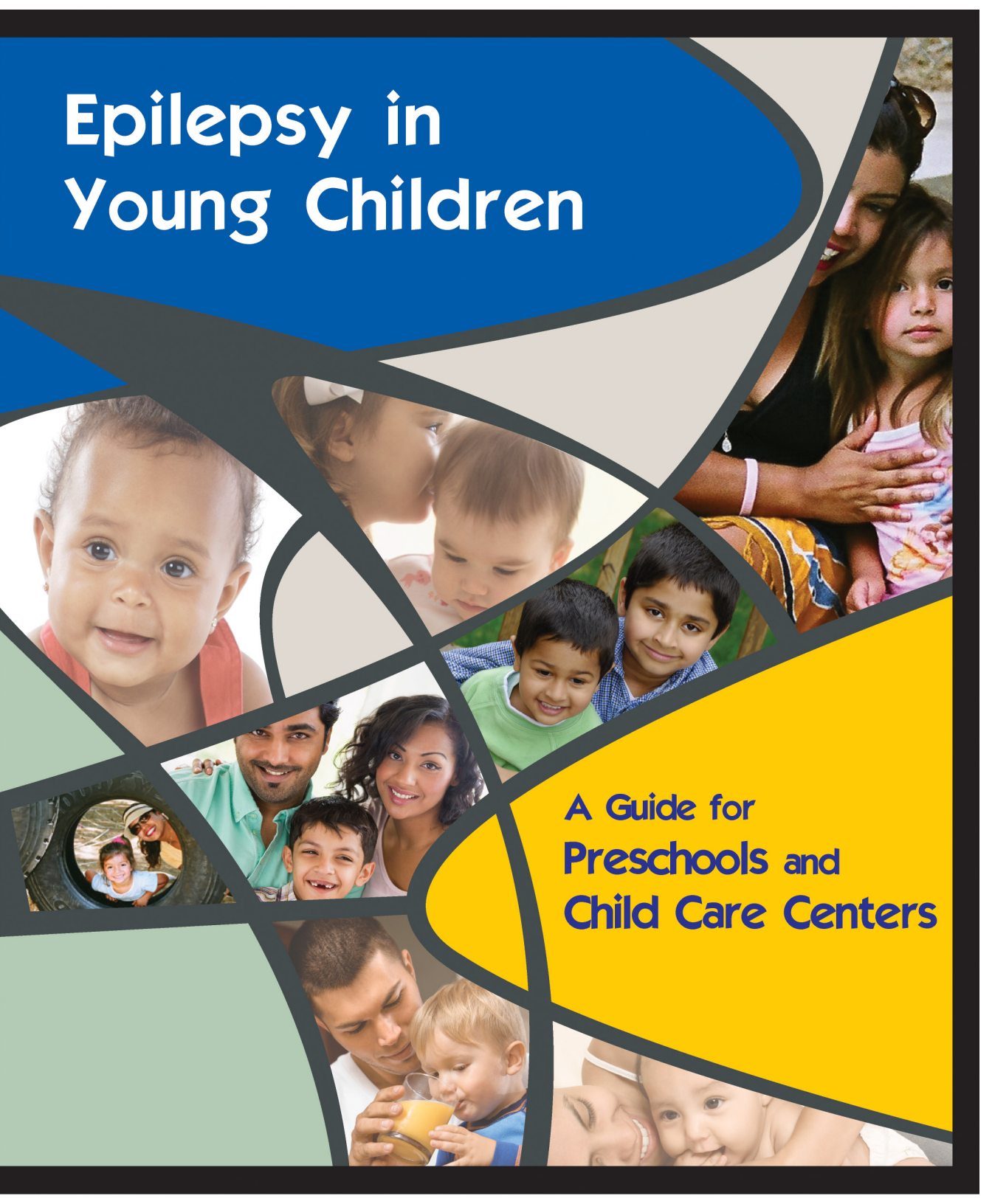


Epilepsy in Young Children

A Guide for
Preschools and
Child Care Centers



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Introduction to the Guide

Dear Teacher or Caregiver,

Children are one of life's greatest gifts. As caretakers, we want to do all we can to nurture the children under our care. As a caretaker of a young child with epilepsy, also referred to as a seizure disorder, you face the additional challenge of learning as much as you can about managing a child's special needs. This Guide was written with you in mind. It was written to give you some very basic information, including an introduction to epilepsy and seizure disorders. It is not intended to provide medical advice. Any questions related to the medical treatment of a child should always be addressed to a child's parents, pediatrician, family physician or neurologist.

Throughout (this Guide), we include information about how epilepsy can affect a young child's mental health and resiliency as well as how to help other children understand epilepsy. While this Guide may not provide all of the information you are looking for, it will help prepare you to address the special needs of a child with epilepsy.

Many parents of children with epilepsy have helped us develop this guide and its contents under the federally-funded project: Improving Access to Care for Children, Youth and their Families in Rural and Frontier Communities. This guide is a supplement to *Epilepsy and Seizure Disorders: A Resource Guide for Parents* and has been adapted from the Epilepsy Foundation's pamphlet, *Epilepsy in Children: The Teacher's Role*. The contents reflect what parents of children with epilepsy want teachers and caregivers to know.

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This guide was written by the University of Southern California University Center for Excellence in Developmental Disabilities at Childrens Hospital Los Angeles in partnership with Epilepsy Foundation of Northern California. The content of this guide has been adapted from the National Epilepsy Foundation's *Epilepsy in Children: The Teacher's Role*.

Facts for those who Care for Young Children



"Seizures are not a mental health disorder. Instead, epilepsy is a neurological condition that is still not completely understood."



What is epilepsy/seizure disorder?*

Epilepsy is an illness, that for a short time only, changes the way a child's brain works. Although seizures can vary in how they look or feel, they are all caused by a sudden surge of electrical energy in the child's brain. This leads to sudden changes in how a young child may act, move or feel. Seizures may last a few seconds or a couple of minutes, and then the brain goes back to normal again. The child may not remember what happened.

Seizures present in many ways:

- The child may suddenly fall, getting stiff with shaking or jerking of an arm or leg or all over.
- The child may be seen experiencing episodes of blank staring that last only for a few seconds.
- The child may have changes in mood, feeling afraid or angry for no apparent reason.
- The child may appear confused, with almost trance-like behavior during which the child's consciousness is impaired.

Many physical injuries or illnesses can cause a single seizure in a child. However, a single seizure is not epilepsy. Epilepsy means recurrent seizures.

For most children, their seizures will respond to medication, and they will enjoy a typical and active childhood. However, young children who are still having seizures may run into problems at preschool and child care, relating to the child's fear about what has happened and reactions from other children.

The way that the teacher responds to the child having a seizure influences how the child copes with the experience and begins to learn to see it as just a part of life. Teachers also influence how the other children learn to understand the experience and how they will respond to it.

“Educate yourself with regard to epilepsy.”

-parent of a child with epilepsy



* Some people use the term “seizure disorder” instead of “epilepsy” to describe this condition. In fact, both terms mean the same thing – an underlying tendency to experience seizures.



“Ask parents for signs of a seizure and develop a plan with parents of how to respond when the young child has a seizure.”

—parent of a child with epilepsy



SEIZURE MANAGEMENT

ABSENCE SEIZURES

During an **absence** seizure it might seem like the child is daydreaming. However in an absence seizure the child cannot be made alert or woken up. The child's consciousness is temporarily impaired and he/she is totally unaware of what is happening around them. These seizures usually last a few seconds only.

Management: Make sure the child did not miss any key parts of the lesson or activity.

SIMPLE PARTIAL SEIZURES

Simple partial seizures are limited to one area of the brain. Consciousness is not lost, though the child may not be able to control body movements. Examples of symptoms include the movement of an arm or leg, tingling sensations, experiencing a smell or a taste, and becoming pale or sweating.

Management: If the child seems confused or frightened, comfort and reassure him/her by explaining that what happened is just a part of the seizure, and that everything is going to be all right.

GENERALIZED SEIZURES

Other **generalized** seizures produce sudden changes in muscle tone that may cause the child to fall abruptly, or jerk the whole body. A child with this kind of seizure may have to wear a helmet to protect the head. These seizures are more difficult to control than some of the others and, in some cases, may be accompanied by some degree of developmental delay.

Management: The child should be helped up, examined for injury from the force of the fall, reassured, and allowed to sit quietly until fully recovered.

COMPLEX PARTIAL SEIZURES

Complex partial seizures produce a variety of behaviors. The child loses awareness. Repetitive movements such as chewing or lip smacking may occur. The child may get up and walk around, be unresponsive to spoken direction, may mutter, or tap a desk in an aimless way. He may appear to be sleepwalking or drugged. This type of seizure usually lasts only a minute or two, but feelings of confusion afterwards may be prolonged. The child will not remember what he did during the seizure. The child's actions will not have been under his control.

Management: If a child has an episode of this type and appears dazed and oblivious to his surroundings, the preschool teacher can take the child's arm gently, speak to him/her calmly, and guide carefully back to his/her activity. Do not grab hold or speak loudly. If the child resists, just make sure he/she is not in any danger. If the child is seated, ignore the automatic behavior but have him/her stay in the classroom until full awareness returns. Help re-orient the child if he/she seems confused afterwards.

GENERALIZED TONIC-CLONIC SEIZURES

With **generalized tonic-clonic** seizures, the child becomes stiff and falls to the ground. Teeth clench and the arms, and usually the legs, begin to jerk rapidly and rhythmically. Seizures usually last a minute or two, after which the jerking slows and stops.

Management: When this type of seizure happens, the preschool teacher and child care provider should:

- *KEEP CALM. Reassure the other children that the child will be fine in a minute.*
- *Ease the child gently to the floor and clear the area around the child of anything that could hurt him/her.*
- *Put something flat and soft (like a folded jacket) under the child's head so it will not bang against the floor as the child's body jerks.*
- *Turn the child gently onto one side. This keeps the airway clear and allows any fluid in the mouth to drain harmlessly away. DON'T try to force the child's mouth open. DON'T try to hold on to the child's tongue. DON'T put anything in the child's mouth. DON'T restrain the child's movements.*
- *When the jerking movements stop, let the child rest until full consciousness returns. Deal with the situation in a reassuring matter of fact way.*
- *Breathing may have been shallow during the seizure, and may even have stopped briefly. This can give the child's lips or skin a bluish tinge, which corrects naturally as the seizure ends. In the unlikely event that breathing does not begin again, check the child's airway for any obstruction. It is rarely necessary to give artificial respiration.*
- *Keep a diary that details the child's seizure, including type of movement, level of alertness and length of seizure.*

Some children recover quickly after this type of seizure; others need more time. A short period of rest, depending on the child's alertness following the seizure, is usually advised. However, if the child is able to remain in the classroom afterwards, he or she should be encouraged to do so. Staying in the classroom (or returning to it as soon as possible) allows for continued participation in classroom activity and is emotionally less difficult for the child. Of course, if he has lost bladder or bowel control, he should be allowed to go to the restroom first. Keeping a change of clothes will reduce embarrassment when this happens.

Emergency Management

The average seizure in a child who has epilepsy is not a medical emergency. The seizure usually resolves without problems. It does not require immediate medical attention unless:

- A child has a seizure and there is no known history of epilepsy. Some other medical problem might be causing the seizure and emergency treatment of that problem might be required.
- Consciousness does not return after the seizure ends.
- A second seizure begins shortly after the first one without the regaining of consciousness in between.
- The seizure shows no sign of ending after 5 minutes.

If a child has a history of prolonged seizures, the physician may prescribe so-called “rescue medicine” in a form that can be used at the pre-school or child care program by a trained adult to bring the seizure to an end.

If a child hits his head with force, either during the seizure or just before it begins, one or more of the following signs call for immediate medical attention:

- Difficulty in rousing after twenty minutes
- Vomiting
- Complaints of difficulty with vision
- Persistent headache after a short rest period
- Unconsciousness with failure to respond
- Dilation of the pupils of the eye, or if the pupils are unequal in size. If a seizure occurs while swimming and there is any possibility that the child has ingested any water, he should be checked by a doctor as soon as possible even if he seems to be fully recovered.



“Stay calm when my child has a seizure.”

-parent of a child with epilepsy

Building Resilience in Young Children

All preschool age children need a loving and supportive environment in order to thrive. The preschool environment that nurtures self-mastery and meaningful teacher-child relationships lays the foundation for child well-being, school readiness and child resilience.

Meaningful relationships provide the child with reliable affection, protection from fears, help in resolving conflicts, and guidance to develop reciprocal social interactions. Resilient children expect to get what they need, and have the skills and social supports to get their needs met. All children have natural resilience that helps them deal with stress in their daily lives. How a child is supported to deal with the stress will determine the child's capacity to cope.



“Do not treat my child differently.”

-parent of a child with epilepsy

A child with seizures may experience the world as stressful, unpredictable and frightening. The fear or anxiety a young child may experience from a seizure means there may be more challenges to overcome in order for him to develop a sense of self-competence, self-confidence and self-esteem.

A major challenge for children with epilepsy stems from the well meaning efforts of adults to protect them from harm. Caregivers may limit a child's participation in the usual childhood activities because of fear that a seizure will occur during the activity, or that exertion will somehow trigger a seizure. It is important that the child is not excluded from experiences that would help her develop social skills and self confidence. This sense of being different, of being unable to join what others are doing, encourages dependence in the child and keeps her socially immature. A full range of childhood experiences, keeping safety in mind, lays the foundation that will enable the child to grow into a competent teenager and later an independent adult.

Role of Stress

Recent infant brain research has provided valuable information about the role of stress in a child's life and the development of resilience that allows the child to become stress-resistant. The unpredictable, frightening experience of a seizure can be a source of significant stress for young children, leading to increases of heart rate and stress hormones, such as cortisol.

In addition, young children quickly pick up teacher anxieties. Adult anxiety about a child's seizure compounds a child's fears, adds to increased heart rate and stress hormones, and may ultimately lead to learned helplessness or acting out behavior. It is extremely important for adults to refrain from communicating their anxiety. Adults need to try to adopt a matter-of-fact approach to seizures and medications.

Stress becomes tolerable when it is buffered by nurturing adults who help the child adapt. Caring relationships provide a protective shield that enhances a child's capacity to manage stress. When a caregiver responds in a warm composed manner, it calms the child's heart rate and the surge of stress hormones. The child begins to learn that seizures are a normal part of his life and that he can handle them. In this manner, the child learns how to cope with unpredictable and frightening experiences, which is an important part of healthy child development.

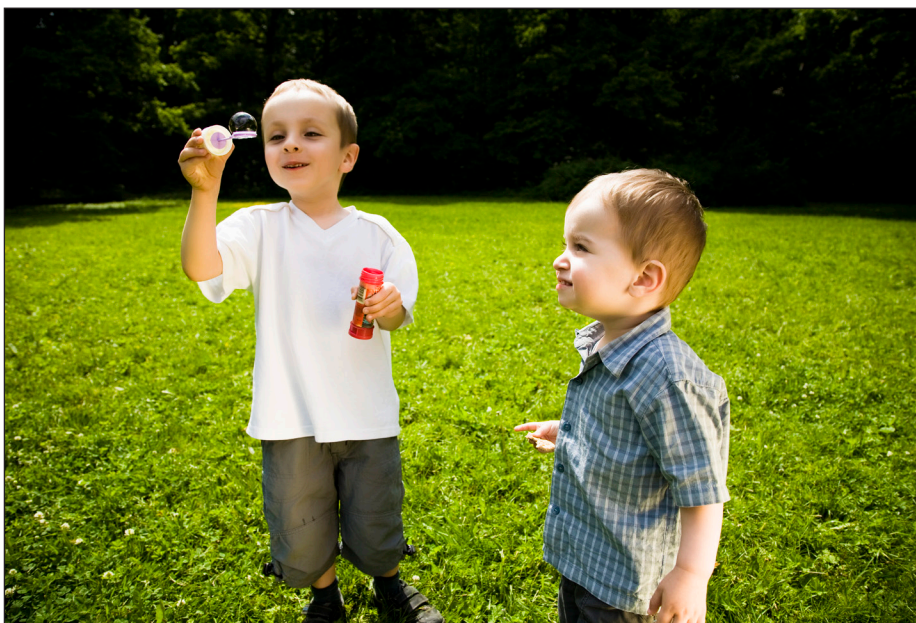


Strategies that Build Resilience

Routines and rituals at home and at preschool/child care are important because they help children feel secure. Routines, such as a story before nap-time, provide predictability in a child's life, offering a level of security that alleviates anxiety about the unknown. Rituals, such as always sitting at the same place, are meaningful routines that provide a sense of good feeling and a sense of belonging. Classroom rituals, such as making greetings personalized for each child and celebrating special activities, such as birthday parties, help connect the children to the teachers and to each other. This makes everyone feel more secure and part of the group.

The lack of predictability of seizures causes many children, especially those with more sensitive temperaments, to become fearful about all types of change. Transitions, such as being dropped off at preschool, going outside or moving from one activity to another, can be stressful and result in emotional breakdowns. Children with epilepsy who also have sensitive temperaments may have more difficulty regulating their emotions and behavior and will need preparation and support when changes are made in their lives and within the routines of daily activities.

However, too many restrictions undermine self-confidence and foster anxiety in children. What the adult may see as protection or nurturance, the child may experience as a message that the adult doubts his competence to master age appropriate expectations. The hovering teacher inadvertently gives a child a message that the world is a threatening place and that the child lacks the competence to make decisions. This impedes the important developmental task of learning how to take turns, share, and assert oneself in a healthy manner. Caregivers instill developmental



"The example you give will set the stage for my child's school experience."

-Parent of a child with epilepsy

competence when they provide a couple of safe choices that allow young children to think and make decisions about their own preferences relating to things, activities, or the order in which activities are done. The young child also learns that others have preferences and need to be part of decision making in sharing and taking turns.

Learning to recognize, name, accept and express their own feelings and the feelings of others is an important core of emotional development. Being able to state feelings of sadness, fear, anger, love, and joy are all part of learning to cope with one's own feelings and those of others. Practicing the

identification and the verbal expression of feelings leads to a better understanding that it is okay to be angry or scared or sad. This provides a foundation for discussing how to express feelings in a positive way rather than acting them out. Children need the opportunity to play out, talk about or use art materials to express their feelings.

Self-esteem comes from a sense of competence. A significant strategy that leads to self-esteem is the assignment and guidance of developmentally appropriate responsibilities that can be attended to by the children on an every day basis. Teachers help children thrive when they look for ways to promote success for each child.

"Do not be afraid of my child."

-Parent of child with epilepsy



Behavior

The average child with epilepsy will not have behavior problems and will respond to appropriate discipline in the classroom in the same manner as all the other children. However, teacher concerns about the child's illnesses may lead to lowered expectations for age-appropriate behaviors. Too few expectations and a lack of limit setting undermine the child's developing sense of self-mastery. Age-appropriate behavior should be expected.

When children with epilepsy have behavior problems, these may be caused by any one of several factors: the seizure activity itself, the medication, the child's own anxiety, or a caregiver's overprotection or over indulgence.

Children with epilepsy may have difficulty paying attention due to unrecognized seizure activity in the brain. Anxiety over the possibility of having a seizure may also affect attention. It is important for the teacher to use repetition and direct instruction when the young child appears to have difficulty focusing.

Occasionally a child may also have significant behavior problems that have nothing to do with the seizure disorder.

Behavioral Signs of Stress in Preschoolers

- Frequent tantrums
- Relentless aggression
- Self-isolation from peers
- Extreme hyperactivity
- Inconsolable crying
- Excessively withdrawn
- Persistent inattention

Identifying the source of behavior problems in an individual child is the first step in dealing effectively with them. Depending on the severity of the behavior, the child's parents, physician and other professionals may be involved in this process.

"Psycho-social side effects may make a child drowsy, aggressive or harsh."

-parent of a child with epilepsy

Helping Children Understand

When a child has a seizure in the classroom or at day care, all the children are affected. The unusual behavior may frighten the other children.

They may be afraid for the welfare of the affected child. They may become upset at the sight of a classmate who had seemed as healthy as they had only a few moments before. They may feel scared for themselves and worried they may 'catch it.'

When this happens, children need information suitable to their age. They need reassurance that what has happened poses no danger to them or to the child who had the seizure.

Unless handled appropriately, the fear generated by the event may be translated into fear of the child who had the seizure. This kind of progression can cause the child to be shunned, teased, or both.

When the teacher explains to the other children what has happened, answers their questions, and gives them a chance to say how they feel about what occurred, the social

impact of the seizure can be reduced. This discussion should take place as soon as possible after the seizure.

During the classroom discussion, the teacher should first describe what caused the seizure and then invite the children to ask questions and express their feelings about what happened.

Key points to help children understand:

- What happened to the child is called a seizure.
- It happened because for just a minute or two the child's brain got mixed up and sent mixed up messages to the rest of his body. Now that the seizure is over, his brain and his body are working properly again.
- Seizures are not like a cough or a cold; they can't be caught from other children.
- Seizures stop by themselves.
- We help the child who is having a seizure if we stay quiet and do not get in his way, keep him safe, and be a friend when it is over
- Encourage other children to ask questions.



“Develop a plan of how to talk with the other children after a seizure occurs.”

-parent of a child with epilepsy

Seizure Prevention

Many children with epilepsy gain complete control of their seizures with regular use of seizure preventing medicines. These medicines may have to be taken during the school day.

Successful treatment depends on keeping a steady level of medication in the child's blood at all times, so it is important that doses not be missed or given late.

It is important that there is a staff member who will look after the medicine and give it to the child each day. The time when it is given, and the amount, should be arranged with the parents according to the doctor's instructions.

Medicines that prevent seizures may be affecting the child's ability to participate. If the child becomes excessively aggressive, sleepy, lacking of energy or appears clumsy, parents should be told.

Parent-Teacher Communication

All parents are always concerned about how their young child's teachers are going to support, protect, nurture and guide the children in their care. Parents of a child with a health care need are particularly sensitive to the special needs of their child. It is important for teachers to respect and understand parents' concerns, and not be offended by the many questions parents may have on how their child is doing.

When good communications exist between parents and teachers, the teacher can feel comfortable asking questions that will lead to a plan that helps him/her do her best for the child. These questions may include:

- What kind of seizure does your child have? What are the signs and what do they look like?

- Can you tell me the best way to handle your child's seizures?
- Can you give me some tips on the best way to handle the experience with your child afterwards? Do you want to be called immediately? Will your child need to go home?
- How often do the seizures occur? How long do they usually last?
- Is medicine going to be given or taken at school? What arrangements should we make for that?
- How have you explained the seizures to your child, so that I may use the same words to explain them to classmates?
- Do you wish for me to discuss seizures with the class before one occurs? Would you like to participate?

If the child is having very infrequent seizures, or has complete seizure control, this kind of basic information may be all that is needed.

However, if the seizures are frequent, the teacher will want to discuss with the parents how they should be handled.



Summary

When a child has epilepsy, a caring and informed teacher is essential to the child's social and emotional development.

- The teacher's understanding of the condition will enable her to handle a seizure calmly and effectively.
- The teacher's observation and reporting of any changes in the child will help parents to work more effectively with the child's physician to control the seizures.
- The teacher's response to a child's seizure will influence how the other children learn to understand and respond to the experience.
- Most importantly, a caring, well informed teacher can help prevent the damaging social impact of epilepsy in childhood and help the affected child learn that having a seizure disorder can be just a part of life.

This brochure is an adaptation of the *Epilepsy in Children: The Teacher's Role* developed by the Epilepsy Foundation. Adaptations were made with input from parents of children with epilepsy, child development specialists and pre-school teachers and child care providers.

The following parents and individuals with epilepsy contributed to this brochure:

Darlinda Bell

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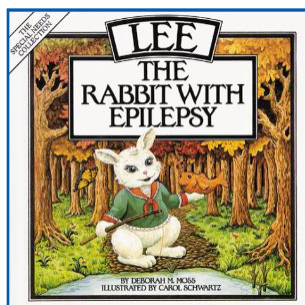
Tracie Romo

Yvonne Stevens

Storybooks

about Epilepsy

Epilepsy is a complex condition that can be difficult for children to understand. As parents and educators, we know that children enjoy learning through stories and that stories are often a role model of behavior. The following list of children's books is suggested to help children and their classroom peers to understand epilepsy. Parents and teachers can also use these books to help other children learn about and understand epilepsy.



Lee the Rabbit with Epilepsy

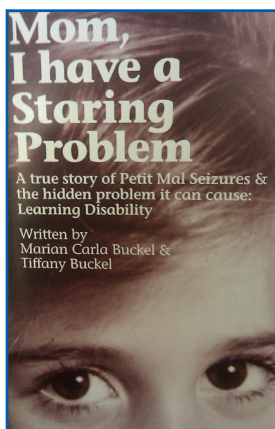
Deborah M. Moss

Woodbine House, Inc., 1989

Ages 4-8

ISBN: 0-933149-32-8

Description: When Lee loses her fishing pole while having a seizure, she is scared she won't be able to do normal things she loves. But, with Dr. Bob's help, she learns how to control her epilepsy and learns she can still have fun doing all the things she used to.



Mom, I have a Staring Problem

Marian Carla Buckel & Tiffany Buckel

M.C. Buckel, 1992

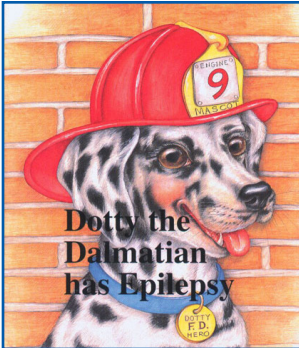
Ages 4-8

ASIN: B0006EZ87A

Description: This is an encouraging true story written through the eyes of a child who struggles to keep up with the rest of the first grade. Her absence seizures went unnoticed to anyone until a doctor finally caught on to the cause of her delayed learning. When she was finally able to take control of her seizures, she was also able to shine academically.

Storybooks

about Epilepsy



Dotty the Dalmatian has Epilepsy

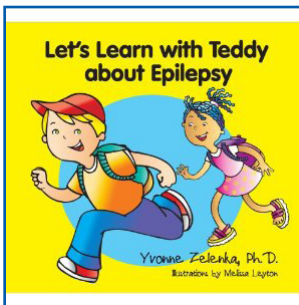
Tim Peters and Company Inc., 1985

Woodbine House, Inc., 1989

Ages 4-8

ISBN: 1-879874-35-0

Description: This is a story about a young Dalmatian who dreams of becoming a firehouse mascot one day. When she discovers she has epilepsy she feels ashamed and is sad that she will not be able to help the firefighters, but little does she know, her life as a firehouse dog is far from over.



Let's Learn with Teddy about Epilepsy

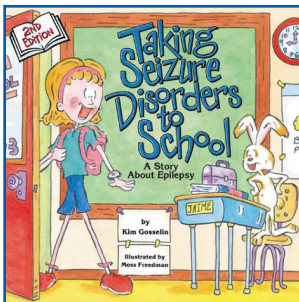
Yvonne Zelenka, Ph. D

Medicus Press, 2008

Ages 4-8

ISBN: 978-0-9787727-2-7

Description: Teddy has a seizure while playing video games, and learns he has epilepsy after a visit to the doctor. He is excited to show off his MRI in school and is even happier to learn that not much has changed.



Taking Seizure Disorders to School: A Story About Epilepsy

Kim Gosselin

JayJo Books, 2001

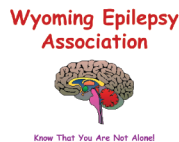
Ages 4-8

ISBN: 978-1891383168

Description: In this story, a young girl teaches her classmates all about epilepsy and seizure disorders.

An electronic version (PDF format) of the Guide can be accessed via the Internet at the Epilepsy Foundation of Northern California website:

www.epilepsynorcal.org/docs/Preschool_Guide.pdf



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