A Family Guide to Epilepsy

Resources for Parents of Children with Epilepsy to Help You with Your Child's Epilepsy Diagnosis

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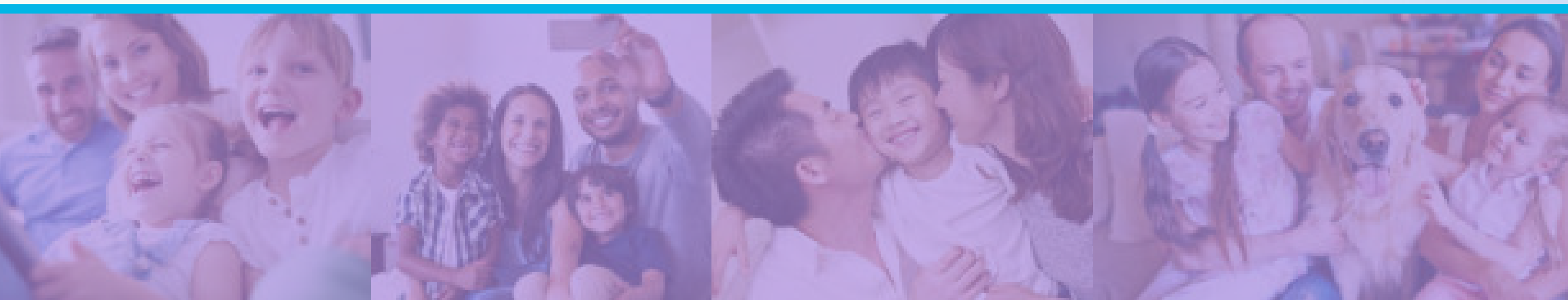

A Family Guide on Epilepsy

Resources for Parents of Children with Epilepsy to help you manage your child's epilepsy diagnosis.

Epilepsy affects everyone in the family
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What Should I Be Concerned About as A Parent?
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Resources
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A message to parents/caregivers

Your child has just been diagnosed with epilepsy. Now what? We know this can be a challenging time for you and your family. Besides the valid emotions involved such as worry and anxiety, there is also the myriad of the responsibilities that come along with your child's diagnosis. Epilepsy Alliance Florida is here for you.

Each year, about 150,000 Americans are diagnosed with epilepsy, and of those, approximately 50,000 are children. According to the CDC about two-third of those diagnosed with epilepsy as children will grow out of it by the time they are teenagers. The goal of eliminating seizures while preventing side effects is achievable for most children and youth, but it requires an organized system of care to ensure uniformity in the provision of services and support. As a parent, you want to help your child maintain a healthy lifestyle and ensure he/she has productive medical visits. We are on your team.

We also understand that this "team" has many members, and as such, we are providing the A Family Guide: Resources for Parents of Children with Epilepsy to help you manage your child's epilepsy diagnosis. This Family Guide includes forms, resources, and educational materials pertaining to your child's diagnosis.

We advise you to take this guide with you to medical appointments, emergency room visits, and other appointments related to your child's epilepsy. This is your child's care portfolio and we hope you find the guidance and resources useful and comforting as you remember, you are not alone.

Best Regards,

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About Epilepsy

What is Epilepsy?

Epilepsy is a neurological disease, which causes your child to have recurring unprovoked seizures.

What Are Seizures?

Seizures are strong bursts of electrical activity in the neurons (nerve cells) of the brain. During normal brain activity, nerve cells fire as different parts of the brain are activated. Those different nerve cells alternate their firing patterns as they send their messages throughout the brain. However, during a seizure, large groups of nerve cells fire all at the same time. A seizure is like an electrical storm in your brain.

A child's brain has billions of nerve cells that "talk" or communicate with each other through tiny electrical charges. If too many of these cells suddenly fire together, a wave of electrical energy sweeps through the brain and causes a seizure.

There are many different kinds of seizures which typically fall under two categories; either **generalized seizures** affecting the whole brain or **focal seizures** affecting only part of the brain.

Focal seizure

Generalized seizure

Some children have just one type; others may have a combination of seizure types. Risk of injury, changes in behavior and treatment depend on the type of seizures they have. It is important to help your doctor identify what type of seizures your child is having.

A seizure can manifest itself in different ways depending on the type of seizure. A child could either stare blankly or repeatedly fumble with clothing, all the way to losing consciousness and having convulsions. Most seizures last 2 – 3 minutes and afterwards the child might feel sick, weak or confused.

Included in the Forms section, you will find a Seizure Recognition and First Aid table and Seizure Record form to help you document your child's seizure activity. It may be helpful to give teachers and other caregivers copies as well.

Epilepsy is more common than you think!

Around **50 million people** worldwide have epilepsy, making it one of the most common neurological diseases globally. It is estimated that up to 70% of people living with epilepsy could live seizure-free if properly diagnosed and treated. (WHO) That is what we want for your child!

Yearly there are approximately 50,000 newly diagnosed cases of epilepsy in children and adolescents under the age of 18. An epilepsy diagnosis may come after a child has had two or more unprovoked seizures not caused by another treatable condition. The manner in which epilepsy affects a child depends on age, types of seizures, response to treatment and/or whether or not the child has other health issues.

Seizures are often controlled with medicine and/or other treatment types. In some cases, children might even outgrow epilepsy while in other cases it can pose a lifelong challenge.

Epilepsy can affect anyone at any age even those with no family history of seizures at all. Brain malformations, tumors, brain trauma or hemorrhage, metabolic/genetic conditions, infectious diseases such as meningitis or encephalitis, birth trauma and high-risk pregnancies are some of the known causes.

The treatment of epilepsy has seen many improvements in recent years, making it a manageable condition for most. Epilepsy Alliance Florida keeps up with new development in treatments through various sources. We invite you to utilize these resources as well.

Don't downgrade your dream to fit your reality, upgrade your conviction to match your destiny.

Myth & Facts

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

Myth: A child having a seizure can swallow his tongue.
Fact: No one can swallow his or her tongue. Do not put anything in the child's mouth. No spoon. No wallet. Any efforts to hold the tongue down or put something in the mouth of a child having a seizure can hurt the teeth or jaw.

Myth: People with epilepsy are possessed by spirits and/or cursed.
Fact: That is silly. Epilepsy is simply a neurological (brain) disorder.

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

Myth: You should perform artificial respiration on someone having a seizure.
Fact: Artificial respiration is only needed if the person does not start breathing after the seizure has stopped.

Myth: People with epilepsy and seizures are mentally ill or intellectually or developmentally disabled.
Fact: Epilepsy is a neurological condition not a mental illness or intellectual disability.

Myth: You can tell that a person has epilepsy by the way he or she looks.
Fact: There is no way to tell that someone has epilepsy and seizures just by looking at them.

Myth: If someone in the family has epilepsy, the children will too.
Fact: Epilepsy can happen when there is no family history at all. Sometimes children of a parent with epilepsy will have seizures, but it is far more likely that they will not.

How is Epilepsy Diagnosed?

You likely witnessed, or were informed of, a frightening seizure-type situation involving your child, which initiated you to seek help. You did the right thing! It is recommended that all children who have never had an unprovoked seizure seek emergency medical attention immediately following the initial seizure and then follow up with their primary care physician soon thereafter. Provoked seizures are single seizures that may occur as the result of trauma, low blood sugar (hypoglycemia), low blood sodium, high fever, or alcohol or drug abuse. Fever-related (or febrile) seizures may occur during infancy but are usually outgrown by age 6. After a careful evaluation to estimate the risk of recurrence, patients who suffer a single seizure may not need treatment. If seizures reoccur, a specialist should see the child as soon as possible to ensure precise and early diagnosis and initiation of appropriate therapy.
In children, approximately a third of seizures are caused by a sudden illness or injury such as a fever, brain trauma or brain or spinal fluid infection. An epilepsy diagnosis is generally made when seizures occur more than once without identifiable reasons.
Doctors will try to determine what caused the seizure during the diagnostic process and will begin to check for signs of epilepsy along with other treatable conditions.

Although the diagnostic process may vary, the major steps should include:

- **Family History and Medical History** – A family history helps the doctor understand if there is any family tendency to have seizures. This may include questions regarding the mother's pregnancy and delivery, any relatives with epilepsy. The medical history helps the doctor understand if any medical conditions your child has had might be causing the seizure such as whether the child had a high fever, serious head injury. He would also consider incidents such as any periods of staring, inattention or breath holding, etc.

- **Detailed Account of the Seizure** – It is recommended that the person who was present at the time of your child's seizure provide a detailed account of the incident to share with the doctor.

- **Physical and Neurological Examination** – This includes an assessment of cardiac, neurological and mental status.

- **Blood Test** – This is to help identify potential causes and/or to identify other significant illness.

- **CAT (Computerized Axial Tomography) or CT Scan** – This scan can help determine whether seizures are caused by an acute or chronic brain lesion.

- **EEG (Electroencephalogram)** – These record electrical activity in the brain such as brain waves and can be used to assess the risk of seizure recurrence, and it may also help determine seizure type and epilepsy syndrome. An EEG also helps determine where seizures are coming from in the brain.

- **MRI (Magnetic Resonance Image)** – This imaging uses magnetic fields to see if there are any structural changes in the brain, such as brain tumors, that might be causing the seizures.

The doctor will use exams, tests and a period of observation to determine whether your child's seizures are unprovoked or due to a treatable condition. If your child does receive a diagnosis of epilepsy from the doctor request they classify what types of seizures your child is having and discuss different treatment options that are available. Seizures often do not happen in the doctor's office, so it is important that parents and caregivers observe any unusual behavior and report these to their doctors. The Seizure Recognition and First Aid table and Seizure Record form included in this toolkit will help you keep track of that information.

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

What are the Treatments?

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

Epilepsy is often treated by family doctors, pediatricians or internists, but your child may be referred to a neurologist or epileptologist. Doctors and parents should work together to determine the best treatment (or combination of treatments) for a child.

Medication - Most children are initially treated with medication. There are currently more than 20 medications available. The doctor will choose the best one depending on your child's seizure type and syndrome, as well as possible side effects or other medications your child might be taking. Good history taking and an accurate diagnosis by your child's doctor are essential in determining the right medication as different medicines may be more effective for specific seizure types. Sometimes children have to try a number of different medications before finding one that works or they may need to take multiple medications or a combination of drugs, so it is important to stay optimistic and patient during this time. If your child's seizures continue while on medication, you and your doctor may want to consider:

Ketogenic Diet – an extremely strict diet that helps stop or control seizures for some children. It should be treated like serious medicine and must be closely supervised. Other more easily tolerated diets may be used in some children such as modified Atkins diet or low glycemic index diet.

Vagus Nerve Stimulation (VNS) – a small battery implanted under the skin in the chest wall that sends small, regular bursts of electrical energy to the vagus nerve, a large nerve in the neck that leads directly to the brain. It is currently only approved for children 12 and over.

Surgery – this option is most commonly used when the brain tissue causing seizures is confined to a small focal area of the brain, which can be safely removed without damaging function.
More information on epilepsy treatment including seizure rescue medications and seizure alert and monitoring devices can be found on our resources page.

An Epilepsy Care Team

Who are all of these medical providers that might be on my team? Well, depending upon how epilepsy is affecting your child, your health care coverage and what is available in your community, there are many different providers who may be part of your child's medical team and the treatment process. These may include:

- **Pediatrician** – a doctor who specializes in treating children. Some insurance plans call them a "primary care provider". Though he/she will likely refer your child to a doctor who specializes in epilepsy or brain disorders, it is important to keep your pediatrician involved in your child's care.

- **Neurologist** – a doctor who specializes in treating brain disorders, including epilepsy. A pediatric neurologist specializes in children's brain disorders.

- **Epileptologist** – a neurologist who specializes in epilepsy treatment. This is usually only recommended if standard treatment is not working or if diagnosis remains unclear.

- **Nurse Practitioner (NP)/Advanced Practice Nurse** – a registered nurse with advanced nursing training whom usually works with a pediatrician, neurologist or epileptologist.

Additional members of the healthcare team may include:

- **Neuropsychologist** – a psychologist who specializes in the assessment of the brain's cognitive functioning. If your child is experiencing learning difficulties related to epilepsy you may need to search for a Neuropsychologist who specializes in academic achievement as well.

- **Mental Health Counselor** – a psychologist, social worker or psychiatric nurse who has specialized training to help children and their families with mental health issues, such as anxiety, depression and behavioral problems.
- **Nurse Practitioner** - is an Advanced Practice Registered Nurse who has earned at least a Master's degree and completed additional training in a specialty area of medicine. Because of their advanced skills, NPs have more authority for administering patient care compared to Registered Nurses.
- **Physician Assistant (PA)** – a health care professional who is trained to practice medicine as part of a team with a physician.
- **Psychiatrist** – a doctor who specializes in treating psychiatric and mental health problems.
- **Psychologist** – a licensed mental health practitioner (PhD or PsyD) who specializes in evaluation and treatment of children with behavioral and learning problems.

An initial epilepsy diagnosis can be overwhelming and frightening for the family however, with a good support system and education which includes health care providers and organizations such as Epilepsy Alliance Florida, parents can ensure their child has a meaningful and happy life.

Managing Epilepsy

Each member of your child's support system has an essential role to play in the common goal of your child's well-being. All those who interact with your child on a regular basis are considered part of this team, including family members, medical providers and staff, teachers, school nurses, coaches/instructors, babysitters, and others.
The American Academy of Pediatrics recommends that all children with special health care needs have access to a medical home. This is a comprehensive approach to primary care which entails a coordinated relationship and open dialogue between the child, the clinicians, all medical staff and families. More information on a medical home can be found here:
National Center for Medical Home Implementation:
https://medicalhomeinfo.aap.org/Pages/default.aspx

As the team manager of your child's care, you will want to manage each component of your child's care. This Family Guide is your playbook. We recommend maintaining a care notebook or organizer to house all the forms included in this guide along with copies of your child's various tests and reports and any other information related to your child's care.

American Academy of Pediatrics:
https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx
Below are some tips:

Home

- Make sure your child is taking all **medications** as directed. It helps to have a convenient and designated spot in your home so that it becomes routine. This also helps should you have a sitter or some other kind of caregiver.

- If your child is on a special **diet** (such as Keto), make sure he/she is adhering to that diet.

- Of course, sleep is important for all of us, but even more so for a developing brain. It is especially important for your child who suffers from seizures. Sleep deprivation is a known trigger.

- Don't forget to document in this guide any side effects, seizure triggers, a pattern or specific time of seizures, or anything else you see that is important for your doctor to know. Remember, that all caregivers need to know the game plan.

Medicines

- Make sure your child is given the **proper dosage** and does so **on time**. Use a daily alarm. Speak to your doctor about what to do if your child misses a medication dose.

- Take notes and **document in this guide**, any medication side effects you may notice such as rash, fatigue or tiredness, nausea, loss of balance, vision changes, and/or weight gain.

- Do not take your child off their medication or reduce dosage just because it is working.

Sometimes, the medicines work so well, the parent will decide he/she doesn't need them anymore and will take the child off or reduce dosage. As tempting as it may be, **don't take it upon yourself to decide dosage**. It can have severe consequences and/or cause an increase in seizures.

Doctor Visits

- Keep a note in your calendar and the Family Guide of any and all upcoming doctor visits. There are forms included in this guide to help you keep these organized.

- Before your doctor visits, bring a copy of your notes with any questions you want to ask. Don't be afraid to tell your doctor about your concerns or ask if there are other treatments to consider. Please refer to the Health Literacy infographic and the Medical Visit form included in the forms section to help you.

- Other useful materials to help you document, organize and manage your child's care include a Care Notebook or Organizer, which houses all the forms included in this guide, along with copies of your child's various tests/reports, notes and any other information related to your child's care. You can create your own or choose from several versions available here:

American Academy of Pediatrics:
https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx

Epilepsy Alliance Florida:
www.epilepsyalliancefl.com

School/Camp/Etc.

- If your child needs to take medicine at school, you'll need to make arrangements with the teacher or school nurse to disseminate his/her medicines.

- Make sure all teachers, school nurses, coaches and bus-drivers know seizure recognition and basic Seizure 1st Aid. **Epilepsy Alliance Florida can provide this service at no cost.** If you elect to do so, you can also request to educate his/her classmates on Epilepsy and First Aid for Seizures.

- Complete, share and discuss the Seizure Action Plan form included in the Forms section of this Family Guide.

What should you do if your child has a seizure?

If you are witnessing a seizure for the first time, it can seem like it lasts forever, but it usually doesn't. They typically end after 2 – 3 minutes without harm and usually do not require a trip to the emergency room. In fact, most seizures in children with epilepsy are not medical emergencies.

Refer to the **Seizure Recognition and First Aid** table for how to respond, based on your child's type of seizure.

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

However, you should get immediate medical care if:

- The seizure lasts more than five minutes, the child has a series of cluster seizures or if another seizure occurs before your child returns to normal
- The seizure happened in water as drowning is a major risk factor, whether in a pool or a bathtub
- The child has diabetes, a high fever, a head injury, or other injury
- The child is having trouble breathing after the seizure

How can I keep my child safe?

You want your child to have a fulfilling childhood, but you also want to protect him/her from any seizure related accidents. When your child has epilepsy, everyday things, such as climbing steps, riding a bike and swimming in the local pool can be dangerous. Each family has to make their own decisions about what is safe for their child. This will vary depending on your child's age, interests, and type of seizures and how well the seizures are being controlled. If there is any doubt, talk to your doctor.

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

You should always:

- Supervise young children during baths and have older children take showers. Adjust the water temperature in your house to low in order to avoid serious injury if a child has a seizure when hot water is running. Make sure the drain works well and won't clog. Never let your child swim without an adult watching.
- As with all children, those with epilepsy should wear helmets when bicycling, skateboarding, etc. If your child has seizures that cause sudden falls, your doctor might also recommend wearing a helmet when playing outdoors around steps, and/or other areas that may impact the severity of a fall. Children with epilepsy can participate in many organized sports. Your physician or allied health professional should be consulted regarding any questions you may have. For the older child, be aware of the potential risks related to cooking such as injuries from hot water and stove tops.

- Two of the most important things you can do to protect your child are to make sure that:

1. Your child takes medication as directed.

2. There is always someone with your child who knows what to do if your child has a seizure.

Epilepsy affects everyone in the family

Daily Life with Epilepsy

How parents can help

In addition to the daily epilepsy medical management mentioned under the Managing Epilepsy section of this guide, there are ways you can help your child thrive socially and have a fulfilling and successful childhood. This includes an open dialogue of support and encouragement. Here are ten tips to remember:

- Educate yourself about epilepsy
- Discuss epilepsy openly and honestly with your child
- Avoid saying things that could make your child feel like a burden or problem
- Be positive
- Praise your child's success
- Teach them how to fail gracefully because nobody is successful all the time
- Encourage sports, hobbies and other interests
- Encourage your child to make friends
- Work with your child to explain epilepsy to friends, relatives, teachers and others
- Continue family activities and traditions
- Make time for yourself without feeling guilty

How epilepsy affects family life?

Remember, this is a team effort! When a child has epilepsy, it affects the whole family. While everyone is doing everything they can to help and support your epileptic child, this can, at times, make other siblings feel that that their emotional and physical needs are not being met. Depending on the severity of your child's epilepsy, this may be partially true. It is important to remind them that you are a family and that you are in this together. Making the entire family feel equally addressed may entail setting aside a certain amount of alone time to spend with other family members and inquire about their day. If possible, plan special outings or activities with them. Just ten minutes reading a book, a walk to get ice cream or watching a movie together can help children feel special. It is also important to continue to make time for traditions and celebrations (holidays, birthdays, vacations, etc.) that are so important to family life.

This is a Team effort!
When a child has epilepsy it affects the whole family.

During this time with your other children, try to understand their concerns. Having a sister or brother with epilepsy often means they get less time with their parents. Seeing their sibling have a seizure could be frightening or even embarrassing for them.

Encourage them to talk about their feelings and let them know that it is okay to have them. As soon as they are old enough to understand, explain to them what epilepsy is, make them part of the game plan. Include the siblings in your routine. No, routine is not a bad word. In fact, a good routine has been proven to make the busiest of households more manageable. Schedule a regular time for homework. Give your child chores such as setting the table, picking up toys or getting water for a pet. Giving your child responsibilities will make him/her feel like a fully contributing member of the family. It's part of the game plan.

You may also be uncomfortable telling relatives because you don't want them to worry. This is also a valid emotion. They love your child and may have a fear that they are not capable of handling the situation should your child have a seizure in their care. You want them to feel comfortable having all of the children at family events so education can help alleviate this. Refer to the Managing Epilepsy page.

Then there is you! If your child has numerous doctor appointments or is hospitalized, it can mean time away from work, adding to your stress and possible financial concerns. Use your team! Do not try to do it all alone. **One of the most important things you can do for your family is to build a support network.**

Epilepsy Alliance Florida is a great place to start. See "Where to Find Support" at the end of this section for other tips.

Remember to take a break for your health. Respite allows you to take care of yourself so that you are physically and mentally better able to care for your child while having a fulfilling role within your own home team.

Helping your child at school

As stated within the section, Managing Epilepsy, you should begin each school year by scheduling a meeting with your child's teacher and school nurse. Epilepsy Alliance Florida's educators can instruct your school nurses, teachers, and students about Epilepsy and Seizure 1st Aid for free. Make sure you complete and discuss the Seizure Action Plan with them and ensure that they have a copy and know the protocol should your child have a seizure while in school. Keep in touch throughout the school year about your child's progress and make sure that other adults who supervise your child at school know what to do if your child has a seizure. Please feel free to contact us for instruction any time during the year.

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

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

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

Who qualifies for services under IDEA?

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

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

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

Ask the teacher to discuss epilepsy with the class in a way that is age appropriate and comfortable for your child. Having a seizure at school can be embarrassing for a child and frightening for others. It is better if everyone knows about seizures in advance. Contact Epilepsy Alliance Florida for assistance and ask if they can conduct a classroom presentation.

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

While you are busy controlling the seizures by ensuring your child has his/her medicine and managing the frequent doctor visits, your child may be dealing with feeling different from everyone else. Children with epilepsy often feel as if they have to constantly explain what epilepsy is. They also might face stigma or discrimination because of the condition. Helping the people in your child's world understand epilepsy will allow them to be more comfortable with it.

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

For example, if a child said, "Gavin is weird. Yesterday he dropped down out of nowhere and started shaking all over." You could say, "I'm sure it was frightening for everyone, but it's important for us to think about how Gavin felt and to try to understand what happened. Gavin had a seizure. For just a couple of minutes his brain was not able to control what he was doing. Your teacher knows how to make sure that Gavin doesn't get hurt when he has a seizure and what to do to make sure that he is OK afterwards. If a child were to ask, "What can I do to help?" you could reply, "I am so glad you asked because there are two important things you can do to help Gavin."

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

With adults, you can start by giving them a copy of the Epilepsy Fact sheet to provide them with a basic overview of epilepsy. Use the Seizure Action Plan form to make sure that teachers, coaches, babysitters and others who are with your child know what to do if your child has a seizure.

Where to Find Support

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

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

Opening up to the idea of a support group is sometimes the hardest thing for people to do, but they are usually glad they did. The school nurse, Epilepsy Alliance Florida, government organizations and online forums are all examples of where you can find these support groups as well as other resources and relevant information. However, most of the time, you will need to seek out this support. Your support team also includes your friends, family, school, epilepsy chat room on social media, as well as organized support groups.

Epilepsy may always be a part of your child's life. Understanding the condition and knowing about the many resources to support people with epilepsy will help your child live as happy and fulfilling a life as possible. To find support groups and services available in your area, contact your nearest Epilepsy Alliance Florida office listed in the Resources section. You can also check with your local hospital and/or Epilepsy Center and ask if they hold parent support groups. For online support, visit **https://www.epilepsyalliancefl.com** where you'll find online discussion groups, articles about other families with epilepsy and more.

Specific online support networks you can visit include:

www.epilepsyalliancefl.com

Facebook and Twitter: The Epilepsy Alliance America

www.epilepsyallianceamerica.org/ and several of the local affiliates host pages for announcements, information, and discussion:

www.facebook.com & www.twitter.com (search for epilepsy)

You've got this! You are not alone on this journey.

Life Stages with Epilepsy

Epilepsy is the type of disorder that is not restricted to a certain age or stage of life. It can affect anyone at any time. It is never too early to start the conversation about epilepsy with your child but assessing what is appropriate for their age and comprehension is key in initiating these conversations. First, seek to learn all that you can about epilepsy then encourage conversation with them and be ready to answer their questions as well. Your local Epilepsy Alliance Florida office can assist you with locating a doctor or resources to aid in the education of your children surrounding this topic. In addition, please see the Resources section for educational material on epilepsy. Professionals may be needed in this process including your child's teacher or caregiver as well as professional counselors and psychologists. It is important to remember that factors such as the type of epilepsy your child has, seizure triggers and more will determine how it affects their life.

Epilepsy can feel very isolating so consider ways to keep your child engaged in social activities including Epilepsy Alliance America summer camps held each year.

Infants and Toddlers

While seizures can occur at any stage of life, it happens most frequently in infants and toddlers. This may be attributed to the fact that this stage is characterized by the most changes and growth in the brain. Observing any irregular behavior or events and informing your health care provider is essential in early diagnosis and getting seizures under control. This is especially essential for younger children who cannot communicate what happened and how they are feeling as yet. Childcare centers and schools can often be a challenge for parents of children with epilepsy whether due to refusing to accept these children or refusing to be responsible for the administration of rescue medication. These centers or schools may not be allowed to make such restrictions under the Americans with Disabilities Act. Contact your local Epilepsy Alliance America member for further information on local laws and resources.

Children

The impact of epilepsy may not just be physical especially for children as they get older. It is not uncommon for epilepsy to affect their academic performance, social relationships and the types of activities they may or may not be allowed to participate in. Addressing concerns with your child's teacher or a psychologist may be needed. In addition, keeping your child active and socially engaged especially among peers who understand epilepsy and will not treat them differently is important for your child's development. Having routines and boundaries is also essential as with any child. For assistance in disciplining your child if there is concern of triggering a seizure speak with your child's doctor.

It is only natural for a parent to worry about their child with epilepsy. The risk of injury and even death are possible if your child has seizures but there must be a balance between keeping your child safe and overprotecting your child at the expense of valuable life experiences such as your child's need to explore and master his environment, which is crucial for healthy development. Children with epilepsy need to play and take responsible risks.

Adolescents

The adolescent stage early teen years is also a stage typically characterized by many new changes and experiences. Social relationships are especially important to them at this age and they want to be treated like everyone else. Encourage open and honest conversation with your adolescent child about epilepsy and what that means for them. For examples of conversations between parents and teens about epilepsy:
https://www.cdc.gov/epilepsy/toolkit/parents-guide.htm

Contact your local Epilepsy Alliance America member, for resources on online discussion groups they can join to meet peers also living with epilepsy. Some other things to consider:

- **Puberty** – Hormonal changes not only affect your child's appearance at this stage but can also trigger seizures for some people. Talk to your doctor about any changes to expect and anything that you notice.

- **Social Life** – At this age social interaction is very important to your child. Encourage them to speak to their friends about epilepsy and participate in epilepsy and seizure first aid education training as a group.

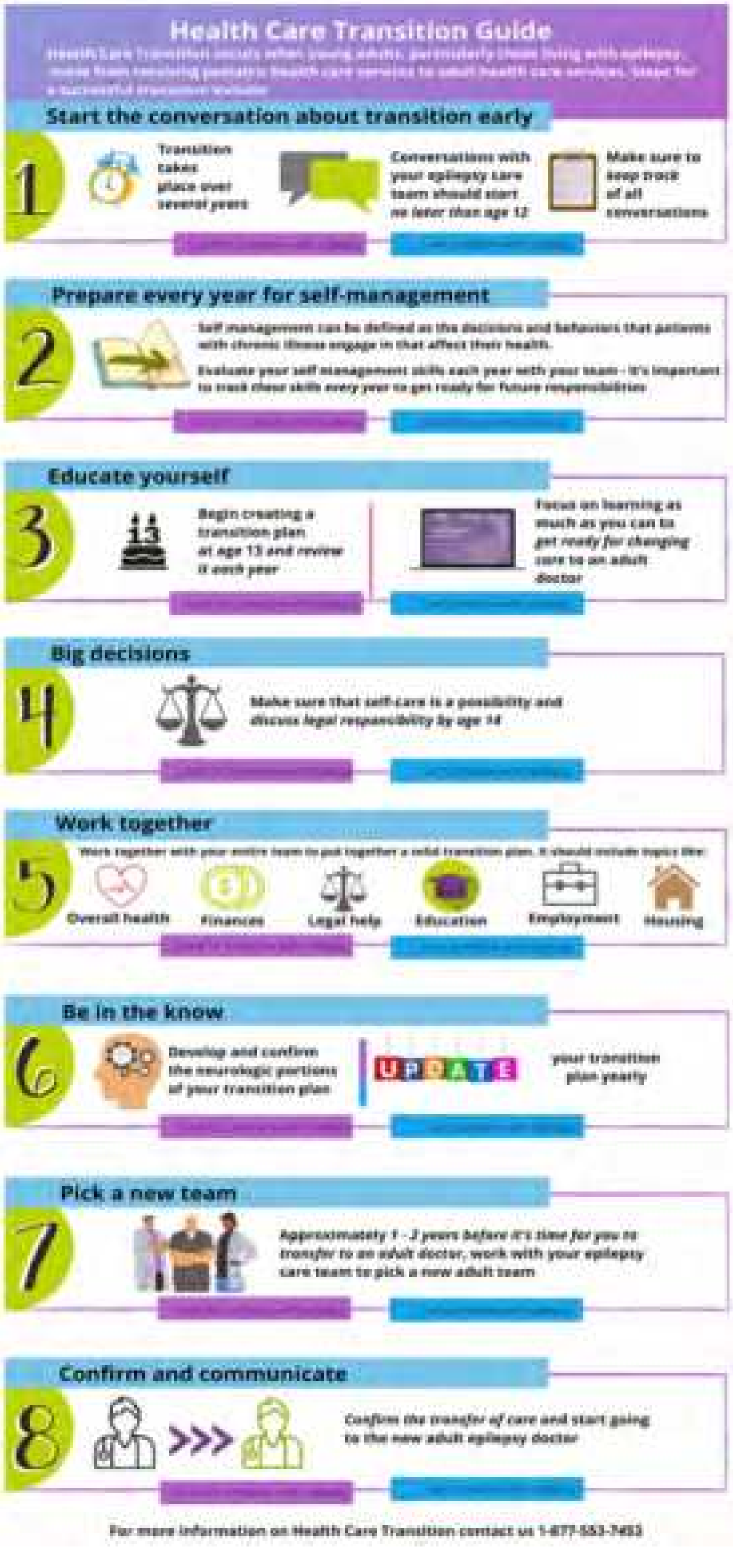
- **Pregnancy** – If your teen girl is sexually active, there is a possibility that she may get pregnant. While some women have pregnancies unaffected by their epilepsy it is important for you to know, however, that pregnancies may be higher risk for women with epilepsy. It is recommended that every female of childbearing age should take folate. If your teen becomes pregnant speak with your doctor about concerns and medication. Your teen should not abruptly stop their treatment plan at any time unless directed by their doctor.

- **Substance Abuse** – Alcohol and drugs can have dangerous effects especially for those taking medication for epilepsy. Have open and regular conversations about the risks involved and talk about ways to handle uncomfortable situations. For help with talking to your child about possible drug or alcohol use, visit
www.timetoact.org/

- **Driving** – Each state has its own laws regarding epilepsy and eligibility to drive. Contact your local Epilepsy Alliance America member for more information on local laws. In addition, speak with child's neurologist and find out what you need to do to comply with your state's rules regarding driving.
www.epilepsy.com/driving-laws

For more information: **www.healthychildren.org**

Once your youth with epilepsy turns 12, it is time to start having conversations with the Epilepsy Care Team about preparing for transition to adult healthcare. On the next page you will find a health care transition infographic and we have included a healthcare transition family guide for transition age youth with epilepsy here for your convenience.



Health Care Transition Guide

Health Care Transition occurs when young adults, particularly those living with epilepsy, move from receiving pediatric health care services to adult health care services. Steps for a successful transition include:

1 Start the conversation about transition early

Transition takes place over several years

Conversations with your epilepsy care team should start *no later than age 12*

Make sure to keep track of all conversations

2 Prepare every year for self-management

Self management can be defined as the decisions and behaviors that patients with chronic illness engage in that affect their health.

Evaluate your self management skills each year with your team - it's important to track *these skills every year* to get ready for future responsibilities

3 Educate yourself

Begin creating a transition plan *at age 13 and review it each year*

Focus on learning as much as you can to *get ready for changing* care to an adult doctor

4 Big decisions

Make sure that self-care is a possibility and *discuss legal responsibility by age 14*

5 Work together

Work together with your entire team to put together a solid transition plan. It should include topics like:

6 Be in the know

Develop and confirm the neurologic portions of your transition plan

UPDATE your transition plan yearly

7 Pick a new team

Approximately 1 - 3 years before it's time for you to transfer to an adult doctor, work with your epilepsy care team to pick a new adult team

8 Confirm and communicate

Confirm the transfer of care and start going to the new adult epilepsy doctor

For more information on Health Care Transition contact us 1-877-553-7453

Health Literacy

Health literacy is the ability to understand basic health information in order to make appropriate health decisions.

Tips to improve your health literacy:

1 **Use and ask for plain language**

Ask your provider to explain everything to you in plain language and tell your provider when you do not understand what he or she is saying

2 **Use the teach back method**

When your doctor gives you instructions, repeat it back to him or her - but in your own words

3 **Ask questions**

Don't be afraid to ask questions to clarify terms or instructions you do not understand

4 **Ask for additional resources**

Ask for visuals or an interpreter if that will help you understand the information better

Checkpoints on your roadmap to healthcare coverage:

- Learn key insurance terms
- Understand your health care system and your health insurance plan
- Understand your costs involved
- Know the services covered by your plan
- Know how to navigate your services

What Should I Be Concerned About as A Parent?

Health Care Transition

What is Health Care Transition?

Health Care Transition occurs when young adults move from receiving pediatric health care services to adult health care services. After transition is completed, the youth's care is no longer child oriented, but adult oriented. During this time, the youth learns to rely less on his parents for handling his health care and moves into handling such needs on his own.

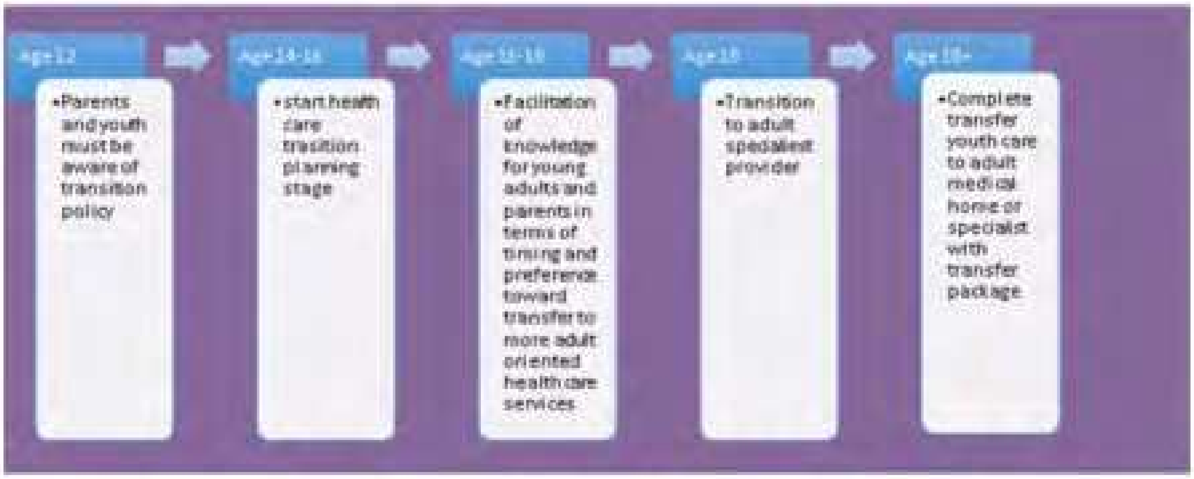
Health care transition is a gradual process and consists of three main phases:

- Planning
- Transfer
- Integration into adult health care

Health care transition aims to improve transition from pediatric to adult health care through use of innovative, high quality, developmentally appropriate, and uninterrupted health care services that will maximize the lifelong functioning and potential of the youth through his transition from childhood to adulthood.

When to Start Planning Healthcare Transition?

Parents/Caregivers can begin planning their children's transition around age 12. Although each child has his own unique situation and challenges, this process should occur between ages 18 to 21.



Why Health Care Transition is Important to Your Child?

Studies show that health care transition enables young adults to develop such skills as self-care, independent health care decision-making, self-advocacy, and a sense of self-reliance and independence. As it relates to young adults with disabilities, goals for health care transition consist of improving health care and social services in order to properly identify health, family and environmental issues, and develop the proper responses to these issues.

Ensuring a successful health care transition can also have a positive affect on other areas of the young adult’s life that are not directly related to his health care (i.e. living arrangements, transportation, schooling and education, work-life factors, social/family connections, and socioeconomic status). For example, transportation plays a role in self-care by providing access to health care services; although health care professionals do not directly influence the young adult’s transportation needs, awareness of such needs is necessary to ensure that health care transition needs are adequately met.

Health care transition is also influenced by public policies related to health insurance, available technologies, self-care services, housing, vocational training, education, and financial factors. Some of the possible policies and environmental influences that play a role in health care transition are as follows:

Health Care Transition Importance:

- Improvement in overall health
- Better adherence to health care
- Improved quality of life
- Increased independence
- Develop health care management skills
- Better service utilization
- Lower rates to ER visits and hospitalization
- Reduced time gap between last primary care and the first adult specialist visit
- Reduction in costs of care

Usually, parents are the primary individuals responsible for the management of their children’s medical needs during the childhood stage, they do everything from setting up appointments, attending visits, making medical decisions, filling out forms, to keeping track of their medications, and more. The question is what will happen when your young adult gets older.

Once an individual turns 18, he is no longer considered a minor and will have to make his own legal decisions. If an individual has intellectual disabilities, he is given the opportunity to gain a sense of independence. However, the young adult's new role may trouble family members who were once relied upon to take care of his needs. Family members sometimes fear that their young loved one will make decisions for himself that are different than the decision made for him in the past, in a sense family members may mourn the loss of control of healthcare and management to the young adult.

To successfully assist the young adult in obtaining this level of independence, parents will have to consider learning about the health care transition process, building health care skills, preparing for an adult model of care, and transferring them to new providers.

There are several steps you can take to make sure the transition to adult health care goes smoothly. Each child transferring from their child neurologist to their new adult neurologist will have his/her own experiences, challenges, and needs. The Epilepsy Alliance Florida team will dedicate all their efforts to support the families and their youth toward a smooth health care transition and will ensure that they are provided with the appropriate community resources, education, and support needed to complete this process successfully.

How Can You Help Your Youth to Become More Independent?

- Promote independence.
- Start considering independent living options and explore available supports.
- If your youth will be living in your home, enable them to input assistance and responsibility just as any other adult would if they were living with you. Treat them age appropriately.
- Allow your child to be a part of the decision making process.
- Assist your youth in looking for personal care assistant services. This option can help your young adult with his/her own care needs at home, school, or work, which has the potential to increase their sense of independence.

Remember... consistent social interaction is essential. Encourage social interactions with old and new friends in settings such as church groups, volunteer and work activities, classes, clubs, and other social events.

It is important to also consider based on your child's case whether it will realistically be possible for them to be fully independent or whether they will need the assistance of another for the rest of their life. If they will need assistance indefinitely then you will need to have a long term plan detailing who will care for them especially if one of you as parents were to pass away.

How Can Epilepsy Alliance Florida Help You Plan for Transition?

Epilepsy Alliance Florida continuously implements innovative health care transition initiatives that aim to assist families and their youth with an easier and smoother transition. Our Epilepsy Alliance Florida family will provide all the support, education, guidance, and community resources available to their members to achieve these goals. The health care transition toolkit located in the FORMS section that we have prepared for you will be a good guide for starting the planning stage.

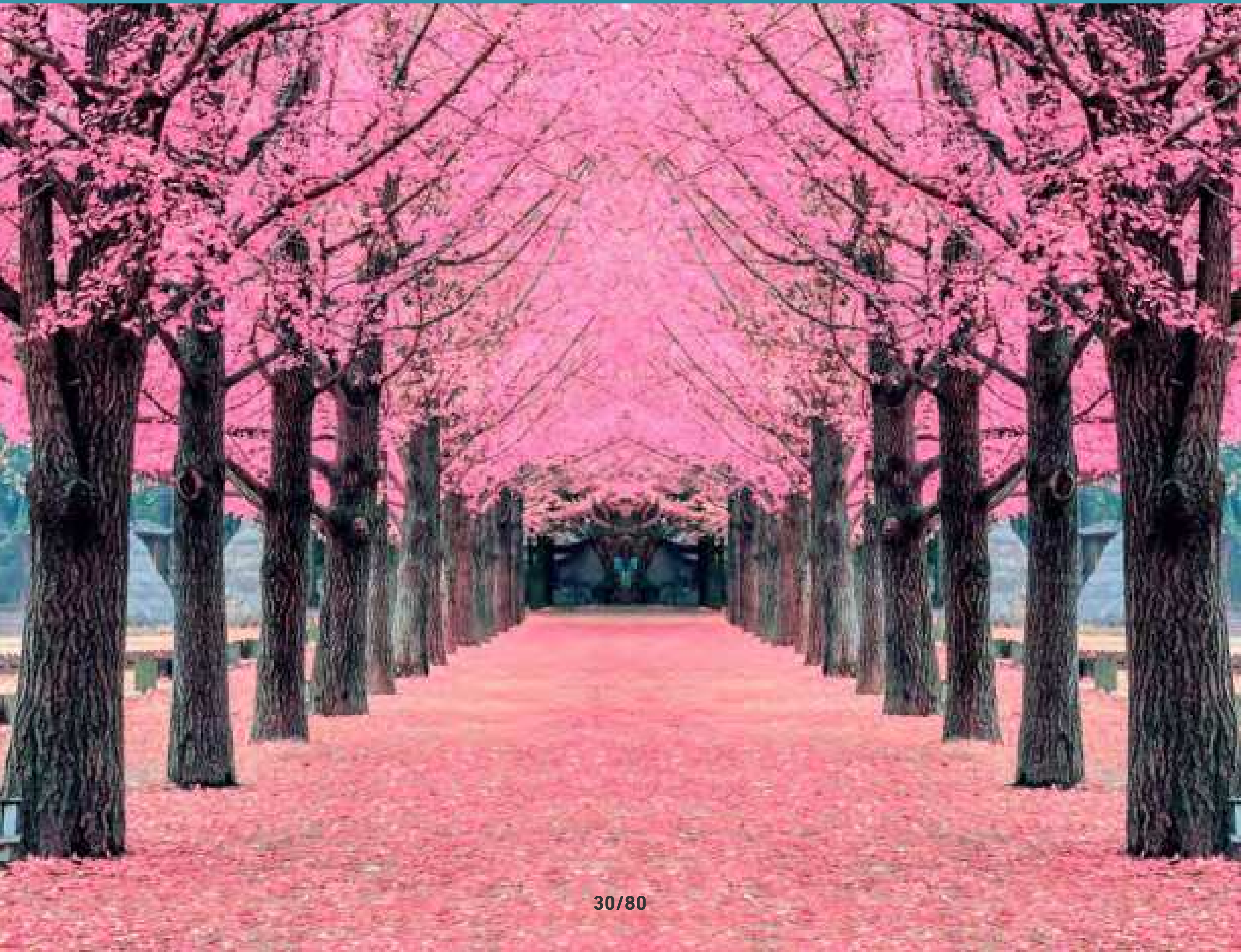
The Health Care Transition Tools Include:

- Sample Transition Policy
- Sample Transition Checklist
- Transfer Letter
- Plan of Care
- Medical Summary
- Community Resources Guide-Resources section
- Health insurance enrollment for uninsured youth in Federally Qualified Health Centers (FQHC) or community health centers-Resources section

The initial diagnosis of your child with epilepsy can be quite daunting as a parent. Learning as much as you can about epilepsy is the first step in overcoming this feeling. Below is a list of available resources to support you in this journey. In addition, reach out to your local Epilepsy Alliance Florida office for information about epilepsy and seizure first aid education sessions.

Learn seizure first aid so you know what to do if your child has a seizure.

Resources



Websites

Epilepsy Alliance America
www.epilepsyallianceamerica.org/

Centers for Disease Control and Prevention – Epilepsy Programs
www.cdc.gov/epilepsy
Government agency responsible for addressing public health issues related to epilepsy to improve health, quality of life, and decrease the stigma associated with this condition.

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

School Stuff
www.epilepsy.org.uk/info/children/schoolstuff
Developed to provide parents and teachers with tools to help change the perception of epilepsy in a child's school. The program works to educate your child's teachers and classmates, but also to empower your child to go to school confidently each day.

American Academy of Pediatrics Build Your Own Care Notebook
https://medicalhomeinfo.aap.org/tools-resources/Pages/For-Families.aspx
A tool to help parents/caregivers maintain an ongoing record of their child's care, services, and providers, along with other notes. This notebook empowers families to become experts on their child's care and is also a way to maintain the lines of communication between the many providers and services that help care for a child and their family.

Family Voices & Family-to-Family Health Information Centers (F2F HICs)
www.familyvoices.org
Organization focused on family-centered care and support for all children and youth with special health care needs. F2F HICs are nonprofit, family run organizations that assist families of children and youth with special health care needs by providing support, information, resources, and training.

Parent-to-Parent USA
www.p2pusa.org
A national organization providing parent-to-parent programs that offer emotional and informational support to families of children who have special needs, most notably by matching parents seeking support with an experienced, trained support parent.

Pacer Center

www.pacer.org

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

Parent Training& Information Centers and Community Parent Resource Centers

https://www.parentcenterhub.org/find-your-center/

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

Exceptional Parent Magazine

www.eparent.com

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

Center for Parent Information and Resources

https://www.parentcenterhub.org/

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

Community Services Locator

https://www.mchlibrary.org/

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

National 211

www.211.org

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

Transition Age Youth Links & Resources

Supporting Links and Resources

Downloadable Apps (Medications Control)
My Medical: **www.mymedicalapp.com**

Mobile App to Empower Young Adults with Special Healthcare Needs (DE UCEDD)
https://play.google.com/store/search?q=healthy%20transitions

Social Security Benefits (English/Spanish/Creole)
www.floridahats.org/health-insurance-financing/

Legal Assistance Resources

Guardianship and Other Decision-Making Alternatives (English/Spanish/Creole)
www.floridahats.org/wp-content/uploads/2016/03/Guardianship.pdf

Florida Legal Services
www.floridalawhelp.org

The Florida Bar
www.floridabar.org

Youth Leadership, Self-Advocacy, and Volunteering Opportunities Supporting Resources

National Youth Leadership Network
www.nyln.org/Clearinghouse/resourceclearinghouse.html

Self Advocacy: Find the Captain in You! (video from the Pacer Center)
www.youtube.com/watch?v=NUQDozx7aug

Advocating for Yourself in School (English) (Spanish) (Haitian Creole) Tips for Middle and High School Students
www.floridahats.org/wp-content/uploads/2016/03/School_Advocacy-1.pdf

Adult Model of Care/Transfer to Adult Providers

Finding and Using Adult Health Care
www.chfs.ky.gov/agencies/ccshcn/Documents/FindingAdultCare.pdf

Planning to Move from Pediatric to Adult Care? Here's How They Can Differ
www.gottransition.org/resourceGet.cfm?id=5

System Differences Between Pediatric and Adult Health Care
www.gottransition.org/resourceGet.cfm?id=490

National Center for Cultural Competence
https://nccc.georgetown.edu/

The Transition to Adult Health Care For Youth with Special Health Care Needs
https://pediatrics.aappublications.org/content/pediatrics/126/Supplement_3/S129.full.pdf

Education and Transition

National Secondary Transition Technical Assistance Center (NSTTAC)
https://transitionta.org/

Employment and Transition

Institute for Educational Leadership
http://iel.org/

National Collaborative on Workforce and Disability for Youth
www.ncwd-youth.info/

Federal and State Transition Resources

Federal Transition Initiatives
https://www.gottransition.org/resources-and-research/#federaltransitioninitiatives

State Transition Initiatives
https://www.gottransition.org/resources-and-research/#statetransitioninformation

Association of Maternal & Child Health Programs (AMCHP)
www.amchp.org/Pages/default.aspx

Foster Care and Transition

Foster Care Transition Toolkit
www2.ed.gov/about/inits/ed/foster-care/youth-transition-toolkit.pdf

Casey Family Programs
www.casey.org/

FosterClub
www.fosterclub.com/

Guardianship and Decision-Making

Turning 18: What it Means for Your Health
www.gottransition.org/resourceGet.cfm?id=446

Cumplir 18 años: Qué significa para tu salud
www.gottransition.org/resourceGet.cfm?id=475

Got Transition Webinar: Understanding Guardianship and the Alternatives for Decision Making Support
www.youtube.com/watch?v=0xXELClMHHE&feature=youtu.be

Guardianship and Alternatives for Decision-Making Support
www.gottransition.org/resourceGet.cfm?id=17

National Resource Center for Supported Decision Making
www.supporteddecisionmaking.org/

Health Insurance

Catalyst Center
www.ciswh.org/project/the-catalyst-center/

HealthCare.gov Young Adult FAQs
www.healthcare.gov/young-adults/

Health Insurance Basics
www.teenshealth.org/en/teens/insurance.html?WT.ac=t-ra

Health Insurance Help Guide for College Students
https://www.affordablecollegesonline.org/college-resource-center/student-health-insurance/

National Disability Navigator Resource Collaborative
www.nationaldisabilitynavigator.org/

Independent Living and Transition

Independent Living Research Utilization Program (ILRU)
www.ilru.org/

Institute for Community Inclusion (ICI)
www.communityinclusion.org/

National Center on Health, Physical Activity and Disability
www.nchpad.org/

Mental Health and Transition

Research and Training Centers
www.pathwaysrtc.pdx.edu/pdf/projPTTP-Community-Support-Tip-Sheet.pdf

- Transition Mental Health Service Provider Core Competencies (Portland State)
www.pathwaysrtc.pdx.edu/pdf/projPTTP-core-competencies-2018.pdf
- Transition Service Provider Competency Scale (Portland State)
www.pathwaysrtc.pdx.edu/pdf/projPTTC-Transition-Service-Provider-Competency-Scale.pdf
- Promoting Positive Pathways to Adulthood: Pathways Transition Training Toolkit (Portland State)
www.pathwaysrtc.pdx.edu/pathways-transition-training-modules
- Transitions to Adulthood Center for Research (University of Massachusetts)
www.umassmed.edu/TransitionsACR/

Policy Recommendations

2018 AAP/AAFP/ACP Clinical Report on Transition
https://pediatrics.aappublications.org/content/142/5/e20182587

2011 AAP/AAFP/ACP Clinical Report of Transition
https://pediatrics.aappublications.org/content/128/1/182

2002 AAP/AAFP/ACP Statement
https://pediatrics.aappublications.org/content/110/Supplement_3/1304.short

“Standards for Systems of Care for Children and Youth with Special Health Care Needs”
http://www.amchp.org/programsandtopics/CYSHCN/Documents/Standards%20for%20Systems%20of%20Care%20for%20Children%20and%20Youth%20with%20Special%20Health%20Care%20Needs%20Version%202.0.pdf

Relationships, Sexuality, and Pregnancy Prevention

You’ve Got a Friend: Supporting Family Connections, Friends, Love, and the Pursuit of Happiness
https://www.mass.gov/doc/healthy-relationships-sexuality-and-disability-resource-guide-0/download

ReachOut
https://au.reachout.com/

Feature Issue on Sexuality and People with Intellectual, Developmental and Other Disabilities
https://publications.ici.umn.edu/impact/23-2/from-the-editors

Sexuality Education for Children and Adolescents with Developmental Disabilities
https://pediatrics.aappublications.org/content/pediatrics/118/1/398.full.pdf

National Campaign to Prevent Teen and Unplanned Pregnancy
www.powertodecide.org/

Ask Alice!
www.goaskalice.columbia.edu/

Self-Care

5 Steps to Prepare for Health Care Transition
www.gottransition.org/resourceGet.cfm?id=540

You're Not a Kid Any More Ages 12-14 (Envisioning a Future)
www.floridahats.org/wp-content/uploads/2017/01/Booklet_SYNAKA-web.pdf

Now That You're in High School Ages 15-17 (Age of Responsibility)
https://www.floridahats.org/wp-content/uploads/2017/01/Booklet_NTYIHS-web.pdf

When You're 18, You're in Charge of Your Health Ages 18+ (Age of Transition)
www.floridahats.org/wp-content/uploads/2017/01/Booklet_WY18-web.pdf

The Medical ID Feature on iPhone Health App
www.gottransition.org/resourceGet.cfm?id=437
- A guide describing how to set up your Medical ID app successfully on both Apple and Android phones.
- La característica Medical ID en la aplicación Salud de Apple
https://www.gottransition.org/resource/?setting-up-medical-id-smartphones-es
- A guide describing how to set up your Medical ID app successfully on both Apple and Android phones (in Spanish)

The Medical ID app for Android phones
www.gottransition.org/resourceGet.cfm?id=439

Instalación de la característica Medical ID en teléfonos Android
https://www.gottransition.org/resource/?setting-up-medical-id-smartphones-es

Questions to Ask Your Doctor about Transitioning to Adult Health Care
https://www.gottransition.org/resource/?hct-questions-ask-doctor-youth

Preguntas para realizar a tu médico sobre la transición hacia la atención médica adulta
https://www.gottransition.org/resource/?hct-questions-ask-doctor-youth-es

Becoming an Adult: Taking Responsibility for Your Medical Care
www.youtube.com/watch?v=cjXurYrFMZM

Moving into Adult Health Care: A Guide for Parents
https://uconnucedd.org/wp-content/uploads/sites/1340/2016/06/young_adults_need_to_know.pdf

How to Advocate for Your Health and Health Care
https://www.medicalhomeportal.org/living-with-child/navigating-transitions-with-your-child/transition-to-adulthood/self-advocacy

Communicating with Doctors and Other Health Care Providers
Questions to Ask Your Child's Doctor (gottransition.org)
https://www.gottransition.org/resource/?hct-questions-ask-doctor-parents

Talking with your Doctor
Talking With Your Doctor and Other Health Care Providers - YouTube
https://www.youtube.com/watch?v=qAqVL5We8X0

NY Transitions: Skills for Moving from Pediatric to Adult Care
www.healthytransitionsny.org/skills/

Special Education

Health Care Transition Readiness Assessment for Students with an IEP
www.gottransition.org/resourceGet.cfm?id=526

Evaluación de la preparación para la transición de la atención médica para estudiantes con un IEP
www.gottransition.org/resourceGet.cfm?id=527

IEP Sample Goals
www.gottransition.org/resourceGet.cfm?id=528

SSI Benefits and Transition

Social Security Administration (SSA)
www.ssa.gov/

Supplemental Security Income: What Happens to My SSI When I Turn 18?
https://www.ssa.gov/pubs/EN-05-11005.pdf

Youth and Family Organizations

A Family Toolkit – Pediatric to Adult Health Care Transition
www.gottransition.org/resourceGet.cfm?id=542

Health Care Transition Timeline for Youth and Young Adults
www.gottransition.org/resourceGet.cfm?id=538

Health Care Transition Timeline for Parents and Caregivers
www.gottransition.org/resourceGet.cfm?id=541

Got Transition's National Family Transition Advisory Group
Got Transition® - Advisory Groups
https://www.gottransition.org/about-us/advisory-groups.cfm

Family Voices
www.familyvoices.org/

Military Parent Technical Assistance Center
https://branchta.org/

National Federation of Families for Children's Mental Health
www.ffcmh.org/

The Native American Parent Technical Assistance Center
http://naptac.org/

Pacer Center
www.pacer.org/

Parent Center Hub (National Center for Parent Information and Resources)
www.parentcenterhub.org/

Physician Parent Caregivers
www.physicianparent.org/

TASH
www.tash.org/

Youth Action Council on Transition (YouthACT)
www.ncwd-youth.info/news_post/youth-action-council-on-transition-publishes-two- briefs-for-policymakers-focusing-on-community-engagement-and-transition/

Youth Move National
www.youthmovenational.org/

Young Invincibles (YI)
www.younginvincibles.org/

Youth and Family Transition Stories, Webinars, and Videos

Parent Guide to New National Transition Report
www.gottransition.org/resourceGet.cfm?id=497

Young Adult Health Care Transition Social Media Toolkit
Young Adult Health Care Social Media Toolkit - FVNCFPP (fv-ncfpp.org)
http://www.fv-ncfpp.org/young-adult-health-care-social-media-toolkit/

Books for Children

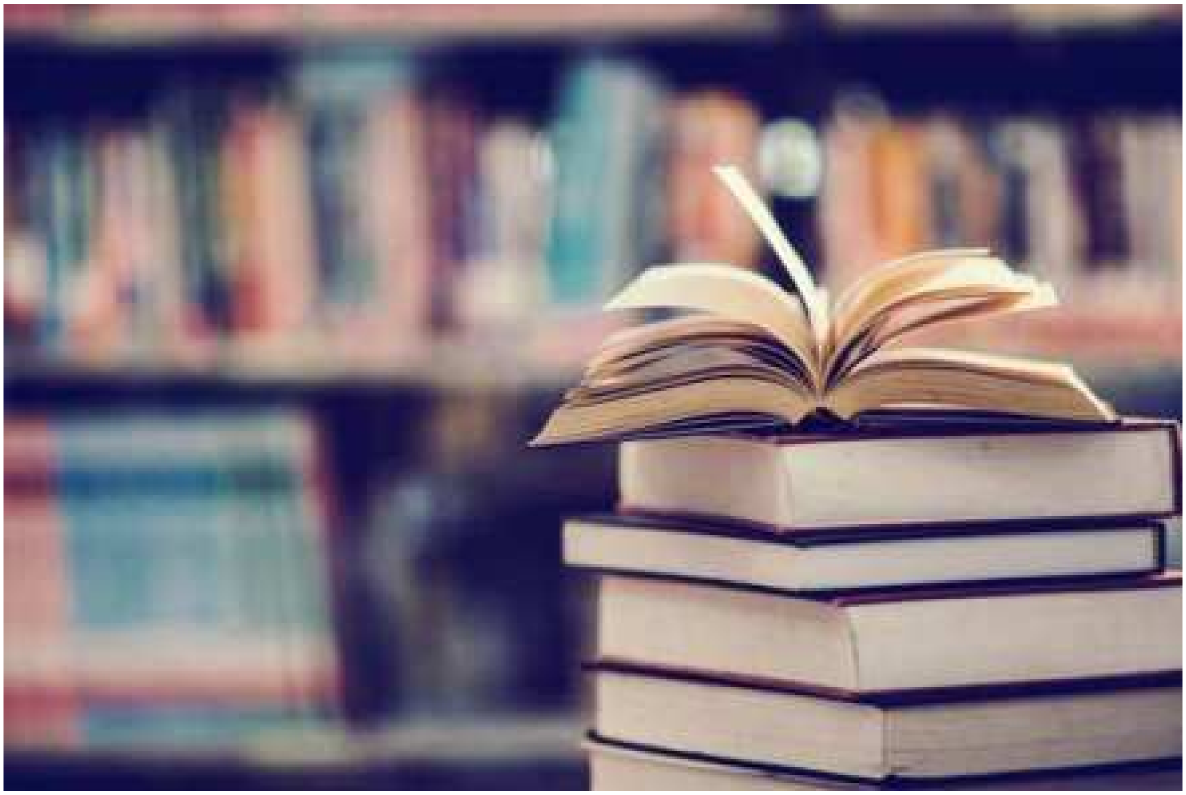
Mommy, I Feel Funny (2009)
by Danielle M. Rocheford

Being Sara (2009)
by Chris Passudetti

Through His Eyes (2009)
by Lisa M. Loiodice

Becky the Brave: A Story about Epilepsy (2002)
by Laurie Lears

Let's Learn with Teddy about Epilepsy (2008)
by Yvonne Zelenka, Ph.D. Koko Th Service Dog (2008) by Lisa Mink, M.S.



Frequently questions

What is epilepsy?

Epilepsy is a chronic neurological disease characterized by recurrent, unprovoked seizures. A person is considered to have epilepsy if any of the following conditions are met: 1) a person has at least two unprovoked (or reflex) seizures that occur more than 24 hours apart; 2) a person has one unprovoked seizure and it is suspected that there is a minimum of a 60% likelihood of recurrence within the next ten years; and 3) a person is diagnosed as having an epilepsy syndrome. Seizures and epilepsy are not the same entity, although a seizure is the principal clinical manifestation of epilepsy, the incidence of a single seizure does not necessitate an epilepsy diagnosis. (see About Epilepsy for more information)

What is a seizure?

A seizure is an event in the brain that causes abnormal changes in movement, behavior, perception or consciousness. Epilepsy is the disease which involves recurrent, unprovoked seizures. Most last a few seconds or minutes. (see About Epilepsy for more information)

What causes epilepsy?

In about seven out of ten people with epilepsy, no cause can be found. This is called idiopathic epilepsy. Among the remaining 30% of persons with epilepsy, the cause may be any one of a number of things for example, head injuries, birth trauma, brain tumors, lead poisoning, problems in development of the brain before birth and infections like meningitis or encephalitis. Genetics can also play a role.

How common is epilepsy?

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

Treatment and First Aid

Which doctors treat epilepsy?

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

How is epilepsy treated?
Epilepsy is most often treated with medication. There are many seizure-prevention drugs (also known as antiepileptic, anticonvulsant or anti-seizure drugs) available and it can sometimes take a while to find the one or combination of drugs that works best for each child. It is important to follow your doctor's instructions about when and how much medication to give your child. The medication won't work properly until it reaches a certain level in the body, and that level has to be maintained. The goal is to keep the blood level high enough to prevent seizures, but not so high that it causes excessive sleepiness or other unpleasant side effects. If medication doesn't work, other options include surgery, a medical device or a very specialized, high-fat diet (ketogenic).
Research has shown that the ketogenic diet can reduce or even eliminate seizures in some individuals impacted by epilepsy – particularly those who have not gained seizure control after trying two or more treatment options. But why does keto work for these individuals and how do doctors decide which patients to recommend for this treatment? For more information on the subject visit CURE
www.cureepilepsy.org. For keto friendly recipes visit: **https://charliefoundation.org/recipes/**

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

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

Raising Children with Epilepsy

This is all so new and frightening; how can I help my child get through it?
As a parent, there are many things you can do to support your child:

- Learn as much as you can about epilepsy
- Discuss epilepsy openly and honestly with your child
- Avoid saying things that could make your child feel like a problem or burden
- Be positive
- Praise your child's success
- Encourage sports, hobbies and other interests
- Help your child make friends

- Work with your child to explain epilepsy to friends, relatives, teachers and others
- Continue family activities and traditions
- Make time for yourself without feeling guilty

What should I tell teachers and friends?

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

Will my child be able to live a normal life?

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

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

- Help your child talk openly and honestly with others about epilepsy
- Encourage your child to go online and visit various epilepsy-related child and teen-tailored Web sites
- Consider sending your child to an Epilepsy camp such as Camp Boggy Creek where Epilepsy Alliance Florida sponsors children to attend at no cost to parents
- If your child is facing teasing or bullying, visit the Stop Bullying Web site **www.StopBullying.gov**

Where can I find help?

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

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

Additional information on these organizations can be found in the **Resources** section of this Family Guide.

Epilepsy Terms/ Glossary

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

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

Affect: mood, level of emotional responsiveness.

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

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

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

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

Anticonvulsant: an agent that halts or prevents convulsions.

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

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

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

Apnea: cessation of breathing.

Ataxia: inability to coordinate muscle movement.

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

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

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

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

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

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

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

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

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

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

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

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

Clonic: seizure involving muscle contractions and relaxations.

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

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

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

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

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

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

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

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

Cryptogenic: of unknown origin.

CURE Epilepsy - Citizens United for Research In Epilepsy-promoting and funding patient-focused research

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

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

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

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

Epilepsy Alliance America: non-profit organization that provides local and national services for people with epilepsy.

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

Etiology: cause of a disease or medical condition.

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

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

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

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

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

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

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

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

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

Hippocampal sclerosis: cell loss and hardening of the hippocampus.

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

Hyperventilation: rapid, deep breathing.

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

Ictus: a seizure or stroke.

Idiopathic: of unknown origin or cause.

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

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

Interictal: the period of time between one seizure and another.
International Bureau for Epilepsy (IBE): the international lay organization concerned with medical, social and scientific aspects of epilepsy that exchanges information and experience on care of patients with seizures.
International classification: a periodically updated classification of seizure types, behaviors and causes used to characterize seizure disorders and epileptic syndromes.
International League Against Epilepsy (ILAE): the international professional organization for physicians which encourages scientific research on epilepsy and the exchange of information.

Intractable: not responding to treatment.

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

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

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

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

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

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

Lissencephaly: refers to an abnormal smooth brain without folds.
Lobe: any rounded, projecting part of the anatomy; the brain has four lobes: frontal, parietal, temporal and occipital.

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

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

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

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

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

Monotherapy: treatment with a single drug.

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

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

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

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

Neurologist: a specialist in the diagnosis and treatment of nervous system diseases and disorders such as epilepsy. Neurons (or nerve cells): the cells that form the brain and send and receive messages to and from the rest of the body. Nocturnal seizures: seizures that occur routinely in the evening hours and, especially, during sleep.

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

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

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

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

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

Pharmacotherapy: medication therapy.

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

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

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

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

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

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

Refractory: difficult to treat, unresponsive or of limited response to medication. Responsive nerve stimulator (RNS): a battery powered device to reduce severity of seizures through electrical stimulation which is placed in the patient's skull.

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

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

Seizure semiology: the clinical symptoms of a seizure.

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

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

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

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

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

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

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

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

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

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

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

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

Trans-cranial magnetic stimulation: an unproven experimental procedure that exposes the brain to a strong magnetic field as a potential treatment for epilepsy.
Vagus nerve: a nerve which begins at the brain stem and passes through the cranial cavity past the jugular to the throat, larynx, lungs, heart, esophagus, stomach and abdomen.

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

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

Local Epilepsy Alliance America Members

Florida
Epilepsy Alliance Florida
Miami, FL
1-877-553-7453
Fax: 305-670-0904
www.epilepsyalliancefl.com

Louisiana
Epilepsy Alliance Louisiana
Baton Rouge, LA
Office: (225) 298-5499
Toll Free: (800) 960-0587
www.epilepsylouisiana.org/

New Jersey
Epilepsy Services New Jersey
East Windsor, NJ
Phone: 800-336-5843
www.epilepsyservicesnj.org/

North Carolina
Epilepsy Alliance North Carolina
Winston-Salem, NC
Phone: 800-451-0694
Local: 336-716-2320
www.epilepsync.org

Ohio
Epilepsy Alliance Ohio
Cincinnati, OH
Phone: (513) 721-2905
Toll free: (877) 804-2241
Fax: (513) 721-0799
www.epilepsy-ohio.org

New York
Epilepsy Pralid Inc
Rochester, NY
Ph: (585) 442-6420
Fax: (585) 442-6964
www.epiny.org/index.php

Pennsylvania
Epilepsy Association of Western and Central PA
Pittsburgh, PA
Phone: 412 322 5880/800 361 5885
www.eawcp.org

Puerto Rico
Sociedad Puertorriqueña de Epilepsia,Inc
Bayamón, PR
Phone: 787-782-6200
www.sociedadepilepsiapr.org

Forms

- Seizure recognition & first aid fact sheet
- Seizure first aid poster
- Child epilepsy management check list
- Seizure log
- Seizure observation record
- Seizure action plan
- Medications schedule/record form
- Medical visit
- My healthcare team
- Questions for my healthcare team
- Transition readiness assessment for youth
- Transition checklist
- Sample transfer letter
- Sample plan of care

First aid for seizures

TYPE OF SEIZURE	CHARACTERISTICS	PHYSICAL AID	EMOTIONAL AID	SOCIAL AID	SCHOLASTIC AID
Absence	• 1-10 seconds long • Stares • Eyelids flutter • Resume activity immediately	• None	• Listen patiently • Repeat what was said when necessary	• Help others understand what is happening • Help develop patient attitude	• “Buddy System” (someone to help keep up with directions, etc.)
Generalized Tonic Clonic	• 1-3 minutes long • May cry out • Fall to ground • Stiffen • Jerking of whole body in rhythmic manner • Lose urine or stool • Salivate • Skin may turn blue • Tired after seizure with possible headache/muscle soreness	• Help to lying position • Loosen tight clothing • Place hand under head • Clear area of hard objects • Do not force anything into mouth or restrain person • Turn onto side	• Reassure, “it’s okay” • Let person know what happened • Chat with person or read to them • Allow to rest if desired • Bring back to group as soon as possible	• Help others understand what is happening • Carry on business as usual • Give others opportunity to discuss it • Help others learn to react in an “accepting manner”	• Aid with work when needed
Focal Impaired Awareness	• 2-4 minutes long • May: ○ Smack lips ○ Mumble ○ Wander ○ Pick at clothes ○ Repeat a behavior automatically • Confused after seizure	• Do not restrain • Remove harmful objects • Guide gently away from danger	• Talk gently • Reassure, “It’s okay” • Let person know what happened • Help reorient after seizure • Chat with person	• Help others understand what is happening • Carry on business as usual • Help others learn to react in an “accepting manner	• Aid with work when needed

SEIZURE FIRST AID

(FOR GENERALIZED TONIC-CLONIC)

T **Turn person on the side**

R **Remove objects/glasses**

U **Use something soft under their head**

S **Stay calm & stay with the person**

T **Time seizure**

DID YOU KNOW?

- Epilepsy is not contagious
- People with epilepsy want to be treated just like everyone else
- Most people with epilepsy no longer have seizures when taking medications

REMEMBER...

Never put anything in anyone's mouth or hold a person down when they are having a seizure.

CALL 911 IF:

- Seizure lasts more than 5 minutes (unless otherwise noted)
- They have another seizure
- If they have never had a seizure before

epilepsy ALLIANCE FLORIDA

www.epilepsyalliancefl.com

EPILEPSYFLA EPILEPSYFLA EPILEPSYFLA

Managing Your Child's Epilepsy: A Checklist

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

Managing

Epilepsy

Medical Visit

☐ Find out from your doctor what your immediate next steps should be.

☐ Ask questions and use the **Medical Visit** form included in this toolkit to record important information from the visit.

☐ Get copies of all your child's test results and any other documents for your records.

☐ Find out if and when you need to schedule follow-up appointments with any other providers (specialists, primary care physician, psychologist, school nurse, etc.)

☐ Develop a care plan with your doctor.

☐ Make sure your child has the opportunity to ask questions.

Medication

☐ Follow all instructions provided by the doctor.

☐ Have your child's prescription filled **exactly** as prescribed (make sure the pharmacist has not switched manufacturer) and begin giving your child the medication **exactly** as the doctor instructed.

☐ Keep careful watch for any side effects and/or changes you see in your child and record them in the **Medication Record** form included in this toolkit to tell the doctor during the next visit.

☐ If medication is to be taken at school, ask your pharmacist to prepare a labeled

prescription bottle for school nurse.

Seizure Control

If your child has a seizure:

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

Managing Life with Epilepsy

Educating Yourself, Your Child and Others

Understand your child’s diagnosis. Your doctor should have provided you with the following information during your medical visit:

- ☐ Background information about epilepsy
- ☐ Your child’s specific epilepsy syndrome and seizure type
- ☐ Prognosis
- ☐ Diagnosis and treatment options
- ☐ Medication and side effects & management
- ☐ Managing seizures – triggers, first aid, emergencies
- ☐ Epilepsy Management and self-care
- ☐ Safety – risks and precautions
- ☐ Learning and/or psychological issues
- ☐ School issues
- ☐ Resources – information, support programs/services

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

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

School

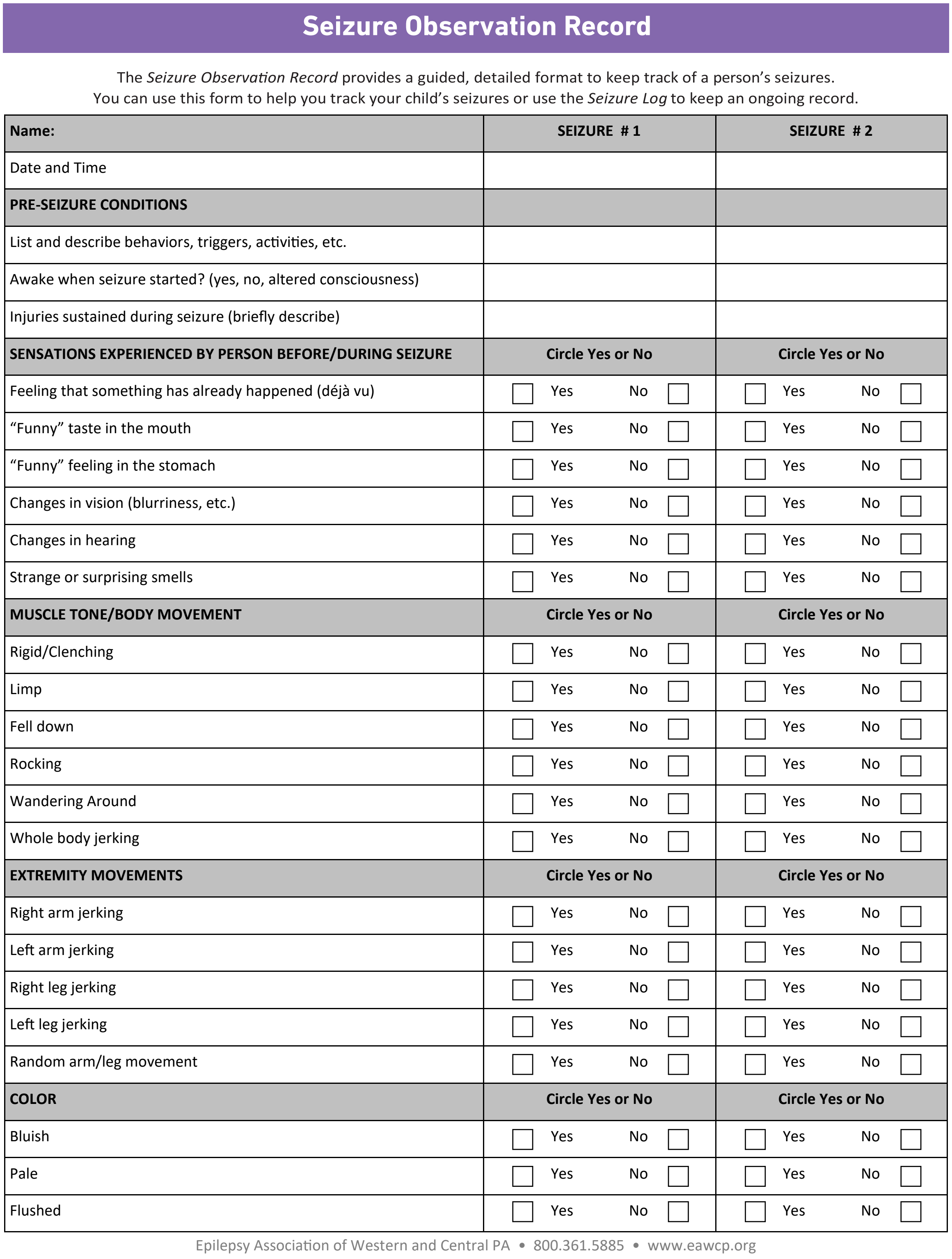
- ☐ Schedule an appointment with your child's teacher(s), school nurse, coaches, bus driver(s), etc. to make them aware of your child's epilepsy and the role each of them will have to ensure proper management.
- ☐ Complete the ***Seizure Action Plan*** with the school nurse.
- ☐ Discuss the need for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

Support/Coping

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

Seizure Observation Record

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



Seizure Observation Record

The *Seizure Observation Record* provides a guided, detailed format to keep track of a person's seizures.
You can use this form to help you track your child's seizures or use the *Seizure Log* to keep an ongoing record.

Name:	**SEIZURE # 1**	**SEIZURE # 2**
Date and Time		
PRE-SEIZURE CONDITIONS		
List and describe behaviors, triggers, activities, etc.		
Awake when seizure started? (yes, no, altered consciousness)		
Injuries sustained during seizure (briefly describe)		
SENSATIONS EXPERIENCED BY PERSON BEFORE/DURING SEIZURE	**Circle Yes or No**	**Circle Yes or No**
Feeling that something has already happened (déjà vu)	☐ Yes No ☐	☐ Yes No ☐
"Funny" taste in the mouth	☐ Yes No ☐	☐ Yes No ☐
"Funny" feeling in the stomach	☐ Yes No ☐	☐ Yes No ☐
Changes in vision (blurriness, etc.)	☐ Yes No ☐	☐ Yes No ☐
Changes in hearing	☐ Yes No ☐	☐ Yes No ☐
Strange or surprising smells	☐ Yes No ☐	☐ Yes No ☐
MUSCLE TONE/BODY MOVEMENT	**Circle Yes or No**	**Circle Yes or No**
Rigid/Clenching	☐ Yes No ☐	☐ Yes No ☐
Limp	☐ Yes No ☐	☐ Yes No ☐
Fell down	☐ Yes No ☐	☐ Yes No ☐
Rocking	☐ Yes No ☐	☐ Yes No ☐
Wandering Around	☐ Yes No ☐	☐ Yes No ☐
Whole body jerking	☐ Yes No ☐	☐ Yes No ☐
EXTREMITY MOVEMENTS	**Circle Yes or No**	**Circle Yes or No**
Right arm jerking	☐ Yes No ☐	☐ Yes No ☐
Left arm jerking	☐ Yes No ☐	☐ Yes No ☐
Right leg jerking	☐ Yes No ☐	☐ Yes No ☐
Left leg jerking	☐ Yes No ☐	☐ Yes No ☐
Random arm/leg movement	☐ Yes No ☐	☐ Yes No ☐
COLOR	**Circle Yes or No**	**Circle Yes or No**
Bluish	☐ Yes No ☐	☐ Yes No ☐
Pale	☐ Yes No ☐	☐ Yes No ☐
Flushed	☐ Yes No ☐	☐ Yes No ☐

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Seizure Observation Record (continued)

	SEIZURE # 1	SEIZURE # 2
EYES	**Circle Yes or No**	**Circle Yes or No**
Pupil Dilated	☐ Yes No ☐	☐ Yes No ☐
Turned to one side (right or left)	☐ Yes No ☐	☐ Yes No ☐
Rolled up/Not visible	☐ Yes No ☐	☐ Yes No ☐
Staring or Blinking	☐ Yes No ☐	☐ Yes No ☐
Closed	☐ Yes No ☐	☐ Yes No ☐
MOUTH	**Circle Yes or No**	**Circle Yes or No**
Salivating	☐ Yes No ☐	☐ Yes No ☐
Chewing	☐ Yes No ☐	☐ Yes No ☐
Lip Smacking	☐ Yes No ☐	☐ Yes No ☐
OTHER SYMPTOMS (PLEASE DESCRIBE)	**Circle Yes or No**	**Circle Yes or No**
Verbal Sounds (gagging, talking, throat clearing, etc.)	☐ Yes No ☐	☐ Yes No ☐
Breathing (normal, heavy, stopped, noisy, etc.)	☐ Yes No ☐	☐ Yes No ☐
Incontinence (urine or feces)	☐ Yes No ☐	☐ Yes No ☐
Other		
POST-SEIZURE OBSERVATION	**Circle Yes or No**	**Circle Yes or No**
Confused	☐ Yes No ☐	☐ Yes No ☐
Sleepy/Tired	☐ Yes No ☐	☐ Yes No ☐
Headache	☐ Yes No ☐	☐ Yes No ☐
Slurred Speech	☐ Yes No ☐	☐ Yes No ☐
Other		
OTHER DETAILS	**SEIZURE # 1**	**SEIZURE # 2**
Seizure Length		
How long to full awareness?		
Parent/Guardian Notified? (Time of Call)		
EMS Called? (Time of Call and Arrival Time)		
Observer’s Name		
Additional Comments		

SEIZURE ACTION PLAN FOR SCHOOL

Student Name________________________ D.O.B.__________ ID #________

School ______________________ Teacher ______________________

Student Picture

Physician ______________________ Phone: ________________________

EMERGENCY CONTACTS

	Name	Relationship	Home #	Work #	Cell #
1.					
2.					
3.					

Type of seizure: ____

What does the seizure look like and how long does it usually last? ______________________

____

Possible triggers that should be avoided: ______________________________

____

Does student need any special activity adaptations/protective equipment (e.g., helmet) at school?
_____No ______ Yes (explain) ______________________________________

____

Is student allowed to participate in physical education and other activities? ____ No ____ Yes (explain)

____

ARE MEDICATIONS NEEDED TO CONTROL THE SEIZURES? _______ No ________ Yes (List below the medications needed)

MEDICATIONS	**AMOUNT TAKEN**	**HOW OFTEN AND FOR WHAT SIGNS**
1.		
2.		
3.		

List medications needed at school (name, dosage/route, and frequency) ______________________

____

Possible side effects that must be reported to parent or physician: ______________________

____

IF GENERALIZED SEIZURE OCCURS:

1. If falling, assist student to floor, turn to side.
2. Loosen clothing at neck and waist; protect head from injury.
3. Clear away furniture and other objects from area.
4. Have another classroom adult direct students away from area.
5. TIME THE SEIZURE.
6. Allow seizure to run its course; DO NOT restrain or insert anything into student's mouth. Do not try to stop purposeless behavior.
7. During a general or grand mal seizure expect to see pale or bluish discoloration of the skin or lips. Expect to hear noisy breathing.

If smaller seizure occurs (e.g., lip smacking, behavior outburst, staring, twitching of mouth or hands)

1. Assist student to comfortable, sitting position.
2. Time the seizure.
3. Stay with student, speak gently, and help student get back on task following seizure.

If student exhibits:
1. Absence of breathing or pulse.
2. Seizure of 10 minutes or greater duration.
3. Two or more consecutive (without a period of consciousness between) seizures which total 10 minutes or greater.
4. Continued unusually pale or bluish skin or lips or noisy breathing after the seizure has stopped.

Intervention:
1. Call 911.
2. START CPR for absent breathing or pulse.

When seizure completed:
1. Reorient and assure student.
    a. Assist change into clean clothing if necessary.
    b. Allow student to sleep, as desired, after seizure.
    c. Allow student to eat, as desired, once fully alert and oriented.
2. A student recovering from a generalized seizure may manifest abnormal behavior such as incoherent speech, extreme restlessness, and confusion. This may last from five minutes to hours.
3. Inform parent immediately of seizure via telephone conversation if:
    a. Seizure is different from usual type or frequency or has not occurred at school in past month.
    b. Seizure meets criteria for 911 emergency call.
    c. Student has not returned to “normal self” after 30-60 minutes.
4. Record seizure on Seizure Activity Log.

If you want

If symptoms are ____

____

Give (medication/dose/route) ____

____

Possible side effects ____

____

Physician Signature ____________________________ Date ______________________

Print Name ___________________________________ Phone _____________________

I want this plan implemented for my child, ______________________, in school. I hereby give my permission for exchange of confidential information contained in the record of my child between the nurse and physician and my signature is an informed consent to share this medical information with school staff as a need to know for academic success and emergency plan as determined by the nurse.

Parent/Guardian Signature: ________________________ Date: ______________________

Approved by School Nurse

School Nurse Signature: ___________________________ Date: ______________________

STUDENTS WITH SPECIAL HEALTH CARE NEEDS

EMERGENCY PLAN NON-MEDICAL STAFF

STUDENT NAME:______________________________DOB:_________TEACHER:_______________RM/GRADE:__________

PARENT/GUARDIAN: __________________________________PREFERRED HOSPITAL:___________________________

HOME PHONE #: ________________________WORK #:____________________CELL #:____________________________

EMERGENCY CONTACT:______________________________PHONE:________________OTHER PHONE:__________

PHYSICIAN: _____________________________ PHYSICIAN TEL:________________PHYSICIAN FAX:________________

STUDENT-SPECIFIC EMERGENCIES

IF YOU SEE THIS	***DO THIS***

IF AN EMERGENCY OCCURS:

1. If the emergency is life-threatening, immediately call 911.
2. Stay with student or designate another adult to do so.
3. Call or designate someone to call the principal and/or school nurse.
    a. State who you are.
    b. State where you are.
    c. State problem.

DOCUMENTATION OF STAFF TRAINING

DATE:	**TRAINED BY:**	**STAFF NAME:**
__________	_______________________	______________________________
__________	_______________________	______________________________
__________	_______________________	______________________________
__________	_______________________	______________________________

STUDENTS TRANSPORTED WITH SPECIAL EQUIPMENT/NEEDS

DRIVER/ATTENDANT INFORMATION SHEET

STUDENT NAME: ______________________ SCHOOL: ____________
ADDRESS: ______________________ TEACHER: ____________
PARENT/GUARDIAN: ______________________ AM ROUTE: ___ PM ROUTE: ___
HOME PHONE #: __________ WORK #: ________ CELL #: ____________
EMERGENCY CONTACT: __________ PHONE: ______ OTHER PHONE: ______
PHYSICIAN: ________ PHYSICIAN TEL: ______ PHYSICIAN FAX: ______

SPECIAL EQUIPMENT OR MEDICAL NEEDS ON BUS

I.E. OXYGEN TANK, WHEELCHAIR, SEIZURES, GO-BAGS, ETC. - PLEASE INCLUDE SIZE AND DIMENSIONS OF ALL EQUIPMENT

EMERGENCY BUS PLAN

IF YOU SEE THIS	*DO THIS*

BEHAVIOR PLAN

BEHAVIOR OR DISABILITY : ______________________

INTERVENTION TO MANAGE THE BEHAVIOR/DISABILITY

OTHER SPECIFIC NEEDS FOR SAFELY TRANSPORTING STUDENT

DATE ______ **DRIVER/ATTENDANT NAME** ______ **NURSE/SCHOOL OFFICIAL** ______

Medication Record

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

Medication	Dose	Start / Stop Date	Comments / Notes

Medical Visit

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

Appointment Date: ______________________

Doctor's Name: ________________________

BEFORE THE VISIT

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

DURING THE VISIT

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

My health care team

Instructions: Developing your health care team may take time. You may not need many people if your seizures are well-controlled or don't lead to many problems. Or you may have many people on your team, depending on how epilepsy affects your life, your age, and other concerns you may have. Your team may include both health care and community supports as well as family and friends. Use this form to help you keep track of who they are and how to contact them most easily.

Type of Provider	Provider Name	Adress / Phone	Email	Best way / time to contact

Consider the following people who may be part of your health care team:

- Neurologists (or epileptologists)
- Epilepsy Nurse
- Social worker
- School psychologist or counselor
- Epilepsy
- Independent living or other community organization
- Hospital used for emergency purposes
- Primary care doctor
- Psychologist or neuropsychologist
- Other counselor
- Job counselor or specialist
- Rehabilitation therapists
- Pharmacy
- Health care proxy/agent
- Neurosurgeon
- Psychiatrist or neuropsychiatrist
- School nurse
- Rehabilitation therapists
- Service Coordinator
- Preferred Hospital

Questions for my health care team

Instructions: Write down questions for your doctor or other member of your health care team. Check off when you get your questions answered and what you need to do next. For example, an answer to one question may lead you to update your Seizure Plan or Diary.

Date	Questions to ask	Who to ask	Next steps	Check when done

SAMPLE TRANSITIONS POLICY (PEDIATRIC PROVIDER)

YOUNG ADULTS WITH NEUROLOGIC DISORDERS

Our medical practice is committed to helping our patients make a smooth transition from pediatric to adult health care.

We begin at ages 12 to 14 to prepare for the change from a “pediatric” model of care—where parents make most decisions—to an “adult” model of care—where youth take full responsibility for decision-making.

To accomplish this there will be time during visits with the teen without the parent present. This assists the youth in more independence in their health care.

At age 18, the youth legally become adults. At that time, the young adult’s consent will be required to discuss any personal health information with family members.

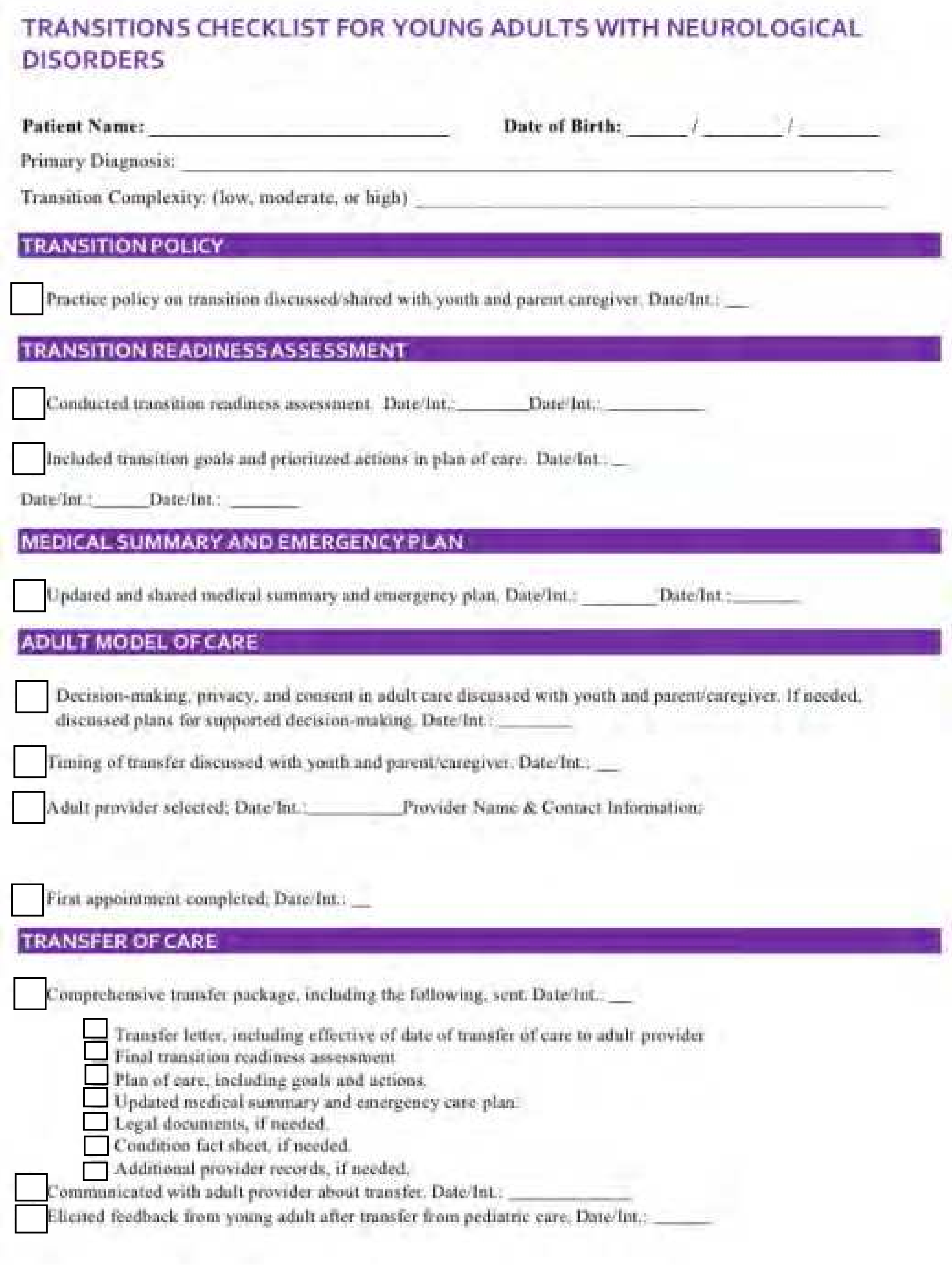
If the youth has a condition that prevents health care decision-making then the parents/caregivers need to consider legal options required to become responsible for the decision-making. This should happen before the youth turns age 18.

We will work in partnership with youth and families regarding the age for transferring to an adult provider. We do recommend that this occur before age 22.

We will assist with this transfer process, including:

*helping to identify an adult provider;
*sending medical records; and
*communicating with the adult provider about the unique needs of each of our patients.

As always, if you have any questions or concerns, please feel free to contact us.



TRANSITIONS CHECKLIST FOR YOUNG ADULTS WITH NEUROLOGICAL DISORDERS

Patient Name: ________________________________ **Date of Birth:** ______ / ________ / ________

Primary Diagnosis: ____

Transition Complexity: (low, moderate, or high) ____

TRANSITION POLICY

☐ Practice policy on transition discussed/shared with youth and parent caregiver. Date/Int.: __

TRANSITION READINESS ASSESSMENT

☐ Conducted transition readiness assessment. Date/Int.:________Date/Int.: ___________

☐ Included transition goals and prioritized actions in plan of care. Date/Int.: __

Date/Int.:______Date/Int.: ________

MEDICAL SUMMARY AND EMERGENCY PLAN

☐ Updated and shared medical summary and emergency plan. Date/Int.: ________Date/Int.:_______

ADULT MODEL OF CARE

☐ Decision-making, privacy, and consent in adult care discussed with youth and parent/caregiver. If needed, discussed plans for supported decision-making. Date/Int.: ________

☐ Timing of transfer discussed with youth and parent/caregiver. Date/Int.: __

☐ Adult provider selected; Date/Int.:__________Provider Name & Contact Information:

☐ First appointment completed; Date/Int.: __

TRANSFER OF CARE

☐ Comprehensive transfer package, including the following, sent. Date/Int.: __

  - ☐ Transfer letter, including effective of date of transfer of care to adult provider
  - ☐ Final transition readiness assessment
  - ☐ Plan of care, including goals and actions
  - ☐ Updated medical summary and emergency care plan
  - ☐ Legal documents, if needed
  - ☐ Condition fact sheet, if needed
  - ☐ Additional provider records, if needed

☐ Communicated with adult provider about transfer. Date/Int.: _____________

☐ Elicited feedback from young adult after transfer from pediatric care. Date/Int.: ______

Patient Transfer Letter Sample

ADULT PROVIDER NAME
ADDRESS
CITY, STATE, ZIP

Dear Dr. (Adult Provider),
(Patient's Name) is a (age) year-old patient of our practice who will be transferring to your care on (date). The patient's primary chronic condition is (condition), and secondary conditions include (conditions). The following are included in the *Transfer Package*:

1. Medical summary and emergency care plan
2. Medications
3. Specialists
4. Transition readiness assessment.
5. Legal status: The patient acts/cannot act as his or her own guardian.

I am very familiar with this patient's health condition. I would be happy to provide any consultation assistance to you during the initial phases of transition to adult health care. Please do not hesitate to contact me by phone or email if you have further questions. Thank you very much for your willingness to assume care.

Sincerely,

PEDIATRIC PROVIDER NAME

Sample Transition Package

YOUNG ADULTS WITH NEUROLOGIC DISORDERS

Patient Name: Date of Birth:

Primary Diagnosis:

TRANSFER OF CARE

- ☐ Comprehensive transfer package, including the following, sent. Date: ______________
    - ☐ Transfer letter, including effective of date of transfer of care to adult provider
    - ☐ Final transition readiness assessment
    - ☐ Plan of care, including goals and actions.
    - ☐ Updated medical summary and emergency care plan.
    - ☐ Legal documents, if needed.
    - ☐ Condition fact sheet, if needed.
    - ☐ Additional provider records, if needed.
- ☐ Communicated with adult provider about transfer. Date: ______________
- ☐ Elicited feedback from young adult after transfer from pediatric care. Date: ______________

Additional Comments/Notes:

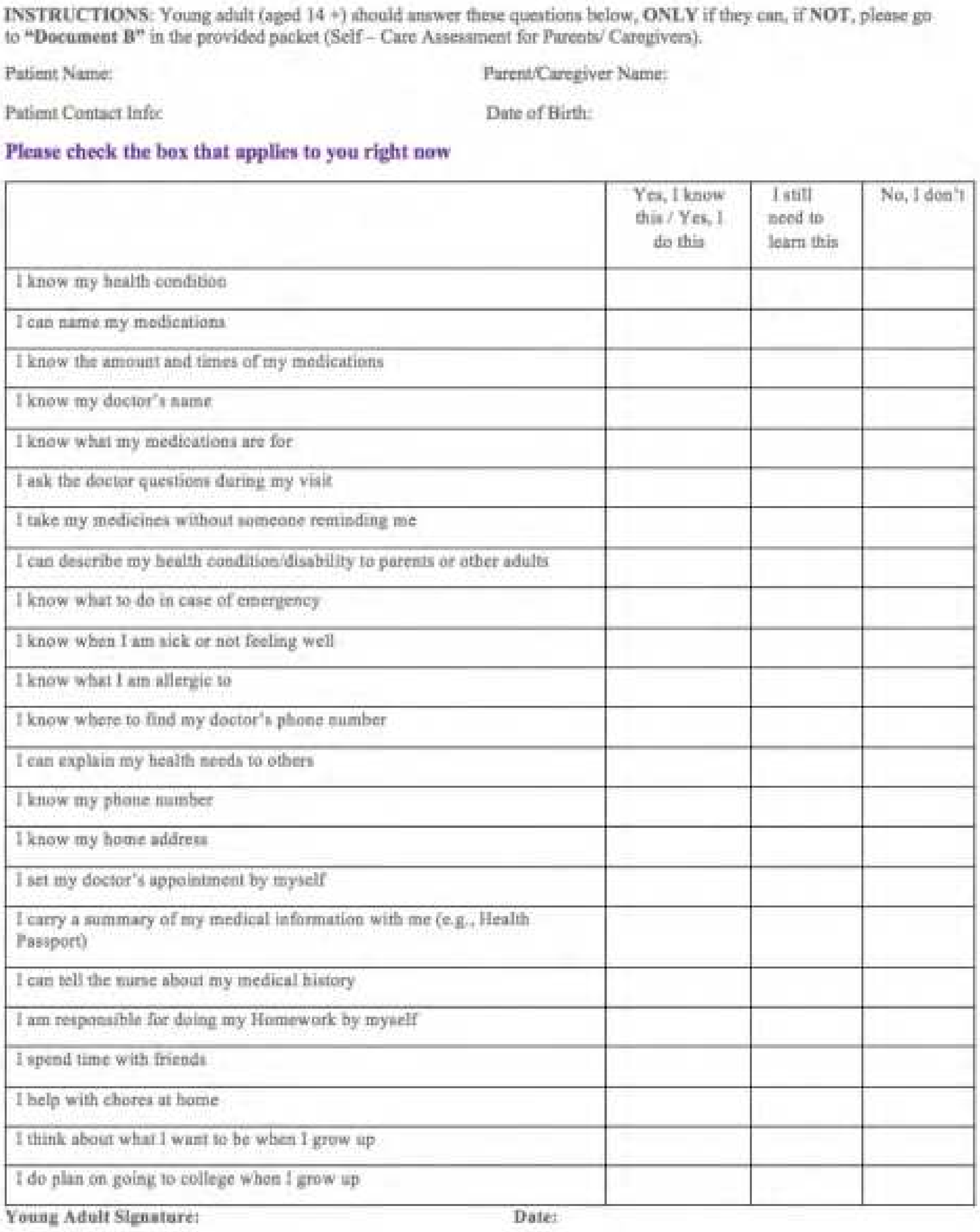
____

____

____

TOOL DEVELOPED BY THE CHILD NEUROLOGY FOUNDATION AS PART OF THE ACP HVC PEDIATRIC TO ADULT CARE TRANSITION PROJECT. AVAILABLE AT: WWW.CHILDNEUROLOGYFOUNDATION.ORG/TRANSITIONS © 2017 CNF (APRIL

Self - care assessment for youth aged (14 +) Document A



INSTRUCTIONS: Young adult (aged 14 +) should answer these questions below, **ONLY** if they can, if **NOT**, please go to **"Document B"** in the provided packet (Self – Care Assessment for Parents/ Caregivers).

Patient Name:

Parent/Caregiver Name:

Patient Contact Info:

Date of Birth:

Please check the box that applies to you right now

	Yes, I know this / Yes, I do this	I still need to learn this	No, I don't
I know my health condition			
I can name my medications			
I know the amount and times of my medications			
I know my doctor's name			
I know what my medications are for			
I ask the doctor questions during my visit			
I take my medicines without someone reminding me			
I can describe my health condition/disability to parents or other adults			
I know what to do in case of emergency			
I know when I am sick or not feeling well			
I know what I am allergic to			
I know where to find my doctor's phone number			
I can explain my health needs to others			
I know my phone number			
I know my home address			
I set my doctor's appointment by myself			
I carry a summary of my medical information with me (e.g., Health Passport)			
I can tell the nurse about my medical history			
I am responsible for doing my Homework by myself			
I spend time with friends			
I help with chores at home			
I think about what I want to be when I grow up			
I do plan on going to college when I grow up			

Young Adult Signature:

Date:

Self - care assessment (parents/caregivers) Document B

Instructions: The parent and/or caregiver of the youth/young adult with a neurologic condition should complete this document. If possible, the youth/young adult should also complete the "Self-Care Assessment (Youth/Young Adult)" form.

Intent: This document will help us see what your youth/young adult already knows about his/her health; and will help us find areas that you think they (or you) need to know more about. If you need help filling out the form, please let us know.

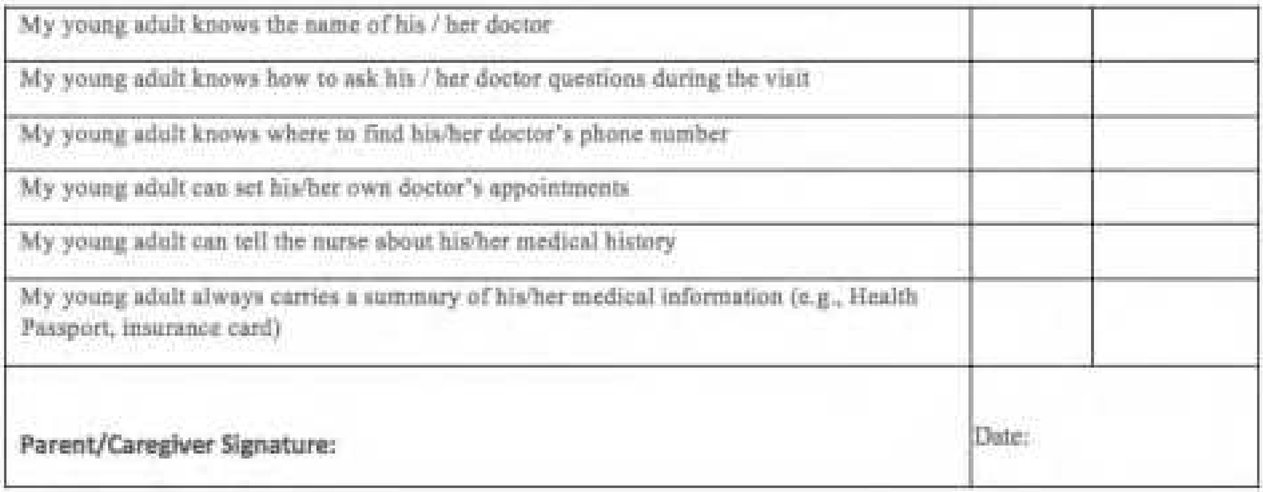
Date:

Patient Name:	Date of Birth:	Primary Diagnosis:
Caregiver Name:	Relationship to Patient:	Are you the main caregiver? (Yes/No)

From the table below, please check the box that applies to your young adult

☐ Check if none of the options below applies (e.g., totally dependent care)

	Yes/No	Will work on this skill Yes/No
My young adult knows my phone number		
My young adult knows his/her phone number		
My young adult knows my home address		
My young adult knows his / her health condition		
My young adult can describe his/her health condition/disability to parents or other adults		
My young adult can explain his/her health needs to others		
My young adult knows what he/she is allergic to		
My young adult knows when he/she is sick or not feeling well		
My young adult knows what to do in case of emergency		
My young adult knows the names of his / her medications		
My young adult knows the amount and times of his / her medications		
My young adult knows what his / her medications are for		
My young adult remembers his/her medicines times without me reminding him/her		



My young adult knows the name of his / her doctor		
My young adult knows how to ask his / her doctor questions during the visit		
My young adult knows where to find his/her doctor's phone number		
My young adult can set his/her own doctor's appointments		
My young adult can tell the nurse about his/her medical history		
My young adult always carries a summary of his/her medical information (e.g., Health Passport, insurance card)		
Parent/Caregiver Signature:	Date:	

Plan of Care

Young Adults with Neurologic Disorders

Instructions: This plan of care is a written document developed jointly with the transitioning youth to establish priorities and a course of action that integrates health and personal goals. Information from the transition readiness assessment can be used to guide the development of health goals. The plan of care should be updated regularly and sent to the new adult provider as part of the transfer package. Adapted from www.gottransition.org

Patient Name: ______________________ Date of Birth: ______________________

Primary Diagnosis: ______________________ Secondary Diagnosis: ______________________

What matters most to you, as you become an adult?

Prioritized Goals	Issues of Concern	Actions	Person Responsible	Target Date	Complete Date

Initial Date of Plan: ______________________ Last Updated on: ______________________

Initial Date of Plan: ______________________ Last Updated on: ______________________

Parent/Caregiver Signature: ____

Clinician Signature: ____

Care Staff Name and Contact Information: ____

Anti-Seizure Medication Side Effects

The information contained in this anti-seizure medication side effects guide is not-all inclusive nor intended to be a substitute for professional medical advice. A physician should be consulted about medication treatment options and any potential risks or side effects.

Brand Name	Medication	Side Effects
Aptiom	Eslicarbazepine acetate	Dizziness, drowsiness, nausea, headache, double vision, vomiting, fatigue, loss of concentration, rash
Ativan	Lorazepam	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
Banzel	Rufinamide	Fatigue, vomiting, nausea, headache, poor coordination, dizziness, double vision
Briviact	Brivaracetam	Dizziness, sleepiness, fatigue, mood changes
CBD	Cannabidiol	Somnolence, decreased appetite, diarrhea, transaminase elevations, malaise, rash, insomnia
Depakene, Stavzor	Valproic acid	Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor
Depakote, Depakote ER, Depakote sprinkles	Divalproex sodium	Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor
Diamox	Acetazolamide	Appetite loss, frequent urination, drowsiness, confusion, numbness of extremities, kidney stones
Dilantin, Phenytek	Phenytoin	Poor coordination, insomnia, fatigue, nausea, rash, gum overgrowth, hairiness, thickening of features
Epidiolex	Cannabidiol	Somnolence, decreased appetite, diarrhea, transaminase elevations, fatigue, malaise, asthenia
Felbatol	Felbamate	Anorexia, vomiting insomnia, nausea, headache, liver and blood toxicity
Fycompa	Perampanel	Dizziness, headache, fatigue, loss of coordination, irritability, aggressive behavior
Gabitril	Tiagabine	Nausea, dizziness, anxiety, insomnia, fatigue, tremor, difficulty with concentration
HP Acthar Gel	Repository corticotropin injection	Insomnia, weight gain, irritability, fluid retention, increased appetite
Keppra, Keppra XR	Levetiracetam	Behavior changes, irritability, fatigue, dizziness, headache
Klonopin	Clonazepam	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
Lamictal, Lamictal ODT, Lamictal XR	Lamotrigine	Dizziness, headache, blurred vision, clumsiness, fatigue, tremor, nausea, rash, life-threatening skin rash (rare)
Lyrica	Pregabalin	Sleepiness, dizziness, clumsiness, fatigue, tremor, fluid retention, weight gain
Mysoline	Primidone	Clumsiness, dizziness, appetite loss, fatigue, drowsiness, hyperirritability, insomnia, depression, hyperactivity
Neurontin, Gralise, Horizant	Gabapentin	Sleepiness, dizziness, clumsiness, fatigue, twitching, fluid retention, weight gain
Onfi	Clobazam	Fatigue, lethargy, insomnia, unsteadiness, behavioral changes, changes in appetite
Phenobarbital	Phenobarbital	Drowsiness, irritability, restlessness, difficulty concentrating, depression
Sabril	Vigabatrin	Visual issues, abnormal MRIs, fatigue, poor coordination, weight gain, behavioral changes
Sympazan	Clobazam	Constipation, drowsiness, sleepiness, fever, lethargy, drooling
Tegretol	Carbamazepine	Dizziness, drowsiness, blurred vision, nausea, skin rashes, abnormal blood counts (rare)
Topamax, Trokendi XR, Qudexy XR	Topiramate	Confusion, sleepiness, dizziness, clumsiness, difficulty thinking or talking, tingling sensation of the skin, nausea, decreased appetite, kidney stones
Trileptal, Oxtellar XR	Oxcarbazepine	Dizziness, drowsiness, nausea, headache, double vision, vomiting, fatigue, loss of coordination, rash
Tranxene	Clorazepate	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
Valtoco, Diastat Acudial, Valium	Diazepam	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
Vimpat	Lacosamide	Dizziness, headache, nausea, vomiting, double vision, unsteadiness, fatigue, tremor
Zarontin	Ethosuximide	Appetite loss, nausea, drowsiness, headache, dizziness, fatigue, rash, abnormal blood counts (rare)
Zonegran	Zonisamide	Sleepiness, dizziness, decreased appetite, headache, nausea, irritability, difficulty concentrating, unsteadiness, kidney stones, rash

Anti-seizure medications are associated with various side effects such as those listed in the table above and others. Many adverse effects, such as sleepiness and drowsiness, mental slowing, and “brain fog,” can be addressed early on with dosage adjustments. Patients are encouraged to pay attention to these and work alongside their treating neurologist early in treatment to address these and maintain medication compliance. Patients should be informed of other adverse effects, such as allergic rashes and hypersensitivity risk, at the initiation of treatment.

This publication is supported by the Health Resources and Services Administration (HRSA) of the U.S. Department of Health and Human Services (HHS) as part of a financial assistance award funded by HRSA and HHS under grant number H98MC33240, Transforming Access to Care for Children and Youth with Epilepsy cooperative agreement. The contents are those of the author(s) and do not necessarily represent the official views of, nor an endorsement by, HRSA and HHS, or the U.S. Government.

SUDEP: when Sudden and Unexpected Death occurs in a person with EPilepsy

SUDEP came to the forefront of the world's mind in 2019 when Disney star Cameron Boyce tragically passed away from SUDEP at the age of 20. While this was the first time many people heard about SUDEP, many others continue to face the risk of SUDEP every day. For people living with epilepsy, SUDEP is the leading cause of death.

SUDEP affects 1 in 1,000 people with epilepsy, and 1 in 150 people with uncontrolled seizures. SUDEP takes more lives in the United States than sudden infant death syndrome every year.

Efforts to educate the public and individuals with epilepsy continue. In 2013, the Danny Stanton SUDEP Act mandated that SUDEP be considered when examining deaths of individuals with epilepsy.

The best defense is to manage epilepsy well:

1. Avoid missing medications

- Take medications as prescribed
- On time, every time

2. Avoid missed sleep

- Lack of sleep is a common trigger for seizures
- The majority of SUDEP cases occur at night

3. Limit alcohol and illicit substances

- Alcohol increases the risk of seizures
- Illicit substances may have unknown effects

4. Find support for uncontrolled seizures

- Consider your options
- Speak to an epilepsy specialist about risk and precautions

Why does SUDEP occur?

Research suggests that SUDEP, while not fully understood, may occur in certain conditions. Most often, SUDEP occurs during or immediately after a seizure - but not always. SUDEP can happen many ways:

- Interruptions in breathing (e.g., apnea, airway obstruction)
- Interruptions in heart rhythm or by heart failure
- A combination of these or other causes

How can I help my loved one?

- Discuss SUDEP with your loved one's doctor
- Get trained in seizure first-aid
- Address uncontrolled seizures with your loved one's doctor
- Educate yourself, your loved one and others.

SUDEP action day is October 23 - But you can take action everyday

epilepsy
ALLIANCE
FLORIDA

Resources and additional reading:

Sudden Unexpected Death in Epilepsy (SUDEP)
SUDEP Information for Parents of Children with Epilepsy
Managing Epilepsy
Checklist
CDC Parent's Guide

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