



H.O.P.E.

MENTORING PROGRAM™

Helping Other People with Epilepsy



Seizures
in Childhood



EPILEPSY
FOUNDATION®

Not another moment lost to seizures™

About the Epilepsy Foundation

The Foundation's mission is to ensure that people with epilepsy have access to all life experiences and to prevent, control and cure epilepsy through research, education, advocacy and services.

The Foundation offers information and assistance to people with epilepsy and their families through its Epilepsy Resource Center.

The Epilepsy Foundation's H.O.P.E. (Helping Other People with Epilepsy) Mentoring Program offers mentoring and educational presentations on epilepsy to individuals, families and in community living settings.

To find out more about the H.O.P.E. Mentoring Program or the name of a participating Epilepsy Foundation near you, call 877-467-3496, or visit www.epilepsyfoundation.org

About our cover:

Ivy has generalized seizures. Last summer she attended a week long overnight summer camp for children with epilepsy. Her mom gave a presentation about the disorder to her class at the beginning of the school year. Ivy enjoys writing poetry, reading poetry, horses and playing beginners violin. She is happy to say that she has not had a seizure in a long time!

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This pamphlet is designed to provide general information about epilepsy to the public. It is not medical advice. Parents of children with epilepsy should not make any changes in treatment or activities based on this information without first consulting a physician.

The children featured in the pamphlet and their experiences with epilepsy are actual case histories and appear with permission of their families.



Zachary has benign rolandic epilepsy and is now seizure free. He is very open with his classmates and tells them a lot about epilepsy and what happens when he has a seizure. Zach's hobbies include taking piano lessons, swim classes, and participating in Cub Scouts!

Seizures in Childhood

More than 300,000 American children have recurrent seizures, otherwise known as epilepsy.

While epilepsy can begin at any time of life, the disorder is one of the most common neurological conditions affecting children, possibly because immature brains are more prone to seizures.

In many cases, seizures and epilepsy can be successfully treated, but children often face special challenges in living with and adjusting to the condition.

This pamphlet will explore some of these issues and, we hope offer information that will be helpful to children living with seizures and to those who care for them.

About Epilepsy

Epilepsy is a disorder of the brain, a sudden change in the brain's electrical system which controls everything a child feels and does.

These brief malfunctions (called seizures) may temporarily block a child's awareness of time and place.

Or they may affect the senses, cause confusion or uncontrollable shaking.

Sometimes a first seizure is a symptom of an unrelated health problem that may need immediate attention. After a first seizure of any type, parents should let the doctor know so that a full examination of the child can take place.

Anyone at any age can have a seizure in certain circumstances, such as in meningitis, alcohol withdrawal, and other acute situations that anyone can experience.

A single seizure isn't epilepsy.

Epilepsy is the name given to seizures that happen more than once because of an underlying condition in the brain. Some

people used to describe the condition as a "seizure disorder" but that term is no longer favored.

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Types of Seizures

The kind of seizure a child has depends on where in the brain the electrical disturbance takes place and how much of the brain is affected.

In partial seizures, the electrical disturbance is limited to a particular area of one side of the brain. They are the most common type of seizure. Generalized seizures happen when the child's whole brain is affected at once.

A child may have just one type of seizure, or more than one type.

Simple partial seizures typically affect speech, movement or sensations. Children may see, hear, feel things that are not really there. They may shake, or tremble or feel sudden anger or fear.

Complex partial seizures occur in areas of the brain involving consciousness or memory.

Common Symptoms

SIMPLE PARTIAL SEIZURES

- Changes in vision and hearing
- Odd feelings
- Staring
- Jamais vu (familiar things suddenly seem unfamiliar)
- Trembling that moves up one side of the body

COMPLEX PARTIAL SEIZURES

- Lip smacking
- Swallowing
- Picking at clothes
- Wandering
- Senseless, clumsy movements
- Lost time
- Lack of awareness or response to others
- Repeating phrases
- Taking off clothes
- Unaware of danger or pain

GENERALIZED SEIZURES

- Convulsions
- Sudden falls
- Brief blackouts, staring
- Sudden muscle jerks
- Spasms in infants



Noah developed epilepsy when he was 11 months old. He has some developmental delays and receives speech therapy. He is currently on three medications to control his seizures. Yet, he still has 10-20 seizures per month, usually lasting between 30 and 90 seconds. Noah loves to paint and has had his artwork published. He also loves to ice skate and roller blade and takes swimming lessons weekly.

Children having complex partial seizures can't interact normally with things or people around them during the seizure. They appear unaware of their surroundings and may injure themselves as a result. They usually will not remember what happened during the episode.

Generalized seizures cause a sudden loss of consciousness, although it can be very brief.

A generalized tonic-clonic (grand mal) seizure typically starts with a cry, caused by air being forced out of the lungs. The child slumps in place or falls to the ground, unconscious. The body stiffens briefly and then begins to jerk as muscles contract and relax.

The child may bite his tongue. A frothy saliva may appear around the mouth. Breathing may be very shallow and even stop for a few moments. Sometimes the skin turns a bluish color because the child's blood is not getting as much oxygen as usual.

After a minute or two, the jerking movements slow down, normal breathing returns and the seizure ends.

Bladder or bowel control may be lost as the body relaxes after the seizure. Consciousness will then slowly return.

Seizure First Aid

Fortunately, basic seizure first aid involves just a few common-sense steps that protect the child from harm until full awareness returns. What you *shouldn't* do is just as important as what you *should* do.

FIRST AID FOR CONVULSIONS (grand mal, generalized tonic-clonic seizures)

- Ease the child having the seizure into a reclining position on the floor or flat surface.
- Put something soft and flat under the head.
- Turn him or her gently on one side to prevent choking and keep the airway clear.
- Check the time the seizure starts and ends.

What not to do:

- Don't try to force anything into the child's mouth. Seizures do not cause children to swallow their tongues.
- Don't try to give the child anything to drink until the seizure is completely over and the child is fully alert again.
- Don't try to restrain the jerking movements; they will slow down on their own

FIRST AID FOR SEIZURE-RELATED CONFUSION

Confusion and inability to interact with others may be part of the seizure itself (particularly partial seizures), or it may happen during the recovery period. In either case, the same basic rules apply:

- Remove anything from the area that might injure a child who is temporarily unaware of where she is or what she is doing.
- Don't try to restrain a child who is wandering and confused during a seizure. If danger threatens, block access or gently guide the child away.
- Be reassuring, comforting and calm as awareness returns.

CALL FOR 911?

Unless your doctor has advised otherwise there's probably no need to call 911 for every seizure, so long as your child recovers after a couple of minutes and is breathing normally.

However, a call for help is advisable in the following situations:

- A convulsion lasts longer than 5 minutes, or the child experiences a cluster of seizures.
- A non-stop seizure, called status epilepticus, is dangerous and prompt medical care is needed to bring it to an end. (If your child often has prolonged seizures, or seizures that happen in a cluster, ask your doctor about treatment you can give at home during the seizure).
- The child is injured or there is any unusual pain after a seizure. Headaches are quite common, but a severe headache after a seizure in a child who normally doesn't have one should be checked out.
- Awareness does not return until a few minutes after the seizure ends. While children are often confused following a seizure, confusion lasting more than one hour after a seizure may signal that the seizure is not over.



Shanique has faced every obstacle including brain surgery, with courage and grace, despite generalized seizures that have been hard to control. Children at school have made fun of her seizures, but Shanique decided she would try to change their attitudes. She enjoys reading, playing the flute and swimming.

Always check with your child's health care team on the best way to respond when your child has a seizure.

Epilepsy— Why Did It Happen?

In more than half of cases of childhood epilepsy, the cause is not known. Possible causes include:

- Problems with brain development before birth.
- Lack of oxygen during or following birth.
- A severe head injury that leaves a scar on the brain.
- Unusual structures in the brain.
- The after-effects of severe brain infections such as meningitis or encephalitis.
- Certain genetic disorders.

TREATING CHILDHOOD SEIZURES

Doctors usually treat childhood epilepsy with seizure-preventing medicines called antiepileptic or anticonvulsant drugs.

If the drugs don't work, or the child has a lot of side effects, surgery, the ketogenic diet or vagus nerve stimulation (VNS) may be tried.

MEDICATION

Children take their medication in the form of tablets, sprinkles, capsules or in syrup. The drugs are designed to prevent seizures. Whenever possible, doctors try to control seizures with one drug. Some children, however, may need to take more than one if their seizures are hard to control.

THE RIGHT DRUG FOR EACH CHILD

The search for the best medicine for each child may take a long time. Children respond to medication in different ways.

COMMON SIDE EFFECTS OF MEDICATION:

- Fatigue
- Nausea
- Changes in vision
- Weight gain or loss

A child may have to try several drugs and sometimes combinations of drugs to achieve the goal: best seizure control, lowest level of side effects at the lowest possible dose.

In some cases, side effects go away after the child becomes accustomed to the

new medication. Occasionally, serious reactions occur. Parents should check with the doctor if there are any unexpected changes in a child's health when taking antiepileptic drugs.

Surgery for seizures. If medicines don't control a child's seizures, he or she may be a candidate for surgery. The most common form of epilepsy surgery is to remove a small part of the brain where seizures begin. Other kinds of operations may also be done.



Emily Grace was three years old when she began having 200-250 absence (staring spell) seizures a day, as well as other types of seizures. A year later, she started the ketogenic diet and her seizures have been controlled ever since. Now seven, Emily Grace is an outgoing happy child who likes bike riding, choir, working in the garden, and pottery class.

If your child is being considered for brain surgery for epilepsy, you will want it to be done in a special center by a medical team who perform a lot of these operations. All the risks and potential benefits should be discussed with you in advance.

Vagus nerve stimulation (VNS) is a type of treatment that sends small, regular bursts of electrical energy into the brain via wires linked to a large nerve in the neck. The energy is generated by a small battery, about the size of a thin stopwatch, surgically placed under the skin in the chest wall.

Children treated with VNS generally stay on medication, but may be able to reduce how much they take. Although complete relief from seizures is unusual, some improvement with VNS is likely, especially over a period of time.

The ketogenic diet keeps calories low and makes fat products the primary food that the child is getting. Burning fat for energy reduces or controls seizures in two out of three children who go on the diet.

Each diet meal that a child eats has about four times as much fat as protein or carbohydrate. The amounts of food and liquid for each meal have to be carefully worked out and weighed.

The ketogenic diet is not a “do-it-yourself” diet. Trying to put a child on the diet without medical guidance puts a child at risk of serious problems. An experienced treatment team, usually based at a specialized medical center, is needed to manage each step of the diet.

Living With Seizures

Studies show that having epilepsy is often hard on children’s self esteem. Parents say that encouraging a special skill, activity or hobby helps children maintain a positive view of themselves.

Having seizures at school can be embarrassing for the child and frightening to others. But it doesn’t have to be. A well-informed school and involved parents can make all the difference.

Some children may think that seizures are contagious. The Epilepsy Foundation has educational materials for school staffs to use in removing such fears and helping to create a more accepting, positive environment for school children with seizures.



Cody developed epilepsy at age three as a result of a brain tumor. Since then, he’s had two surgeries to remove the tumor. Afterwards, he had to re-learn how to walk and talk. Side effects from epilepsy medicines have been tough on Cody. Now he hopes his VNS implant will help control his seizures. Cody works hard to overcome his problems and loves music, animals, challenger baseball and his weekly swimming lessons.



Kevin has been seizure free on medication for three years and his mother hopes the doctor will say his medicine can be slowly tapered down to the point that he will be off medicines and free of seizures. Kevin is a cheerful, confident child who likes Harry Potter books, baseball and school.

Parents who meet with the school staff early in the year to answer their questions and reassure everyone involved may also create a more welcoming school setting for their children.

MANAGING RISKS

Parents worry about risks of injury when a child has a seizure. Those risks increase when a child’s seizure happens near water, at heights, near traffic or in any setting in which sudden loss of awareness could be dangerous.

However, excessive concern about risk may isolate children with epilepsy from others and reduce social interaction. It’s easy for parents to become overprotective. The following information may help you strike a balance.

WATER SAFETY

- Supervise young children closely during tub baths or whenever they are near water. Never leave them alone.
- Have older children take showers, not tub baths.

- Set water temperature low so a child won't be scalded if he blacks out while hot water is running.
- Make sure shower and bath drains are running.
- Make sure an older child swims with a buddy who knows about epilepsy and what to do if he or she has a seizure.
- Tell lifeguards at local pools or beaches that a child has seizures.

SPORTS SAFETY

In general, school sports activities and gym should be open to all children, including children with seizures. Safety measures such as harnesses, shock absorbing mats and adult supervision should reduce risks.

Coaches and other officials should be aware that the child has seizures, and how the parent wants them to be managed.

Wearing safety helmets when riding a bicycle, or for sports where head injury is possible, should also reduce risk.

EDUCATIONAL ACHIEVEMENT

While some children with seizures do very well at school, as a group they tend to achieve at lower levels than other children, even when seizures are controlled and IQ is within normal range.

Possible reasons for this include: the effects of seizures or medicines on memory and concentration (all skills that affect learning) and time missed from school because of seizures or visits to the doctor. Sometimes the same conditions in the brain that are causing seizures may also interfere with learning.



At age four, Brittany developed generalized and partial seizures. After trying a few medications to control her seizures, she is now seizure free. Brittany is comfortable telling other children and adults about epilepsy. In fact, when the Epilepsy Foundation came to her school to present a puppet show about epilepsy, Brittany conducted a forum to answer questions from her classmates and teachers.

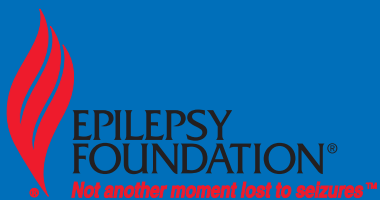
If a child with seizures is falling behind at school, special help may be needed to enable her to achieve her full potential. Testing, including neuropsychological tests, may also help identify the cause of the problem.

Epilepsy Today

Epilepsy is common in children and seizures may go into remission as a child grows. For other children, seizures continue despite treatment, or may be successfully controlled to the point where they occur very infrequently. Research has yielded new treatments and given children new hope for a normal life.

The Epilepsy Foundation is committed to continuation of research towards the nationwide prevention and cure of epilepsy and to provide services that help children and families deal with epilepsy's many challenges.

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