- 12** Children's Hospital Colorado Therapy Care, Parker
- 13** Memorial Hospital, pediatric expertise provided by Children's Colorado
- 14** Children's Colorado Urgent and Outpatient Specialty Care at Briargate, Colorado Springs
- 15** Children's Colorado Therapy Care at Printers Park, Colorado Springs
- 16** Children's Colorado Therapy Care, Pueblo





WELCOME TO THE NEUROLOGY DEPARTMENT

WELCOME TO THE NEUROLOGY DEPARTMENT AT CHILDREN'S HOSPITAL COLORADO

My Healthcare Team

Urgent Line: 720-777-6895

24/7

Non-Urgent Lines:

Epilepsy: 720-777-8405

Movement Disorders, Neuromuscular,
and Stroke Team: 720-777-8406

General/Headache: 720-777-8404

Neurology Nurse Fax: 720-777-7196

Neurology Model of Care

The Division of Neurology functions under a team model. Our goal is to provide you the very best in quality comprehensive neurology services, and we feel that teamwork is very important.

- Our health team includes neurologists, nurse practitioners, physician assistants, residents, fellows, neuropsychologists, neuropsychology technicians, registered nurses, medical assistants, social workers, nutritionists, and EEG technologists.
- We are a teaching institution; therefore we frequently have students visit, including medical students, nurse practitioner students, physician assistant students, and nursing students. These students will see your child and discuss your child's history and presenting symptoms, and then will work with your child's team to coordinate the plan of care.

Care Team Members

- **Neurologist:** a doctor that has completed specialized medical training in the care of children and adolescents with disorders of the brain, spinal cord, nerves, and muscles.
- **Fellow Physician:** a doctor who has completed residency training and is completing additional training in a pediatric specialty.
- **Resident:** a doctor who has graduated from medical school and is now training in a specific field. Doctors spend from three to seven years in residency training before receiving board certification in their specialty. Residents providing care are supervised by attending physicians who must approve their decisions.
- **Nurse Practitioner (NP):** a nurse that has advanced training in a particular area, such as family practice or pediatrics. NPs often take the medical history, administer physical exams, perform procedures, order diagnostic tests, prescribe medication, and provide preventive healthcare. They are also licensed to treat illnesses and injuries.
- **Physician Assistant (PA):** a healthcare professional licensed to treat illnesses and injuries, orders tests and interpret results, provide preventative health care counseling, and prescribe medications. Under the supervision of a trained doctor, PAs often take the medical history, administer physical exams, perform procedures, order diagnostic tests, and prescribe medication.
- **Registered Nurse (RN):** a licensed nurse that can administer medication, provide patient instructions, perform basic procedures, and provide patient education. The nurse works closely with providers in the child's plan of care.
- **Medical Assistant (MA):** a trained medical professional who help the doctor by doing basic clinical skills, such as checking the height, weight, temperature, and blood pressure of each patient.
- **Social Worker:** a licensed provider who focuses on improving the emotional wellbeing of kids and their families and helps coordinate healthcare. In addition to offering emotional support, a social worker can also help facilitate improvements a child needs at school or at home.
- **Dietician:** a nutrition expert who works on our team to help manage prescribed epilepsy diets.
- **Neuropsychologist:** a psychologist who treats changes that may occur in learning, speech, memory, reading, behavior, and other skills. When evaluating children who have seizures, the neuropsychologist can help parents to understand whether their child is having learning problems that are related to the seizures, medications, or other causes. He or she can help your provider understand if your child is having increasing problems. Specific evaluations are done when seizure surgery is being considered. If undergoing a neuropsychological evaluation, you should expect to be in the clinic for one to four hours if your child is less than five years of age, and five to seven hours if your child is older.
- **Epileptologist:** a neurologist who has taken at least an additional two years of specialized training in diagnosing and treating epilepsy.



To Contact Your Provider

Please call during office hours. We make every effort to return your call within two working days. Please call if you have not heard back from a nurse or provider on the third day. Any urgent calls will be returned as soon as possible.

Urgent and After-Hours Calls

For any **URGENT** phone calls outside of normal business hours you may call **720-777-6895**, and talk with the **on-call doctor**. Please do not call the on-call doctor for refill requests. **Refill requests are managed during normal business hours.** Your pharmacy will provide you with enough medication to get through until nurses can be reached during normal business hours. If your medication is a controlled substance, you will be responsible for calling during office hours to get the refill.

Emergencies

If you have a medical emergency please call 911 or go to your local emergency department.

Test Results

Please call the nurse line or use MyChart to request lab, blood, or MRI results in two to three days if the test is done at Children's Colorado. If you have a test done at another facility, the results need to be faxed to us at 720-777-7196. If you obtain an EEG or MRI/scan at an outside hospital, you will need to bring the results and the images on a compatible disk from the facility to be reviewed at your next appointment. Please note that send-out genetic tests may take four to six weeks.

Medication Refills

Please call your pharmacy and have them fax us a refill request to the fax number 720-777-7196. **Refill requests may take up to 72 hours to process.**

Forms

All forms should be filled out entirely and brought to your child's office visit to be signed by the provider. If you need a school form filled out; please fill out the form entirely (including medications and all other needed information) and sign it before providing it to the school. The school should then email the form to neurologynursing@childrenscolorado.org or fax it to 720-777-7196.

Please note that any faxed forms can take up to a week to be completed and returned. If sent to us in at the beginning of the school year, forms can take up to two weeks to be signed and returned.

Follow-up Appointments

It is the responsibility of the patient and/or family to call and make follow up appointments. To schedule an appointment, call 720-777-6895. You should call at least two months before the needed appointment. For example, if you need an appointment in March, you should call in January. Please remember the schedule is only open for booking appointments three months in advance.

MyChart

MyChart allows you to send messages to your doctor, view your test results, renew your prescriptions, schedule appointments, and more. To register for MyChart, use the access code provided to you at the end of your visit. This code is included in your After Visit Summary paperwork if your child is over 15. If your child is under 15 please stop at the checkout desk for your access code.

How Do I Sign Up?

1. In your Internet browser, go to mychart.childrenscolorado.org.
2. Click on the New User link in the Sign In box.
3. Enter your MyChart access code. You will not need to use this code after you have completed the sign-up process. If you do not sign up before the expiration date, you must request a new code. Codes can only be requested and given at appointments.
4. Enter your ZIP code and date of birth as indicated and click next.
5. Create a MyChart ID. This will be your MyChart login ID and cannot be changed, so think of one that is secure and easy to remember.
6. Create a MyChart password. You can change your password at any time.
7. Enter your password-reset question and answer and click next. This can be used at a later time if you forget your password.
8. Select your communication preference, and if applicable enter your email address. You can receive email notification when new information is available in MyChart by choosing to receive email notifications and filling in your email.
9. Click Sign In. You can now view your medical record.

Remember, MyChart is not for urgent needs. For immediate assistance from a nurse, please call the urgent nurse line at 720-777-6895. For medical emergencies, dial 911. If you have questions, call 720-777-4357 to talk to our MyChart staff, or email mychart@childrenscolorado.org.

Referrals

Since Neurology is a specialty department, all referrals to other specialists will need to be discussed with and approved by your child's primary care provider (PCP). The PCP needs to remain the primary caretaker for your child and is often required by insurance. If we make a recommendation for a referral, the parent should contact the child's doctor to discuss this recommendation and request a referral.

Medical Records

To request medical information such as tests or exams, please call medical records at 720-777-6343. The parent of the child will need to sign a release of information form to have the information released to any outside resource.

To find the form:

- Go to childrenscolorado.org
- Click on **About Us**
- Click on **About Your Bill**, Insurance or Medical Record
- Select **Medical Records**

To obtain a copy of any imaging on a disc, please call Radiology at 720-777-6541.

Holidays

Please note that the department is closed on holidays. Please request refills through your pharmacy in advance. An on-call doctor will be available at all times to consult on urgent medical concerns.



SEIZURES AND EPILEPSY

What is a seizure and what is epilepsy?

A **seizure** happens when a brief, strong surge of electrical activity affects part or all of the brain. One in 10 people will have a seizure sometime during their life.

Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. It's also called a seizure disorder. When a person has two or more seizures that are not the result of another medical condition, they are considered to have epilepsy.

How common is epilepsy?

- Over 200,000 new cases of epilepsy are diagnosed each year.
- Incidence is highest under the age of 2 and over 65.
- The basic, underlying risk of developing epilepsy is about 1 percent. Individuals in certain populations are at higher risk. For example, it is estimated that epilepsy can be expected to develop in:
 - 25.8 percent of children with intellectual disability
 - 13 percent of children with cerebral palsy
 - 50 percent of children with both disabilities

How likely is it that seizures will stop?

- 60 percent of people with epilepsy can be expected to enter remission, defined as five or more years seizure-free while on medication.
- 10 percent of new patients gain control of seizures treated by a second or third medication and 30 percent will have intractable (difficult to control) seizures.
- 35 percent of people with intellectual disability, cerebral palsy, or other underlying neurological conditions will enter remission.
- 75 percent of people who do not have a seizure while on medication for two to five years can be successfully withdrawn from medication.

What are some common seizure triggers?

- Seizures may be triggered or irritated by a variety of mechanisms. The most common trigger is missed medication, whether intentional or unintentional. Changes in sleep and wake cycles and stress can also influence seizure frequency. Women can be affected by pregnancy and menstrual cycles.
- Use of alcohol or drugs, illness, or fever can trigger seizures. Adding or suddenly removing prescription medications or supplements can trigger seizures, and should therefore be managed gradually by your neurologist.
- Some studies indicate that emotional stressors such as worry, anxiety, and anger may cause seizures, especially if combined with fatigue or chronic sleep loss. Practicing relaxation techniques and treating disorders contributing to sleep loss (such as sleep apnea) may decrease seizure frequency.
- Unpredictable changes in metabolic factors, such as vomiting, diarrhea, and physical exertion can also contribute to seizures.
- In contrast, reflex epilepsy is a condition in which seizures can be provoked by an external stimulus (such as flashing lights) or, occasionally, by an internal mental process (such as mathematical calculation). Reflex seizures are fairly predictable in response to specific stimuli.
- For the most part, once triggers have been identified, exposure can be limited. This is the typical treatment, along with standard anti-seizure medication.

What types of testing can we expect to undergo?

- The doctor's main tool in diagnosing epilepsy is a careful medical history with as much information as possible about what the seizures looked like and what happened just before they began.
- A second diagnostic tool is an electroencephalograph (EEG). This is a machine that records brain waves picked up by tiny wires taped to the head. Electrical signals from brain cells are recorded as wavy lines by the machine. Brain waves during or between seizures show patterns which help the doctor decide whether or not someone has epilepsy.
- Imaging methods such as CT (computerized tomography) or MRI (magnetic resonance imaging) scans may be used to search for any growths, scars, or malformations in the brain that may be causing the seizures.
 - Computerized Tomography (CT): A scanning method that uses X-rays and computers to create images of the internal structure of the brain.
 - Magnetic Resonance Imaging (MRI): An imaging method using magnets instead of X-rays. This method produces detailed pictures of the internal structure of the brain. There is no radiation exposure during this test.

Some other helpful tips:

- Ask your child's doctor ahead of time what to do if your child misses a dose of medication.
- Do not stop your child's medicine suddenly. It could cause non-stop seizures that would put your child in the hospital and might even threaten your child's life.
- Tell your child's doctor if you notice any unusual changes in health, feelings, or behavior when your child is taking their medication.
- Make sure your child gets enough sleep.
- Think about things you want to ask before you see the doctor and write them down to bring to your child's visit.
- Keep follow-up appointments. Your child may need special tests from time to time to make sure medications aren't doing anything to your child's body that might be damaging.
- Tell doctors planning surgery for your child or treating your child for other medical conditions that your child has epilepsy, and what medicine he or she takes for it.
- Ask your child's doctor if there are any cold pills, fever medicines, or other drug-store products you should avoid because your child takes epilepsy medicine.
- If your child's doctor changes your child's medicine, don't let your child drive until you know how it's going to affect him or her.

Types of Seizures

Seizures can take many different forms, often not resembling the convulsions that most people associate with epilepsy.

- **GENERALIZED TONIC CLONIC** (*Grand Mal*) – Convulsions, muscle rigidity, jerking.
- **ABSENCE** (*Petit Mal*) – Blank stare lasting only a few seconds, sometimes accompanied by blinking or chewing motions.
- **COMPLEX PARTIAL** (*Psychomotor/Temporal Lobe*) – Random activity where the person is out of touch with his surroundings.
- **SIMPLE PARTIAL** – Jerking in one or more parts of the body or sensory distortions that may or may not be obvious to onlookers.
- **ATONIC** (*Drop Attacks*) – Sudden collapse with recovery within a minute.
- **MYOCLONIC** – Sudden, brief, massive jerks involving all or part of the body.

IMPORTANT HOSPITAL PHONE NUMBERS

To reach a number while you are inside the hospital, dial 7 plus the last four digits of the phone number. To reach a number outside the hospital, dial 9 plus the complete phone number. Cellular phones can be used throughout the hospital.

Children's Hospital Colorado Main Number	720-777-1234
Toll Free	800-624-6553
Association of Volunteers	720-777-6887
Billing Questions	720-777-6422
Chapel/Garden of Hope	720-777-6325
Clinical Social Work	720-777-6895
Creative Play Center	720-777-6999
Family Advisory Council	720-777-5865
Family Health Library	720-777-6378
Financial Counseling	720-777-6422
Medical Interpreter Services	720-777-2525
Medical Records	720-777-6343
Patient Representatives	720-777-6887
TTY (Hearing Impaired)	720-777-6887
Radiology	720-777-6541

Neurology contacts and numbers

Ketogenic Nutrition	720-777-5883
Neurology Main Line	720-777-6895
Neurology Insurance Coordinator	720-777-8130 (to request insurance approval of medications and tests)
Outpatient Lab, Main Campus	720-777-8175
Hours: Monday - Friday, 7 a.m. to 5:30 p.m. Saturday, 8 a.m. to 12 p.m.	
Radiology	720-777-5650 (to schedule an MRI, CT scan, or X-ray)
Schedule a Routine EEG	720-777-4513



HAVE A PLAN

HAVE A PLAN

Having a child with Epilepsy can be challenging, but not unmanageable. Please use this guide to come up with a plan specific to your child.

Things to consider include:

- Travel
- Babysitting
- Emergencies
- School or daycare
- Medical ID bracelets and necklaces
- Monitoring
 - Record the frequency of seizures on a calendar.
 - Ensure your child is getting their medication daily and on time.
 - Monitor the side effects of seizure medication.

Seizuretracker.com is a resource with many free templates. You can download these onto your computer, your phone, or you can print them. They have trackers specific to different types of seizures and trackers to help to monitor appointments and medications.

Emergency Plan

The average seizure in a child who has epilepsy is not a medical emergency. It ends naturally by itself. But every rule has an exception or two, and that's true of epilepsy as well.

When to Call 911

Emergency symptoms:

- Not breathing/blue. (Cyanosis, or turning blue, is common with seizures; even so, check fingertips for color. If fingers look okay, your child should be fine. If you are unsure, always call 911.)
- Generalized tonic-clonic seizures that last longer than five minutes, especially after administration of Diastat/Midazolam
- Repeated seizures without any response to touch and sound between seizures
- Fall before, during, or after seizure
- Different or new type of seizure activity
- Seizures during pregnancy
- Seizures in water, such as a pool or bathtub
- No response to painful stimuli after seizures, especially if accompanied by facial twitching, mouth movement, or eye fluttering, which may indicate non-convulsive status epileptics
- Neurological symptoms after the seizure, such as weakness on one side, that are not usually present or lasting longer than usual
- Vomiting during a seizure, followed by unconsciousness or not breathing properly

When to Call your Neurologist:

- Previous history of seizures, coupled with fever (an underlying illness can trigger seizures)
- Mental Decline — the child is not acting in his or her usual way
- An unexpected seizure or a seizure outside your child's normal pattern

Home Care Advice

- Keep calm. You cannot stop a seizure.
- Do not try to hold your child or stop his or her movements.
- Stay with your child until he or she is fully awake.
- Remove harmful objects near your child or stand in front of dangerous areas such as stairways. If needed, gently lead your child away from dangerous areas.
- Know that your child may not hear you or be aware of what he or she is doing.
- Write down how long the seizure lasts and what your child did. After your child rests, ask what he or she remembers about the seizure.
- Call your child's doctor to let them know that a seizure occurred.

Caring for a child during a tonic-clonic seizure and generalized seizure

- Keep calm. You cannot stop a seizure.
- Do not try to hold your child or stop his or her movements.
- Help your child lie down.
- Gently roll your child onto one side. After a seizure, your child may throw up. Lying on one side helps saliva and vomit drain from the mouth.
- If your child has anything visible in the mouth, clear it with your finger to prevent choking.
- Do not force anything between your child's teeth, as this may hurt your child and you. Your child will not swallow his or her tongue.
- Loosen your child's collar and put something flat and soft under his or her head.
- Clear the area of hard, sharp, or hot objects that may harm your child. You may also gently pull your child to a safe area.
- Remove your child's eyeglasses.
- Stay with your child until the seizure is over.
- Watch your child during the seizure. Time the seizure. Write down which parts of his or her body were moving during the seizure. Note any unusual movements or behavior that happened just before the seizure. After your child rests, ask what he or she remembers about the seizure.
- If your child stops breathing for a few seconds during the seizure, stay calm. Breathing should return as soon as the seizure is over. If not, start CPR and call 911.
- Let your child rest after the seizure.
- Call your child's doctor to let them know that a seizure occurred.
- **If the seizure lasts longer than five minutes, administer Diastat or your emergency medication.**

Caring for a child during a febrile seizure

- Bringing your child's fever down as quickly as possible may shorten the seizure.
- Remove your child's clothing and apply cold washcloths to the face and neck.
- If seizure persists, sponge the rest of the body with cool water. As the water evaporates, your child's temperature will fall.
- When the seizure is over and your child is awake, give a dose of acetaminophen or ibuprofen per your child's weight and age. Giving Tylenol will not stop a seizure from occurring but it is still okay to give to comfort your child.
- Encourage your child to drink cool fluids.



SAFETY

SAFETY

Driving

For all state driving laws visit: epilepsy.com/living/wellness/transportation/drivinglaws.cfm

State	Colorado	Nebraska	New Mexico	Montana	Wyoming
Seizure-Free Period	No set seizure-free period	No set seizure-free period	One year (less with recommendation of Medical Advisory Board)	No set seizure-free period; Doctor's recommendation	Three months with exception
Periodic Medical Updates Required After Licensing	At discretion of DMV	No set period	At discretion of Medical Advisory Board	No	At discretion of Medical Advisory Board
Doctors Required to Report Epilepsy	No	No	No	No	No
DMV Appeal of License Denial	Yes	Yes	Within 20 days	Yes	Within 20 days

Water Safety

Your child could drown during a seizure that occurs in water. Use one-on-one adult supervision for swimming. Encourage your child to tell his or her friends that they have seizures. Have your child take showers instead of baths. If seizures are frequent, buy a plastic shower chair and a flexible water hose. Removing the drain plug in tub/shower combos because during a seizure your child can fall on it and engage the plug. Have a no-locked bathroom door policy.

Burn Safety

If your child has uncontrolled seizures, be very careful around heat or flames. Cook on the back burner — your child is less likely to lean on the burner or turn over the soup during a seizure. Don't smoke, which is good advice for other reasons as well. Set the maximum house hot water temperature to 110 degrees Fahrenheit. Put guards on open fireplaces, wood stoves, or radiators.

Heights

Occasional use of ladders and going up and down stairs is a reasonable risk. If your child's seizures are not in control, then your child should not work on ladders or unprotected heights for prolonged periods. If your child falls with some of his or her seizures, fall-proof your child's environment. Put in carpets, cover sharp corners, and consider having him or her wear a protective helmet in some circumstances.

Equipment and Power Tools

Cutting, chopping, and drilling equipment should have safety guards; otherwise, do not use them if your child's seizures are not fully controlled. Do not use movers lacking automatic stop switches. Do not use chain saws.

Sports Safety

The Epilepsy Foundation is the leading expert on sports safety for your child. The below summarizes key details, but please visit [epilepsy.com/get-help/staying-safe/safety-exercise-and-sports](https://www.epilepsy.com/get-help/staying-safe/safety-exercise-and-sports) for more information. Always ask your Neurologist if a certain activity or sport is appropriate for your child.

Recreational activities can improve both mental and physical health for people with epilepsy. Very rarely, exercise is a trigger for seizure activity, but for the vast majority of epilepsy patients, the benefits of exercise far outweigh the risks. Of course, common sense dictates that certain activities need special accommodations or should be avoided. The greater the frequency and severity of an individual's seizures, the greater the need for that person to limit or modify athletic activities.

Most sports can be safely pursued by individuals whose seizures are not fully controlled. With just a few extra safety precautions, they can enjoy most activities, even ones that many would consider dangerous. For instance, a woman with complex partial seizures enjoyed downhill skiing and was able to continue in the sport by always skiing with her husband and using only beginner or intermediate trails. A man with rare tonic-clonic seizures roller blades every weekend and stays safe by consistently wearing a helmet and knee and elbow pads.

Water Sports

Water sports, including swimming, jet-ski riding, windsurfing, and sailing, are risky for people with epilepsy, but with a few accommodations they also can be safely pursued.

Water sport safety tips:

- Your child should never do water sports alone.
- Always have your child wear a medical alert bracelet or necklace.
- A child with epilepsy — or any child — should never swim alone or be on a boat or close to water (including backyard wading pools) without a flotation device or life jacket.
- Carefully supervise children near water.
- Make sure an adult is present who knows your child has epilepsy and is a good enough swimmer to help if your child has a seizure in the water.
- Tell lifeguards or swimming instructors at local pools or beaches that your child has seizures.

If a child has a seizure in water, he or she should be checked by a lifeguard or parent. If there is any possibility that water has been swallowed or breathed into the lungs, get a medical checkup.

Contact Sports

Contact sports such as football, rugby, basketball, soccer, and ice hockey are generally safe for people with seizures. However, family members may worry about the chance of head or bodily injury, which is common in these sports.

People with epilepsy have no greater chance of injury during these sports than people without epilepsy. The chances of serious injury are small compared with the positive effects of team participation.

Most individuals with epilepsy can safely exercise in a gym and use exercise equipment. For those who have uncontrolled seizures, a buddy system may be needed when using equipment like treadmills or bicycles. For example, Susan, who has occasional complex partial seizures, only exercises on the treadmill when her friend is present. The friend supervises the exercise to prevent injury if Susan has a seizure.



Recreation Safety Tips

Recreational activities are very important for socializing and happiness. Achieving the balance between a safe life and an active life is possible by just making a few adjustments.

- Always have a “buddy” for activities that require considerable exertion or have a high risk of injury.
- Take frequent breaks and drink plenty of water.
- Wear protective clothing (elbow or knee pads, helmet, protective eyeglasses, or goggles) whenever possible.
- When bike riding, avoid busy streets; ride on bike paths or side streets.
- Always wear a medic alert bracelet or necklace or carry a medic alert card.

Authored by: Steven C Schachter, MD | Patricia O. Shafer, RN, MN | Joseph I. Sirven, MD on 9/2013



FIRST AID FOR SEIZURES

Convulsive, Generalized Tonic-Clonic, Grand Mal

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

- Cushion head, remove glasses
- Time the seizure with a watch
- Loosen tight clothing
- Turn on side
- Look for medical alert identification
- As seizure ends, offer help
- **Don't put anything in mouth**
- **Don't hold down**

But sometimes there are good reasons to call for emergency help. A seizure in someone who does not have epilepsy could be a sign of a serious illness.

Other reasons to call an ambulance include:

- A seizure that lasts more than five minutes
- No “epilepsy” or “seizure disorder” identification
- Slow recovery, a second seizure, or difficulty breathing afterwards
- Any signs of injury or sickness

Complex Partial, Psychomotor, Temporal Lobe

Recognize common symptoms:

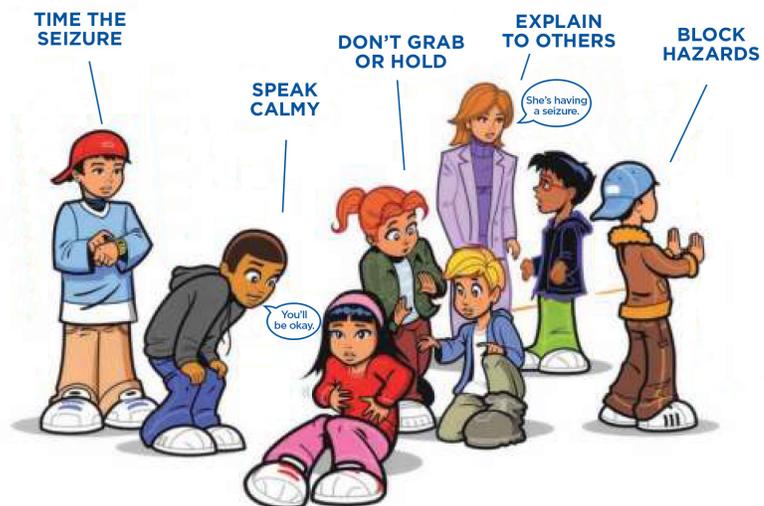
- Blank staring
- Chewing
- Fumbling
- Wandering
- Shaking
- Confused speech



Follow first-aid steps:

- Time the seizure
- Speak calmly
- Don't grab or hold
- Explain to others
- Block hazards

People who've had this type of seizure should be fully conscious and aware before being left on their own. Make sure they know the date, where they are, and where they're going next. Confusion may last longer than the seizure itself and may be hazardous. If full awareness does not return, call for medical assistance.





SCHOOL AND DAYCARE INFORMATION

SCHOOL AND DAYCARE INFORMATION

Always inform your child’s school or daycare that your child has seizures. They will most likely ask you to fill out a “My Seizure Plan,” form found on the Epilepsy Foundation website epilepsy.com, or a “Seizure Preparedness Plan for Back to School,” form found at diastat.com.

One of these forms needs to be filled out or updated every year so that your child’s school can be prepared and educated in the event of a seizure.

Please inform your school nurse that they are always welcome to call us if they have any questions or concerns. You must fill out a consent form for us to be able to speak with them.

Below is a copy of the “My Seizure Plan” form.

MY SEIZURE PLAN			
Name: _____		Birth Date: _____	
Address: _____		Phone: _____	
1st Emergency Contact: _____		Relation: _____	
Phone(s): _____		Email: _____	
2nd Emergency Contact: _____		Relation: _____	
Phone(s): _____		Email: _____	
SEIZURE INFORMATION			
Seizure Type/Nickname	What Happens	How Long It Lasts	How Often
TRIGGERS			
DAILY SEIZURE MEDICINE			
Medicine Name	Total Daily Amount	Amount of Tab/Liquid	How Taken (time of each dose and how much)
OTHER SEIZURE TREATMENTS			
Device Type: _____ Model: _____ Serial#: _____ Date Implanted: _____			
Dietary Therapy: _____ Date Begun: _____			
Special Instructions: _____			
Other Therapy: _____			
© 2007 epilepsy.com A service of the Epilepsy Foundation			

MY SEIZURE PLAN			
SEIZURE FIRST AID			
<input type="checkbox"/> Keep calm, provide reassurance, remove bystanders <input type="checkbox"/> Keep airway clear, turn on side if possible, nothing in mouth <input type="checkbox"/> Keep safe, remove objects, do not restrain <input type="checkbox"/> Time, observe, record what happens <input type="checkbox"/> Stay with person until recovered from seizure <input type="checkbox"/> Other care needed: _____			
WHEN SEIZURES REQUIRE ADDITIONAL HELP			
Type of Emergency (long, clusters or repeated events)	Description	What to Do	
"AS NEEDED" TREATMENTS (VNS magnet, medicines)			
Name	Amount to Give	When to Give	How to Give
CALL 911 OR SEEK EMERGENCY MEDICAL ATTENTION IF ...			
<input type="checkbox"/> Generalized seizure longer than 5 minutes <input type="checkbox"/> Two or more seizures without recovering between seizures <input type="checkbox"/> "As needed" treatments don't work <input type="checkbox"/> Injury occurs or is suspected, or seizure occurs in water <input type="checkbox"/> Breathing, heart rate or behavior doesn't return to normal <input type="checkbox"/> Unexplained fever or pain, hours or few days after a seizure <input type="checkbox"/> Other care needed: _____			
HEALTH CARE CONTACTS			
Epilepsy Doctor: _____		Phone: _____	
Nurse/Other Health Care Provider: _____		Phone: _____	
Preferred Hospital: _____		Phone: _____	
PCP or Other Doctor: _____		Phone: _____	
Pharmacy: _____		Phone: _____	
SPECIAL INSTRUCTIONS:			
My signature _____		Provider signature _____ Date _____	
© 2007 epilepsy.com A service of the Epilepsy Foundation			



ACTIVITIES

ACTIVITIES

Discuss all risks and benefits with your neurologist and coaches before your child decides to play a sport.

The Epilepsy Foundation is the leading expert on safety for your child. The below summarizes key details, but please visit [epilepsy.com/get-help/staying-safe/safety-exercise-and-sports](https://www.epilepsy.com/get-help/staying-safe/safety-exercise-and-sports) for more information.



Summer Camps

Please ask your provider for a brochure.

- **The Jason Fleishman Summer Camp**, provided by the Epilepsy Foundation of Colorado, is located at the YMCA of the Rockies in beautiful Estes Park, Colo. This 5-day overnight camp allows teens ages 13-17 with seizures to focus on what they CAN do through the support and encouragement of caring peers and camp staff. The campers build confidence and knowledge about epilepsy while having fun and making new friends. Camp activities include the zip line, rock climbing, horseback riding, arts and crafts and more. To ensure the safety of the campers, we have a team of licensed medical staff on site at all times along with experienced counselors. The cost is \$550 and scholarships are available. For more information, call 303-377-9774.
- **Rock’N’Rally Camp**, provided by the Epilepsy Foundation of Colorado, is located at the Cal-Wood Education Center in Jamestown. This overnight weekend camp allows a child with seizures to focus on what they CAN do through the support and encouragement of caring peers and camp staff. This is often a child’s first time away from home so we realize the importance of making this a positive, safe experience. It can be a great place to build confidence, make new friends, have fun in the great outdoors and learn more about epilepsy. To ensure the safety of the campers, we have a team of licensed medical staff on site at all times along with experienced counselors. The cost is \$250 and scholarships are available. For more information, call 303-777-9774.
- **Center for Courageous Kids** is a world-class medical camp designed specifically for children living with medical challenges who cannot attend a traditional camp. Visit [courageouskids.org](https://www.courageouskids.org) for more information.
- **Victory Junction Gang** is a free-of-charge, year-round camp for children with special needs and their families located in North Carolina. Find more information at [victoryjunction.org](https://www.victoryjunction.org).
- **Round Up River Ranch** is a camp for youth living with epilepsy and their families. There is no cost to attend Round Up River Ranch. Please ask for a brochure or go to [roundupriverranch.org](https://www.roundupriverranch.org).



EMERGENCY MEDICATION

EMERGENCY MEDICATIONS

ALL emergency medications need to go where your child goes.

Emergency Medications are prescribed on an individual basis. Below are the four most common emergency medications that our neurology team prescribes. Please speak with your provider or nurse if you have any questions regarding the emergency medications.

Diastat

Diastat is an emergency medication used for a seizure lasting over five minutes or per your provider's instructions.

- Make sure your child's school or daycare has an extra Diastat syringe for your child and that they know how to properly and safely administer Diastat.
- **IMPORTANT: If the green ready band is not visible, do not use. This may mean that an incorrect dose may be administered to the patient. Once green ready band is confirmed, the patient should be positioned on his or her side (facing the person administering Diastat), with the top leg bent forward.**
- Insert rectal tip (lubricated) into rectum and push in plunger gently for three seconds. Hold tip of rectal syringe in rectum for three additional seconds, and then remove the syringe. Hold buttocks together for three seconds after removal of rectal syringe.
- Diastat requires no refrigeration or special handling, and has a four-year shelf life.
- Sleepiness is the most common side effect. Less frequent side effects include rash, dizziness, headache, stuffy nose, abdominal pain, nervousness, diarrhea, and wheezing. You should tell your doctor about any side effects your child develops.
- **Please keep the Diastat handout with your Diastat.**

Diastat Patient Assistance Program

- Application requires a signature from your child's doctor.
- The patient's family must have an income at or below 200 percent of the federal poverty level.
- The family may not be enrolled in Medicare Part D or have any prescription drug coverage.
- Call 732-507-7445 or ask the Neurology Department for more information.

Midazolam Nasal Spray

Midazolam is an emergency medication used for a seizure lasting over five minutes or per your provider's instructions.

Make sure your child's school or daycare has a single dose vial or prefilled syringe and a complete administration kit (product kit MAD140) including needleless adaptor or needle, syringe, and atomizer for child, and that they know how to properly and safely administer Midazolam. **IMPORTANT: If you have a vial of Midazolam (not a prefilled syringe), DO NOT use it without the complete administration kit including the atomizer.**

- Remove the plastic cap from Midazolam vial (5mg/mL or 10mg/2mL).
- Place the needleless adapter or needle on syringe.
- Draw up the prescribed dose of Midazolam into the syringe.
- Remove the needleless adapter or needle and replace with atomizer.
- Place the tip of the atomizer into a nostril and spray the prescribed dose as instructed into each nostril.
- Midazolam requires no refrigeration or special handling, and is good for 28 days once drawn up into the syringe. If drawn up and not used, label the syringe with the name of medication, date drawn up, and 28-day date of expiration. Keep the pre-drawn syringe out of reach of children.
- Your child may feel sleepy or lightheaded, or have difficulty thinking clearly. Have your child avoid tasks or activities that require alertness or clear vision until you see how this medicine affects him or her.
- You should tell your doctor about any side effects your child develops.
- **Please keep the Midazolam handout with your Midazolam.**

For a video on how to administer, visit childrenscolorado.org/conditions-and-advice/conditions-and-symptoms/conditions/epilepsy-seizures

Ativan

Ativan, also called Lorazepam, calms the brain.

- Your child may start feeling better soon after starting this medicine.
- Side effects may include lightheadedness or sleepiness, blurred vision, or difficulty thinking clearly. Have your child avoid tasks or activities that require alertness or clear vision until you see how this medicine affects him or her.
- Dry mouth is also a common side effect. Frequent mouth care may help. Older children may suck hard, sugar-free candy.
- Unexpected excitement can rarely occur.

Clonazepam Wafers

Clonazepam, also called Klonopin, works by calming the brain.

- This medicine is used to prevent or control seizures.
- Do not push tablet through foil when opening. Use dry hands to remove from foil. Place the wafer on your child's tongue and let it dissolve. Water is not needed. Encourage your child not to chew, break, crush, or swallow it whole.
- Your child may start feeling better soon after starting this medicine.

When should I call my child's healthcare provider?

- If your child shows signs of a life-threatening reaction, call your healthcare provider or emergency department immediately. Life-threatening reactions may include chest tightness; fever; itching; bad cough; blue skin color; fits; swelling of the face, lips, tongue, or throat; or if your child exhibits any other unusual behavior.
- If your child is feeling very nervous and excitable.
- If your child's seizures are worse or different after starting a new medicine.
- If you are unable to wake your child.
- If your child develops a rash.
- If you believe your child's condition has not improved or is worse.





MEDICATION

MEDICATION

Please ask the Neurology Team for a handout for the seizure medication your child is on.

It is very important to know:

- Your child's medications
- The side effects
- Your child's dose (write it down where you can find it)
- What the medication looks like

Never skip doses unless instructed by your neurologist, and always take medication at the same time of day.

Side Effects

Parents and patients on seizure medications need to be aware of the side effects of their seizure medications and report any changes in health, behavior, or mood to their neurologist immediately.

Side effect warning signs include:

- Prolonged fever
- Rash
- Severe sore throat
- Mouth ulcers
- Easy bruising
- Pinpoint bleeding
- Weakness
- Excessive fatigue
- Swollen glands
- Lack of appetite
- Increased seizures

Like all drugs, epilepsy medicines have side effects. Some are dose-related and become more likely as the dose increases. Sleepiness, slurring of speech and unsteadiness are common effects of seizure drugs at high doses. Similar effects may occur at standard doses at the beginning of treatment but they typically decrease as the body becomes used to the medication.

Other side effects are associated with specific medications, and occur fairly frequently, regardless of dose. Depending on the drug involved, these effects may include double vision, weight gain, hyperactivity, sleep disturbances, irritability, gum dysplasia, and changes in mood.

The most common side effects associated with epilepsy medicines are drowsiness, irritability, nausea, rash, and clumsiness. Some drugs produce changes in emotions, memory, or behavior, or affect learning. Occasionally, a drug will increase the number of seizures a person is having.

A third, rarer, type of side effect develops because of individual sensitivity or allergic reaction to a particular drug or drugs. Potentially fatal liver damage, anemia, and the severe rash of Stevens Johnson syndrome and related disorders are among the serious reaction group.



Medication

Children take the same anti-epilepsy medications as adults do. Medication may be prescribed as tablets, sprinkles, capsules, or in syrup.

These drugs are designed to prevent seizures. Some are successful with a limited number of seizure types; others have a broader range of action. Wherever possible, doctors try to control seizures with one drug. Some children, however, may have to take more than one.

A child may respond so well to medication that no further seizures occur so long as the medication is taken regularly and an effective level is maintained in the child's blood.

A Continuing Need

Not having seizures does not mean that the medication is no longer needed. Most patients require a minimum of several years of therapy. Always ask your doctor before stopping antiepileptic medication.

Taking only part of your medication or stopping medication abruptly can cause a serious increase in seizure activity.

Finding the Right Drug

The search for the best medication for any individual child may take a long time. Children, like adults, respond to medications in different ways. Several drugs and different combinations of drugs may have to be tried in an effort to get the seizures under control.

The goal of treatment is to achieve the greatest level of control with the lowest level of side effects at the lowest possible dose.

Antiepileptic Drugs and Contraception

Hormonal contraceptives do not reduce the efficacy of antiepileptic medications. However, there is an increased risk for women who take antiepileptic medications that any hormone-dependent contraceptive system will fail. This is the result of enhanced metabolism of the steroid hormones (estrogen and progesterone). Please talk to your provider if you have any questions regarding antiepileptic drugs and contraception.

NON MEDICATION TREATMENTS

If medications don't work, or if the child has a lot of side effects, your doctor may recommend surgery or the ketogenic diet.

If surgery is not an option, or the diet does not work, vagus nerve stimulation (VNS) can also be effective.

Vagus Nerve Stimulation

Vagus nerve stimulation therapy is another form of treatment that may work when medications fail to stop seizures. It is currently approved for use in adults and children over the age of 12, and children under 12 under specific circumstances. Those approved may have partial seizures that resist control by other methods. The therapy is designed to prevent seizures by sending regular small pulses of electrical energy to the brain via the vagus nerve, a large nerve in the neck. The energy is delivered by a flat, round battery, about the size of a silver dollar, which is surgically implanted in the chest wall. Thin wires (electrodes) are threaded under the skin and wound around the vagus nerve in the neck. The battery is programmed by the health team to send a few seconds of electrical energy to the vagus nerve every few minutes. If the person with the system feels a seizure coming on, he or she can activate the discharge by passing a small magnet over the battery. In some people, this has the effect of stopping the seizure. It is also possible to turn the device off by holding the magnet over it.

Side effects of VNS therapy are mostly hoarseness and, sometimes, discomfort in the throat. There may be a change in voice quality during the actual stimulation. Although complete seizure control is seldom achieved, the majority of people who use VNS therapy experience fewer seizures. In some its effectiveness increases with time, and patients report an improved quality of life. As with surgery and the ketogenic diet, it will almost always be necessary to continue anti-epileptic medication although the patient may be able to take less medication than in the past.

Ketogenic Diet

What the Diet Does

Normally, our bodies run on energy from glucose, which we get from food. We can't store large amounts of glucose, however. We only have about a 24-hour supply. When a child has no food for 24 hours — which is the way the diet begins, usually in a hospital — he or she uses up all the stored glucose. With no more glucose to provide energy, the child's body begins to burn stored fat.

The ketogenic diet keeps this process going. It forces the child's body to burn fat round the clock by keeping calories low and making fat products the primary food that the child is getting. In fact, the diet gets most (80 percent) of its calories from fat. The rest comes from carbohydrates and protein. Each meal has about four times as much fat as protein or carbohydrate. The amounts of food and liquid at each meal have to be carefully worked out and weighed for each person.

Doctors don't know precisely why a diet that mimics starvation by burning fat for energy should prevent seizures, although this is being studied. Nor do they know why the same diet works for some children and not for others.

Trying to put a child on the diet without medical guidance puts a child at risk of serious consequences. Every step of the ketogenic diet process must be managed by an experienced treatment team, usually based at a specialized medical center.

Chances of Success

Often, a period of fine-tuning is needed before it's clear whether or not a child is going to respond to the ketogenic diet. Doctors often ask parents to try the diet for at least one month, and even as long as two or three, if it's not working at first.

A child on the diet usually continues taking anti-seizure medicine, but may be able to take less of it later on. If a child does very well, the doctor may slowly taper the medication with the goal of discontinuing it altogether.

About a third of children who try the ketogenic diet become seizure free, or almost seizure free. Another third improve but still have some seizures. The rest either do not respond at all or find it too hard to continue with the diet, either because of side effects or because they can't tolerate the food.

A side benefit of the diet is that many parents say their children are more alert and make more progress when on the diet, even if seizures continue. If the diet seems to be helping, doctors will usually prescribe it for about two years. Then, they may suggest that parents slowly begin including regular food in the child's diet to see if the seizures can still be controlled, even with a normal diet.

Sometimes a small amount of seizure medication is started again after the diet is stopped. However, some children may be able to stay seizure free without any further treatment. If the seizures return, the doctors may recommend putting the child back on the diet.

Side Effects

Like all the other treatments for epilepsy, the ketogenic diet has some side effects, which may or may not affect a particular child. Some side effects may go away if caught and managed early on. Knowing what to look for can make a big difference. Reported side effects include dehydration, constipation, and, sometimes, complications from kidney stones or gall stones.

Adult women on the diet may have menstrual irregularities. Pancreatitis (inflammation of the pancreas), decreased bone density, and certain eye problems have also been reported. Again, this is why the medical team closely follows children or adults who are on the diet.

The diet lacks several important vitamins which have to be added through supplements. Sometimes high levels of fat build up in the blood, especially if a child has an inborn defect in his ability to process fat. This possibility can lead to serious effects, which is another reason for careful monitoring.



Making the Decision

Most experts say the diet is worth trying when two or more medications have failed to control seizures, or when medications cause side effects that are having a harmful effect on a child's life. It also helps to have a child who is willing to try foods that he might otherwise not be enthusiastic about, and is tolerant and not fussy about eating.

The diet seems to work for more than one kind of seizure, and for children who have a lot of seizures or few seizures. Most doctors say it shouldn't be used instead of medications if the drugs are working and the child is not having bad side effects. Parents generally decide to try the diet because they hope it will give their child a better chance for a normal life.

However, the diet can be a barrier to some normal life experiences for children, especially those that revolve around food and holidays. Like other treatments for epilepsy, it also can have side effects that affect some children more than others. As with any kind of treatment, there's a lot to think about before deciding to try the diet.

Going over all the possibilities with your doctor is the best way to make the decision. It may also be helpful to talk with other parents whose children have been on the diet.



RESOURCES

RESOURCES

Hospital Services

We know hospital visits, whether for a short appointment or for a longer stay, can be challenging. At Children's Hospital Colorado, we provide a range of services to help make any visit more comfortable for you and your family.

Creative Play Center for siblings

The Creative Play Center is located on the first floor, just off the west end of the Fresh Market Place. Staffed by a supervisor and trained volunteers, the center offers a free and safe area for patients' brothers and sisters. The center is available on a first-come, first-served basis for children up to eight years old. This is a great place to play while you and your child are meeting with your care team. **Hours:** Monday - Friday, 9 a.m.-noon; 1-4 p.m.; Phone: 720-777-6999

Teen Zone

The Teen Zone is a space just for teenagers (kids 13 years and older) within the hospital. Patients and their siblings can enjoy this state of the art 3000 square foot lounge that offers a variety of activities. Located on the second floor of the hospital, this teen-only environment gives teenagers and young adults a place to relax and be themselves. Amenities include a craft area, a gaming area where a variety of video games can be played, a music and reading room, a kitchen, basketball arcade hoop, pool table and computers. There is even a big-screen movie theater with movable seats to accommodate hospital beds and medical gas hook-ups. **Hours:** 1 - 4 p.m. and 6 - 9 p.m. daily, based on volunteer availability. Call the Information Desk at 720-777-1234 for more information.

The Melvin and Elaine Wolf Family Health Library

Children's Colorado is home to one of the area's best pediatric health libraries: The Melvin and Elaine Wolf Family Health Library. Located on the first floor of the hospital, the library has information on illnesses, wellness, and parenting; audio books for children; and recreational reading for all ages. There, staff librarians can assist you with in-depth research on medical conditions. Or you can phone and request an information packet on your child's illness, which will be delivered to his or her bedside. In the library, parents can also send and receive faxes, use computers with internet access, and make photocopies. For more information call 720-777-6378.

Family Advisory Council

The Family Advisory Council creates a partnership between family members of patients and hospital staff to ensure that the voice of families is heard in decisions that can impact them. Over the years, the Family Advisory Council has offered valuable insights and advice on the design and delivery of services. The Family Advisory Council meets regularly. For more information, please email us at familyadvisorycouncil@childrenscolorado.org.

Youth Advisory Council

The Youth Advisory Council (YAC) is a group of teens and siblings who have had experiences at Children's Hospital Colorado. The goal of the Council is to create a better environment for pediatric patients at Children's Colorado. YAC provides the opportunity for the patients and siblings to have a voice in decisions for the hospital.

For questions about YAC, contact Carla Oliver, MSW/CCLS, at 720-777-4658 or Suzanna Paisley, MS, CCLS, at 720-777-3209.

Neurology Family Navigator

The Family Navigator (FN) helps to provide resources and navigation assistance to our patients and families. The FN role was established to help ensure families are informed and connected to resources within the disability world.

FN's Primary Responsibilities:

- Contacts referred families during time in the Neurology Department
- Assesses needs and links families to appropriate resources. This process may include making contact with agencies on behalf of families
- Determines the complexity of the patient's needs and follows up accordingly
- Communicates with referring staff members regarding status of referrals and outreach efforts

Types of Navigation Assistance:

- Public systems (Social Security, Medicaid, and other state or government programs)
- Housing
- Prescription assistance
- Employment assistance
- School or IEP issues
- Durable medical equipment
- Support group information
- Private insurance issues
- Transportation needs
- Respite resources
- Medicaid waiver information
- Early intervention services
- Transition resources
- Mental/behavioral health resources
- Specific community resources such as the Community Centered Boards, Health Care Program for Special Needs Children (HCP), local churches, United Way, and others.

Social Workers

Clinical social workers give emotional support to families and children in crisis or during a long hospital stay. They assist with problems associated with healthcare issues, including financial pressures. You may request the involvement of clinical social workers at any time. Neurology Social Workers: Laura Neff and Joanna Reeder 720-777-6895

Social Work may become involved in your child's care in the following situations:

Diagnosis or Illness

- Failure to thrive
- Newly diagnosed patient whose diagnosis is life-threatening, acute, or seriously complicated
- Severe psychiatric condition of patient or caregiver
- Ingestions
- Trauma cases

Family Issues

- Lack of social supports (family, friends, etc.)
- Language or cultural challenges
- Homelessness
- Death of significant family member (sibling, grandparent, etc.)
- High levels of stress within the family and/or home environment
- Chronic illness in caregiver
- Single caregiver with multiple children or other children with chronic illness
- Recent relocation

Psychological or Social Issues

- Financial problems (such as lack of transportation, money to eat, insurance, housing, utility services, telephone, etc.)
- Repeated hospitalizations
- Not attending school

Legal Issues

- Adoptions, foster care placements, and/or relinquishments
- Abandonment of patient
- Custody or guardianship issues or conflicts
- Previous involvement with Social Services
- Consideration of DNR or termination of life support
- Caregiver imprisoned, hospitalized, or residing in a drug or alcohol treatment facility
- Religious beliefs contrary to customary medical practices (i.e., Jehovah's Witness, Christian Scientist, etc.)



Community Resources

There are hundreds of community resources in the community. These are just a few of them.

Health Care Program for Children with Special Needs (HCP)

The Health Care Program for Children with Special Needs is a unique resource for families, health care providers, and communities to connect kids with the care they need. This organization seeks to help improve the health, development, and wellbeing of Colorado's children with special health needs via information, referral, and family support. For more information, visit colorado.gov/cdphe/hcp

Parent to Parent of Colorado (P2P)

P2P connects families of children and adults with disabilities or special healthcare needs with other parents who have similar experiences. This parent-initiated, parent-controlled, and parent-organized group supports families with special healthcare needs. Visit p2p-co.org or call 877-472-7201.

Family Voices

Family Voices Colorado promotes improving access to health care for children with special care needs. Visit familyvoicesco.org or call 303-691-9339.

The ARC in Colorado

The ARC in Colorado advocates for children with developmental disabilities. Visit thearcofco.org or call 800-881-8272.

Peak Parent Center

Peak helps families of children with disabilities rebuild their dreams for their children. Peak hosts support groups and advises families on special education rights, Individual Education Plans (IEPs), and early childhood services. Visit peakparent.org or call 800-284-0251.

Colorado Cross-Disability Coalition (CCDC)

Information and assistance on disability rights issues for youth and adults. Visit ccdconline.org or call 303-839-1775.

Colorado Department of Education – Exceptional Student Leadership Unit (CDE – ESLU)

The CDE's website provides resources on special education law, school/district programs, educational specialists, parent-professional partnerships, and more. Visit cde.state.co.us/cdeesped/index.asp or call (303) 866-6694.

Children's Special Health

Children's Special Health is a program for Wyoming residents that provides assistance for children with special needs. Visit health.wyo.gov/familyhealth/csh/index.html or call 307-777-7941.

Division for Developmental Disabilities (DDD) and Community Center Boards (CCB)

Both DDD and CCB provide various services to individuals with developmental disabilities. For more information, visit colorado.gov/pacific/hcpf/community-centered-boards or call 303-866-7450.

El Grupo VIDA

El Grupo VIDA provides information, referrals, and support groups for Spanish-speaking parents. Visit elgrupovida.org or call 303-335-9875.

Parents Encouraging Parents (PEP)

PEP brings together parents and professionals for education on supporting children in school and in the community. Visit cde.state.co.us/cdesped/pep or call 303-866-6943.

The Legal Center for People with Disabilities and Older People

This organization offers advice on the legal rights of people with disabilities. Visit thelegalcenter.org or call 800-288-1376.

Wrightslaw

Wrightslaw is a good information resource for parents about special education process, law, and advocacy. Visit wrightslaw.com.

Sports Made Possible

This organization provides an opportunity to play baseball as a team in an organized league for children and adults living with various mental and/pr physical challenges. Visit sportsmadepossible.org or call 303-409-2613.

Assistive Technology Partners

This program through the University of Colorado School of Medicine helps people with cognitive, sensory, and/or physical disabilities reach their highest potential at home, school, work, and play through assistive technologies. Visit assistivetechologypartners.org Call 303-315-1280.

Epilepsy Resources

The Epilepsy Foundation is our number-one resource. Please visit epilepsy.com or epilepsycolorado.org, or call 303-337-9774.

The Epilepsy Foundation has a support group for families facing epilepsy surgery that meets every Tuesday from 12 to 1 p.m. at Children's Colorado in the Huron Peak room on the first floor. Families can connect with other families currently going through surgery, testing, or other procedures.

Other Resources:

- American Epilepsy Society: aesnet.org
- Finding a Cure for Epilepsy and Seizures (FACES): nyufaces.org
- National Institute of Neurological Disorders and Stroke: ninds.nih.gov

Medication Resources

These organizations provide help with the cost of medicine.

- **NeedyMeds:** needymeds.org
- **Prescription Assistance Program:** pparx.org
- **Medscape:** emedicine.medscape.com
- **Abbott Patient Assistance:** 800-222-6885
Medications covered: depakene, depakote, Depakote ER
- **CephalonCares Foundation Patient Assistance Program:** 877-237-4881
Medication covered: gabitril
- **Eisai Neurology Patient Assistance Program:** 866 694-2550
Medications covered: banzel, zonegran
- **GlaxoSmithKline Bridges to Access:** 866-728-4368
Medications covered: lamictal, lamictal XR
- **Janssen Ortho Patient Assistance Foundation:** 800-652-6227
Medication covered: topamax
- **Lundbeck's SHARE Call Center:** 888-457- 4273
Medication covered: Sabril
- **Meda Pharmaceuticals Patient Assistance Program:** 800-678-4657
Medication covered: felbatol
- **Novartis Patient Assistance Foundation Program:** 800-277-2254
Medications covered: tegretol, tegretol XR, trilepta
- **Pfizer Connection to Care:** 800-707-8990
Medications covered: dilantin, lyrica, neurontin, zarontin
- **Valeant Pharmaceuticals International Patient Assistance Program:** 800-511-2120
Medications covered: Diastat, AcuDial, rectal gel, mysoline
- **Shire Pharmaceuticals Carbatrol Patient Assistance Program:** 866-325-8224
Medication covered: carbatrol
- **UCB Patient Assistance Program:** 866-395-8366
Medications covered: keppra, keppra XR, vimpat



The following programs provide generic medications at a discount:

- **Express Scripts Specialty Distribution Services Rx Outreach Medications:** 800-769-3880
Medications covered: carbamazepine, clonazepam, diazepam, divalproex, gabapentin, lorazepam, phenytoin
Xubex Pharmaceuticals
- **Xubex Patient Assistance Program:** 866-699-8239
Medications covered: carbamazepine, clonazepam, clonazepam potassium, diazepam, divalproex, gabapentin, lamotrigine, lorazepam, phenobarbital, topiramate, zonisamide
- **Vagus Nerve Stimulator Cyberonics:** 800-332-1375, ext. 7493
The BJ Wilder Therapy Program provides assistance if the patient has no insurance and cannot afford the VNS stimulator
- **Ketogenic Diet - The Charlie Foundation:** charlifoundation.org
The Charlie Foundation is a group dedicated to promoting the use of the ketogenic diet for children with epilepsy.
- **Matthews Friends:** matthewsfriends.org
This informative website supports those who wish to use the ketogenic diet as a treatment for childhood epilepsy. The aim of the website is to inform parents and promote the diet among health professionals so that it becomes more available.
- **Nutritia KetoCal:** myketocal.com
KetoCal is a medical food designed for children on the ketogenic diet.
- **La Dieta Cetogénica:** leland.stanford.edu/group/ketodiet/
La Dieta Cetogénica: Materiales de referencia para ustedes y su familia, el medico, o el pediatra, en español (Centro de Epilepsia de Stanford).

Find more information on the Ketogenic diet at epilepsy.com.

IEP and Education

PEAK Parent: peakparent.org, 800-284-0251

One of the Epilepsy Foundation's main parent resources for help, advocacy, and advice on the IEP Process.

The Legal Center: thelegalcenter.org, 800-288-1376

A resource on legal rights for people with disabilities at school.

Wrightslaw: wrightslaw.com

Accurate, reliable information for parents, educators, and attorneys about special education law, education law, and advocacy for children with disabilities.

Friedman Foundation: friedmanfoundation.org

Information on special needs school vouchers state-by-state.

Sibling Support

Sibling Support: siblingsupport.org

The Sibling Support Project is a national effort dedicated to the lifelong concerns of brothers and sisters of people who have special health, developmental, or mental health concerns

Special Needs Support

Hope for Support: hopeforsupport.com

This parent-created website catalogues resources and information for parents of children with special needs or illnesses.

Seizure Support: seizuresupport.com

Seizure Support is a parent-created website detailing resources and products for children with epilepsy.

Seizure Assist Dogs

4 PAWS for Ability: 4pawsforability.org

Information on how to obtain a seizure alert dog

Special Needs Trust and Planning

Special Needs Planner: specialneedsanswers.com

The purpose of this site, sponsored by the Academy of Special Needs Planners, is to provide a general overview of strategies parents and others can use to plan for their own futures and for those of family members with special needs.

Wish Foundation

Make-A-Wish Foundation: wish.org

A network of nearly 25,000 volunteers enables the Make-A-Wish Foundation to serve children with life-threatening medical conditions. Volunteers serve as wish granters, fundraisers, special events assistants, and in numerous other capacities.

Travel Assistance

Angel Flight: angelflight.com

Angel Flight is a nonprofit charitable organization of pilots, volunteers, and friends that arranges free air transportation for any medical need. This service is available to individuals and health care organizations.

Ronald McDonald House: rmhc.org

The Ronald McDonald House provides help with staying near and supporting hospitalized children in another city while the child is undergoing treatment.

Special Needs and Medical Equipment

Cooling Vest: coolsport.net

Cooling vests can help children whose seizures are triggered by heat distress.

EEG/Diagnostic Services: sleepmed.md

The SleepMed/DigiTrace website provides useful information for those interested in learning more about seizure disorders, epilepsy, or unusual spells that can't be explained.

MedScope: medscope.org

MedScope provides medical alert systems to seniors and handicapped individuals with an aim to promote independent living.

My Pool Pal: mypoolpal.com

My Pool Pal's flotation swimsuit, personal flotation device, swim diapers, and sun-protective accessories can help children with epilepsy swim safely.

Special Needs Stroller: adaptivemall.com

These special strollers are designed specifically for children with special needs.

Medical Information Devices

American Medical ID: IdentifyYourself.com

Medical jewelry that alerts medics and other medical professionals of an emergency

Medic Alert: medicalert.org

Jewelry supported by on site medical professionals that will relay your vital medical information to emergency personnel

Lauren's Hope: laurenshope.com

A place to purchase stylish medical-alert bracelets as well as medical-alert watches and pill boxes with built-in alarms

Sticky Jewelry Incorporated: oneida-medical-jewelry.com

A family-owned business that designs custom-engraved medical ID bracelets and jewelry

911 Life: 911life.com

Custom medical ID tags and cards that you can create online

Medication Reminders

WatchMinder: watchminder.com

A vibrating alarm watch capable of up to 16 daily reminder alarms and 70 pre-programmed messages

Texting 4 Control: epilepsy.com

A service provided by the Epilepsy Foundation for patients aged 13 and older that allows children to receive medication reminders, motivational messages and more

To obtain a helmet:

Contact your child's neurologist and ask for a prescription for a helmet. You will be referred to Children's Colorado Rehabilitation Medicine for evaluation and fitting.

Seizure Alarms and Tracking

Easylink: easylinkuk.co.uk

Easylink manufactures several kinds of epilepsy alarms.

Giant Biosensor: giantbiosensor.com/EpilepsyAlarms

Giant Biosensor manufactures alarms including epilepsy bed movement alarms.

seizuretracker.com

SeizureTracker.com is dedicated to providing people living with epilepsy and their doctors with free comprehensive tools to help understand relationships between seizure activity and anti-epileptic medications.





Children's Hospital Colorado

Anschutz Medical Campus
13123 East 16th Avenue
Aurora, CO 80045

childrenscolorado.org/neuro