

Epilepsy

NICHCY Disability Fact Sheet #6
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Jeremy's Story

When Jeremy was 4 months old, he had his first seizure. His mother Caroline knew at once that something was wrong, because she'd never seen him so stiff and pale, with his eyes rolling back.

The seizure passed quickly, although, to Caroline, it seemed to last forever. Then Jeremy took a deep breath, opened his eyes, and looked at her. Soon afterward, the baby fell into a deep sleep.

That was 15 years ago. Jeremy's a teenager now, and you wouldn't guess from his alert eyes, quick smile, or quirky sense of humor that his brain is subject sometimes to brief, strong surges of electrical activity that dramatically affect his cognition and physical functioning. It's taken a lot of doctor visits, different medications, and one brain surgery to get his epilepsy under control. He still has seizures, but they don't happen very often now, much to everyone's relief, especially his mom and dad.

This year, for the first time, Jeremy and Caroline took part in the National Walk for Epilepsy, where they joined



with thousands of others to raise funds for research, education, advocacy, and services for people with epilepsy and their caregivers.

The best part of the day for Jeremy and Caroline was meeting so many other people who live with epilepsy every day, just like they do themselves.

Definition

Epilepsy is a *seizure disorder*. According to the Epilepsy Foundation of America, a seizure happens when a brief, strong surge of electrical activity affects part or all of the brain.¹



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Seizures can last from a few seconds to a few minutes. They can have different symptoms, too, from convulsions and loss of consciousness, to signs such as blank staring, lip smacking, or jerking movements of arms and legs.²

Some people can have a seizure and yet not have epilepsy. For example, many young children have convulsions from fevers. Other types of seizures not classified as epilepsy include those caused by an imbalance of body fluids or chemicals or by alcohol or drug withdrawal. Thus, a single seizure does not mean that the person has epilepsy. Generally speaking, the diagnosis of epilepsy is made when a person has two or more unprovoked seizures.³

Incidence

About three million Americans have epilepsy. Of the 200,000 new cases diagnosed each year, nearly 45,000 are children and adolescents.⁴

Epilepsy affects people in all nations and of all races. Its incidence is greater in African American and socially disadvantaged populations.⁵

Characteristics

Although the symptoms listed below do not necessarily mean that a person has epilepsy, it is wise to consult a doctor if you or a member of your family experiences one or more of them:

- “Blackouts” or periods of confused memory;
- Episodes of staring or unexplained periods of unresponsiveness;
- Involuntary movement of arms and legs;
- “Fainting spells” with incontinence or followed by excessive fatigue; or
- Odd sounds, distorted perceptions, or episodic feelings of fear that cannot be explained.

Doctors have described more than 30 different types of seizures.⁶ These are divided into two major categories—generalized seizures and partial seizures (also known as focal seizures).

Generalized Seizures

This type of seizure involves both sides of the brain from the beginning of the seizure. The best known subtype of generalized seizures is the **grand mal seizure**. In a grand mal seizure, the person’s arms and legs stiffen (the tonic phase), and then begin to jerk (the clonic phase). That’s why the grand mal seizure is also known as a generalized tonic clonic seizure.

Grand mal seizures typically last 1-2 minutes and are followed by a period of confusion



and then deep sleep. The person will not remember what happened during the seizure.

You may also have heard of the **petit mal seizure**, which is an older term for another type of generalized seizure. It’s now called an **absence seizure**, because during the seizure, the person stares blankly off into space and doesn’t seem to be aware of his or her surroundings. The person may also blink rapidly and seem to chew. Absence seizures typically last from 2-15 seconds and may not be noticed by others. Afterwards, the person will resume whatever he or she was doing at the time of the seizure, without any memory of the event.

Partial Seizures

Partial seizures are so named because they involve only one hemisphere of the brain. They may be **simple partial seizures** (in which the person jerks and may have odd sensations and perceptions, but doesn’t lose consciousness) or **complex partial seizures** (in which consciousness is impaired or lost). Complex partial seizures often involve periods of “automatic behavior” and altered consciousness. This is typified by purposeful-looking behavior, such as buttoning or unbutton-

ing a shirt. Such behavior, however, is unconscious, may be repetitive, and is usually not remembered afterwards.

Diagnosis

Diagnosing epilepsy is a multi-step process. According to the Epilepsy Foundation of America:

...the doctor’s main tool...is a careful medical history with as much information as possible about what the seizures looked like and what happened just before they began. The doctor will also perform a thorough physical examination, especially of the nervous system, as well as analysis of blood and other bodily fluids.⁷

The doctor may also order an electroencephalograph (EEG) of the patient’s brain activity, which may show patterns that help the doctor decide whether or not someone has epilepsy. Other tests may also be used—such as the CT (computerized tomography) or MRI (magnetic resonance imaging)—in order to look for any growths, scars, or other physical conditions in the brain that may be causing the seizures. Which tests and how many of them are ordered may vary, depending on how much each test reveals.⁸

Treatment

Anti-epileptic medication is the most common treatment for epilepsy. It’s effective in stopping seizures in 70% of patients.⁹

Interestingly, it's not uncommon for doctors to wait a while before prescribing an anti-seizure medication, especially if the patient is a young child. Unless the EEG of the patient's brain is clearly abnormal, doctors may suggest waiting until a second or even third seizure occurs. Why? Because studies show that an otherwise normal child who has had a single seizure has a relatively low (15%) risk of a second one.¹⁰

When anti-epileptic medications are not effective in stopping a person's seizures, other treatment options may be discussed. These include:

- surgery to remove the areas of the brain that are producing the seizures;
- stimulation of the vagus nerve (a large nerve in the neck), where short bursts of electrical energy are directed into the brain via the vagus nerve; and
- a ketogenic diet (one that is very high in fats and low in carbohydrates), which makes the body burn fat for energy instead of glucose.

According to the Epilepsy Foundation of America, 10% of new patients cannot bring their seizures disorder under control despite optimal medical management.¹¹

Educational and Developmental Considerations

It's not unusual for seizures to interfere with a child's development and learning. For example, if a student has the type of seizure characterized by periods of fixed staring, he or she is likely to miss parts of what the teacher is saying. If teachers—or other caregivers such as babysitters, daycare providers, preschool teachers, K-12 personnel—observe such an episode, it's important that they document and report it promptly to parents (and the school nurse, if appropriate).

Because epilepsy can affect a child's learning and development (even babies), families will want to learn more about the systems of help that are available. Much of that help comes from the nation's special education law, the Individuals with Disabilities Education Act (IDEA), which makes available these two sets of services:

- **Early intervention** | A system of services to help infants and toddlers with disabilities (before their 3rd birthday) and their families.
- **Special education and related services** | Services available through the public school system for school-aged children, including preschoolers (ages 3-21).

In both of these systems, eligible children receive special services designed to address the developmental, functional, and educational needs resulting from their disability.

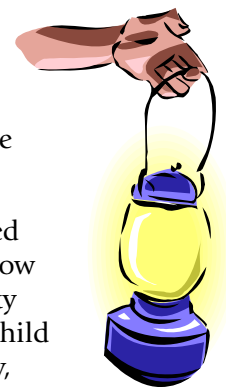
To access *early intervention services* for a child up to his or her 3rd birthday, consult NICHCY's *State Resource Sheet* for your state (available online at: <http://www.nichcy.org/families-community/states/>). You'll find the listing for early intervention under the first section, State Agencies. The agency listed there will be able to put you in contact with the early intervention program in your community.

To access *special education services* for a school-aged child, get in touch with your local public school system. Calling the elementary school in your neighborhood is an excellent place to start.

More about Services under IDEA

The process of finding a child eligible for early intervention or special education and related services under IDEA begins with a comprehensive and individual evaluation of the child in order to:

- establish that the child does, indeed, have a disability;
- get a detailed picture of how the disability affects the child functionally, developmentally, and academically; and
- document the child's special needs related to the disability.



This evaluation is provided **free of charge** through either the early intervention system (for infants and toddlers under the age of 3) or through the local school system (for children ages 3-21). Under IDEA, children with epilepsy are usually found eligible for services under the category of "Other Health Impairment" (OHI). We've included IDEA's definition of OHI in the box below.

When a baby or toddler is found eligible for early intervention, parents meet with the early intervention staff, and together they develop what is known as an **Individualized Family Service Plan**, or **IFSP**. The IFSP will describe the child's unique needs as well as the services the child will receive to address those needs. The IFSP will also emphasize



the unique needs of the family, so that parents and other family members will know how to help their young child with epilepsy. Early intervention services may be provided on a sliding-fee basis, meaning that the costs to the family will depend upon their income.

When a child is found eligible for special education and related services, school staff and parents meet and develop what is known as an **Individualized Education Program**, or **IEP**. This document is very important in the educational

life of a child with epilepsy, because it details the nature of the child's needs and the services that the public school system will provide free of charge to address those needs.

Succeeding at School

Special education and related services can be very helpful to children with epilepsy attending public school. Because the disorder affects memory and concentration, accommodations in the classroom and during testing are key to students' academic success. Some common accommodations and services provided to students with epilepsy are listed in the box on the next page.

Related services may be every bit as important for children with epilepsy, especially *school health services* and *school nurse services*—which can provide the child's medication during school hours or give first aid instruction on seizure management to the student's teachers, for example.

Depending on the child's unique needs, other related services may also be necessary so that the student benefits from his or her special education program—for example, counseling services. Children and youth with epilepsy must deal with the psychological and social aspects of the condition. These include public misperceptions and fear of seizures, loss of self-control during the seizure episode, and compliance with medications. Counseling services may help students with epilepsy address the complexities of living with this disorder. The school can

IDEA's Definition of "Other Health Impairment"

The nation's special education law specifically mentions *epilepsy* in its definition of "Other Health Impairment," a category under which children may be found eligible for special education and related services. Here's IDEA's definition.

(9) *Other health impairment* means having limited strength, vitality, or alertness, including a heightened alertness to environmental stimuli, that results in limited alertness with respect to the educational environment, that—

(i) Is due to chronic or acute health problems such as asthma, attention deficit disorder or attention deficit hyperactivity disorder, diabetes, **epilepsy**, a heart condition, hemophilia, lead poisoning, leukemia, nephritis, rheumatic fever, sickle cell anemia, and Tourette syndrome; and

(ii) Adversely affects a child's educational performance.

34 CFR §300.8(c)(9)



also help by providing epilepsy education programs for staff and students, including information on how to recognize a seizure and what to do if a seizure occurs.

It is important that the teachers and school staff are informed about the child's condition, possible effects of medication, and what to do in case a seizure occurs at school. Most parents find that a friendly conversation with the teacher(s) at the beginning of the school year is the best way to handle the situation. Even if a child has seizures that are largely controlled by medication, it is still best to notify the school staff about the condition.

School personnel and the family should work together to monitor the effectiveness of medication as well as any side effects. If a child's physical or intellectual skills seem to change, it is important to tell the doctor. There may also be hearing or perception problems caused by changes in the brain. Written observations of both the family and school staff will be helpful in discussions with the child's doctor.

Accommodations in the Classroom

The accommodations that a child with epilepsy receives are determined by his or her IEP team (which includes the parents). Here are some possibilities to consider.¹²

To address memory deficits

- Provide written or pictorial instructions
- Use voice recordings of verbal instructions
- Have a peer buddy take notes for the student or permit tape recording
- Divide large tasks into smaller steps
- Provide a checklist of assignments and a calendar with due dates
- Decrease memory demands during classwork and testing (e.g., use recognition rather than recall tasks)

To address health concerns

- Be flexible about time missed from school to seek treatment or adjust to new medications
- Provide extra time for assignments and a modified workload (fatigue is a common side effect of seizures and medications)
- Replace fluorescent lighting with full spectrum lighting
- Provide private area to rest or recover from a seizure

References

- ¹ Epilepsy Foundation of America. (n.d.). *What is epilepsy?* Available online at: <http://www.epilepsyfoundation.org/about/>
- ² *Ibid.*
- ³ National Institute of Neurological Disorders and Stroke. (2010, May). *NINDS epilepsy information page.* Available online at: <http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm>
- ⁴ Epilepsy Foundation of America. (n.d.). *Epilepsy and seizure statistics.* Available online at: www.epilepsyfoundation.org/about/statistics.cfm
- ⁵ *Ibid.*
- ⁶ National Institute of Neurological Disorders and Stroke. (2010, May). *Seizures and epilepsy: Hope through research.* Available online at: http://www.ninds.nih.gov/disorders/epilepsy/detail_epilepsy.htm
- ⁷ Epilepsy Foundation of America. (n.d.). *Epilepsy and seizure statistics.* Available online at: <http://www.epilepsyfoundation.org/about/diagnosis/>

⁸ *Ibid.*

⁹ Epilepsy Foundation of America. (n.d.). *Epilepsy and seizure statistics*. Available online at: www.epilepsyfoundation.org/about/statistics.cfm

¹⁰ Epilepsy Foundation of America. (n.d.). *The decision to treat*. Available online at: <http://www.epilepsyfoundation.org/about/treatment/>

¹¹ Epilepsy Foundation of America. (n.d.). *Epilepsy and seizure statistics*. Available online at: www.epilepsyfoundation.org/about/statistics.cfm

¹² Kitchen, S.G. (2010). *Accommodation and compliance series: Employees with epilepsy*. Available online at the Job Accommodations Network website: <http://askjan.org/media/epilepsy.html>

Resources of More Information

Epilepsy Foundation of America | Your premier source of information and guidance on epilepsy, including state and local chapters and support groups.

- English | www.epilepsyfoundation.org/
1.800.332.1000
- Spanish | www.fundacionparalaepilepsia.org/
1.866.748.8008

epilepsy.com | A website of the Epilepsy Therapy Project, a leading source of support for translational research and new therapy projects. A wealth of information is available for families and professionals, at: <http://www.epilepsy.com/>

National Institute of Neurological Disorders and Stroke (NINDS) | Find detailed medical information on epilepsy, including research, clinical trials being conducted at NIH, helpful organizations, and a long list of related publications.
1.800.352.9424 | <http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm>

Talk About It! | A website dedicated to ending the stigma associated with epilepsy through “talking about it.” Lots of info here!
<http://www.talkaboutit.org/flash.shtml>

The Epilepsy Health Center | The Epilepsy Health Center at webmd.com has detailed, medically based information to offer on the subject.
<http://www.webmd.com/epilepsy/default.htm>

For Families

Epilepsy Foundation eCommunities | Over 10,000 members. | <http://epilepsyfoundation.ning.com/>

Parent to Parent | Talk with other parents affected by epilepsy through the Parent to Parent Program in your state. | <http://www.p2pusa.org/>

Parent Training and Information Center | Have questions about early intervention or special education? Want to know local and state resources? Find your state’s PTI for a wealth of information just for parents. | <http://taalliance.org/ptidirectory/pclist.asp>

On Education

Teaching Students with Epilepsy: Strategies for Educators | http://www2.massgeneral.org/childhoodepilepsy/pdf/strategies_for_educators.pdf

How to Work with a Child with A Seizure Disorder in the Classroom | http://www.ehow.com/how_2208632_work-child-seizure-disorder-classroom.html

Education of Kids with Epilepsy | http://www.epilepsy.com/info/family_kids_education



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