



Health Services Newsletter

What is Epilepsy?

Epilepsy is the most common childhood brain disorder in the United States —nearly 450,000 American children have this condition. About two-thirds of all children with epilepsy outgrow their [seizures](#) by the time they are teenagers¹.

Epilepsy is a brain disorder where a person has recurring seizures. The seizures are triggered by changes in the electrical and chemical activity in the brain.

There are many different [types of seizures](#). Some are very short, lasting only a few seconds, while others can last a few minutes. The type of seizure a person has depends on where the seizure occurs in the brain and how much of the brain is involved. Seizures can look very different and might include: loss of consciousness, whole body shaking, confusion, brief periods of staring, sudden feeling of fear or panic, uncontrolled shaking of an arm or leg, nodding of the head, or flexing, stiffening, jerking or twitching of the upper body. Seizures often scare people who do not know about them, but usually they will not physically harm the child who has one.

Making a diagnosis involves identifying a condition or disease based on signs and symptoms. An epilepsy diagnosis is generally made when seizures occur more than once without an identifiable reason, such as fever or injury.

Any child without a known diagnosis who experiences an unprovoked seizure needs immediate emergency medical attention along with a follow-up primary care visit. If seizures reoccur, children should see a [pediatric neurologist](#), a specialist who manages seizures and epilepsy. Epilepsy can increase a child’s chance of having a mood or [learning disorder](#). Headaches, ulcers, and other physical conditions are also common. These children can be safely cared for in early childhood programs with proper training and collaboration among caregivers, family, and health care providers.



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¹<https://www.healthychildren.org/English/health-issues/conditions/head-neck-nervous-system/Pages/Epilepsy-in-Children-Diagnosis-Treatment.aspx>.

How is Epilepsy Treated?

Treatment for epilepsy usually begins with medication. However, other treatment options may include surgery, electrical devices, or special diets. It is important to remember that epilepsy is a complex condition and every child is different. Not every child responds to treatment in the same way, so there is no one “right treatment.”

Because young children are in a period of rapid growth, this may impact seizure activity and medication levels. For example, medication dosages may need to be increased as a child grows. The medication will not work properly until it reaches a certain level in the body, and that level has to be maintained. For this reason, it is especially important for families (and trained staff if administered during the program day) to follow the doctor’s specific medication instructions.



Identifying Seizures in Young Children

Seizures occur most frequently during the first few years of life, during a time when the brain is going through its most dramatic growth and changes. Recognizing and treating seizures as early as possible can help avoid learning and developmental delays. However, diagnosing seizures in infants can be difficult, as they cannot communicate what they are feeling after a seizure or during medical tests. Family and early care and education provider observations are especially valuable and necessary for doctors to effectively treat infants and toddlers with epilepsy. As ECE staff observe seizures, it is important to gather as much information as possible to share with the family and health care provider. The following forms can help to record observation information. Families may also use one of these forms as they begin to track their child’s seizures and triggers. There are forms that can be used, such as those from the Epilepsy Foundation on:

- [Tips for Seizure Observation & Recording](#)
- [Child Seizure Record Form](#)
- [Seizure Description Form](#)
- [Seizure Tracking Apps](#)
- [Seizure Activity Log](#)

What Programs Can Do to Support Young Children with Epilepsy

Children with epilepsy may be eligible for special education and related services under the Individuals with Disabilities Education Act (IDEA). Epilepsy could be classified as “other health impaired” and an Individualized Family Service Plan (IFSP), or an Individualized Education Program (IEP) (depending on the age of the child) would be developed to specify appropriate services.

SEIZURE ACTION PLAN

What's included in a Seizure Action Plan?

The seizure action plan should be signed by the child's health care provider, reviewed by the early care and education program with the family present and should include the following information:

- Detailed information about the child's epilepsy.
- What to do if a child has a seizure in the early care setting or the bus.
- A list of anti-seizure medications that the child currently is taking, including how and when the medications are given, as well as any side effects.
- Special instructions for the use of rescue medications, in the case of an emergency, should also be included. If a child has a vagus nerve stimulator (VNS), then instructions on how to use the VNS magnet should also be included.
- A clear definition of what constitutes an emergency for an individual child, and what the program should do if one occurs.

What else is important for early care settings to do if a child is using a Seizure Action Plan?

- Review and update the plan regularly. It is especially important to update when the medications change or dosages are increased or decreased. It is also important for staff working directly with children to know the symptoms or changes will come with the medication adjustment so that they can observe and share with parents.
- Ensure that the Seizure Action Plan information is available at all times (even field trips) and clearly considers all places a child might go within the course of the program, such as the playground, indoor play areas and vehicles.



To best individualize to the needs of a child with epilepsy, it is important that ECE staff are informed about the child's condition, possible triggers, side effects of medication or other treatments, and what to do in case a seizure occurs while in their care.

Program staff and the family should work together when a child starts a new medication or dosage to monitor any changes in behavior or physical appearance. If any changes are observed, written observations of both the family and early childhood staff may be helpful in discussions with the child's doctor.

In addition to medication management, early childhood staff and families should be aware of the behavioral and psychological impact of epilepsy on children including public misperceptions and fear of seizures, uncertainty about when seizures will occur, and loss of self-control during the seizure episode. Often, these unseen aspects of epilepsy can lead to difficulty with treatment compliance as well as mood disorders including anxiety and depression. Early childhood staff can help children in a variety of ways with the psychological impact of epilepsy such as providing epilepsy education programs for staff, including information on seizure recognition and first aid, collaborating with mental health consultants to promote an environment that is accepting of children with chronic medical conditions, and working with families to better understand how to communicate with their children

about their illness Staff can also work with families to refer children to a mental health provider such as a pediatric psychologist if they suspect symptoms of a mood disorder such as withdrawn or aggressive behavior.

Children benefit the most when both the family and early care and education program are working together. There are many materials available for families and ECE staff so that they can understand how to work most effectively as a team.

FOR FAMILIES

Guidelines for Keeping Children Safe at Home & in the Community

There are a few basic things families can do to make sure their child is safe.

- Teach family members and friends proper [seizure first aid](#), and encourage them to take a first aid course
- Inform family and friends when to call 911 for help when the child's seizure would be considered an emergency.
- Have your child wear a medical alert bracelet or necklace that states he or she has epilepsy.
- Ensure that medication is given using the rights of administration: the right medication at the right time in the right dose given the right way. This is very important to reduce chance of seizures.
- Make sure the child gets enough sleep. Not getting enough sleep can lead to more seizures.
- Consider a helmet for the child, if he or she has seizures that cause frequent falls.
- A [Seizure Action Plan](#) can be a useful tool to share with family and friends. It can help everyone know what to do if case of a seizure.
- It is important to clearly and frequently communicate with care givers about any changes in medication, signs of a seizure occurrence, normal patterns, and how the child responds after a seizure.

Simple Steps to “Safety Proof” Your Home

Here are a few simple things families can do to make their [home safer](#) for a child with epilepsy.

- Place padding on sharp corners, like those on tables and counters.
- Avoid glass tables.
- Have your child sleep on a low-lying bed.
- Use non-slip rugs.
- Avoid throw rugs.

If a child wanders during a seizure, try the following:

- Shut and lock doors that lead outside. Consider putting alarms on doors to alert the household that a door has been opened.
- Put a locking “safety gate” at the top of stairs.



Additional Resources

Epilepsy Fact Sheet (ECLKC)

https://eclkc.ohs.acf.hhs.gov/hslc/tta-system/teaching/Disabilities/Services%20to%20Children%20with%20Disabilities/Disabilities/disabl_fts_00013_061105.html

Epilepsy Foundation Seizure Action Plan

http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/seizure-action-plan-pdf_0.pdf

Epilepsy Foundation

<http://www.epilepsy.com/>

Epilepsy Foundation Seizure Training for Child Care Personnel

<http://www.cdc.gov/epilepsy/professionals.htm>

California Childcare Health Program Seizure Care Plan

<http://cchp.ucsf.edu/sites/cchp.ucsf.edu/files/SeizureCarePlan.pdf>

Healthy Childcare America Medication

Administration Course

<http://www.healthychildcare.org/PDF/MedAdminAccessFlyer.pdf>

Medication Administration layer of the VEEC

<https://eclkc.ohs.acf.hhs.gov/hslc/tta-system/health/health-services-management/program-planning/veec.html>

Medication Administration Webinar

<https://eclkc.ohs.acf.hhs.gov/hslc/tta-system/health/safety-injury-prevention/medication-administration/health-issues-in-head-start-medication-administration.html>

Medication Administration resources

<https://eclkc.ohs.acf.hhs.gov/hslc/tta-system/health/docs/handout-medication-administration-resources.pdf>

Mental Health and Behavior Among Children with Epilepsy

https://www2.massgeneral.org/childhoodepilepsy/child/mental_health.htm



NATIONAL CENTER ON

Early Childhood Health and Wellness

CONTACT US

The National Center on Early Childhood Health and Wellness welcomes your feedback on this newsletter issue, as well as your suggestions for topics for future issues. Please forward your comments to health@ecetta.info or call 866-227-5125.

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School readiness begins with health!