



# WELCOME

## Wyoming Statewide Training: Managing Students with Epilepsy

Training will start at 12:30



UNIVERSITY OF WYOMING  
Wyoming Institute for Disabilities

# **Wyoming Statewide Training: Managing Students with Epilepsy**

David B Wheeler, MD, PhD, Director  
Wyoming Epilepsy Center

[www.wyomingneurology.com](http://www.wyomingneurology.com)

# Acknowledgment of Sources

This presentation is adapted from the following online programs of the Epilepsy Foundation:

- ***Managing Students with Seizures*** provides school nurses with continuing education to address the real and immediate needs of managing students with epilepsy.
- ***The School Personnel Training*** provides school staff with information about epilepsy, seizures, seizure first aid, and the effects epilepsy can have on the child as a whole.

<http://www.epilepsy.com/get-help/services-and-support/training-programs/seizure-training-school-personnel>

# Purpose of Training

- To enable school personnel to more effectively manage seizures in students by:
  - Creating a safe and supportive school environment
  - Supporting positive treatment outcomes
  - Teaching school personnel about seizure recognition and first aid
  - Maximizing educational and developmental opportunities

# Roles of School Nurses

- Help to create an environment in which the child continues to achieve educational goals
- Recognize seizure activity and the impact on a student's health and daily life
- Ensure appropriate seizure first aid is given
- Coordinate ongoing treatment with the student, parents, the school and the healthcare team
- Train teachers and other personnel to recognize seizures and provide first aid and other out of hospital intervention

# Objectives

- Describe classifications of seizures and epilepsy, potential triggers, and risk factors for seizures and emergencies.
- Describe common treatments for epilepsy, potential side effects, and when referral to epilepsy specialist is necessary.
- Provide appropriate first aid for a student during and after a seizure.

# Objectives

- Implement a **Seizure Action Plan** in a school environment utilizing safe practices for medication administration.
- Implement strategies to alleviate psychosocial aspects of epilepsy for students, parent and teachers.
- Utilize resources to train school personnel on safe care and assistance in students with seizures.

# Classifications of seizures and epilepsy

Potential triggers, and risk factors for  
seizures and emergencies



# Seizures and Epilepsy

- Seizure is a symptom of a disturbance in the electrical activity of the brain
- Epilepsy is a disorder characterized by a tendency for recurrent unprovoked seizures
  - *Recurrent* - 2 or more
  - *Unprovoked* - not caused by other known medical issues
- Epilepsy = SEIZURE DISORDER

# Epilepsy is a Common Problem

- About 2.2 million Americans have epilepsy
- More than 65 million worldwide have epilepsy
- Affects more than 315,000 students in the U.S.
- 150,000 people/year newly diagnosed epilepsy
- 1:26 people will develop epilepsy in their lifetime
- Epilepsy is the 4<sup>th</sup> most common neurological disorder after:
  - 1) Migraines
  - 2) Stroke
  - 3) Alzheimer disease

# What Causes Epilepsy?

- For approximately 70% of students who are diagnosed with epilepsy the cause is either:
  - Unknown
  - Presumed to be genetic
- For the remaining 30%, the seizures are symptoms of a known cause such as:
  - Stroke, hypoxic injury, tumor, trauma, fever, infection, intoxication, demyelination...

# Risk Factors for Childhood Onset Epilepsy

- Seizures onset before 1 year of age
- Prior provoked seizures
- Neuro-developmental delays
- Intellectual disability and cerebral palsy
- Prolonged or complex febrile seizures

# Seizure Triggers and Precipitants

- Missed or late medication
- Emotional stress
- Sleep deprivation
- Hormonal changes
- Alcohol
- Recreational drugs
- Drug interactions
- Missed meals, specific foods or drinks
- Nutritional deficiencies
- Specific stimuli
  - Flashing lights or patterns (flashing lights, videogames, computers)
  - Hyperventilation
  - Loud or specific sounds
  - Other stimuli

# Phases of a Seizure

- **Prodrome** – Behavioral changes seen hours or days before a seizure
- **Aura** – First symptom of a seizure, often called a “warning,” most commonly seen with partial seizures
- **Ictus** – What is seen/felt during a seizure
- **Postictal** – What is seen/felt after the seizure, until the brain recovers to baseline

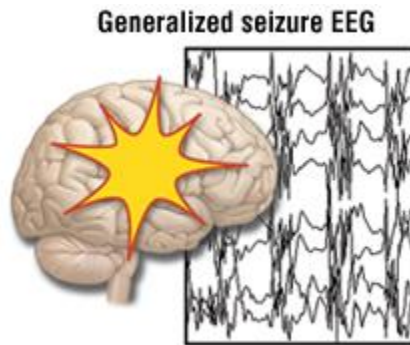
# Seizure Behaviors or Characteristics

- Behaviors in a seizure are:
  - Episodic
  - Often sudden and unexpected
  - Stereotypic - look the same or similar each time
  - Variable intensity
- Seizure behaviors may or may not be modifiable by environmental or behavioral factors

# Seizure Classification

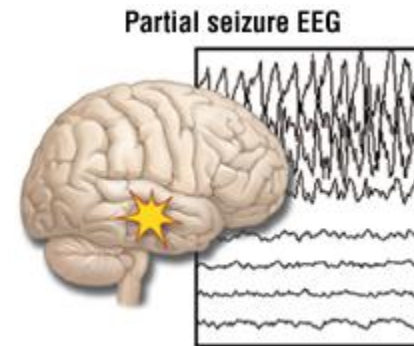
## Generalized Seizures

- Involves whole brain
- Convulsions, staring, muscle spasms, and falls
- Most common are absence and tonic-clonic



## Partial or Focal Seizures

- Start in one part of brain
- Symptoms relate to the part of the brain effected





# Tonic-Clonic Seizure

- A sudden hoarse cry
- Loss of consciousness; may fall if standing
- Muscles become tonic or stiff
- Convulsions (stiffening of arms and legs followed by rhythmic jerking)
- Shallow breathing and drooling may occur
- Possible loss of bowel or bladder control
- Occasionally **cyanosis** (skin, nails, lips may turn blue)
- Generally lasts 1 to 3 minutes
- Usually followed by confusion, headache, tiredness, soreness, speech difficulty
- Biting of tongue or inside of mouth may occur

# Absence [ab-sahns] Seizures

- Pause in activity with blank stare
- Brief lapse of awareness
- Possible chewing or blinking motion
- Usually lasts 1-10 seconds
- May be confused with:
  - daydreaming
  - inattentiveness
  - ADD

# Other Generalized Seizures

- *Myoclonic* – rapid, brief muscle contractions, may occur singly or in clusters, affect certain muscle groups, or one or both sides of body
- *Tonic* – bilateral stiffening or posturing of body
- *Atonic* (drop attack) – loss of tone, may result in drop of head, trunk, or whole body

# Simple Partial Seizures

- Consciousness is not impaired
- Involuntary movements (isolated twitching or movements of arms, face, legs)
- Sensory symptoms (tingling, numbness, sounds, smells, tastes, visual distortions)
- Psychic symptoms (déjà vu, hallucinations, fear, anxiety, “a feeling they can’t explain”)
- Duration is usually less than 1 minute
- May be confused with: acting out, mystical experience, other sensory experiences, psychological problems

# Complex Partial Seizures

- Altered awareness
- Blank stare/dazed look
- Automatism
  - repetitive hand movements, lip smacking, chewing)
- Nonsensical speech, content inappropriate, or unable to talk
- Clumsy or disoriented movements
- Aimless walking
- Picking things up
- Often lasts 1 to 3 minutes
- Often followed by tiredness, headache or nausea
- May be confused with:
  - drunkenness or drug abuse
  - aggressive behavior

# Secondarily Generalized Seizures

- Partial seizure spreads to involve entire brain
- Begins with simple or complex partial seizure
- May spread rapidly or occur after a typical partial seizure
- Generalized seizure may consist of:
  - Tonic – stiffening of muscles, rigid tone
  - Atonic – loss of tone
  - Tonic clonic – stiffening and jerking movements

# Non-Epileptic Seizures or Events

- Events that look like epilepsy seizures but on EEG monitoring have no correlate (abnormal electrical discharges at time of clinical symptoms)
- Video-EEG monitoring is the most effective way of diagnosing events
- Can be caused by a variety of physical or psychological factors (depression; anxiety; PTSD; sexual, physical or emotional abuse)

# Students with Epilepsy – Outlook

- Students may outgrow epilepsy – may be seizure free and off medications as adults
- Majority of seizures are not medical emergencies and end on their own
- Some students have more than one type of seizure
- ~2/3 of students have complete or almost complete seizure control when they take medication as prescribed
- ~30% do not achieve control with medical therapy



# Intractable or Refractory Epilepsy

Students with intractable seizures:

- Have failed at least two adequate trials of appropriate medications for their seizure type
- May have underlying structural changes in the brain and other neurological problems
- *Pose the greatest challenge for the school nurse*

# Risks with Seizures and Epilepsy

- Seizures *can* result in injury or adverse events
- Seizure emergencies, though rare, can be life-threatening
- Seizures and seizure emergencies are unpredictable and episodic – a rapid response to appropriate treatment is crucial

# Types of Emergencies in Students with Epilepsy

- Seizure emergencies
  - *Potential emergency* – changes in typical seizure clusters or frequency
  - *Actual emergency* – status epilepticus
- Injuries or adverse events
  - Physical injuries
  - Delayed or unrecognized complications of seizures
    - aspiration pneumonia, head trauma, fracture
  - Serious treatment side effects
  - Worsening of comorbid conditions

# Convulsive Status Epilepticus

- One tonic clonic seizure lasting 5 minutes or longer
- Multiple seizures occur without recovery to baseline between events

# Non-convulsive Status Epilepticus

- Usually involves partial or absence seizures
- Prolonged or clusters of seizures
- Multiple seizures without recovery to baseline
- Difficult to detect – student may appear confused or in a postictal phase of a seizure

# Death in Epilepsy

- People may die during a seizure or due to complications from a seizure or status epilepticus
- The most common form of death in epilepsy is **SUDEP**, Sudden Unexplained Death in Epilepsy
  - applies to a sudden death in someone known to have epilepsy, in the absence of an obvious cause for the death

# Common treatments for epilepsy

Potential side effects, and when  
referral to epilepsy specialist is  
necessary.

# Treatment Options

- Antiepileptic Drugs (AEDs)
  - Chronic management – prevent seizures
  - PRN or rescue AEDs – stop seizures and prevent emergencies
- Surgery
- Dietary therapy
- Devices - Vagus Nerve Stimulation (VNS)



# Effectiveness of AEDs

- Before 1993, drug choices for epilepsy were limited
- Since 1993, many new products
- 50 to 60% of those with newly-diagnosed epilepsy become seizure free on medication
- About 1/3 of people with epilepsy have seizures that are not controlled by medication

# Older AEDs

- Carbamazepine (Tegretol, Tegretol XR, Carbatrol)
- Clorazepate (Tranxene)
- Clonazepam (Klonopin)
- Ethosuximide (Zarontin)
- Phenobarbital
- Phenytoin (Dilantin, Phenytek)
- Valproic acid (Depakene)
- Valproate sodium (Valproate)

# Newer AEDs (since 1990)

- ACTH (Acthar)
- Clobazam (Onfi)
- Ezogabine (Potiga)
- Felbamate (Felbatol)
- Gabapentin (Neurontin)
- Lacosamide (Vimpat)
- Lamotrigine (Lamictal)
- Levetiracetam (Keppra)
- Oxcarbazepine (Trileptal)
- Perampanel (Fycompa)
- Pregabalin (Lyrica)
- Rufinamide (Banzel)
- Tiagabine (Gabitril)
- Topiramate (Topamax)
- Vigabatrin (Sabril)
- Zonisamide (Zonegran)

# Side Effects of AEDs Overview

- Side effects can be unpredictable. Some are dose dependent, others occur regardless of dose
- Newer AEDs generally have fewer cognitive effects
- Behavior and mood changes are often difficult to sort out and are not necessarily dose-related
- Long term effects unclear, but even mild side effects can have a significant impact on individual student
- Report any physical, cognitive, mood or behavioral changes to student's family and to health care provider as requested

# Common AED Side Effects

## Dose-related/toxic:

- Diplopia, blurry vision
- Dizziness, lightheadedness
- Sedation
- Slowed thinking
- Feeling drunk
- Coordination problems
- Unsteady walking

## Drug-related:

- Cognitive problems
- Fatigue, sedation
- Weight gain or loss
- Cosmetic – acne, excessive hairiness, or hair loss
- Hyperactivity
- Personality changes
- Mood changes, depression

# Drug Reaction Warning Signs

- Rash
- Prolonged fever
- Severe sore throat
- Mouth ulcers
- Easy bruising
- Weakness
- Excessive fatigue
- Swollen glands
- Lack of appetite
- Increased seizures

Contact Child's Healthcare Provider

***THESE ARE SERIOUS BUT NOT COMMON!***

# Generic versus Brand Name AEDS

- In most situations, generic forms of AEDs are appropriate
- Change in seizures or side effects may occur with some drugs
- Switching between formulations is the major concern
  - From brand to generic or generic to brand
  - From one generic manufacturer to another

# Concerns with Generic AEDs

- Avoid switching between formulations without approval of epilepsy provider
- Some students may need to remain on brand or use consistent manufacturer of a generic AED
- Family, student and school nurse should be aware of when change in formulation occurs
  - watch for change in seizures or side effects



# When to Refer to an Epileptologist?

- Failure of two or more appropriate trials of seizure medication
- Uncontrolled seizures and status epilepticus
  - When not already under the care of a specialist
- Difficult to diagnose events or spells
- Significant mood and anxiety disturbances
- Major memory and learning deficits
- Sudden change in seizure type
- Signs of medication side effects or intolerance

# Epilepsy Surgery

- Considered for people with refractory epilepsy
- Surgical evaluations:
  - Video EEG monitoring
  - neuropsychological testing
  - Imaging: MRI, SPECT, PET
  - Magnetoencephalography (MEG)
- Different types of surgery: focal resection, lesionectomy, hemispherectomy, corpus callosotomy

# Epilepsy Surgery

- Post-surgical seizure-free rates vary
  - temporal lobectomy > lesionectomy > non-lesional
- Usually requires short hospital stay
  - student likely will miss several weeks of school which may require a home school plan
- Accommodations may be needed for before and after surgery for a period of time

# Transient Surgical Side Effects

- Headaches
- Dizziness and unsteadiness
- Aching jaw
- Swelling or bruising of head and face
- Blurred vision
- Depression or mood changes, usually temporary
- Sensory changes, especially numbness around the operation site

# Dietary Therapies

- Ketogenic diet
- Modified Atkins diet
- Low Glycemic diet



# Ketogenic Diet

- Produces ketotic state using diet high in fat, low in carbohydrates, and adequate protein
- Easiest to use in children when food choices can be controlled
- Effective for all seizure types
- May require hospitalization to start strict diet
- May require 2-3 days of fasting before the diet begins
- Side effects can include constipation, metabolic acidosis, weight changes, dyslipidemia, renal calculi

# Modified Atkins & Low Glycemic Diets

## MAD

- No restrictions on fluid, calories or proteins
- Monitors carbohydrates,
- Encourages fats

## LGD

- focuses on carbohydrates with low glycemic index and portion size
- Used as add-on therapy with AEDs
- More liberal food choices and amounts
- More palatable (or agreeable) and less restrictive than KD
- Often better adherence

# Considerations: Dietary Therapy

- Be aware of hidden sources of carbohydrates
  - toothpastes, mouth swabs, mouthwash, sugarless gums, diet or sugar-free drinks
- Need strategies for managing intercurrent illnesses
  - what OTC medicines can be used
  - what to do when child can't eat or drink

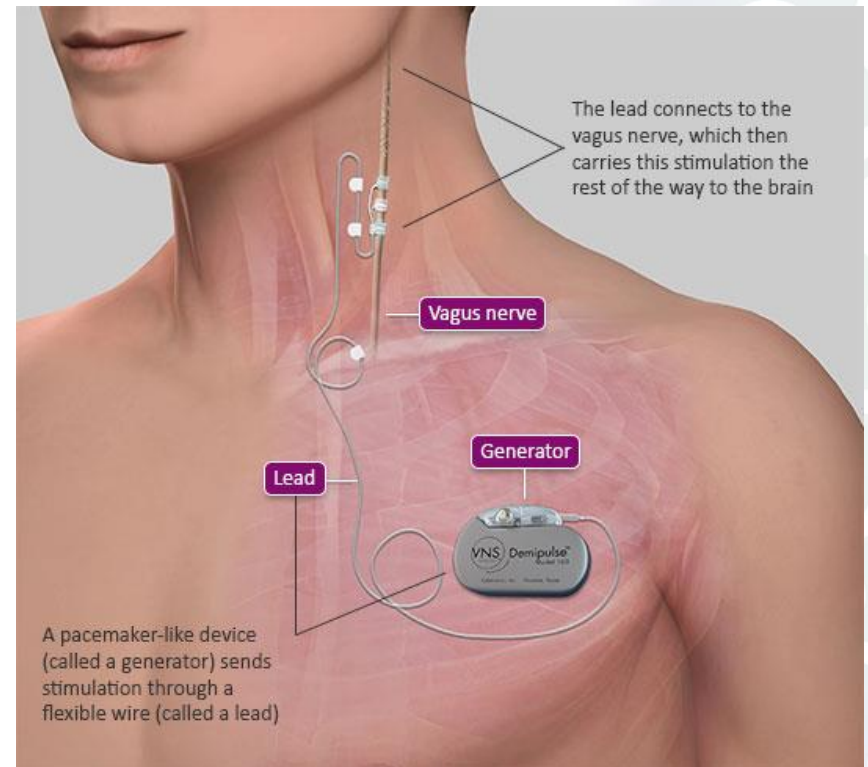


# Managing Diet Therapies at School

- Ensure that child:
  - Eats only food sent from home or approved by parent(s)
  - Completes entire meal and recommended fluids
  - Avoids fluids with carbohydrates
- School nurse should:
  - Notify parent(s) if student doesn't complete meals
  - Work with parents on allowed foods/fluids for parties or special occasions, i.e. ketogenic or specified treats

# Vagus Nerve Stimulation (VNS)

- A programmable pulse generator implanted subcutaneously in upper left chest or left armpit
- Electrode wrapped around the left vagus nerve
- Side effects at time of stimulation may include hoarseness, coughing and shortness of breath
- Settings or 'dose' of stimulation is preprogrammed during clinic visits



# **First aid for a student during and after a seizure.**

# Using VNS Magnet to Shorten / Stop Seizures

- **To stop or shorten a seizure:** the student or an observer may swipe the magnet over the VNS generator when seizure symptoms are seen or felt to trigger a burst of stimulation
  - Magnet may be used multiple times as needed, typically with at least a minute between swipes
- **To turn off stimulation** (i.e. to prevent side effects): tape or secure the magnet over the generator.
- Typically worn on wrist or belt
- Include magnet use in **Seizure Action Plan**
- For a free video and more information visit [www.vnstherapy.com](http://www.vnstherapy.com)

# Rescue Medications for Seizures

- Prescribed for students who tend to have seizure clusters or are at risk for seizure emergencies
- Rescue medicines include:
  - lorazepam, diazepam, midazolam
- May be given in different ways:
  - oral, sublingual, buccal, rectal, intranasal
- Current common forms include:
  - Lorazepam oral, sublingual or buccal
  - Diazepam rectal gel
- Other medicines and delivery systems being tested such as intranasal midazolam

# Diazepam Rectal Gel (Diastat™)

- Most commonly prescribed medication for out-of-hospital use
- Comes in pre-packaged syringes for rectal administration
  - Concerns expressed by other school nurses include privacy, ability to assess when to administer, and respiratory depression
- Dosages are tailored to the child's weight
- Begins working within 15 minutes
- Usually well-tolerated, but some students may be tired after the drug is given
- respiratory depression is **NOT** a common side effect!

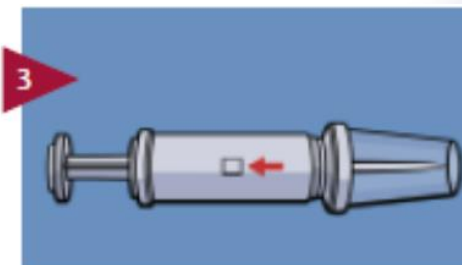
# Diastat™ Administration



1 Put person on their side where they can't fall.



2 Get medicine.



3 Get syringe. Note: seal pin is attached to the cap



4 Push up with thumb and pull to remove cap from syringe. **Be sure seal pin is removed with the cap.**



5 Lubricate rectal tip with lubricating jelly.



6 Turn person on side facing you.



7 Bend upper leg forward to expose rectum.




8 Separate buttocks to expose rectum.



9 Gently insert syringe tip into rectum. Note: rim should be snug against rectal opening.


# Diastat™ Administration (cont'd)

**SLOWLY...** **COUNT OUT LOUD TO THREE... 1...2...3**




**10**

Slowly count to 3 while gently pushing plunger in until it stops.



**11**

Slowly count to 3 before removing syringe from rectum.



**12**

Slowly count to 3 while holding buttocks together to prevent leakage.

**ONCE DIASTAT® IS GIVEN**



**13**

Keep person on the side facing you, note time given, and continue to observe.

**CALL FOR HELP IF ANY OF THE FOLLOWING OCCUR**

- Seizure(s) continues 15 minutes after giving DIASTAT® or per the doctor's instructions:

- Seizure behavior is different from other episodes
- You are alarmed by the frequency or severity of the seizure(s)
- You are alarmed by the color or breathing of the person
- The person is having unusual or serious problems

Local emergency number: \_\_\_\_\_ Doctor's number: \_\_\_\_\_  
(Please be sure to note if your area has 911)

Information for emergency squad: Time DIASTAT® given: \_\_\_\_\_ Dose: \_\_\_\_\_

**DIASTAT® Indication**

DIASTAT® AcuDial™ (diazepam rectal gel) is a gel formulation of diazepam intended for rectal administration in the management of selected, refractory patients with epilepsy, on stable regimens of AEDs, who require intermittent use of diazepam to control bouts of increased seizure activity, for patients 2 years and older.

**Important Safety Information**

In clinical trials with DIASTAT®, the most frequent adverse event was somnolence (23%). Less frequent adverse events reported were dizziness, headache, pain, vasodilatation, diarrhea, ataxia, euphoria, incoordination, asthma, rash, abdominal pain, nervousness, and rhinitis (1%–5%).

**Diastat**  
(diazepam rectal gel)

**Diastat AcuDial™**   
(diazepam rectal gel)



# Routine First Aid: Care and Comfort

- **DO NOT GIVE ANYTHING** by mouth until the student is back to normal state and able to swallow normally
- Most seizures are not medical emergencies
- Basic first aid may vary depending on whether there is:
  - No change in awareness or consciousness
  - Altered awareness
  - Loss of consciousness

# Interventions for Seizure First Aid

- **VNS Magnet** - May be used at any time during a seizure
- **Rescue Medications** - May be prescribed after a specific number of seizures, length of seizure, or change in pattern
- **ALWAYS** refer to student's **Seizure Action Plan** for what to use and when to intervene

# No Change in Consciousness:

## Simple Partial Seizure

- Stay calm
- Time seizure
- Reassure student that he or she is safe
- Explain to others if necessary
- Protect student's privacy

# Altered Awareness:

## Complex Partial Seizure

- Speak softly and calmly
- Guide away from potentially harmful objects such as tables, chairs and doors
- Allow for wandering in a contained area
- If event lasts beyond what is routine for that student or another seizure begins before full awareness is regained, follow emergency protocol
- **DO NOT** restrain or grab (may result in combativeness)
- **DO NOT** shout or expect verbal instructions to be obeyed

# Loss of Consciousness:

## Generalized Tonic-Clonic Seizure

- Protect from harm
  - Cushion and protect head
  - Remove harmful objects
- Ensure airway is unobstructed
  - Turn student on one side
  - Keep head in neutral position
- Observe and time events
- Remain with student until fully conscious
- Follow the student's **Seizure Action Plan**

- **DO NOT** put anything in mouth
- **DO NOT** restrain

# When is a Seizure an Emergency?

- First time seizure
- Convulsive seizure lasting more than 5 minutes
- Repeated seizures without regaining consciousness
- More seizures than usual or change in type
- Student has diabetes or is pregnant
- Seizure occurs in water or fluid is aspirated
- Student is injured
- Parents request emergency evaluation
- Problem breathing after seizure ends

Follow the seizure emergency definition and protocol as defined by healthcare provider and in **Seizure Action Plan**

# Use of PRN Rescue Medications

- Prescribed for seizure clusters and prolonged seizures
- Emergency protocol should include:
  - Medication name and dosage
  - How and when it should be given
  - Specific administration instructions
  - What to do following administration
- Monitor responses and side effects

Follow **Seizure Action Plan** emergency response protocol

# Tonic-Clonic Seizure in a Wheelchair

- Do not remove from wheelchair unless absolutely necessary
- Secure wheelchair to prevent movement
- Fasten seatbelt (loosely) to prevent student from falling from wheelchair
- Protect and support head
- Ensure breathing is unobstructed and allow secretions to flow from mouth
- Pad wheelchair to prevent injuries to limbs
- Follow relevant seizure first aid protocol



# Tonic-Clonic Seizure on School Bus

- Safely pull over and stop the bus
- Place the student on one side across a seat facing away from the seat back (or in the aisle if necessary)
- Follow standard seizure first aid protocol until the seizure abates and child regains consciousness
- Contact relevant school or emergency personnel or continue to the destination based on the student's **Seizure Action Plan** and school policies

# Tonic-Clonic Seizure in Water

- Place the student on their back and support head so that their head, mouth and nose are always above the water
- Remove the student from the water as soon as it can be done safely
- If the student is not breathing, begin rescue breathing
- Always transport the child to the emergency room even if he/she appears fully recovered

# Seizure Action Plan

Implementation in a school environment utilizing safe practices for medication administration.

# Seizure Action Planning

- Assess student needs and gather information
- Customize a **Seizure Action Plan**
- Teach school personnel and tailor interventions as needed

# Seizure Action Planning Process

- Requires input and planning by the health care provider(s), parent(s), student, and school nurse
- Provides basic information about student's seizures, seizure first aid, safety, and emergency response
- Should generally be signed and approved by the treating health care provider, parent, and school nurse
- Distribute to relevant school personnel with parent(s) permission at the beginning of a school year, upon diagnosis or when a change in health status occurs
- Copy of **Seizure Action Plan** should be maintained by family and student's doctor or epilepsy team

**Epilepsy Foundation** **Seizure Action Plan** Effective Date \_\_\_\_\_

This student is being treated for a seizure disorder. The information below should assist you if a seizure occurs during school hours.

Student's Name \_\_\_\_\_ Date of Birth \_\_\_\_\_

Parent/Guardian \_\_\_\_\_ Phone \_\_\_\_\_ Cell \_\_\_\_\_

Other Emergency Contact \_\_\_\_\_ Phone \_\_\_\_\_ Cell \_\_\_\_\_

Treating Physician \_\_\_\_\_ Phone \_\_\_\_\_

Significant Medical History \_\_\_\_\_

Seizure Information			
Seizure Type	Length	Frequency	Description

Seizure triggers or warning signs: \_\_\_\_\_ Student's response after a seizure: \_\_\_\_\_

<p><b>Basic First Aid: Care &amp; Comfort</b></p> <p>Please describe basic first aid procedures: _____</p> <p>Does student need to leave the classroom after a seizure? <input type="checkbox"/> Yes <input type="checkbox"/> No</p> <p>If YES, describe process for returning student to classroom: _____</p>	<p><b>Basic Seizure First Aid</b></p> <ul style="list-style-type: none"> <li>• Stay calm &amp; track time</li> <li>• Keep child safe</li> <li>• Do not restrain</li> <li>• Do not put anything in mouth</li> <li>• Stay with child until fully conscious</li> <li>• Record seizure in log</li> </ul> <p>For tonic-clonic seizure:</p> <ul style="list-style-type: none"> <li>• Protect head</li> <li>• Keep airway open/watch breathing</li> <li>• Turn child on side</li> </ul> <p><b>A seizure is generally considered an emergency when:</b></p> <ul style="list-style-type: none"> <li>• Convulsive (tonic-clonic) seizure lasts longer than 5 minutes</li> <li>• Student has repeated seizures without regaining consciousness</li> <li>• Student is injured or has diabetes</li> <li>• Student has a first-time seizure</li> <li>• Student has breathing difficulties</li> <li>• Student has a seizure in water</li> </ul>
----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------	----------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------------

**Emergency Response**

A "seizure emergency" for this student is defined as: \_\_\_\_\_

**Seizure Emergency Protocol**  
(Check all that apply and clarify below)

Contact school nurse at \_\_\_\_\_

Call 911 for transport to \_\_\_\_\_

Notify parent or emergency contact \_\_\_\_\_

Administer emergency medications as indicated below

Notify doctor \_\_\_\_\_

Other \_\_\_\_\_

Treatment Protocol During School Hours (include daily and emergency medications)			
Emerg. Med. <input checked="" type="checkbox"/>	Medication	Dosage & Time of Day Given	Common Side Effects & Special Instructions

Does student have a Vagus Nerve Stimulator?  Yes  No If YES, describe magnet use: \_\_\_\_\_

**Special Considerations and Precautions (regarding school activities, sports, trips, etc.)**

Describe any special considerations or precautions: \_\_\_\_\_

Physician Signature \_\_\_\_\_ Date \_\_\_\_\_

Parent/Guardian Signature \_\_\_\_\_ Date \_\_\_\_\_

Copyright 2008 Epilepsy Foundation of America, Inc. 09C772

# Assessment & Information Gathering

- Have parent or guardian complete and sign a Parent Questionnaire
- Gather seizure history and treatment information
- Speak with the student's medical team to clarify treatment and emergency response protocol
- Observe and document any in-school seizures
- Plan with teachers and other school personnel and family about:
  - Possible seizure precipitants (triggers)
  - Observed or perceived impact on learning and behavior

# Assessment & Information Gathering

- Consider transportation issues
- Complete a school safety assessment
  - Identify student activities that may need to be modified or necessitate special precautions
  - Identify environmental risks and need for safety precautions
- Determine best method to communicate with parents and medical team

## Questionnaire for Parent(s)

- Encourage parent(s) to complete form May take persistence or help
- Interview the parent(s) to obtain and clarify information
- Update annually and when any changes occur



### Questionnaire for Parent of a Student with Seizures

Please complete all questions. This information is essential for the school nurse and school staff in determining your child's special needs and providing a positive and supportive learning environment. If you have any questions about how to complete this form, please contact your child's school nurse.

Contact Information			
Student's Name	School Year	Date of Birth	
School	Grade	Classroom	
Parent/Guardian	Phone	Work	Cell
Parent/Guardian Email			
Other Emergency Contact	Phone	Work	Cell
Child's Neurologist	Phone	Location	
Child's Primary Care Doctor	Phone	Location	
Significant Medical History or Conditions			

Seizure Information			
1. When was your child diagnosed with seizures or epilepsy? _____			
2. Seizure type(s) _____			
Seizure Type	Length	Frequency	Description
3. What might trigger a seizure in your child? _____			
4. Are there any warnings and/or behavior changes before the seizure occurs? <input type="checkbox"/> YES <input type="checkbox"/> NO			
If YES, please explain: _____			
5. When was your child's last seizure? _____			
6. Has there been any recent change in your child's seizure patterns? <input type="checkbox"/> YES <input type="checkbox"/> NO			
If YES, please explain: _____			
7. How does your child react after a seizure is over? _____			
8. How do other illnesses affect your child's seizure control? _____			

Basic First Aid: Care & Comfort
9. What basic first aid procedures should be taken when your child has a seizure in school? _____
10. Will your child need to leave the classroom after a seizure? <input type="checkbox"/> YES <input type="checkbox"/> NO
If YES, what process would you recommend for returning your child to classroom: _____

Basic Seizure First Aid
<ul style="list-style-type: none"> <li>• Stay calm &amp; track time</li> <li>• Keep child safe</li> <li>• Do not restrain</li> <li>• Do not put anything in mouth</li> <li>• Stay with child until fully conscious</li> <li>• Record seizure in log</li> </ul>
<b>For tonic-clonic seizure:</b> <ul style="list-style-type: none"> <li>• Protect head</li> <li>• Keep airway open/watch breathing</li> <li>• Turn child on side</li> </ul>



## Seizure Observation Record

- To be completed by school personnel when reporting a seizure(s)
- Helps to identify seizure types, duration, triggers, and patterns
- Helpful to use for planning appropriate seizure plans, safety precautions, and need for accommodations or changes



### Seizure Observation Record

Student Name:				
Date & Time				
Seizure Length				
Pre-Seizure Observation (Briefly list behaviors, triggering events, activities)				
Conscious (yes/no/altered)				
Injuries? (briefly describe)				
Muscle Tone/Body Movements	Rigid/clenching			
	Limp			
	Fell down			
	Rocking			
	Wandering around			
	Whole body jerking			
Extremity Movements	(R) arm jerking			
	(L) arm jerking			
	(R) leg jerking			
	(L) leg jerking			
	Random Movement			
Color	Bluish			
	Pale			
	Flushed			
Eyes	Pupils dilated			
	Turned (R or L)			
	Rolled up			
	Staring or blinking (clarify)			
	Closed			
Mouth	Salivating			
	Chewing			
	Lip smacking			
Verbal Sounds (gagging, talking, throat clearing, etc.)				
Breathing (normal, labored, stopped, noisy, etc.)				
Incontinent (urine or feces)				
Post-Seizure Observation	Confused			
	Sleepy/tired			
	Headache			
	Speech slurring			
	Other			
Length to Orientation				
Parents Notified? (time of call)				
EMS Called? (call time & arrival time)				
Observer's Name				

*Please put additional notes on back as necessary.*

# Communication Tips

- Set up a method for communicating with parents/guardians on a daily or weekly basis
- Be a liaison for parents and teachers regarding any status changes
- Have teachers regularly note physical, emotional or cognitive changes
- Create a “substitute teacher” folder with the **Seizure Action Plan** and other relevant information and keep this folder in a secure location

# Tips for Effectively Managing Delegation

- Know state nurse practice act, school district policies, and applicable state and federal mandates and laws
- Recognize that identifying changes in behavior or seizures does not require a skilled nursing assessment and is part of basic seizure first aid
- Bring parents and school personnel together to attempt to find a workable solution
- Explain to all parties that you are obligated to put the health, safety and welfare of the student first

# Tips for Effectively Managing Delegation

- When a school nurse delegates a task under his/her nursing license the nurse is responsible for the following:
  - Ensuring that the delegate is appropriate
  - Providing training and ongoing assessment and documentation of the competence of a delegate
  - Ongoing assessment of the student's health outcome

# Stigma and Epilepsy

Strategies to alleviate psychosocial aspects of epilepsy for students, parent and teachers.

# Factors that Impact the Student with Seizures

## Factors:

- Seizures, postictal effects
- Medication side effects
- Underlying brain abnormalities
- Comorbid conditions
- Attitudes, beliefs, experiences

## Impacts:

- Learning
- Behavior
- Self-concept
- Student achievement
- Stigma
- Psychosocial development
- Overall quality of life

# Impact on Learning

- As many as 2/3 of children with epilepsy have some type of measureable learning problem
- Seizures may cause short-term memory problems
- AEDs may cause drowsiness, inattention, concentration difficulties, and behavior changes which impact ability to learn

# Impact on Learning

- Students with uncontrolled seizures have difficulty with learning, memory, concentration, and attention
- Learning problems can persist even after seizures have been controlled
- Accommodations and help should be tailored to address cause(s) of learning difficulties
- School difficulties aren't always epilepsy-related



# AD(H)D in Students with Epilepsy

- ADD/ADHD is seen in up to 40% of children with epilepsy
- Symptoms may include problems with attention, other executive functions and behaviors.
- Diagnosis of ADD in child requires ruling out seizures, medicines, and other neurological causes first.
- Treating ADD may be as important as treating seizures.

# Impact on Psychosocial Development

- There is an association between seizures/epilepsy and the following:
  - Impaired self-image/self-confidence (shame or embarrassment)
  - Low self-esteem
  - Anxiety, depression
  - Delayed social development

*Once seizures are under control, the psychosocial impact may outweigh the medical impact.*

# Factors that May Increase Risk of Learning, Behavioral, Psychosocial Issues

- Early age of onset
- Multiple lifetime seizures
- High seizure frequency
- Seizures in school
- Memory deficit
- Gross and fine motor ability
- Slowed motor speed
- Language skills

# A Survey of 20,000 Teens...

- More than 50% had never heard of or read about epilepsy
- 37% said teens with epilepsy are more likely to get picked on
- More than 50% said they would not, or were not sure, if they would date a person with epilepsy
- 19% thought that epilepsy was a form of mental illness
- 52% thought that people often die from seizures

Epilepsy Behav. 2002 Aug;3(4):368-375.

# Strategies for Reducing Stigma

- Promote epilepsy education in **health curricula** for all students – *include seizure first aid*
- Appreciate the unpredictability and hidden nature of epilepsy
- Recognize the spectrum of epilepsy – diversity of seizure types, causes, consequences, and experiences
- Be aware of cultural differences
- Support student involvement in extracurricular activities
- Look beyond the seizures – assess the impact, coordinate a team approach

# Strategies for Reducing Stigma

- Help the student and family work with the medical team on appropriate limitations, precautions, and plans
- Educate all school personnel to address stigma
  - (myths, first aid, support strategies)
- Prevent bullying and teasing
- Help enhance independence, address parental over-protectiveness if necessary
- Be a resource. Connect family with the Epilepsy Foundation and other resources in your area

# Supportive Counseling and Self-Management Strategies

- Medication and treatment adherence
- Safety and lifestyle plans
- Learning and school performance
- Dating, driving and disclosure
- Coping with epilepsy, stress management
- Family involvement

# Training your Colleagues

Utilize resources to train school personnel on safe care and assistance in students with seizures.



# Importance of Training Personnel

- Helps enlist the full cooperation of school personnel and family
- Optimizes ability to manage seizures and consequences
- Helps ensure full integration of the student in school activities with appropriate accommodations
- Minimizes stigma

# Goal of Training for School Personnel

- School personnel should be able to:
  - Recognize seizures, aftereffects, and other associated problems
  - Provide appropriate first aid
  - Recognize when a seizure is a medical emergency
  - Provide appropriate social and academic support
  - Understand and use the **Seizure Action Plan**

# Essential Training Topics

- What is a seizure? What is epilepsy?
- Who has epilepsy?
- What do seizures look like?
- What are common myths about epilepsy?
- What causes seizures?
- What is appropriate first aid for seizures?
- When is a seizure an emergency?
- How to use a Seizure Observation Record?

# More Essential Training Topics

- What are common seizure triggers?
- What can be done to prevent stigma?
- What is a **Seizure Action Plan**? How do I use it?
- What safety precautions or accommodations may be needed by the student
- How dietary therapies may impact a child's meals and activities in school

# Optional Topics as Appropriate

- Seizures outside the classroom (playground, field trips, cafeteria)
- Seizures in a wheelchair
- Seizures on a school bus
- Seizures in the water
- Special issues in treatment, including use of:
  - dietary therapies
  - the Vagus Nerve Stimulator magnet
  - all forms of rescue medication, including rectal diazepam

# Where to Find Resources

# Epilepsy Foundation Resources

- [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org)
- *Seizure Training for School Personnel Toolkit*
- *Seizures and You: Take Charge of the Facts* (an Epilepsy Awareness Program for Teens)
- *Managing Students with Seizures: A Quick Reference Guide for School Nurses*
- Brochures, videos, pamphlets, fact sheets, posters

# Epilepsy Foundation Resources

- To review the product catalogue online, go to [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org) and visit the Epilepsy Foundation's **Store**
- Materials may be ordered through the local Epilepsy Foundation affiliate sponsoring this program or by calling 1 (866) 330-2718
- Visit the school nurses section under “Living with Epilepsy”
- **Seizure Action Plan** forms (customizable)



# Epilepsy Foundation Resources

- Downloadable fact sheets on key subjects of interest to school nurses
- Links to other useful information for seizure management
- More detailed medical information is available on the Epilepsy Foundation's website:  
[www.epilepsy.com](http://www.epilepsy.com)