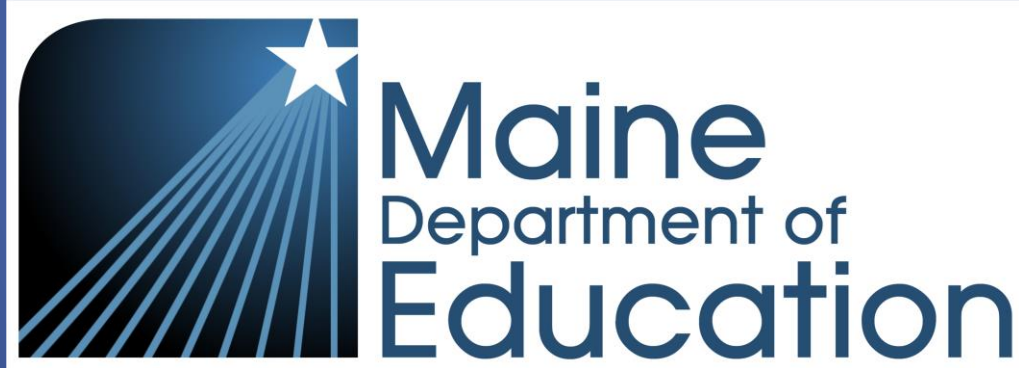


2023



Seizure and Epilepsy Resource Guide

MAINE DEPARTMENT OF EDUCATION
OFFICE OF SCHOOL AND STUDENT SUPPORTS
COORDINATED SCHOOL HEALTH

Updated 2/2023

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Seizure and Epilepsy Management in Maine Schools

Evidence-Based Guidelines for Preschool and School-Age Students

The Maine Department of Education provides this Guide for School Health Services: Seizure and Epilepsy Guide in accordance with Maine Revised Statutes [Title 20-A section 6403-A \(5\)](#) which directs the Commissioner of Education to issue guidelines on the provision of school health services and health-related activities.

While this document intends to summarize currently available resources for the school nurse, it does not replace clinical nursing judgment for their practice. The school nurse is responsible for complying with all federal, state, and local laws, rules, regulations, and ordinances as well as relevant standards of practice.

Introduction

School nurses and staff can be prepared to recognize and treat seizures in the school setting with the awareness that seizures may occur for many reasons including but not limited to infection, fever, traumatic brain injury, neurological disorder, or related to a drug or medication.¹ The Centers for Disease Control and Prevention (CDC) reports that 0.6% of children aged 0 to 17 are estimated to have seizure conditions.² One of the most prevalent neurological illnesses affecting children and young people is epilepsy, a condition characterized by recurrent seizures with no other identifiable cause.^{1,2} According to the United States CDC, in 2015 more than 470,000 children in the US were living with epilepsies.² An epilepsy diagnosis extends beyond having seizures; it can impact many areas of a child's life, including education. It is approximated that about half of the children with epilepsy struggle academically.³ Children with epilepsies commonly struggle with anxiety, depression, social relationships, and [cognitive difficulties](#) and are at greater risk of injuries and suicide.^{1,2}

The purpose of this resource guide is to assist school nurses and school staff in providing a safe and supportive environment for individuals with seizures and epilepsies to maximize educational and developmental opportunities. This document provides relevant information on the most current content available from the Centers for Disease Control and Prevention (CDC), the Epilepsy Foundation, the National Association of School Nurses (NASN), the Mayo Clinic, multiple neighboring states, and professional health organizations to support the safest care practices for individuals with seizures and epilepsies in Maine schools.



Legislation

Federal laws mandate that all students attending public schools have access to health care during the school day and extracurricular school activities, if necessary, for full participation.⁴ The management of seizures and epilepsies during a school day is determined on an individual basis in collaboration with the student, parent, and health care provider. A Sample Seizure Medical Management Plan provided by the physician (sample Appendix A) will guide the development of the 504-plan outlining what accommodations the student will need with parental input and consent. The school administrative unit has a legal obligation to ensure that these accommodations are provided as described in the plan.⁴ The individual health plan (IHP) and 504 plan may be included in the same document. [Sample 504 Plan](#)

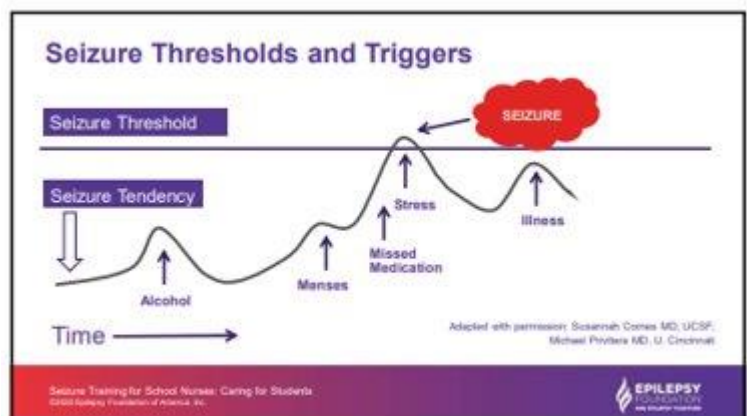
- [Americans with Disabilities Act \(ADA\)](#)
- [Individuals with Disabilities Education Act \(IDEA\)](#)
- [Family Educational Rights and Privacy Act \(FERPA\)](#)
- [Free and Appropriate Public Education \(FAPE\)](#)
- [Section 504 of the Rehabilitation Act of 1973](#)
- [Frequently Asked Questions About Section 504 and the Education of Children with Disabilities](#)

Seizures and Epilepsies

A seizure is a symptom of a provoked or unprovoked disturbance in the brain that causes a sudden release of uncontrolled electrical activity.³ The seizure presents differently depending on the location in the brain.^{5,6} Symptoms may be momentary changes in muscle tone, rhythmic movements, atypical behaviors, sensations, or varying states of awareness.^{5,6} Depending on the type of seizure experienced, individuals can be at risk for falls, and injury.³ A seizure can affect persons of all ages and can be a single acute event or a chronic condition.⁵

A person may be diagnosed with epilepsy after having two or more unprovoked seizures that happen at least 24 hours apart or if an individual has had a seizure and there is evidence that they are at risk for recurrent seizures.³ Epilepsies are diseases of the brain, and because there are so many types, the language has changed to “the epilepsies”.^{3,7} For more information visit [CDC Frequently asked Questions About Epilepsy](#).

An important consideration for the school nurse is that any person exposed to the right combination of circumstances is at risk of experiencing a seizure.³ The seizure threshold refers to how likely a person is to experience a seizure. Many factors can influence the seizure threshold. People with a higher seizure threshold are less likely to experience seizures.³ Persons diagnosed with epilepsy have a lower seizure threshold, and therefore are predisposed to increased risk.³

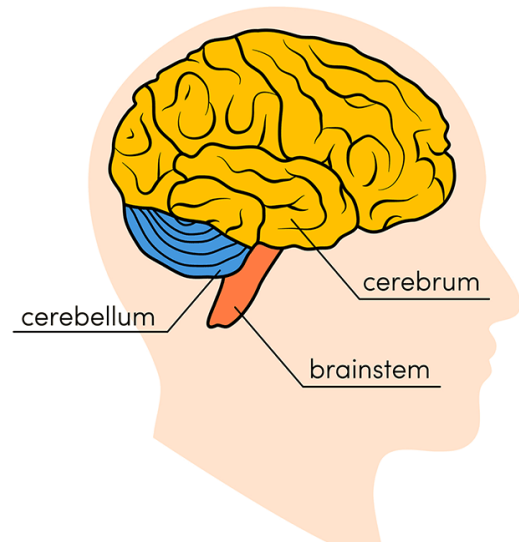


Three Main Structures of the Brain

The cerebrum is the largest part of the brain and coordinates movement, regulates body temperature, enables speech, reasoning, and function of the senses. The cerebral cortex, within the cerebrum, is divided into two hemispheres, each controlling the opposite side of the body. Each hemisphere has four lobes, which control specific functions.

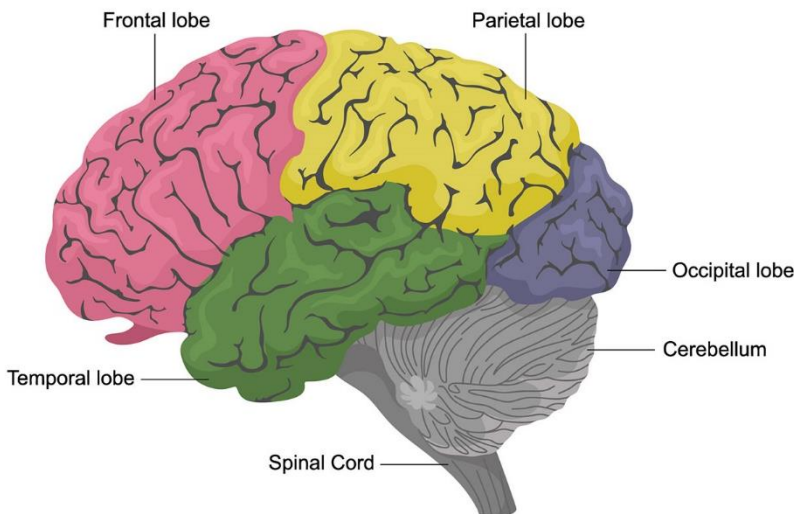
The brainstem connects the cerebrum with the spinal cord and facilitates a variety of functions including hearing, blinking, and breathing.

The cerebellum has two hemispheres and is responsible for controlling voluntary movement and equilibrium. The seizure origin and classification can give valuable information about what functions may be affected.



Lobes of the Brain and Function

Human Brain Anatomy



Frontal

associated with personality, motor function, decision-making, recognition of smell and speech

Parietal

interpreting pain and touch, understanding spoken language

Occipital

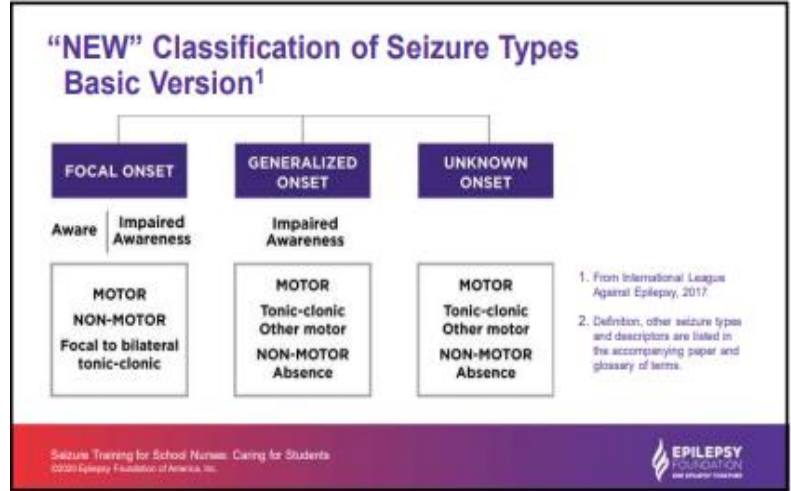
processes visual information

Temporal

short-term memory, speech, musical rhythm and smell

Common Types of Seizures

More than one type of seizure can present in people with epilepsy.⁷ Seizure types are classified by the location in the brain where dysregulated electrical activity begins. For example, a focal onset seizure means that the seizure begins on one side of the brain whereas with generalized onset the seizure begins in both halves of the brain simultaneously.^{3,5,7} Knowing the type of seizure helps guide treatment options and can help the school nurse anticipate and prepare for seizure activity, as well as guide how to recognize unexpected symptoms to document and report.^{3,5}



There are two kinds of focal onset seizures. The following chart is a brief description of what the school nurse may see for symptoms in each type.

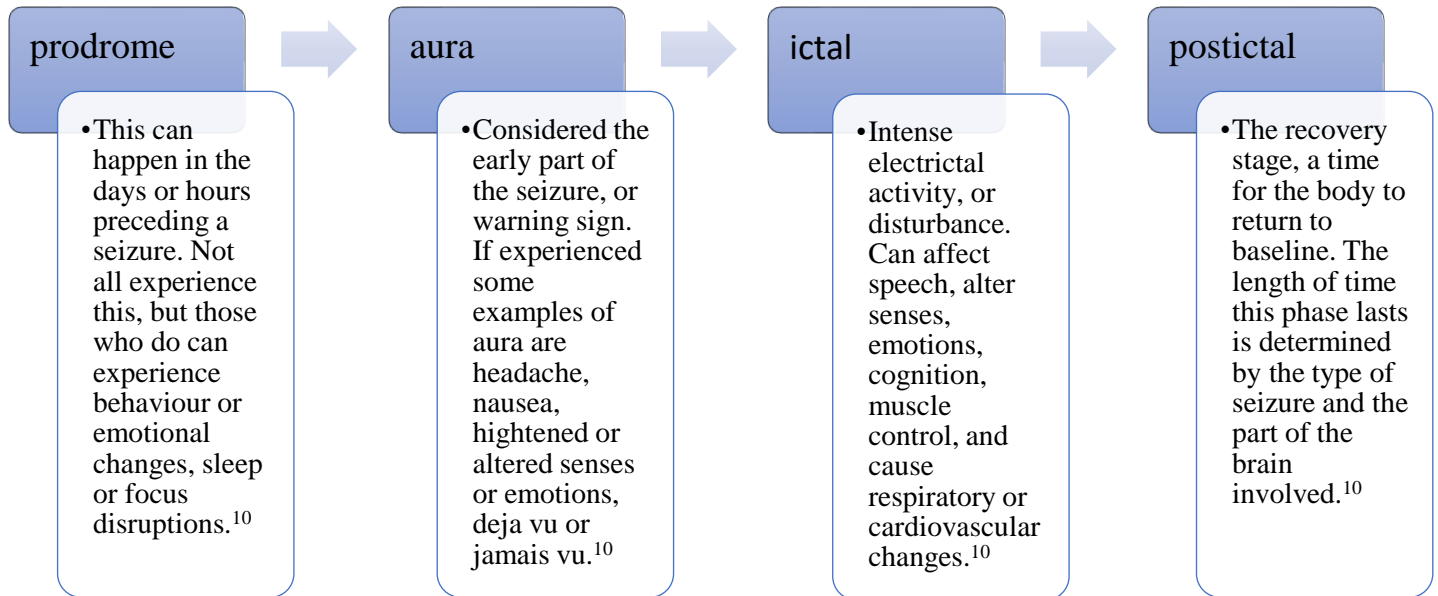
Focal onset seizure without loss of awareness	<ul style="list-style-type: none"> emotional disturbances déjà vu change in sensations such as taste, sound, and smell, tingling in extremities vertigo may have jerking episodes^{5,9}
Focal onset seizure with impaired awareness	<ul style="list-style-type: none"> staring syncope repetitive movements, or walking in circles⁵

Generalized onset is when the seizure affects the entire brain and doesn't originate in one spot.^{3,5,7} There are many types of generalized onset seizures. Symptoms one might exhibit with each type of seizure is represented below.⁵

Absence	Staring, blinking, lip-smacking
Atonic	Loss of muscle tone
Tonic	Full muscle tone, stiffening
Clonic	Rhythmic jerking, usually the neck, face, and arms
Myoclonic	Sudden brief jerks, upper body, arms, and legs
Tonic-Clonic	Stiffening and jerking

Seizure Phases

Seizure activity presents in stages, though not every person experiencing a seizure will experience or be able to identify all stages.^{3,5,10}



Phase Considerations

During each phase of seizure activity, the school nurse, along with school staff, can take steps to promote the best possible outcome. For students who experience and can communicate an aura, staff should notify the school nurse and accompany the student to the nurse’s office, or a private safe location identified in the emergency plan, for observation. During the ictal phase of a seizure, safety is priority. Staff training is essential for keeping individuals safe from injury and assessing need for activating outside emergency medical services (EMS). Privacy should be maintained to the greatest extent possible. During the postictal phase, the student may experience confusion, fear, lethargy, incontinence of stool or urine, weakness or become injured.¹⁰ On average, postictal symptoms last between 5 and 30 minutes.¹¹

School nurses are knowledgeable of and can support education about how seizures and epilepsies can affect the student in school. A [debriefing session](#) may be considered for students and staff who have witnessed the seizure. Communication with family and healthcare providers after a seizure event at school can provide emotional support for the family and address any potential changes in students IHP to ensure continued safety at school. Some debriefing tools that can be used include the [TALK Approach](#) and [Values](#).



Epilepsy Syndromes

Epilepsy syndromes are classified using the [International League Against Epilepsy \(ILAE\)](#) Classification, by the type of seizure, the age of onset, etiology, and clinical course.³ The location in the brain where the electrical activity starts and combination of symptoms that are specific or unique to a particular syndrome are key in diagnosis. The following examples of syndromes may lend insight into similarities and differences between conditions and assist the school nurse in planning.



West Syndrome can contribute to cognitive impairment, however, when effective early treatment is implemented, if there are no underlying brain abnormalities and the student has met developmental milestones before diagnosis, the likelihood of a positive outcome increases.¹²

Juvenile Myoclonic Epilepsy (JME) is often first seen in adolescence, with myoclonic seizures in the first few hours of awakening or falling asleep, most often caused by lack of sleep and stress.¹³ Trigger avoidance raises seizure threshold making it less likely to experience seizures, and 90% of individuals obtain seizure control with medication.¹³

One syndrome that develops early in childhood, [Lennox-Gastaut Syndrome \(LGS\)](#), accounts for 1-2% of epilepsy syndromes.¹⁴ Students with LGS may experience multiple types of seizures, learning challenges and may benefit from life skills programs and additional educational support.¹⁴ With the likelihood of frequent, sometimes daily seizures, students are at increased risk of injury, and helmets may be prescribed for safety.¹⁴

Sunflower Syndrome, sometimes called photosensitive epilepsy, is a rare epileptic disorder when an attraction to light induces seizure activity that includes hand waving and altered consciousness.¹⁵ This syndrome has been stigmatized, and students with Sunflower Syndrome can experience anxiety, bullying and stress. The altered consciousness can affect the student's education. As with all seizures and epilepsies the school nurse can advocate for accommodations specific to each student's needs.¹⁵

For more information about syndromes associated with epilepsy, please visit:

<https://www.epilepsy.com/what-is-epilepsy/syndromes>

[Epilepsy Syndromes in Children](#)

Seizure Triggers

Seizure triggers are circumstances that may provoke a seizure. Common seizure triggers include fever or infection, fatigue, dehydration or electrolyte imbalance, medications, alcohol, illegal drugs, flashing lights, stress, and hormonal changes.¹⁶ Other triggers can be as simple as not eating well, eating specific foods, or an excess intake of caffeine.¹⁷ By understanding a student's seizure triggers, the school nurse can help identify areas that can be addressed in the student's IHP to help reduce exposure. If known, it is important to educate school staff on the typical seizure patterns of a student.¹⁶

Comorbidities

Students with seizures and epilepsies are at an increased risk of experiencing medical and psychological comorbidities.¹⁷ Some comorbidities are the result of seizure activity, some are adverse effects of antiseizure medication or the individual may have underlying predispositions.^{7,17} Comorbidities may include attention deficit hyperactivity disorder, migraines, depression or anxiety, and students' self-esteem may be affected.^{3,17} Students may have sleep dysfunction, or interrupted sleep, adversely affecting education and quality of life.^{3,17} The school nurse is a valuable resource, supporting and educating the school community and staff and empowering the student to be a champion of their health.³ As the health professional within the school, this specialist advocates for assessment, recommends accommodations, can enhance coping, and build resilience for students with seizures and epilepsies.^{3,17}

Seizure Management

Neurological examination along with a comprehensive medical history are initial steps in seizure diagnosis and management. Common diagnostics may include magnetic resonance imaging (MRI), electroencephalogram (EEG), and/or neuropsychological tests to measure verbal and nonverbal skills.^{7,18} Physical and occupational evaluations may also be indicated.¹⁸ Treatment plans are based on specific diagnoses and individualized for optimal seizure control.



Medication

Seizure management often includes routine anti-seizure daily medications as well as emergency, or rescue medicines. The [2022 Medication Administration in Maine Schools: Evidence-Based Guidelines](#) is a comprehensive tool that can assist the school nurse when considering training, coordination, and oversight of medications.

Routine Medication

Students with seizures often take daily medications to reduce or prevent seizure activity.¹⁹ Some medications will be taken at home, while some may need to be administered at school. The resources below may be helpful to learn more about daily medications students may be prescribed.

- [Seizure Medication List - Epilepsy Foundation](#)
- [Summary of Antiepileptic Drugs - Epilepsy Foundation](#)
- [UpToDate-Oral Antiseizure Medication Maintenance Therapy for Children with Epilepsy](#)

Rescue Medication

Rescue medications are rapid-acting and assist in the management of seizure emergencies. Benzodiazepines are commonly used rescue medications and may be prescribed to be administered through various routes including oral, buccal, intranasal, and rectal.³

Emergency action plans should outline who and how prescribed rescue medication will be administered and steps to follow post-administration to ensure student safety. To support a greater understanding of rescue therapy use in the school setting, the Epilepsy Foundation has developed the following comprehensive training: [Using Rescue Therapies in Epilepsy Care](#).

Speed of Action by Route⁴

Route of Administration	Onset
Intravenous	30-60 seconds
Intranasal	3-5 minutes (up to 10 minutes)
Sublingual	15-30 minutes
Intramuscular	10-20 minutes
Rectal	5-30 minutes
Ingestion	30-90 minutes

FDA Approved Rescue Medications Comparison⁴

	Onset	Peak	Half-life	Frequency
Rectal Diazepam gel For ages 2 and older	<15 minutes	90 minutes	3-60 hours	Weight-based, repeat once as needed 4-12 hours after the first dose. Use it no more often than every 5 days.
Nasal Diazepam Spray For ages 6 and older	< 15 minutes	90 minutes	3-60 hours	Repeat the dose in 4-12 hours as needed. it Use no more often than every 3 days.
Nasal Midazolam Spray For ages 12 and older	< 10 minutes	17 minutes	2-7 hours	May repeat in 10 minutes following the first dose if needed. Use no more than 2 intranasal doses to treat 1 episode. it Use no more often than every 3 days.

Both Charts were adapted utilizing Epilepsy Foundation. Seizure Training for School Nurses: Using Rescue Therapies

Diet

Specialized diets with a focus on fat, protein, and carbohydrates have been shown to have an overall reduction in seizures of approximately 50%.³ These prescribed diets often require supervision by the student’s healthcare provider.³ The role of the school nurse in dietary management at school includes education and collaboration with school staff and including accommodations in the students’ IHP.³ Deviations from the prescribed diet must be communicated with parent(s)/guardian(s) and the school nurse.³

Ketogenic Diet

In the classic ketogenic diet, the body uses fat instead of carbohydrates for energy in a metabolic state called ketosis.^{20, 21} This high-fat, low-protein, and carbohydrate diet mimics the fasting state; and has been used since the 1920s.²¹ Over half of the children have a 50% reduction in seizures, and up to 10-15% may become seizure-free, with this restrictive diet.²⁰



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The mechanism by which seizures are controlled by a ketogenic diet is thought to be related to the low glucose levels in the cerebral spinal fluid altering the excitability of the brain and raising the seizure threshold.²¹ A ketogenic diet needs to be medically supervised to monitor for side effects and malnourishment.²¹ The initial start of a ketogenic diet occurs in the hospital to ensure safe conversion to ketosis.²¹ Education will be provided by hospital staff at discharge.

Medium-Chain Triglyceride Diet (MCT)

The MCT diet is more flexible than the classic ketogenic diet; higher carbohydrate and protein allowances offer a larger variety of food.²² The MCT ketogenic diet uses a fat supplement that consists only of MCT fats which produce ketones easily in comparison to long-chain triglycerides (LCT).²² The flexibility and higher carbohydrate and protein allowances make this option attractive to older children and families.²²

Modified Atkins Diet (MAD)

The Modified Atkins Diet is like the classic ketogenic without fluid, calorie, or protein restrictions allowing for a wider variety of foods.²³ Carbohydrates are limited and monitored while eating fat is encouraged. This is the most common epilepsy diet used for adults and teenagers and is started outside of the hospital.²³

Low Glycemic Index Treatment (LGIT)

This treatment is the least restrictive with a focus on carbohydrates that have a low impact on raising blood sugar quickly, such as foods with dietary fiber like whole grains and berries.²⁴ With this diet, exact measurement is not necessary; quantity is based on portion sizes with 60% of daily calories from fat, allowing this diet to be initiated as an outpatient.²⁴


Surgical Intervention

Epilepsy surgery is considered for those whose seizures do not respond to medication, removing or ablating the area of the brain where the person’s seizures originate.^{3,25} There are several surgical interventions outlined in the following table to treat epilepsy with the goal of stopping or limiting seizures with or without medication.

Type of Surgery	Purpose	Recovery	Side Effects
Lobectomy	Removes a part of the brain (ie., temporal or frontal)	4-6 weeks	Headaches, aching jaw, swelling
Lesionectomy	Removes a lesion or mass that causes the seizures	4-6 weeks	Headaches, aching jaw, swelling
Corpus Callosotomy	Disconnects nerves in corpus callosum to stop spread of seizure activity	6-8 weeks	Fatigue, headache, depression, low motivation, difficulty speaking, naming, weakness, difficulty walking
Laser Ablation	Destroys small seizure focus in certain areas of the brain	1-7 days	Mild headache

<https://www.epilepsy.com/learn/treating-seizures-and-epilepsy/surgery>
<https://www.brainrecoveryproject.org/parents/brain-surgeries-to-stop-seizures/lesionectomy/>
<https://my.clevelandclinic.org/health/treatments/11546-corpus-callosotomy/procedure-details>

Seizure Training for School Nurses: Caring for Students
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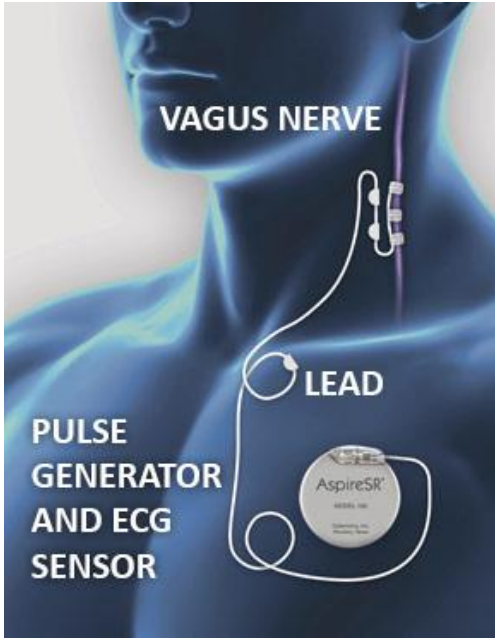
Neuromodulation Therapy

An additional treatment option that may be helpful for individuals with refractory or drug-resistant epilepsy is neuromodulation. Three common neuromodulation therapies act by stimulating parts of the brain where seizures originate.^{3,26}

For individuals, 4 years and older with [focal or partial seizures](#) who are not candidates for surgery and don’t respond to [seizure medications](#), Vagus Nerve Stimulator (VNS) therapy is a neuromodulation intervention approved by the Federal Drug Administration (FDA).²⁶

School Nurse Actions

- 1 Collaborate with parents/physicians
- 2 Obtain physician orders
- 3 Create the Individualized Health Plan
- 4 Research the type of device
- 5 Prepare an emergency kit
- 6 Train school staff



With VNS therapy, the device is implanted under the skin, usually in the left chest, with wires that connect to the vagus nerve.²⁶ The vagus nerve, part of the autonomic nervous system, is the communication pathway between the body and the brain. The VNS provides continuous stimulation at programmed intervals to the vagus nerve to work as a preventative treatment.^{3,26} For some individuals, once a seizure has begun, the VNS magnet can be waved over the implanted device to deliver added stimulation to the vagus nerve, stopping or lessening the severity of the seizure.^{3,26} While it is not clear how the VNS helps inhibit seizures, research suggests increased blood flow and neurotransmitters, and changes in electroencephalogram patterns during a seizure have been detected.²⁶

Responsive Neurostimulation (RNS) and Deep Brain Stimulation (DBS) are also neuromodulation treatments used for individuals 18 years or older, that have failed treatment with at least two seizure medications, are not candidates for surgery, and have one or two localized seizure foci.^{3,27}



The RNS device is placed in a small tray in the skull, undetectable underneath the scalp.²⁷ The leads from the device are placed either in or on the parts of the brain where the seizures originate.²⁷ The device can monitor brain activity and is programmed to recognize seizure patterns and deliver electrical pulses when any unusual activity is detected, preventing or shortening seizure activity.²⁷ The system records data, and the family can download the information for collaboration with the student's healthcare team.²⁷

[Epilepsy Foundation-Responsive Neurostimulation \(RNS System\)](#)

The DBS System is a device placed under the skin in the chest by a neurosurgeon that delivers tiny leads directly into the targeted area of the brain, the thalamus, to detect and deliver electrical impulses and shorten or lessen the severity of the seizure.³

For further exploration, a timeline of approved treatments for epilepsy can be found on the following website:
[National Institute of Neurological Disorders and Stroke-Brain stimulation therapies for epilepsy](#)

VNS Therapy Resources

[Epilepsy Foundation-Vagus Nerve Stimulation \(VNS Therapy\)](#)

[Kennedy Krieger Institute-Factsheet: Vagus Nerve Stimulator](#)

[The VNS Therapy Magnet](#)

[Epilepsy Foundation-Responding to Seizures When Someone Has an Implanted Device](#)

[Training Checklist Example 1](#)

[Training Checklist Example 2](#)

Seizure Emergencies

Seizures and the epilepsies can be unpredictable, can result in injury, and can be life-threatening.³ Education and preparation are paramount in the school setting to recognize and respond appropriately. School nurse collaboration with the student's family and medical team can ensure detailed documentation of the features of the student's seizure activity, including frequency and patterns, to recognize changes as potential emergencies.³ Careful preparation and adherence to the seizure action plan during a seizure emergency will lead to the best possible outcome. It is important to note that two-thirds of students successfully manage seizure activity with strict medication compliance.³

SUDEP and Status Epilepticus

Sudden unexplained death in epilepsy ([SUDEP](#)) is a rare condition in which young or middle-aged people with epilepsy die without a clear cause.⁷ When a seizure lasts longer than five minutes or repeats within five minutes without returning to consciousness, this is called status epilepticus and is considered a medical emergency.²⁹ Status epilepticus, can often be interrupted with prompt intervention. This occurrence can be convulsive, or non-convulsive and is most often caused in children by a fever or infection.²⁹ Rapid response and urgent medical treatment with emergency medications can prevent complications and death.²⁹

When to CALL 911

- No history of seizures
- Not breathing normally after a seizure
- Injury or suspected injury has occurred
- Seizure occurred while in the water
- Seizure lasts longer than 5-minutes
- Repeated seizure
- Student has diabetes, is pregnant, or suffering illness^{3,28}



SEIZURE PREPAREDNESS KIT CONSIDERATIONS

- Student's name and photo
- Observation record and timer
- Seizure Action Plan
- Emergency medication and supplies (i.e., lubricant)
- Gloves and mask
- Plastic bags and paper towels/tissues in case of vomiting

First Aid

Basic [first aid for seizures](#) is valuable knowledge to have in a school setting. Recognizing signs and symptoms of a seizure and appropriate steps for first aid can save a life. Annual education for school staff is best practice. This includes staff who have primary contact with a student known to have a seizure disorder, along with school staff who may be in classrooms, cafeterias, playgrounds, transportation, and any school-sponsored events including sports. For more information see [CDC Seizure First Aid](#).

As illustrated in the Epilepsy Foundation poster, the first step after recognizing a seizure is to STAY with the person and start timing the seizure. Second, keep the student SAFE by moving any harmful objects and if needed guide the student to the floor. Third, make the student as comfortable as possible and place them on their SIDE if they are not alert and aware. Remember to never hold a person down, put objects in their mouth, give food or water or leave them alone. Use rescue medications as prescribed.

Seizure First Aid Training and Certification can be obtained at the following website:
[Seizure Recognition and First Aid Certification](#)

See page 23 of this document for additional educational opportunities for school nurses and school personnel.

Seizure First Aid

How to help someone having a seizure

1

STAY with the person until they are awake and alert after the seizure.

- ✓ Time the seizure
- ✓ Remain **calm**
- ✓ Check for **medical ID**



2

Keep the person **SAFE**.

- ✓ Move or guide away from **harm**



3

Turn the person onto their **SIDE** if they are not awake and aware.

- ✓ Keep **airway clear**
- ✓ **Loosen tight clothes** around neck
- ✓ Put **something small and soft** under the head



Call
911
if...

- ▶ Seizure lasts longer than 5 minutes
- ▶ Repeated seizures
- ▶ Person does not return to their usual state
- ▶ First time seizure
- ▶ Person is injured, pregnant, or sick
- ▶ Difficulty breathing
- ▶ Seizure occurs in water

Do
NOT

- ✗ Do **NOT** restrain.
- ✗ Do **NOT** put any objects in their mouth.
- ▶ **Rescue medicines can be given** if prescribed by a health care professional

Learn more: epilepsy.com/firstaid



epilepsy.com

24/7 Helpline: 1-800-332-1000

This publication was created by the Epilepsy Foundation, a nationwide network organization, and is part of our END EPILEPSY™ awareness campaign. This publication is made possible with funding from the Centers for Disease Control and Prevention (CDC) under cooperative grant agreement number 1N58DP006256-04-00. Its contents are solely the responsibility of the Epilepsy Foundation and do not necessarily represent the views of the CDC. EFA440/PAB0220 Rev. 02/2020 ©2020 Epilepsy Foundation of America, Inc.

Nonepileptic Events

Psychogenic nonepileptic seizures (PNES) resemble epileptic seizures but are without the electrical brain activity seen with epileptic seizures.³¹ Commonly a patient with epilepsy will have eyes open during a convulsive seizure, while an individual with PNES will have eyes tightly closed eyes, with resistance to eye-opening during an event.³¹ Other movements not consistent with epileptic seizures include shaking, side-to-side head movements, and yelling.³¹

The best method to diagnose PNES is monitoring, by EEG.³¹ Approximately 20% to 40% of people seen at epilepsy centers for intractable seizures are diagnosed with PNES.³¹ Factors that may make a person more vulnerable to developing PNES include a history of difficult experiences or trauma such as sexual or physical abuse, or PTSD.³² Once diagnosed, treatment may include psychological therapy.^{32,33}

Understanding that PNES is a complex reaction to stressful situations and not a conscious act is very important to help with supportive therapy. It is important to acknowledge these seizures are real and cause distress to the patient, family, and friends.³² For a greater understanding, access the Epilepsy Foundations' [Caring for Students with Psychogenic Seizures](#).



Mental Health Considerations

Chronic illnesses can affect physical, cognitive, social, and emotional development that can put children and adolescents at a higher risk for mental health conditions including depression, anxiety, and adjustment disorders.^{7,34} Children and adolescents that are challenged with any chronic illness experience many forms of stress and face more challenges than peers without illness.³⁴ Depression is often a comorbidity and is often underdiagnosed and undertreated in persons with epilepsy.³⁵ Social stigma is a large contributor to depression and anxiety for students with seizure conditions.⁷ The National Institute of Neurological Disorders and Stroke estimates that one in three individuals with epilepsy will suffer from depression, and/or anxiety.⁷

Suicidal ideation and its associated risk for completed suicide is unfortunately prevalent in persons with epilepsy, reportedly at 23.6%.³⁶

The school nurse can collaborate and communicate with family and healthcare providers, with the awareness that disease severity, frequency, and management can affect students and their mental health. Visit [NAMI Maine](#) for invaluable resources for the school nurse, staff, student, family and community.



NAMI Maine Help
Line

[1-800-464-5767](tel:1-800-464-5767) (Press 1)

Maine Crisis Line

[1-888-568-1112](tel:1-888-568-1112) (call or
text)

NAMI Maine Teen
Text Support Line

[\(207\) 515-8398](tel:207-515-8398)

Downloadable Infographics

[Language Matters](#)

[How to Help a Friend](#)

[Getting the Right Start](#)

School Nurse’s Role: A Whole-Child Approach to Seizure Management

Caring for students with chronic health conditions such as seizures and epilepsies requires a team approach. The school nurse collaborates with the student, family, healthcare providers, and school-based health centers when enrolled, along with school staff to help meet and maintain student goals.^{3,7,37,38} Preparing a comprehensive plan for success includes an IHP developed for each student with seizures or epilepsy to maximize participation in all school activities safely and optimize learning. Encouraging participation in afterschool activities and sports is beneficial, with medical clearance, understanding that avoidance of overexertion and dehydration is especially important.⁷ Using a seizure intake form, like the sample provided in Appendix B, can help gather and organize essential information from the family, necessary to create an IHP.

It is important to note that seizures can occur in individuals that have never experienced a seizure before, and school staff should be trained to recognize seizure activity and intervene appropriately. The school nurse enhances the health and safety of school-age children with seizures and epilepsies by utilizing and successfully implementing guidelines provided within this document. Careful consideration and effort can reduce the stigma that often accompanies the epilepsies, as with all chronic health conditions.^{3,7} Empowering student independence and involvement in educating others can benefit school communities as well as the student with epilepsy.³

If the student requires 1:1 nursing, a contracted agency may provide services. The following can be used as a guide for supporting students receiving agency nursing care. [Guidance Document: Agency Nurses in the School Setting](#)

Resources for the School Nurse: Sample Checklist for the School Nurse (Appendix C), Sample Emergency Seizure Action Plan for the Classroom (Appendix D), and Sample Emergency Seizure Action Plan for Transportation (Appendix E).



Improving Access to Care

School nurses work towards health equity within the community by helping students and families navigate the public healthcare system. School nurse assessment can quickly expose challenging barriers to health, or access to appropriate care for students and families. Maine provides multiple resources that can assist the school nurse in [coordination of care](#).

[Department of Health and Human Services: Health Care Assistance](#)

[Maine Community Care Referral Form](#)

[McKinney-Vento Education in Maine](#)

[Maine Department of Education Interpretation & Translation](#)

[Maine Department of Education-Employee and Student Wellness](#)

[Maine Department of Education-Family Engagement and Cultural Responsiveness](#)

[School Nursing & School-Based Health Centers in the United States. Working Together for Student Success](#)

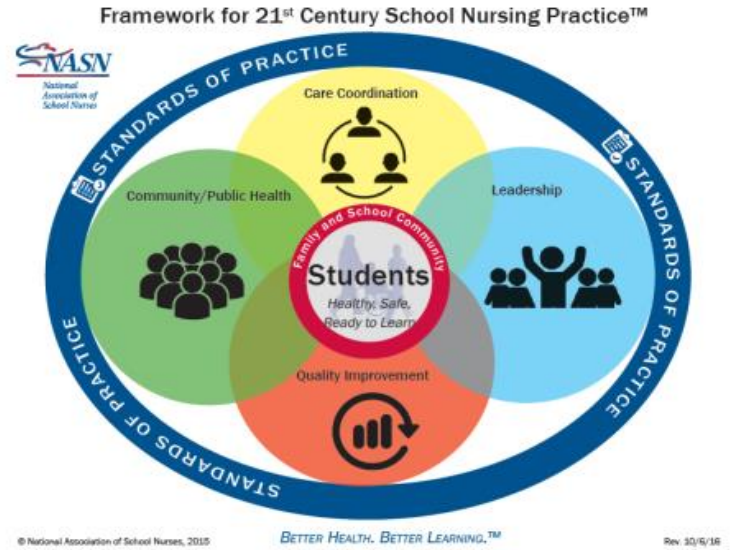


21st Century Framework

NASN provides [School Nursing Evidence-based Clinical Practice Guideline: Students with Seizures and Epilepsy](#) for reference to assist school nurses in care coordination.

Outcomes of implementing NASNs framework in seizure management include:

- Emergency care plans and access to prescribed medications
- Improved seizure first aid and care management
- Decreased unnecessary emergency room visits
- Increased return to the classroom
- Decreased inpatient admission³⁹



Coordination and Oversight

According to the Maine State Board of Nursing, Chapter 6, “the registered professional nurse may coordinate and oversee unlicensed health care assistive personnel for specific tasks for specific patients, consistent with patient safety.”⁴⁰ The school nurse may not coordinate and oversee unlicensed school personnel (USP) any task that requires health counseling, teaching, independent, specialized nursing knowledge, skill, or judgment.⁴⁰ The school nurse will consider multiple factors when determining coordination and oversight including the safety, acuity, condition, and stability of the student; training and capability of the USP, as well as the nature and setting of the tasks.⁴⁰

The [Decision Tree for Coordination and Oversight](#) outlines the steps school nurses should follow in planning for a student who requires care related to health and safety, or medication in school. The school nurse is responsible for developing and revising the student’s IHP and for utilizing the decision tree.

Sample Plans

The [seizure action plan](#) is an essential tool in helping parents and schools work collaboratively to keep students safe and healthy during the school day. The plan will include information on first aid, emergency contacts, medications, and student specific instructions. Included below are samples for reference or use.

- [Seizure Action Plan](#) Epilepsy Foundation (fillable)
- [Seizure Action Plan](#) Child Neurology Foundation

Teaching Children About Epilepsy

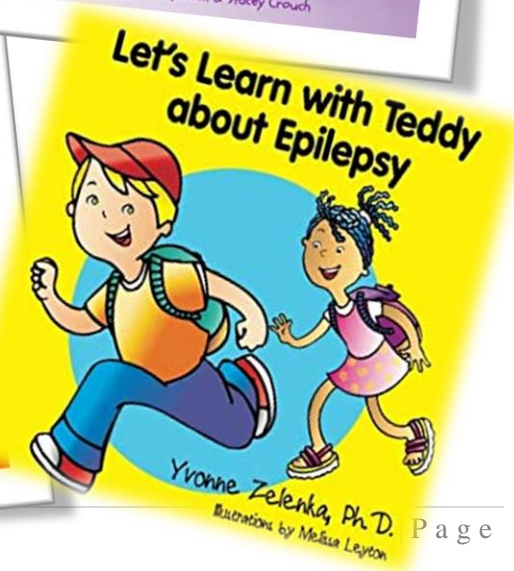
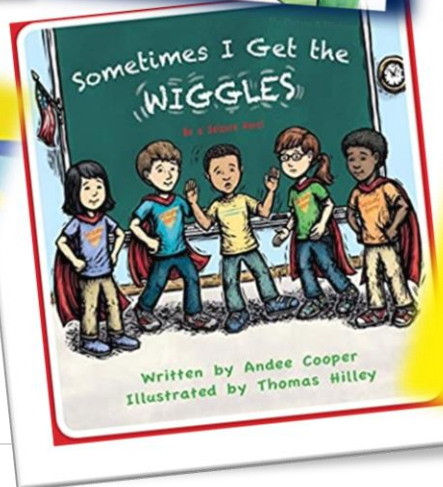
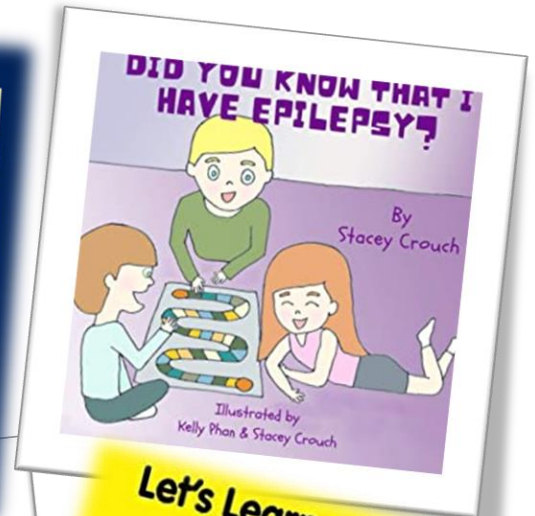
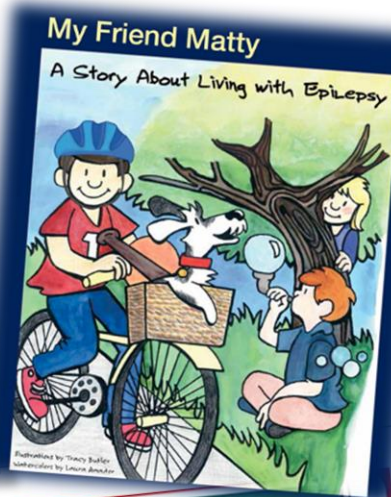
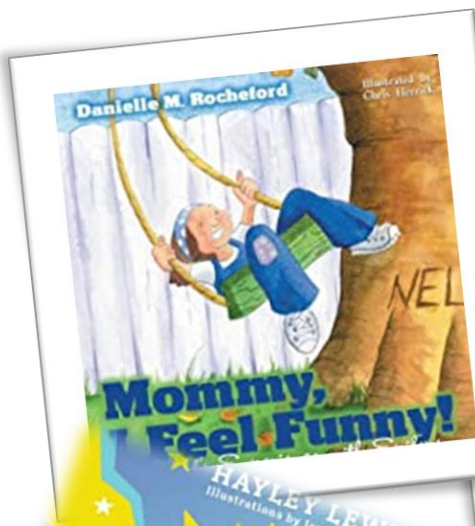
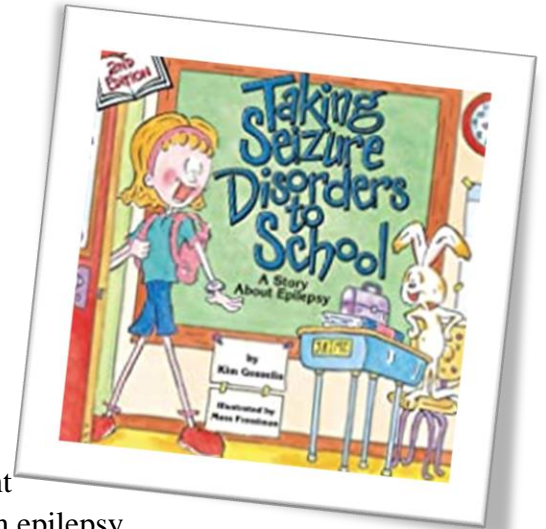
When a student with epilepsy registers at your school, it is important to get permission from parents to provide education to classmates and other students. Tips for teaching:

- Use language, they understand, talk about what a seizure is, what causes it, and reassure them that the new student is safe and being cared for and there is no danger to them
- Explore children's books about epilepsy and videos with students. Classroom games, coloring books and worksheets can also help students understand epilepsy better
- Allow time to talk about student feelings, the feelings of a student with epilepsy, and how they think they should treat someone with epilepsy
- If a student has a seizure that is witnessed by staff or students, provide a debriefing session to process feelings and talk about how the situation was responded to in the school setting
- Make sure to answer any questions to the best of your ability⁴¹

Video Resources:

[Seizures & You: Take Charge of the Storm Jr. \(Grades K-5\)](#)

[Epilepsy Foundation Kids Crew Show](#)



Seizure Training for School Nurses, School Personnel, and School Community

[Epilepsy Foundation-Course Catalog](#)

[Epilepsy Foundation-Seizure Training for School Personnel](#)

[Epilepsy Foundation-Seizure Training for School Nurses: Caring for Students](#)

[Epilepsy Foundation-Seizure Training for School Nurses: Caring for Students with Psychogenic Seizures](#)

[Epilepsy Foundation-Seizure Training for School Nurses: Using Rescue Therapies in Epilepsy Care](#)

Smartphone Applications and Resources for Students and Families

[Epilepsy Foundation-Toolbox](#)

[Epilepsy Foundation- Epilepsy Digital Experience Navigator \(EDEN\)](#)

[Epilepsy Foundation-Seizure Diary App](#)

[Epilepsy Foundation-Epilepsy Device Wiki](#)

[Epilepsy Foundation-Epilepsy Pipeline Tracker](#)



Additional Resources

Sample Seizure Medical Management Plan

Student _____ Date of Birth _____
School _____ Year _____ Grade _____

Seizure Information

Type of Seizure _____
Description of seizure activity _____
Typical duration of seizure _____ How often seizures occur _____
Triggers/warning signs _____
Reactions after seizure _____
Special Diet/Other pertinent information _____

Seizure Medication Management

Daily Medication _____ Dose/Frequency _____ Given at School? Y N Time _____
Daily Medication _____ Dose/Frequency _____ Given at School? Y N Time _____
Student has VNS Magnet? Y N Directions for use: _____

Emergency Medication _____ **Dose** _____ **Route** _____
When to Give _____ **When to repeat dose** _____
For a seizure lasting longer than _____ minutes or _____, CALL 911.

This Seizure Medical Management Plan has been approved by:

Signature of Health Care Provider _____ **Date** _____
Phone _____ **Fax** _____ **E-mail** _____

For Parent /Guardian to complete

I have reviewed and give my permission to the school nurse, and other designated staff member(s) to perform and carry out the tasks as outlined by this Seizure Medical Management Plan for my child. I also consent to the release of information contained in this plan to all staff and other adults who may need to know this information to maintain my child's health and safety at school. I give my permission for the school nurse to contact my child's healthcare provider(s) regarding the above condition.

Parent/Guardian _____ Date _____
E-mail _____ Phone _____ Cell: _____

Appendix B

Sample Seizure Health Intake Form

NOTE: The student's Individualized Health Plan must be updated annually including medication orders.

Student's Name _____ DOB _____ Grade _____ Today's Date _____

Parent/Guardian 1 _____ Contact Information _____

Parent/Guardian 2 _____ Contact Information _____

Name of healthcare provider _____ Last visit _____ Phone Number _____

Name of neurologist _____ Last visit _____ Phone Number _____

Health Insurance Private MaineCare Currently without insurance

Diagnosis _____ Seizure type _____

Medical alert jewelry worn Yes No Current 504 Plan Yes No IEP Yes No

Transportation to school _____ home _____

After-school activity participation Yes No Activities _____

Other related medical conditions _____

Age at onset of seizures _____ Date of student's last seizure _____

Any known triggers (fatigue, heat, etc.) _____

How does the student act before a seizure (vision distorted, hearing or smell, etc.)

What does a student's seizure look like (stares into space, body stiffens, loses bladder control, etc.)

Emergency actions has the student previously needed (medication to stop seizure, ambulance, etc.)?

Frequency of seizures (number in a day, month) _____

How long do the seizures typically last? _____ Single seizure or clusters? _____

Has student ever had a seizure that lasted longer than 5 minutes? Yes No

How does student act after a seizure (sleepy, cries, etc.)? _____

Describe student's understanding of their seizure disorder: None/Limited Basic Knowledgeable

Daily Medications

Medication	Dose	Route of Administration	Prescribed Time

Emergency Medication

Medication	Dose	Route of Administration	Prescribed Time

How often does student require emergency medication? _____ Last dose _____

Typical response to emergency medication _____

When have you been instructed to call 911 after or during a seizure? _____

Does the student have a vagus nerve stimulator? Yes No

If yes, instructions for appropriate magnet use: _____

Special considerations and precautions: Check all that apply and describe any considerations, precautions or strategies that should be taken:

- General _____
- P.E./sports _____
- Learning _____
- Recess _____
- Behavior _____
- Bus transportation _____
- Mood/coping _____
- Other _____

Describe student's response and current coping/adaptation to having seizures: _____

Other important information for school staff to know: _____

Parent/Guardian Signature: _____ Date: _____

Appendix C

Sample Checklist for the School Nurse

This checklist may be a useful guide for the school nurse to use for students with seizures or epilepsies.

1. Gather data

- Ensure medical release for information is on file.
- Obtain orders from the medical provider for medication needed at school and review student's current seizure plan from the health care provider.
- Arrange to conference with student and parent/guardian. Be sure to discuss and include that information will be shared with all of staff who need to keep the student safe.
 - Consider utilizing an intake form (Appendix B) or this to collect appropriate data to move forward with planning.
 - Epilepsy Foundation [forms](#) are available to help students manage seizures.
- Seizure care plans and medical orders should be stored together, preferably with a picture of the student in the confidential health record and with the student's emergency medication.
- Refer to the Maine Department of Education [Decision Tree for Coordination and Oversight](#).

2. Conduct assessment and develop plans for student

- Nursing assessment of student, utilizing input from parents/guardian, student, and provider.
- Advocate for the least restrictive medication choice that is to be given at school.
- Create a [seizure action plan](#).
- Create emergency plans to share with all staff, including substitute staff and bus drivers (see Appendix D and E)
- Develop/implement the student's 504 plan or IEP if indicated.

3. Plan and implement training

Training for school nurses

- [Epilepsy Foundation: Seizure Training for School Nurses](#)

Training for school staff

- [Epilepsy Foundation: Seizure Training for School Personnel](#)
- Identify all staff that will have contact with the student, (teachers, coaches, PE instructor, lunchroom staff, recess staff, and bus driver) and coordinate training.
- Include those involved in the 504, IEP, and other education plans and collaborate with the administration.
- After training has been completed, review roles in carrying out the plan, how roles relate, and when/where to seek help

4. Facilitate school health team meeting

- Review individual plan of care at least annually
- Review the emergency plan with all staff, including substitute staff at least annually
- Monitor compliance and understanding of the plan by school staff
- Facilitate follow-up meetings to discuss concerns and updates, evaluate for potential changes to the plan of care and modify the plan on an ongoing basis

Appendix D

Sample Emergency Seizure Action Plan for the Classroom

Name _____ DOB _____ Allergies _____

<p>School Year _____</p> <p>Specific information for this student:</p> <p>Seizure Type _____</p> <p>Usual Length of Seizure _____</p> <p>Usual symptoms of seizure:</p> <p>Seizure triggers or warning signs:</p> <p>Student's response after a seizure:</p> <p>Other information:</p>	<p>BASIC SEIZURE FIRST AID:</p> <ul style="list-style-type: none"> ➤ Stay calm, stay with the student & time seizure ➤ Keep student safe ➤ Stay with the child until fully conscious/until emergency personnel or school nurse arrives ➤ Record seizure in the log ➤ Do NOT restrain & DO NOT put anything in mouth <p><u>For tonic-clonic (grand mal) seizure:</u></p> <ul style="list-style-type: none"> ➤ Protect head – loosen restrictive clothing ➤ Keep airway open, watch breathing ➤ Turn child on side, provide privacy ➤ Move tables, desks, chairs away from student
<p>A seizure emergency for this student is defined as:</p> <p>Seizure Emergency Protocol:</p> <ul style="list-style-type: none"> ➤ Call 911 ➤ Check for breathing & pulse, if absent, begin CPR ➤ Contact the school nurse at _____ ➤ Notify parent/guardian or emergency contact 	<p>A Seizure is considered an EMERGENCY when:</p> <ul style="list-style-type: none"> ➤ A seizure lasts longer than 5 minutes ➤ Student has repeated seizures without regaining consciousness ➤ Student is injured or diabetic ➤ Student has breathing difficulties ➤ Student has a seizure in the water ➤ Student is not breathing or has no pulse

EMERGENCY SEIZURE MEDICATION/ TREATMENT INSTRUCTIONS

Treatment/Medication _____ Dose _____ How to administer _____

When to give medication: _____

This treatment/medication can be administered by: School Nurse _____

EMERGENCY CONTACT INFORMATION:

Physician Name _____ Phone: _____

Parent/Guardian Name: _____ Phone: _____ Cell: _____

Parent/Guardian Name: _____ Phone: _____ Cell: _____

Other Emergency Contact: _____ Phone: _____

I give permission for school personnel to share this information, follow this plan, administer medication, care for my child and, if necessary, contact our healthcare provider. I assume full responsibility for providing the school with prescribed medication and devices. I approve this Seizure Emergency Care Plan for my Child.

Signature of Parent/Guardian: _____ Date: _____

Information for this document taken from publicly available CDC and Epilepsy websites.

Appendix E

Sample Emergency Seizure Action Plan for Transportation

School: _____ SCHOOL YEAR: 20____/20____

Student name: _____ DOB _____ Grade: _____

Address _____ Bus# _____ Route# _____

School Nurse _____ Phone _____ Main Office _____

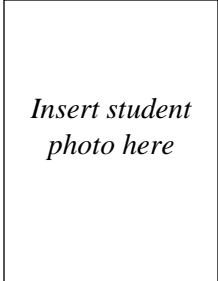
PARENT/GUARDIAN:

Name _____ Phone _____ Cell _____

Name _____ Phone _____ Cell _____

Daycare _____ Phone _____ Cell _____

Emergency Contact: _____ Cell _____



SEIZURE ACTIVITY

Rigid body, sustained jerking movements, non-responsive, may be drooling from the mouth

EMERGENCY PLAN

1. STOP the bus.
2. Assure student safety.
3. Call 911.
4. Evaluate first aid needs, initiate CPR, or other life-saving actions within your level of training and ability.
5. Follow steps in Seizure First Aid Poster provided.

Seizure First Aid

How to help someone having a seizure

1

STAY with the person until they are awake and alert after the seizure.

- ✓ Time the seizure
- ✓ Remain **calm**
- ✓ Check for **medical ID**

2

Keep the person **SAFE**.

- ✓ Move or guide away from **harm**

3

Turn the person onto their **SIDE** if they are not awake and aware.

- ✓ Keep **airway clear**
- ✓ **Loosen tight clothes** around neck
- ✓ Put **something small and soft** under the head

Call 911 if...

- ▶ Seizure lasts longer than 5 minutes
- ▶ Person does not return to their usual state
- ▶ Person is injured, pregnant, or sick
- ▶ Repeated seizures
- ▶ First time seizure
- ▶ Difficulty breathing
- ▶ Seizure occurs in water

Do NOT

- ✗ Do **NOT** restrain.
- ✗ Do **NOT** put any objects in their mouth.
- ▶ **Rescue medicines can be given** if prescribed by a health care professional

Learn more: epilepsy.com/firstaid

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