

# BE SMART

## ABOUT EPILEPSY

**Seizure Management And Responsive Treatment**  
*Manual for Personnel to Assist Students with Epilepsy*  
*Managing Epilepsy in the Schools*

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Comprehensive Resource & Training Manual for School Personnel. The Epilepsy Association, in partnership with the Cleveland Metropolitan School District and the Epilepsy Association's Professional Advisory Board Nurse Advisory Committee, developed this manual through grants provided by the Mt. Sinai Health Care Foundation and Kaiser Permanente.

**Epilepsy Association**

2831 Prospect Ave.  
Cleveland, Ohio 44115  
Phone: 216-579-1330  
Fax: 216-579-1336  
[www.epilepsyinfo.org](http://www.epilepsyinfo.org)

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# Introduction

**Epilepsy affects approximately 2.7 million people in the U.S. and 50 million worldwide. Epilepsy strikes most often among the very old and the very young, although anyone can get it at any age. In the U.S. it currently affects more than 326,000 children under age fifteen. For students in grades K through 12 who have epilepsy, the experience of living with epilepsy is not just based on their management of the condition. The experience of living with epilepsy is also based on their interaction with staff and other students.**

## **DID YOU KNOW?**

Head injury is the primary cause of epilepsy in children.

Of the major chronic medical conditions, epilepsy is among the least understood, even though one in three adults knows someone with the disorder.

Lack of knowledge about proper seizure first aid exposes individuals with epilepsy to injury from unnecessary restraint and from objects needlessly forced into the mouth.

The leading non-medical problem confronting people with epilepsy is discrimination in education, employment, and social acceptance.

Research indicates higher rates of epilepsy among racial and ethnic minorities, people of lower socioeconomic status, people living in rural areas, and males.

Limited public understanding of epilepsy has been found to contribute to the stigma attached to epilepsy by perpetuating negative attitudes towards individuals who have epilepsy.

## **HOW ARE STUDENTS AFFECTED BY EPILEPSY?**

Students with epilepsy are at increased risk for academic underachievement, particularly in the basic skills of reading, language, and arithmetic.

Many students with epilepsy are found to be significantly behind their peers in academic achievement levels, ranging from 16% below their grade in reading to 50% in general knowledge.

Children with epilepsy have been found more likely to have impairment in their self-concept and behavior when compared to children with other chronic illnesses.

Children with severe epilepsy are likely to experience social rejection from peers.

Back-to-back seizures (Status Epilepticus) may result in death for 25% of individuals with epilepsy.

## **GOOD NEWS**

For about 80% of individuals who are diagnosed with epilepsy, seizures can be controlled with adherence to the prescribed treatment regimen.

Triggers to seizures can be monitored to reduce the likelihood of them occurring.

For the 20% of individuals who have uncontrolled seizures, there are other surgical and non-surgical treatment methods that can help to reduce the frequency of seizures.

## **EFFECTIVE SEIZURE MANAGEMENT CAN RESULT IN:**

- A supportive learning environment for students with epilepsy.
- Decreased likelihood of underachievement for students with epilepsy.
- Reduced disruption in the classroom. When staff is knowledgeable about epilepsy and can respond appropriately to a student having a seizure, the uncertainty and fear common among other students in the classroom can be reduced.
- Reduced and appropriate emergency care. Staff members knowledgeable about epilepsy are aware that not every seizure warrants calling 9-1-1.
- If physical education instructors and coaches have an awareness of guidelines for sports safety for students with epilepsy, they are less likely to impose unnecessary restrictions on student participation.
- Increased self esteem for individuals with epilepsy. After a seizure, students who have a positive interaction and experience with staff and peers are more likely to feel better about who they are as a person and that they are not defined by their epilepsy.
- School Staff play a critical role in helping students manage their epilepsy. A collaborative effort of students, parents, and medical providers can create a safe and healthy school environment to ensure best practices in the management and response to epilepsy.

This manual was designed to educate school personnel about epilepsy and help facilitate practices that will lead to an optimal learning environment for students. The manual contains general information about epilepsy, basic seizure first aid, and special considerations for different types of school personnel in their daily interactions with the student with epilepsy.

The information in this manual can be photocopied and distributed to school personnel or other interested individuals. The entire manual is available on the Epilepsy Association website at [www.epilepsyinfo.org](http://www.epilepsyinfo.org).

# Using this manual

to help school personnel increase their awareness of epilepsy and seizures and increase their ability to appropriately respond to students who have seizures. Through a collaboration of students, parents, school personnel, and medical providers, effective epilepsy management and response can be achieved. This is the first step in creating a safe and healthy environment for students with epilepsy and one that will reduce the stigma associated with the condition.

This manual is not intended to replace services provided by the appropriately licensed medical professional or to be a substitute for medical advice provided by physicians. The user should suggest the student’s parent or guardian consult a physician in all matters relating to their child’s health, particularly in respect to any symptoms that may require further diagnostic evaluation or more prompt medical attention.

## **RECOMMENDATIONS FOR USERS OF THIS MANUAL**

All school personnel performing duties that are the primary responsibility of a licensed health care staff member should be appropriately trained in order to meet state/district policies, standards, guidelines and regulations.

Non-medical personnel must be trained to administer medications properly and be overseen by a Registered Nurse (RN) who has evaluated their ability to perform those tasks safely and accurately.

Performing these duties without proper training, licensure, and supervision can put the individual student at risk and increase the liability risk of administrative school personnel.

You should always be aware of the policies and procedures of the School District that guide the actions/response of all district school personnel.

For questions regarding school health issues, including epilepsy, please contact your district’s health service personnel.

## **ACKNOWLEDGMENTS**

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### [Be SMART about Epilepsy Manual](#)

- Pam Lang, Nurse Advisory Committee Chair, M.S.N., R.N., C.N.S., University Hospitals
- Rabon Allen, RNA, BSN, CAN, University Hospitals
- Deborah Brady, R.N., C.P.N. Cleveland Clinic Foundation, Pediatric Epilepsy Center
- Michelle Harrington, R.N., Cleveland Clinic Foundation
- Ria Gibson, R.N., Cleveland Metropolitan School District
- Nancy McCrickard, N.D., R.N., School Nurse, Cleveland Metropolitan School District
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# ▶ What is Epilepsy?

The brain is made up of cells that are like tiny little building blocks. These cells carry an electrical charge and are called neurons. In a normal brain electrical charges pass between nerve cells and to all parts of the body. Those cells “fire” in an orderly and controlled manner. In the brain of a person with epilepsy, overactive nerve cells send out powerful, rapid electrical charges that disrupt the brain’s normal function. During a seizure, brain cells can fire at up to four times their normal rate, temporarily affecting how a person behaves, moves, thinks, or feels.



## WHAT IS A SEIZURE?

A seizure occurs when there is abnormal and overactive electrical activity of brain cells. The seizure may include brief stares and muscle spasms (shaking, lip smacking). Some people with epilepsy have strange or odd sensations (bad smells, unusual or bad tastes, and changes in vision) right before they have a seizure. This “warning” sign of a seizure is called an aura.

## WHERE DO SEIZURES HAPPEN IN THE BRAIN?

Seizures can occur in any part of the brain. The person’s symptoms will vary with the part of the brain where the seizure occurs. If the seizure occurs in the part of the brain that controls arm movement, then the seizure may consist of thrashing arm movements. If the seizure occurs in the part of the brain responsible for sensation, then the seizure may include an unusual feeling like pins and needles.

## WHAT ARE THE SYMPTOMS OF A SEIZURE?

Almost all seizures are relatively brief, lasting from a few seconds to a few minutes. Most seizures last from 1 to 2 minutes. When a seizure stops, people may have:

- Headache
- Numbness or tingling (pins and needles) in a specific body part
- Confusion
- Sore muscles
- Unusual sensations (taste, smell, etc.)
- Extreme tiredness
- Loss of bowel or bladder control (soiling or wetting)

## WHAT CAUSES EPILEPSY?

In 7 out of 10 cases the cause of epilepsy is unknown. Doctors call this idiopathic. Most people with idiopathic seizures are between the ages of 5 and 20 and have no brain injuries or abnormalities of their brain.

The following is a list of factors that have the potential to cause epilepsy:

- Abnormal brain development
- Brain injury with loss of consciousness
- An infection of the brain
- High fever in children under 5 years old
- Hereditary (Genetic) factors
- Loss of oxygen to the brain
- Stroke
- Brain lesion/tumor
- Toxins/poisons
- Unknown cause

## DO PEOPLE KNOW WHEN A SEIZURE IS GOING TO HAPPEN?

Some people do know when a seizure is going to happen. They get a sensation, feeling, emotion, taste, smell that comes before the seizure. This is called an aura. About 20% of people who have a seizure disorder experience an aura.

There are three phases to a seizure. They are:

- **Pre-Ictal:** the time period before a seizure. The person may feel or behave differently from normal.
- **Ictal:** the time during the seizure, when seizure activity is actually happening.
- **Post-Ictal:** the time period after a seizure. The person may be confused, not know their name or where they are, and may need time to rest and often sleep.

## INCIDENCE AND PREVALENCE OF EPILEPSY

Incidence is a measure of the number of new cases of a medical condition that occur in the population during a measured amount of time, usually one year. There are approximately 200,000 new cases of seizures and epilepsy that occur each year. The lifetime incidence of seizures is about 5% to 10%.

Prevalence is the total number of existing cases of a disease in a specific population at a stated point in time. The prevalence of epilepsy is 2.7 million Americans of all ages.

Males are somewhat more likely to have seizures than females. Approximately 10% of Americans will have a seizure in their lifetime. Every year about 300,000 people have the first seizure in their lifetime.

## WHAT TRIGGERS A SEIZURE?

Understanding why seizures happen is complicated. Sometimes seizures are linked to triggers. Listed below are common triggers.

### Common Seizure Triggers:

- Missed medications
- Extreme heat
- Illness (such as cold, high fever, infection)
- Lack of sleep
- Too much alcohol
- Over-the-counter medicine, other prescription medicines, supplements, or herbal remedies
- Use of illegal drugs
- Physical or emotional stress
- Poor eating habits
- Too much caffeine
- Brain disorders (tuberous sclerosis, cerebral palsy, mental retardation, autism, and neurofibromatosis)
- Female hormone fluctuation

Some people feel that they can easily identify their triggers or patterns to their seizures, but keep in mind that seizures are unpredictable. Only about 20% of people experience an aura or a sense that a seizure is going to occur. Doctors recommend that individuals with seizures take their medications regularly and limit their exposure to these triggers.

## FACTS ABOUT EPILEPSY

Unfortunately, there are many false beliefs about epilepsy that have caused a misunderstanding of this condition. The negative impact of false beliefs on the student can be life altering. Students with epilepsy have dealt with social isolation, feeling different from others, not being able to participate in sports and activities, being bullied and teased by other students, and thought of as acting out in class when in fact they were having a seizure.

### The following are facts about epilepsy:

- Epilepsy is not contagious
- Most causes of epilepsy are not inherited; less than 5% of women with epilepsy will have a child with epilepsy
- Epilepsy is a chronic lifelong disorder
- Many people with epilepsy can live normal healthy lives
- People with epilepsy can marry and have children
- People with epilepsy are not violent, mentally challenged, or crazy
- People having a seizure can't swallow their tongue
- Single brief seizures do not cause brain damage
- Most seizures do not require the use of emergency services
- Death resulting from seizures is rare

# Types of Seizures

There are over 40 types of seizures that people can have. Epilepsy is best defined by its classification.

**1** PARTIAL  
SEIZURES

**2** GENERALIZED  
SEIZURES

## **PARTIAL SEIZURES**

(Non-convulsive seizures)

- Affect only one area of one side of the brain

### Simple Partial Seizures

- A person does not lose consciousness
- It may involve uncontrolled movement, emotions, or sensations
- The person does not have convulsions

### Complex Partial Seizures

- Do cause a person to lose awareness
- May start with a blank stare
- Can progress into chewing movements, picking at or fumbling with clothing, mumbling and performing simple, unorganized movements over and over again

## **IMPORTANT**

**Any partial seizure can progress into a generalized seizure.**

## **GENERALIZED SEIZURES**

- Affect both sides of the brain
- Produce a loss of consciousness
- Are categorized into several types

### Generalized Tonic Clonic Seizure

(also known as a grand mal seizure)

- Usually lasts 1 to 3 minutes.
- Begins with stiffening of the limbs
- Followed by jerking of the face and limbs
- Wetting or soiling of clothing may result from the seizure

### Myoclonic Seizures

- Usually lasts 1-2 seconds
- Rapid, jerking movements of the body that are often confused with a person being clumsy
- May occur singularly or in groups

### Atonic Seizure

(Also known as drop attacks)

- Usually last less than 15 seconds
- Sudden loss of muscle tone causes an individual's head to drop and loss in their posture. The student may fall to the ground
- Injury is more common; a helmet may need to be worn to protect the head
- This seizure occurs singularly/rarely in groups

## Absence Seizures

(also known as Petit Mal)

- Usually last less than 10 seconds but can last up to 20 seconds
- The most difficult seizure to recognize
- The student will look like they are daydreaming but if you try to get their attention they will not respond

Not everyone that has a seizure has epilepsy. There are other medical conditions that cause someone to have a seizure.

## Non-Epileptic Seizures

(also known as "Pseudo" or Psychogenic seizures)

These seizures are not caused by excessive electrical discharges in the brain, so the person does not have epilepsy, but seizures due to another cause.

There are many other reasons that can cause a seizure to occur

- High fever in younger children
- Cardiac problems
- Drug overdose/intoxication
- Infectious Disease
- Low-blood sugar
- Stroke
- Lead poisoning
- Head injuries
- Psychological issues/stressors
- Other conditions

If a student does not have epilepsy and you see the individual have a seizure, immediate medical attention is needed. These seizures usually stop when the underlying medical/psychological issue is resolved.

# First Aid For Seizures

**step 1** Do NOT hold down the person having the seizure.

Do NOT put anything in the person's mouth. **step 2**

**step 3** Do not give the person having the seizure water, pills, or food until they come out of the seizure and become aware of their surroundings.

Try to be sensitive to how the person is feeling and let them know that they will be okay. **step 4**

**step 5** If the seizure lasts longer than 5 minutes, 9-1-1 MUST be called.

Stay calm; most seizures last less than a few minutes. Help the person having the seizure from getting hurt by moving any nearby objects out of the way, as necessary. Make the person having the seizure as comfortable as possible (take the person's glasses off; put something soft under the person's head). Pay attention to how long the seizure lasts, look at the clock and time the seizure. Keep other people away from the person having the seizure. Not all seizures require emergency medical attention.

## **WHEN IS A SEIZURE AN EMERGENCY?**

A seizure is considered an emergency when it lasts a long time, or when seizures occur close together and the person does not recover between seizures. Just like there are different types of seizures, there are also different types of emergencies.

### **No need to call an ambulance if a student:**

- Has a seizure that ends in less than 5 minutes and the student is known to have seizures
- Returns to consciousness quickly without further incident
- Student shows no signs of injury, physical distress, or is not pregnant

### **Call an ambulance if a student:**

- Has a seizure in water
- Has no medical ID and no way of knowing if the seizure is due to epilepsy
- Is injured, pregnant, or diabetic
- Has a seizure that lasts more than 5 minutes
- Has a second seizure that starts shortly after the first seizure
- Does not regain consciousness after the shaking stops (for a Grand Mal Seizure)

If the ambulance arrives after a student has regained consciousness, ask the student if the seizure was due to epilepsy and whether they feel they need to be taken to the emergency room.

## **WHEN IS A SEIZURE LIFE THREATENING?**

A seizure is considered to be life threatening when the brain is in a state of continual seizure activity. This term is called status epilepticus. Status epilepticus requires emergency treatment by trained medical personnel in a hospital setting. This situation can be life-threatening, and quick treatment is vital. The outlook for this type of status may vary depending on the cause of the status and if any other medical problems or complications occur.

### **A person would be at risk for status epilepticus if...**

- A tonic-clonic or grand mal seizure lasts 5 minutes or longer, or if seizures continue an additional 5 minutes after administering emergency medication
- A person has 3 or more recurrent seizures that occur within 15 minutes
- In any circumstance that a person does not regain consciousness after a seizure

## **WHY SHOULD AN AMBULANCE BE CALLED IF A SEIZURE LASTS LONGER THAN 5 MINUTES?**

There is evidence that 5 minutes is enough time to cause damage to neurons in the brain and after 5 minutes it is unlikely that the seizure will stop on its own. Data shows that the mortality rate for individuals who go into status epilepticus is high (at least 20%). However, this can be avoided with appropriate responding, which involves calling 9-1-1. It is important to be aware of a student's Seizure Action Plan, which may specify emergency medication that needs to be administered to a student in the event of back-to-back seizures.

# Medical Treatment

**For most individuals with epilepsy, there are treatments available that can successfully prevent seizures.**

## **THERE ARE THREE MAIN GOALS TO TREATING EPILEPSY:**

- Eliminating the seizures or reducing the number of seizures that occur
- Reducing the side effects from medications
- Maintaining or restoring a person's ability to function in their normal day-to-day activities

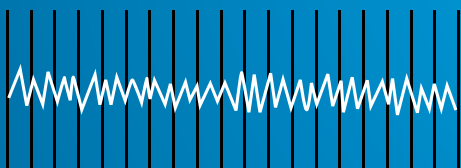
## **MEDICATIONS**

Medications used to prevent epileptic seizures are called antiepileptics (AEDs). There are over 30 different antiepileptic drugs, but they do not all treat the same types of seizures. Often times obtaining seizure control through antiepileptic drugs is a matter of finding the combination, schedule, and dosing of medications that is right for the individual. If a person is seizure free for several years, a physician may reduce or even stop the person's medication. However, epilepsy is a lifelong condition, and there is no permanent cure. For a full list of current antiepileptic drugs, including side effects, please see the section entitled "Special Considerations for Nurses."

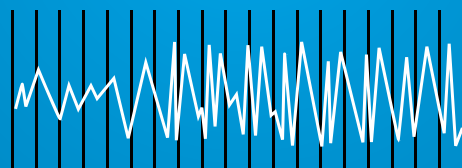
# Diagnosis

A physician must determine the seizure's cause by a physical exam and medical history, including a history of seizures that have occurred. Risk factors such as alcohol use and sleep deprivation need to be assessed, as well as any history of head injury, childhood seizures, or family history of seizures.

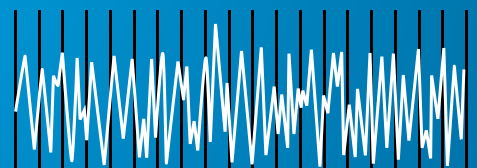
Physicians will also ask patients if they have experienced an aura (the warning sensation that a seizure is going to occur) because that can help confirm that the seizure is due to a brain disorder and help determine its location. The next step is for a physician to identify the type of seizure. An electroencephalograph, also known as an EEG, is a tool for recording electric currents in the brain and can track any unusual electrical activity in the brain.



Normal Adult Brain Wave



Absence Seizure



Tonic-Clonic Seizure





## BRAIN ACTIVITY DURING A SEIZURE

An electroencephalogram (EEG) is a recording of the brain's electrical activity. The procedure is simple and painless. About 20 small adhesive electrodes are placed on the scalp, and the brain's activity is recorded under normal conditions. Then the person is exposed to something, such as bright or flashing lights, to try to cause a seizure. During a seizure, electrical activity in the brain increases, producing a jagged wave pattern. Such recordings of brain waves help identify a seizure disorder. Different types of seizures have different wave patterns.

## EMERGENCY SEIZURE MEDICATION

DIASSTAT AcuDial is an emergency medication used to treat individuals who have prolonged seizures. Diastat is administered rectally. Administration of emergency medication should be done consistent with school policy. About 71% of patients in clinical trials remained seizure free for 12 hours after Diastat administration.

## SURGERY

If treatment with medications does not work, some individuals with epilepsy may be candidates for brain surgery. To be eligible for the surgery the person must have seizures coming from one area of the brain that can be removed without causing damage to the person's ability to function. If a defect in the brain (such as a scar) can be identified as the cause of the seizures and is confined to a small area, surgically removing that area can eliminate seizures in up to 80% of people, or at least reduce the severity and frequency of seizures.

## VAGUS NERVE STIMULATOR

The Vagus Nerve Stimulator is a device that is implanted in a person. Electrical stimulation of the vagus nerve can reduce the number of a certain type of seizures by more than one half in some people. This treatment is used when seizures continue despite use of AEDs and when surgery is not a possibility.

The vagus nerve is thought to have indirect connections to areas of the brain often involved in causing seizures. A device that looks like a heart pacemaker is implanted under the left collarbone and is connected to the vagus nerve in the neck with a wire that runs under the skin. The device causes a small bulge under the skin. The operation to implant the device is done on an outpatient basis and takes about 1 to 2 hours.

When people sense that a seizure is about to begin, they can activate the magnet mode of their device to deliver an on-demand dose of stimulation. Otherwise the device is programmed to deliver intermittent stimulation to the vagus nerve. Vagus nerve stimulation is used in addition to AEDs. Side effects of this device include hoarseness, cough, and deepening of the voice when the nerve is stimulated.

## KETOGENIC DIET

The ketogenic diet, which is very high in fats and low in carbohydrates, was first developed almost 80 years ago. It makes the body burn fat for energy instead of glucose. It has a success rate of 75%, stopping seizures in 50% of individuals and further reducing seizures in 25% of cases. It is a strict diet, and takes a strong commitment from the whole family. The ketogenic diet is not a do-it-yourself diet. It is a serious form of treatment that, like other therapies for epilepsy, has some side effects that have to be monitored. More research is being done to learn about the underlying reasons for the diet's positive effect.

## WHAT CAN THE STUDENT ON THE KETOGENIC DIET EAT AT SCHOOL?

Usually with this type of diet the student will have a dietitian help the parents plan meals that can go to school with the child. Since there are many celebrations at school that involve food, it's very important for all teachers and aides to know that the student cannot have the same treats that the other children get. Teachers should inform parents in advance when treats are planned so that parents can send an appropriate treat substitute with their child. It is important to understand that even half a cookie or a bite of cupcake can lead to seizures, a hospital visit, and the loss of seizure control. The treating physician of the student on this diet will supply a letter to the school nurse who would notify other appropriate staff.

## CAN EPILEPSY BE PREVENTED?

Due to the fact that in many cases of epilepsy there is no known cause, there is no way to prevent epilepsy from occurring. However anything that causes injury to the brain can cause epilepsy.

Good safety practices include:

- Always wear a seatbelt in the car and observe the speed limit
- Always wear appropriate protective gear while skating, playing sports, or riding motorcycles
- Do not abuse any licit or illicit substances
- Do not engage in physical behavior that has the potential to result in head injury
- Immunize children against infectious diseases

# Critical Info for All School Personnel

# Learning & Academic Issues

**Overall, the intellectual ability of individuals with epilepsy and that of individuals in the general population are comparable.**

Students with good seizure control (infrequent seizures or no seizures at all) are able to participate fully in school activities and may have no difficulties with school work. However, students with epilepsy, regardless of their IQ, are at an increased risk of having problems with learning.

Students who do not have good seizure control, resulting in more seizures, often have more problems with thinking and learning. These students may not be readily identified as having a learning disability because their spelling and math skills may be appropriately developed. Their problems tend to lie in the areas of attention, concentration, memory, and organizational skills. Current data tells us that about 25-30% of individuals with epilepsy have poor control of their seizures. Gaining control may be more difficult for those who experience many types of seizures and for those who have difficulty communicating what effect their seizures have on them. It is important to remember that no one factor relating to a student's seizure history can predict the impact it will have, if any, on a student's ability to learn. Just as each individual has a unique personality, epilepsy affects each individual differently.

The reasons that students with epilepsy may have problems with learning include:

- Learning not occurring during the time of a seizure
- Learning can be affected by the fatigue and confusion that occurs after a student has a seizure and can last for minutes or hours
- Fatigue and memory problems can be caused by seizure medications
- Learning can be disrupted by discharges in the brain that occur between seizures. This occurs when the student is not actively having a seizure and research data provides evidence that this can affect the learning process
- Learning can be affected by a student missing school or class time based on a new diagnosis of epilepsy or a student missing school due to seizures or medical appointments for their epilepsy
- The type of seizure that a student has will determine what part of the brain is affected and the result it will have on the student's ability to learn
- Emotional and behavioral issues of the student can also affect learning

When epilepsy affects a student's ability to learn, he or she may be entitled to special education services. The Individuals with Disabilities Education Act (IDEA) is a federal law that says every child with a disability is entitled to a free, appropriate education in the least restrictive (most "normal") setting possible. All students who receive special education services must receive an IEP or Individualized Education Plan. This is a written plan that outlines a student's needs and goals for the school year. Please refer to your school policies/procedures regarding how this process is initiated.

# Emotional & Behavioral Issues

**If a student with epilepsy has emotional or behavioral issues, this can impact the student's learning. These factors can be a cause of academic difficulties and also can be a consequence of academic problems.**

Research has shown that emotional and behavioral difficulties are higher in students with epilepsy. 34.6% of children with epilepsy have psychiatric issues when compared to 6.6% in the general population and 11.6% in children with other chronic illnesses. Some of the more common emotional and behavioral difficulties that children with epilepsy have are depression, anxiety, ADHD (Attention Deficit Hyperactivity Disorder), irritability, and aggression.

A student's chances of having an emotional/behavioral issue in addition to their epilepsy depends on a number of factors, including how often the student has seizures, how much medication he/she is taking and the age of the individual when the seizures began. Not all students with epilepsy will have these issues, but they are at higher risk because they have epilepsy.

## **DEPRESSION**

Research has also shown a strong link between epilepsy and depression. Approximately 50% of individuals with epilepsy also struggle with symptoms of depression.

Even more concerning is that in a recent study researchers found that 39% of patients with epilepsy had never been evaluated for depression despite the fact that they often co-occur.

In 2008 the Federal Drug Administration (FDA) issued an alert on anti-epileptic drugs (AEDs). This alert indicated that individuals taking AEDs may be at a higher risk for suicidal thought or actions. It is important to remember that just because a student is taking an AED does not mean that they will have suicidal thought or actions, but that they may be at higher risk for these behaviors/actions.

## Common signs of depression for the students with Epilepsy

Depression is the most frequently seen psychiatric diagnosis in individuals with epilepsy. Depression is more likely to occur in individuals who have poorly controlled seizures (frequent seizures regardless of treatment with medication).

Despite this fact, depression very often is unrecognized and untreated.

The reasons that this occurs include the following:

- Individuals tend to minimize their psychiatric symptoms for fear of being further stigmatized
- Individuals with epilepsy often have symptoms of depression that look different from those symptoms of other people with depression
- Sometimes physicians fail to ask individuals if they are having any psychiatric symptoms
- Sometimes physicians and patients minimize the importance of the symptoms they are having because they consider them to be part of the process of adapting to having and managing epilepsy
- Concern that antidepressant drugs may lower seizure control has caused physicians to be reluctant in prescribing them

People who are depressed may feel “down in the dumps” for weeks, months, or even years at a time. Individuals with epilepsy often experience symptoms of depression that look different (or atypical) from those symptoms that other people may report.

Students with epilepsy may experience the following symptoms of depression:

- Primary irritability
- Periods of less depressed mood (an individual will be able to experience a brightened mood when good things happen) which is not usually characteristic for someone who is depressed
- Feelings of euphoria (where the individual feels extremely happy or “on top of the world”)
- Feelings of fear
- Reports of pain
- Lack of interest or drive
- Extreme sensitivity to rejection by others that is related to personal or social difficulties (depression may increase this sensitivity, although it is often still present when the person is not depressed)

Even though students with epilepsy may have symptoms of depression that are different from others, they can also have more common symptoms.

Below is a list of more common symptoms of depression:

- Changes in sleep (sleeping more or less, appearing more tired or fatigued)
- Changes in mood (for children and adolescents the mood can be primarily irritable rather than depressed, acting out behavior is seen more in children)
- Changes in appetite (eating more or less, having a more significant weight gain or loss not associated with dieting or with weight loss/gain that may be a side effect of medication)
- Decreased interests in activities that the student used to find enjoyable
- Motor activity (or bodily movement) is slowed down or agitated
- Fatigue or loss of energy
- Suicidal thinking (can be more passive “don’t want to be here anymore” ) or ( more active “I’m going to run in front of traffic tomorrow”) Individuals who are feeling actively suicidal may have a change in behavior (giving important personal belongings away, saying good bye to friends, being more withdrawn in the classroom setting)
- Poor concentration or difficulty in concentrating
- Change in physical appearance (student looking more disheveled or not taking care of their personal hygiene)
- A student may express feelings of guilt, or negative thoughts regarding their sense of self (may say they feel worthless)

## **ANXIETY**

- Anxiety is an experience of fear or apprehension in response to a feeling of danger
- Research has shown that anxiety often co-occurs in individuals who have epilepsy
- Studies have shown that anxiety disorders in individuals with epilepsy range from 25 to 50%
- There is also evidence that some anti-epileptic medications (AEDs) can cause anxiety for some people; since everyone is affected differently by medication, anxiety that is suspected to be the cause of a medication side effect should be discussed with the treating physician.

### **Common signs of anxiety for students with epilepsy**

Symptoms of anxiety for individuals with epilepsy may be caused or increased by the unpredictability of seizures and restrictions that there may be on the person's normal activities as a result of the seizures.

Anxiety can occur before, during, or after a seizure. Data from one study (Torta and Keller) estimated that as many as 66% of patients with epilepsy report anxiety between seizures.

The manual that classifies and describes all mental disorders (which includes anxiety) distinguishes between 11 different types of anxiety disorders. However, if an individual has a significant medical condition, an anxiety disorder is not diagnosed. Because of the difficulty in separating the anxiety that comes with epilepsy from anxiety that is defined as a mental disorder, relatively few studies of anxiety in epilepsy have been done.

## **ATTENTION DEFICIT HYPERACTIVITY DISORDER (OR ADHD) AND ATTENTION DEFICIT DISORDER (OR ADD)**

- Signs and symptoms of ADHD or ADD typically appear before age 7
- About one-fourth to one-third of children with epilepsy show signs or symptoms of ADHD

It can be difficult to diagnose ADHD in children with seizure disorders because its symptoms may look a lot like features of the seizures themselves. Some seizure medications may cause or increase these behaviors. If you have concerns about ADHD and a student's stimulant medications, please address them with the family, as these are issues that should be discussed with the treating physician.

The three primary characteristics of ADD/ADHD are inattention, hyperactivity, and impulsivity. Below are common symptoms that student's may display.

### **Symptoms of inattention in children:**

- Doesn't pay attention to details or makes careless mistakes
- Has trouble staying focused; is easily distracted
- Appears not to listen when spoken to
- Has difficulty remembering things and following instructions
- Has trouble staying organized, planning ahead, and finishing projects
- Frequently loses or misplaces homework, books, toys, or other items

### **Symptoms of hyperactivity in children:**

- Constantly fidgets and squirms
- Often leaves his or her seat in situations where sitting quietly is expected
- Moves around constantly, often running or climbing inappropriately
- Talks excessively, has difficulty playing quietly
- Is always "on the go," as if driven by a motor

### Symptoms of impulsivity in children:

- Blurts out answers without waiting to be called on or hearing the whole question
- Has difficulty waiting for his or her turn
- Often interrupts others
- Intrudes on other people's conversations or games
- Inability to keep powerful emotions in check resulting in angry outbursts or temper tantrums

If you notice that a student is displaying these behaviors, it is important to refer them for further evaluation as dictated by your school's policies/procedures.

### **IRRITABILITY**

Individuals with epilepsy are also known to suffer from irritability. Increased irritability can occur before or after a seizure occurs. Often times irritability occurs along with depression.

Sometimes medications and medication side effects can cause an increase in irritability for the student.

### **AGGRESSION**

Aggression occurs in only a very small proportion of individuals. It may be verbal or behavioral, and it happens without a student being provoked by others.

Some researchers believe that this is caused by certain anti-epileptic medications; often a student is started on higher dose when they are first given a diagnosis of epilepsy.

Sometimes a student can become more irritable or aggressive before a seizure happens.

It is important to remember that, if a student with epilepsy has behavior issues that rise to the level of aggression, other interventions will be needed including discussion of a referral of the student to a psychiatrist.

Often students with epilepsy that display these behaviors are suspended from school rather than being referred for further evaluation.

### **SOCIAL ISSUES**

#### **Bullying**

Bullying and teasing has become a significant issue in studies of children with epilepsy. Rates of bullying and teasing reported by children and adolescents are more than 85%. Certainly, the concern with repeated exposure to bullying is that over time these experiences reinforce the student's negative self-esteem and the student's view of themselves as different from others. If you witness this behavior or become aware of incidents of bullying please follow your school's policy on student harassment, intimidation and bullying.

#### **Socialization**

In order for a child to reach normal development the child must have age appropriate relationships with other students and be involved in physical activities. Despite this well known fact, parents and families of students with epilepsy report that their seizures and the resulting emotional and social problems exclude them from participating fully in academic and social activities. Issues of the student's safety sometimes lead to restriction of their activities in school. This not only causes the child to feel isolated from others, but can lead to the student's negative view of themselves. It is important for school staff to support the student's participation in school activities that increase socialization and interaction with peers.

### In summary, how can school staff support the student with epilepsy?

- View the student as an individual affected by epilepsy and be informed about their seizures.
- Have an awareness of how epilepsy can affect a student's learning. If you suspect he or she is having learning issues related to seizures, there is specialized testing that can be done as part of a comprehensive evaluation for the student. The student may be eligible for special education services.
- Don't dismiss behavior issues as simply acting out. Research shows that students who have seizures may be prone to irritability and/or have behavior issues. Seek out information from the family and student about what constitutes normal behavior for the student. If you should see an increase or drastic change in behavior, talk with the school nurse about notifying the treating physician.
- Support the student with epilepsy; give the student plenty of opportunities to engage with other students in academic, physical, and social activities.



# Special Considerations

- 1** Police, Safety & Security Officers
- 2** Bus Drivers and Monitors
- 3** Social Workers
- 4** School Nurses
- 5** Teachers, Special Education, Preschool Teachers, & Paraprofessionals
- 6** School Psychologists, Occupational, Physical & Speech Therapists, and Guidance Counselors
- 7** Physical Education Teachers & Coaches



# SECTION 1

Police Safety &  
Security Officers

# It is recommended that Safety and Security officers know which students have a history of epilepsy and seizure disorders in their school.

However, the reality is that sometimes a security officer is filling in for someone else or rotates schools and may be unaware of students that have seizures. There have been several incidents in the state of Ohio and nationally where inappropriate responses to a student having a seizure have led to injury for the student. Here is one example:

*John Brooking Jardine, a 37 year old student at Arizona State University, died in Tempe, AZ, on March 30, 1999, following a seizure on campus. Representatives of the plaintiff's estate filed suit in Arizona Superior Court, alleging that Mr. Jardine's death was caused by EMT's use of excessive and inappropriate force used after Mr. Jardine had a seizure. The decedent experienced a seizure in his college class, and his fellow students called 9-1-1.*

*When the EMTs arrived on the scene just after the seizure stopped (knowing that the call had been dispatched as a seizure), Mr. Jardine was confused (common soon after a seizure), and apparently did not comply with EMTs orders to remain seated. EMTs, misinterpreted behaviors associated with his seizure as combative behavior and forcibly restrained Mr. Jardine while he was handcuffed behind his back. The EMTs forced Mr. Jardine to the floor, applying pressure to his shoulders, arms and legs to immobilize him, and strapped him face-down on a gurney. He was still handcuffed. While in route to the hospital, the EMTs noticed that Mr. Jardine had stopped breathing and had no pulse. The handcuffs could not be unlocked, because the key remained with a security guard on campus. Mr. Jardine was pronounced dead by emergency room physicians shortly after his arrival at the hospital.*

Unfortunately, this story represents the worst of what can happen when first responders are unaware of how to manage the student having the seizure.

Currently, the Epilepsy Foundation has a training program for law enforcement and emergency first responders. This training provides critical information on how to appropriately respond to someone having a seizure. This is an online training that can be accessed at: [www.epilepsyfoundation.org/firstresponders](http://www.epilepsyfoundation.org/firstresponders)

[Safe and appropriate response to seizures starts with understanding the condition of epilepsy.](#)

Epilepsy is a medical condition that is considered to be episodic. This means it occurs sporadically and without warning. Students have no control over what happens during the course of a seizure.

When a report comes in about someone acting strangely, or creating a disturbance, always consider the possibility that a seizure is taking place or has just occurred.

When a student has a seizure it can affect speech, consciousness, and movement. This means that a student may not be able to respond to you, or may respond or interact in a manner that does not make much sense. Confusion and disorientation may occur after a student has a seizure and can last for some time. If a student is still disoriented after 30 minutes, further evaluation at an Emergency Department is warranted.

Confusion and disorientation after a seizure can cause a student to not respond to questions, instructions, or directives making them appear to be uncooperative.

Some common seizure symptoms include: running, spitting, biting, shouting, screaming, flailing movements & abusive language.

There are many different types of seizures so behavior will vary. One seizure type is a simple partial seizure. This type of seizure can cause someone to have a blank stare or act dazed. It is often confused with someone being under the influence of drugs or alcohol.

If you are unsure if someone is having a seizure or symptoms of a medical condition, it is best to error on the side of caution and notify the school nurse immediately. The school nurse will assess the situation.

## **WHAT CAN YOU DO TO HELP THE STUDENT WHO IS HAVING A SEIZURE?**

Follow policies on personnel notification in the event of a student seizure.

- Check for a medical identification card or bracelet indicating that the person has epilepsy.
- Time the length of the seizure. A seizure lasting for more than 5 minutes can cause injury to the brain. Unless a rescue medication is available, 9-1-1 should be called for any seizure lasting longer than 5 minutes.
- If bystanders are telling you that the person has epilepsy, assume that the observed behavior is seizure-related.
- Some people have a Vagus Nerve Stimulator (VNS) that works like a pacemaker to help control seizures. The VNS is implanted just under the skin in the upper chest. Check to see if the person has a NCP patient emergency information card and Cyberonics magnet. Follow the instructions on the card.
- Never restrain a student who is having a seizure or who has just had one. Restraints may lead to severe injury.
- Never put anything into the student's mouth.

Place the student having a seizure on their side. Never place a student who is having a seizure, or has just had a seizure face down or in a hold. This can obstruct their breathing and cause death.

- Reassure the student that everything will be okay.

## **WHAT CAN YOU DO TO IF A STUDENT IS HAVING A SEIZURE IN A WHEELCHAIR?**

- Do not remove a student from the wheelchair during a seizure.
- Make sure the wheelchair brakes are on.
- Secure the child in the seatbelt. If there is no seatbelt on the wheelchair, stand in front of the chair so the student does not fall forward.
- Remove or pad any hard object on the wheelchair that may cause injury (i.e., metal arms of the chair).
- Hold the wheelchair in place to prevent toppling to one side.
- If you are able, partially recline the wheelchair. If you are unable to, the child may need to be removed in order to keep the airway open. If the child has to be removed from the wheelchair, follow the basic seizure first aid as previously outlined.

# SECTION 2

## Bus Drivers & Monitors

# Handling a student who is having a seizure can be frightening and school personnel can feel ill-equipped to manage the situation if a planned procedure isn't in place.

Bus drivers and monitors may have to provide seizure first aid while transporting a student. The following are recommendations for responding to a seizure on a school bus.

Following the steps below will ensure effective response to the seizure.

- Safely pull over and stop the bus in order to assess the situation.
- Clear the area around the student who is having the seizure (i.e., remove books or other hazards) and put something soft, like a jacket, under the student's head and body to prevent injury.
- Provide care for the seizure where the student's seizure occurs. If the student falls in the aisle, turn the student on their side and provide care there. If the student has a seizure while in their seat, turn the student on their side, and face the student towards the front of the bus. This will help ensure that the airway is clear and breathing is not obstructed. If a student has a seizure on a bus seat, monitor the student closely to avoid falling or injury.
- If the seizure continues for more than five minutes or is immediately followed by another one, call 9-1-1 to access emergency care. Stay with the student until emergency medical personnel arrive on the scene.
- Once the student is oriented, assist the student in returning to the seated position.

Be sure to follow your school's policy regarding notifying appropriate school personnel when a student has had a seizure.

Additional recommendations to ensure child safety while riding a school bus include:

- Seat the student at the front of the bus where the bus driver can easily get to the child if a seizure should occur.
- Schedule the route so the child is the last stop on the bus route in the morning and the first stop on the route on the way home. This will reduce the time the student spends on the bus, decreasing the likelihood that a seizure will occur on the bus.
- Bus monitors should always escort the child on and off the bus both in the morning and at the end of the school day.
- Bus monitors should be equipped with a walkie-talkie in order to make prompt notification to the appropriate school personnel if a student has a seizure.



# SECTION 3

## Social Workers

# In certain cases, a social worker may be assigned to a family to facilitate education on epilepsy and effective seizure management.

Social workers play an important role in helping the family to understand and accept considerations that must be made in order to ensure safety and more effective functioning of their child. Below are some recommendations for providing age appropriate epilepsy education to the student with epilepsy.

## **PRESCHOOL -5 YEARS**

At this age, the child should have a simple explanation of the illness. The child should understand that something irregular is happening to their body and the role of medication. The focus should be on what the child can do and not any limitations that may be posed by having epilepsy.

## **6-11 YEARS OLD**

Students in this age group will have a more basic understanding of the body, thus the explanation of epilepsy can be more detailed and specific. At this stage of development, the student will have reasoning skills, and will be able to make the connection between having a seizure and taking medication. The student may have concerns about their seizures and may need support and reassurance.

## **12-18 YEARS OLD**

Students in this age group have a higher level of understanding about epilepsy. They should know multiple causes of the illness and the individual factors that can trigger seizure activity. Epilepsy prevention should be explained in detail because the teen needs to be able to determine and weigh risks. The teen may need help in developing coping strategies and should be encouraged to discuss problems and concerns openly. Guided support is needed at this stage; it will help to further develop their independence and self-management of their symptoms.

Social Workers also bring unique knowledge and skills to the school system and the student support services team. Listed below are the primary functions of the school social worker and resources to assist in facilitating linkages/care for the student with epilepsy.

The primary functions of a school social worker are:

- Educating the student about epilepsy
- Providing education and information about community outreach education programs
- Providing Respite Care/Educational and Vocational Resources
- Providing Advocacy/Discrimination Resources
- Providing Medical Resource Information including Medical and Neurology Centers
- Providing Information on Mental Health & Counseling Resources. Click [here](#) for resources to assist in facilitating linkages/care for the student with epilepsy.



# SECTION 4

## School Nurses

**The Seizure Action Plan is a tool to assist school personnel in more effective management/responding to a student's seizures.**

Since the School Nurse is the provider of direct care to students, the school nurse has the primary responsibility of the management of the Seizure Action Plan and facilitating communication with the school team regarding the plan. When a student has specialized needs that require an Individualized Education Plan (IEP), the school nurse ensures that the student's Seizure Action Plan is part of the IEP and that it is implemented with full school team participation. The sample Seizure Action Plan is a printable form that is available [here](#).

## ANTIEPILEPTIC DRUGS

The following provides information about Antiepileptic Drugs (AEDs) which are used to treat epileptic seizures.

- AEDs along with all other medications have the potential to cause side-effects.
- Side-effects don't always happen to everyone. Some are common, some are very rare.
- Side-effects may only happen in certain patient populations (children, elderly).
- Some only happen when the drug is used in a certain way.

## WHAT ARE COMMON SIDE-EFFECTS?

### Dose-Related Side-Effects:

Unwanted physiologic effects of the drug on the brain are related to the dose of medication and are usually related to the nervous system. These effects may present as difficulty concentrating, dizziness, unsteadiness, and double vision. Side effects may happen at low doses; but are more likely at high doses. Once they happen, they tend to get more severe as the dose increases.

### Signs of Dose Related Toxicity:

- With older AEDs such as Dilantin (Phenytoin) ataxia, diplopia (also referred to double vision): decreased concentration, and fatigue.
- With Tegretol (Carbamazepine): ataxia, diplopia, decreased concentration, and fatigue.
- With Depakote (Valproic acid): decreased concentration, tremor.

With newer AEDs, there tends to be less than older drugs, when used alone to treat seizures. Dose related toxicity can occur when combined with other drugs.

### What is the relationship of dose-related side-effects?

Blood levels give an "average" range of the amount of medication in the blood stream that will be high enough to control seizures, but not high enough to cause dose-related toxicity. However, individuals can react differently! Some individuals get side-effects at low levels, and others feel fine at low levels and vice versa.

### What are the psychiatric /behavioral issues with AEDs?

- Some AEDs are more likely to cause psychotic symptoms.
- AEDs that may worsen psychiatric function are Levetiracetam, Topiramate, Zonisamide, Tiagabine, and Phenobarbital.
- Other AEDs may actually improve mood and behavior. AEDs that may improve psychiatric function are Carbamazepine, Valproate, Lamotrigine, and Pregabalin (anxiety).

Be advised: If there are psychiatric issues before starting a drug, the risk of problems is higher. Sometimes psychiatric side-effects are unpredictable. Psychiatric side-effects only affect a small proportion of people who start a drug. Remember that effects vary by individual.

## WHAT ARE THE EFFECTS OF AEDS ON THE BODY?

AEDs can have several different effects on the body. Many AEDs influence liver metabolism and some AEDs will increase or decrease liver metabolism. Drugs that increase metabolism: Phenytoin- Dilantin and Phenytek, Carbamazepine- Tegretol, Tegretol XR and Phenobarbital.

## OTHER BODY EFFECTS

Both Vitamin D (important for bone health) and Vitamin K (important for clotting) can be affected by an increased metabolism from certain AEDs. Less Vitamin D can lead to an increased risk of bone thinning. Compared to the general population, patients with epilepsy are at three times the risk for hip fractures and are at two times the risk for all fractures.

### Hormones that may be affected by antiepileptic drugs:

**Estrogen**- may decrease which can cause obesity, polycystic ovarian syndrome, and may have an effect on libido and other body functions.

**Progesterone**- may decrease this hormone

**Thyroid hormones**- Tegretol (XR and Carbatrol) are the only known AEDs to affect the Thyroid. Interestingly, thyroid function is usually not affected, but TESTS that measure thyroid are.

Some antiepileptic drugs will either cause weight gain or weight loss in individuals. This occurs only in a portion of individuals taking AEDs.

**AEDs that can increase weight:** Depakote, Neurontin, Tegretol, and Lyrica

**AEDs that can decrease weight:** Topamax and Zonegran

## RARE AED SIDE-EFFECTS

Idiosyncratic (those related to the drug)- very rare and unpredictable. Often there is a genetic predisposition that causes this to occur. Almost always this will occur within 2 years of starting a new drug (and most within 6 months).

## LIST OF COMMON ANTI-EPILEPTIC MEDICATIONS AND THEIR SIDE-EFFECTS

### Carbamazepine (Tegretol, Carbatrol)

Potential side-effects include GI upset, weight gain, blurred vision, low blood counts, low blood sodium (hyponatremia).

Carbamazepine causes a rash in only a few percent of individuals. Sometimes this medication can cause a very dangerous rash called Stevens-Johnson syndrome. The Stevens-Johnson syndrome rash may look like hives, however can also have blisters of various sizes and can occur on the upper body, legs, arms, palms, hands, or feet and may involve the face or lips. This rash is often accompanied by the following symptoms: fever, general ill feeling, itching of the skin, and joint aches.

### Clonazepam (Klonopin)

Side-effects include sedation, thinking/memory impairment, mood changes, and addiction.

### Gabapentin (Neurontin)

Side-effects are unsteadiness, weight gain, fatigue, and dizziness.

### Lacosamide (Vimpat)

Side-effects include dizziness, headache, nausea or vomiting, double vision, fatigue, memory or mood problems.

Vimpat may affect the internal organs, blood counts or heart rhythm, but these potentially serious side-effects are infrequent.

### Lamotrigine (Lamictal)

It has the usual side-effects of dizziness and fatigue, usually mild cognitive (thinking) impairment. Severe medical side-effects are unusual. The practical side-effect issue is a rash, which occurs in a larger percent of people who take it, especially if the dose is increased too fast.

### **Levetracetam (Keppra)**

The most common side-effects are dizziness, fatigue and insomnia. The more troublesome side-effects can be irritability and mood changes.

### **Oxcarbazepine (Trileptal)**

Slight different from Carbamazepine, it is at least as effective and may have fewer side-effects. Increased risk for low blood sodium (hyponatremia).

### **Phenobarbital (Luminal)**

Watch for sedation, thinking/memory problems and depression. Phenobarbital can cause long-term bone problems and is mildly addictive and requires slow titration off this medication.

### **Phenytoin (Dilantin)**

Common side-effects are unsteadiness and moderate cognitive problems.

### **Pregabalin (Lyrica)**

Pregabalin has no drug interactions, no liver metabolism issues, no protein binding issues and side-effects are unsteadiness, weight gain, fatigue, and dizziness.

### **Rufinamide (Banzel, Inovelon in Europe)**

Common side-effects include headache, dizziness, fatigue and sleepiness, double vision and tremor (trembling).

### **Topiramate (Topamax)**

Side-effects include thinking and memory problems in about 1/3 of individuals, renal stones in 1-2% of patients. Rare cases of glaucoma (increased eye pressure) and weight loss.

### **Valproic Acid (Depakote)**

Significant side-effects: weight gain, tremor, hair loss, GI upset, blood count decreases, hepatic or pancreatic injury. Over time, bone weakness (osteoporosis), birth defects in up to 10% of individuals (folic acid can help to prevent them).

### **Vigabatrin (Sabril)**

Release in the US was delayed because the drug is toxic to the retina of the eye in up to 30% of patients who take it long-term. This toxicity can result in permanent loss of peripheral vision.

### **Zonisamide (Zonegran)**

Zonisamide is rather similar in its coverage to Topiramate and side-effects are thinking and memory problems in about 1/3 of individuals, renal stones in 1-2% of patients. Some patients have less cognitive impairment than with Topiramate but this is individual and dose dependent.

## **RESCUE MEDICATIONS**

A rescue medication is used to stop a seizure, unusually prolonged cluster of seizures, and to prevent status epilepticus (a prolonged seizure, usually defined as lasting longer than 30 minutes, or a series of repeated seizures without regaining consciousness).

### **Lorazepam (Ativan)**

Side-effects include drowsiness, fatigue, and sleep.

### **Diastat (rectal gel)**

Used as a rescue medication, main side-effect is sleep.

## **GENERAL INFORMATION RECTAL DIAZEPAM (DIASTAT® OR DIASTAT® ACUDIAL™)**

### **Information Regarding Rectal Diazepam**

Rectal Diazepam is used to control clusters of seizures and/or prolonged seizures. It is similar to other benzodiazepines (Valium), but because it is a rectal gel preparation, it is more convenient for patients who cannot swallow during or after seizures. Rectal Diazepam is supplied in a plastic applicator. The dose is determined by child's age and weight.

Be sure to refer to a student's Seizure Action Plan regarding the dosage of this medication prescribed. Upon receipt of physicians' orders for Rectal Diazepam, it is recommended that the school nurse should obtain and record a normal resting breathing rate for the student as a baseline.

#### **Side-effects of Diastat(Rectal Diazepam)**

Sedation is by far the most common and most severe side-effect: some patients are sleepy for up to one day. Headache, diarrhea, and dizziness may also occur. There is significant risk of habituation and addiction if this medication is taken chronically, and risk of worsening seizures if the medication is abruptly withdrawn after chronic use. More rare side-effects include: agitation, anxiety, hallucinations, fainting and decreased respiration rate (<10/minute). A rash can occur if there is an allergic reaction. Rectal Diazepam is a relatively safe medication. If the band is not visible, it should be returned to the pharmacy because the medication dose has not been "dialed" in.

As school personnel may not reliably know about same day use of Rectal Diazepam prior to school or new medications that may alter the effects of Rectal Diazepam, special precautions are recommended for school administration. It is the PARENT'S responsibility to notify school when Rectal Diazepam has been given within a 24-hour period, outside of school hours.

### **DIASTAT (Rectal Diazepam)**

The Diastat rectal delivery system includes a plastic applicator with a flexible, molded tip available in two lengths. The prescribed dose of Diazepam rectal gel should match the physician's order and will be displayed in the dose display window. The green "READY" band will be revealed at the base of applicator.

In order to ensure the safe and timely administration of Rectal Diazepam if it should become necessary during the time the student is at school, Diastat preplanning and administration guidelines are listed below.

## **RECOMMENDED PREPLANNING AND EQUIPMENT**

The following should be in place in order for the procedure to be performed at school.

- A complete report of a current neurological assessment (within one year).
- A Physician's Authorization for medication completed by physician and signed by parent, including indications/contraindications and follow-up plan.
- Properly labeled pharmaceutical container with medication and specific instructions. Prior to storing the medication for future use, the School Nurse must verify the correct dosage has been dialed, and documented on the Seizure Action Plan.
- Oxygen if available and prescribed.
- Seizure Action Plan (that lists emergency meds).
- Gloves.
- Written instruction for administration of this medication.
- Blanket or sheet to provide privacy for the student.

## **DIASTAT ADMINISTRATION**

### Procedure

- Perform basic seizure first aid.
- Time the seizure and observe the seizure pattern (such as the number of seizures clustered together, nature of movements and level of consciousness).
- All students with seizures will have Seizure Action Plan that will list emergency seizure medication.
- Check expiration date on the Diastat and ensure that the protective cap is removed prior to administration.
- Administer Rectal Diazepam as directed.
- Make sure the correct dose appears through the dose display window. This is a visual indication that the barrel of the DIASTAT® AcuDial™ is in the correct position for the desired dose.
- Ensure that the locking ring is engaged. The green “READY” band will be revealed at the base of the DIASTAT® AcuDial™. This allows you to see that the unit has been locked.
- Repeat these steps for each DIASTAT® AcuDial™ received.
- Document seizure action per district policy.

After administering Rectal Diazepam monitor the following for four hours:

- Change in rate of respirations
- Change in color of skin

### **ADDITIONAL RECOMMENDED PROCEDURES FOR RECTAL DIAZEPAM**

- The person administering the Rectal Diazepam should have current certification in CPR.
- The School Nurse needs to verify the dosage received matches the physician’s order and document this.
- Rectal Diazepam medication should be locked in a secure location.

Rectal Diazepam orders must include the following information:

- Duration and type of seizure activity before Rectal Diazepam is administered. Nurses will be provided training on Diastat use per their school’s policy.
- Exact dose of the drug.
- Action to take once seizure activity has been stopped (This can be individualized for each student depending on the outcome of Diastat administration and what is specified in the Seizure Action Plan.
- Action to be taken if child has a bowel movement or otherwise expels the medication.
- Check for any contraindications to the Rectal Diazepam (e.g. fever, respiratory infections, etc.).

For some students, call 9-1-1 for transport. Others may remain in school. Always call 9-1-1 for EMS personnel if:

- Rectal Diazepam has not succeeded in ending seizure.
- Seizure recurs after having Rectal Diazepam on the same school day.
- The student’s very first trial of Rectal Diazepam is being given at school.



# SECTION 5

Teachers,  
Special Education,  
Preschool Teachers, &  
Paraprofessionals

# **A student with seizures may experience the world as stressful, unpredictable and frightening. Fear and anxiety can be related to the unpredictability of their seizures. As a result the student will have more challenges to overcome in order to develop a sense of self-competence and self-esteem.**

It is important that the student with epilepsy is not excluded from experiences that can assist in the development of social skills and self confidence. This sense of being different or unable to join what others are doing encourages dependence in a child. Being aware of safety considerations is important, but should not limit inclusion of the student in daily activities.

## **BUILDING RESILIENCE**

Students can pick up quickly on teacher anxiety. Adult anxiety about a student's seizures compounds a student's fears, increases their stress level, and can lead to learned helplessness or acting out behavior. It is important to refrain from communicating anxiety. Learning about epilepsy and making sure your students are aware of the condition can help to alleviate anxiety. The following are strategies to help the student with epilepsy.

Routines are important. They help a student with epilepsy to feel secure. For younger children, this can include a story before nap time and always sitting in the same place (assigned seating). Classroom rituals, such as making greetings personalized for each student and celebrating special activities, (i.e. birthday parties) help build positive social interactions.

The lack of predictability of seizures causes many students, especially those with more sensitive temperaments, to become fearful about all types of change. Transitions, such as a change in the classroom or with transportation can be stressful and result in emotional breakdowns. Students with epilepsy will benefit from proactive planning and support when changes are made in the school environment.

## **TEACHING STRATEGIES**

Students with epilepsy can have problems with learning, memory, as well as emotional and behavioral issues. For some students learning problems are the direct result of having frequent seizures and side-effects from medication that cause problems with short term memory. When teachers modify teaching styles and strategies to meet the needs of the student, this can have a positive impact on the student's capacity to learn in the classroom. The following teaching strategies are recommended in working with the student with epilepsy.

Try to keep the teaching format structured such as direct instruction. Direct instruction is a general term for teaching a skill-set that emphasizes well-developed and carefully planned lessons designed around small learning increments and clearly defined and prescribed teaching tasks. It is based on the theory that clear instruction eliminates misinterpretation and can greatly improve and accelerate learning.



Research has shown that despite learning difficulties, students with epilepsy can make academic gains when taught by highly structured teaching methods.

- Have clearly written classroom rules posted at all times
- Seat the child near the front of the room to reduce distractions
- Offer audio textbooks
- Allow extra time to take quizzes and tests
- Provide the option to take tests privately and in a separate room if this would help to reduce a student's anxiety
- Modify homework by reducing heavy reading and writing assignments

### **MISSED WORK & CATCH-UP WORK STRATEGIES**

Regardless of what type of seizures a student may have, when a seizure occurs it results in missing information being taught, including teaching instructions, and assignments.

The strategies below are recommended to keep the student on track to be successful in learning:

- Establish a partner system for the child with epilepsy. A student can use the assigned partner as a resource to get missed work, notes, homework, or handouts.
- Have a teacher or teacher's aide check in with the student after each teaching lesson and at the end of the day. Monitoring the student closely will help ensure the student has everything on track for the next lesson and next school day. This will also help to reduce the chance of the child falling behind on schoolwork.

### **TECHNIQUES FOR INCREASING MEMORY**

Those who are living with epilepsy often have memory loss after a seizure.

Some recommendations to help increase memory in the classroom include:

- Use of physical props (pointing to a page, writing on the blackboard)
- Use visual aids
- Repeat the information and employ over-learning techniques (practice or repetition of a skill past the point necessary for retention or recall permits the response to become automatic or internalized)
- Ask the student to repeat an assignment or directions aloud
- Write assignments down in an assignment book

### **TECHNIQUES FOR INCREASING SOCIAL INTERACTION**

- Develop a student tutor or peer program where classmates help the student with epilepsy work on different projects, homework, or a certain subject. This will not only help the child with schoolwork, but also will help increase the social interaction among classmates.
- Incorporate small-group projects into a teaching plan
- Encourage small play groups

## **TECHNIQUES FOR MANAGING FIELD TRIPS**

Students with epilepsy benefit from more hands-on activities. Students should never be excluded from field trips unless specially instructed by a doctor.

Recommendations for a field trip/group outing:

- Have the student wear a medical alert bracelet to indicate he/she has epilepsy
- Have a chaperone or parent accompany the student on the field trip to help monitor the student
- Review basic seizure first aid prior to the trip in the event the student has a seizure
- Carry an emergency contact sheet with important names and numbers including medical history and a list of medications

## **WHAT TO DO IF YOU HAVE AN UNDIAGNOSED STUDENT**

If you think a student has epilepsy, do not diagnose the condition.

Listed below are recommendations to help evaluate and track concerns about a student.

- Document any unusual student behavior. Write down what it looks like, when it happens, how long it lasts, and what the student was doing right before the behavior began. This includes any psychiatric symptoms that you may observe.
- Discuss your observations with the school nurse and other administrators/ teachers at the school to see if they have noticed similar behavior.

## **TIPS FOR PARAPROFESSIONALS IN THE CLASSROOM**

In certain cases, a student with epilepsy may be assigned to a paraprofessional who can help a student with epilepsy in the following ways:

- Monitor behavior
- Document precursors to the seizure
- Document symptoms of a seizure
- Document any behaviors including any psychiatric symptoms

Listed below are ways that paraprofessionals can be helpful to a student with epilepsy:

- Leading small group instruction designed by the teacher
- Gathering materials for students
- Providing assistance with personal care and other physical needs
- Assisting students to follow directives given by the teacher
- Facilitating interactions between students
- Adapting lessons under the teacher's guidance to best meet the needs of the student

## **RECOMMENDED EPILEPSY BOOKS FOR KIDS**

The following is a list of books that may be used with younger children in the classroom to educate students about epilepsy:

- Dotty the Dalmatian has Epilepsy, from the Dr. Wellbrook Collection; Tim Peters & Company.
- Lee, the Rabbit with Epilepsy (intended for ages 3-6)
- My Friend Matty: A Story About Living with Epilepsy, Debra and Richard Siravo; The Drummond Publishing Group.
- Taking Seizure Disorder to School: A Story About Epilepsy, Kim Gossin; Jay Jo Brooks, 1996.

## **SEIZURE DOCUMENTATION FORM**

The Seizure Documentation Form is available as part of this Manual and can be printed for use.

**The Seizure Documentation Form** is a tool for teachers to document what occurs when a student has a seizure so that they can then provide this information to the school nurse. This documentation can be useful in seeing seizure patterns and potential triggers to seizures.

## **EPILEPSY RESOURCES FOR TEENS**

The Epilepsy Foundation has a website that is tailored to meeting the needs of teens: [www.takechargeteens.org](http://www.takechargeteens.org). This website has a chat room for teens with epilepsy and provides information on living with epilepsy, highlighting dating, driving, sports, and activities.

EYC is an interactive website for children and adolescents with epilepsy. This website was produced by the Epilepsy Foundation and can be found at: [www.goeyc.org](http://www.goeyc.org)

## **EPILEPSY RESOURCES FOR TEACHERS/PARAPROFESSIONALS**

Epilepsy in Young Children, A Guide for Preschools and Child Care Centers

Free teaching resources for special education can be found at: [www.senteacher.org](http://www.senteacher.org)

Materials for teaching and resources can also be found at: [www.discoveryeducation.com/epilepsy](http://www.discoveryeducation.com/epilepsy)

Special education form/documents and information can be found at: [www.sstr1.org](http://www.sstr1.org)

National Resource Center for Paraprofessionals website is: [www.nrcpara.org](http://www.nrcpara.org)

[www.epilepsy.com](http://www.epilepsy.com) is a website that provides information on all aspects of individuals living with epilepsy.

# SECTION 6

School Psychologists,  
Occupational,  
Physical & Speech  
Therapists,  
and Guidance  
Counselors

**As the student with epilepsy grows and progresses in school, his or her needs will change. With puberty and body changes there are issues of a change in seizure activity, treatment compliance, new social concerns, and effects of medication changes.**

## **RESEARCH**

These developmental changes should be considered in assessing the changing needs of the student with epilepsy.

There have been many research studies conducted on children/adolescents and epilepsy. The following summarizes some of the current epilepsy research and implications for helping professionals working with the student with epilepsy.

### **Quality of Life**

Quality of life is a measure that has been used extensively in research with this population. Quality of Life research indicates that parent perspectives alone are insufficient to measure their child's quality of life. The CHEQOL-25 is a measurement tool with complementary parent and child versions, which can be used to determine health-related quality of life in children with epilepsy.

### **Epilepsy Management**

Sleep disruption in children/adolescents with epilepsy can lead to excessive daytime sleepiness, worsening seizures, and a poor quality of life. Referral for screening for sleep disorders for students will lead to an overall improved quality of life.

35% of adolescents in one study indicated that they non-compliant with their antiepileptic medications in the prior month. It was recommended that adolescents learn the skills to independently manage their epilepsy.

Assessment of depression and learning must be considered because of their potential impact on parenting stress and the child's quality of life.

Excessive fatigue is a reported barrier to academic and social pursuits; emotional/behavioral distress is heightened by epilepsy related factors such as unpredictability of seizures.

### **Epilepsy and the Family**

Parents of children with epilepsy had significantly lower quality of life scores and higher levels of depression and anxiety. As appropriate, provide support and referrals to parents/families of the student with epilepsy.

Children and adolescents and their families need more than medical therapeutic support to have an increased quality of life. Counseling is recommended to address stress, fears, and negative reactions to epilepsy by family members.

Adolescents' attitudes, attributions, and satisfaction with family relationships are related to depression and should be assessed in the clinical setting.

## **EPILEPSY IDENTIFICATION AND COMPREHENSIVE TREATMENT**

Early identification and treatment of epilepsy can result in increased success in the daily lives of children and adolescents. Follow district policy regarding referral to appropriate school personnel for further evaluation.

The presence of a learning disability and abnormal family function are strongly predictive of social skills impairment in the child with epilepsy.

Attention needs to be directed to assessing the informational and emotional support needs of the child/adolescent with epilepsy during the diagnostic process. Ongoing assessment is critical because children and parents have ongoing needs beyond the initial encounter with healthcare professionals.

Seizures have a significant impact on school attendance and increase academic difficulties in children with intractable epilepsy (epilepsy that does not typically respond to treatment with multiple medications). Accommodations can assist in increasing the success of the student.

Depression and other psychiatric disorders are under-diagnosed and undertreated in children and adolescents with epilepsy. Signs of depression are often dismissed as “normal” reactions. Depression can be a life-threatening illness and a risk factor for suicide. Referral to a psychiatrist should be made if a psychiatric disorder is suspected.

A comprehensive care approach to the treatment of children and adolescents with epilepsy is beneficial. A team approach to psychosocial assessment and treatment must be provided and coordinated with neurologic care for the best treatment outcomes.

Epilepsy surgery in children with intractable epilepsy can result in significant improvements in seizure control, quality of life, and development. It is recommended that if a student does not have good seizure control that the parent (s)/guardian talk to the treating physician regarding evaluation for epilepsy surgery.

### **Epilepsy Specific Measurement Tools:**

- The Pediatric Quality of Life Version 4 (PedsQAL.v4.0)- measures the health-related quality of life from both the parent and child’s perspective
- Parent report and the Quality of Life in Childhood Epilepsy Questionnaire (QOLCE)
- Glasgow epilepsy outcome scale for young persons (GEOS-YP)- is a direct measure of how adolescent perceive epilepsy to impact their quality of life
- Impact of Pediatric Epilepsy Scale (IPES) – is a global instrument available that specifically measures the psychosocial impact of pediatric epilepsy on the family

## **COUNSELING CONSIDERATIONS:**

The majority of students with epilepsy will not need longer term counseling. However, it should be a consideration for students who have been assessed to have more comprehensive care needs. Counseling is a benefit for students in order to obtain a greater understanding of their epilepsy and learn to regain a sense of control over their life. There are counselors who specialize in treating individuals with developmental disabilities. See the social worker resource section for a list of these specialized counselors.

Counseling is effective in addressing fears and anxiety regarding the unpredictability of seizures. It is also a venue for teaching individuals with epilepsy how to self-manage their symptoms. The Disease Management Model is an evidence based practice for symptom self-management that has positive outcomes for individuals with epilepsy increased independent functioning, decreased health care costs, reduced hospitalizations, decreased use of emergency services, increased access to coordinated care, and improved quality of life.

Factors that can influence an individual's ability to self-manage their symptoms are:

- Confidence in one's abilities
- Satisfaction with current medical care
- Communication with doctors and health care providers
- Support
- Emotional well-being or mood
- Stigma
- Feelings of control
- Individualized goals and treatment

It is important to help the individual with epilepsy build confidence and increase their capacity to become independent in order to enhance their quality of life.

Adolescents may benefit from counseling due to specific issues that arise in their life stage such as dating, driving, and employment.

Recommendations for these issues are listed below:

### **Driving**

With driving comes the feeling of independence. This may be a significant issue for adolescents that are unable to drive due to seizures. In the State of Ohio, applicants must state under oath whether or not they have had any seizure activity or similarly impairing conditions and providing false information can result in criminal prosecution. If an individual has had any seizures within the last 5 years, they must submit a certificate from a physician stating that it is safe for them to drive. This must be updated every 6 months until the driver has been seizure-free for 5 years.

### **Dating**

It is recommended that adolescents communicate to their date that they have epilepsy and let them know what to expect in the event that they have a seizure. This may create additional stress for the teen however honest communication will result in a more positive outcome.

### **Employment**

The prospect of employment can become a growing concern for students as they mature. All students should be encouraged to choose a career path that satisfies their interests and capabilities. For most students (when epilepsy does not remit in adolescence) epilepsy is a chronic condition and there may be realistic safety considerations in their choice of professions. Students will benefit from being encouraged to follow a career path that is satisfying and safe based on their seizures and individualized needs.

## **SPEECH AND OCCUPATIONAL THERAPY CONSIDERATIONS**

Students with epilepsy may have a secondary condition that affects movement, coordination, fine motor skills, and speech. Therapy sessions may be recommended by the treating physician to help increase certain skill development. Therapists should be aware of basic seizure first aid in the event that a seizure occurs during the session.

Depending on the type of difficulties the student with epilepsy is experiencing, strategies to assist with language and communication may be warranted. Teachers and parents should ensure that any strategies or support ideas are used as fully as possible in the child's daily activities, including outside school. Landau-Kleffner syndrome, is a type of epilepsy that causes specific problems with language.

Recommendations:

- Students can find it stressful to work with a therapist. A low-key approach may help.
- Seizures might prolong the progression of therapy sessions, but it is important the sessions are not stopped because the child is having seizures.
- In the case of therapy sessions causing increased or extreme seizure activity, the sessions should be stopped and reported to the student's treating physician.

# SECTION 7

## Physical Education Teachers & Coaches

**Epilepsy affects each individual differently, therefore the approach to what a student can do in physical education and what sports they can participate in is individualized.**



The goal should be both student safety and inclusion in all activities in which they can participate. No activity is completely safe for any student, however there are recommended considerations for the student with epilepsy:

- Seizure type and frequency are critical in determining which activities are safe. A student whose motor control or consciousness is impaired during seizures is at higher risk for injuries. A student who has uncontrolled, frequent seizures should know that certain activities are restricted or require supervision (i.e. rope climbing).
- Drowsiness and lethargy are the 2 most common physical effects that result from epilepsy and epilepsy treatment and may affect a student's ability to participate fully in activities.
- Seizures are only rarely provoked by exercise. When this pattern is identified, physical exertion should be limited.
- Participation in sporting events/activities helps to increase a student's sense of belonging and self-esteem and most importantly fosters a sense of independence.
- Serious injuries in children/adolescents with epilepsy are uncommon and rarely occur during participation in sports. Interestingly, bathrooms are much more dangerous to students than playing soccer or ice skating.
- Using a buddy system for swimming and other events/field trips is helpful in monitoring the student.

If there is uncertainty regarding any potential safety risks for the student talk to the parents who can consult with the student's treating physician regarding the level of activity the student can engage in.

#### **RESPONDING TO A SEIZURE IN THE WATER:**

A student with epilepsy should never swim unsupervised. If a student has a seizure in the water the following the steps are recommended:

- Support the student's head and keep it out of the water.
- Assist the student to land as soon as possible and turn the person on one side once they are out of the water.
- Make sure the airway is clear and breathing is not obstructed.
- Notify staff/school personnel that can assist.
- Seek emergency medical treatment if there is any possibility that water has been swallowed or breathed in to the lungs.

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**Epilepsy Association**

2831 Prospect Ave., Cleveland, Ohio 44115

Phone: 216-579-1330 • Fax: 216-579-1336

[www.epilepsyinfo.org](http://www.epilepsyinfo.org)