

Supporting Students with Seizures in School

Standards of Care

including Training Standards for School
Personnel

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Information contained in this guide has been adapted from the Epilepsy Foundation's
Education Program's

Introduction

[Epilepsy is a neurological condition that affects the nervous system.](#) Epilepsy is also known as a seizure disorder. It is usually diagnosed after a person has had at least two seizures (or after one seizure with a high risk for more) that were not caused by some known medical condition. A seizure is a brief disturbance in the electrical activity of the brain that causes temporary changes in movement, awareness, feelings, behavior or other bodily functions.

The seizures in epilepsy may be related to a brain injury or a family tendency, but often the cause is completely unknown. The word "epilepsy" does not indicate anything about the cause of the person's seizures or their severity.

- Many people with epilepsy have more than one type of seizure and may have other symptoms of neurological problems as well. Sometimes EEG (electroencephalogram) testing, clinical history, family history, and outlook are similar among a group of people with epilepsy. In these situations, their condition can be defined as a specific epilepsy syndrome (Epilepsy Foundation, 2014).

School personnel need to be prepared to provide care to students with epilepsy at school and at all school-sponsored activities in which a student with epilepsy participates. In an effort to standardize the support for students with epilepsy in schools, Michigan Departments of Education and Health and Human Services have garnered input from a multi-disciplinary team consisting of national and statewide stakeholders. The work of this team has been incorporated into the Supporting Students with Seizures at School Training Standards.

Standards of Care have been developed to guide schools in providing support to students with chronic health conditions that meets requirements of the law and ensures that best practices are followed. These general standards are outlined in the Standards of Care Document located in the Appendices. The seizure specific standards of care and training standards are included in this document.

Instructions:

Supporting Students with Seizures in School Training Toolkit

The school nurse is the most appropriate person in the school setting to provide care for a student with Seizures. Many schools, however, do not have a full-time nurse, and sometimes a single nurse must cover more than one school. Even when a nurse is assigned to a school full time, she or he may not always be available during the school day, during extracurricular activities, or on field trips. In circumstances where a nurse is absent or unavailable, the school remains responsible for arranging and implementing the agreed upon care that is necessary to enable the student with seizure to participate in school and school-related activities. The school nurse or another qualified health care professional plays a major role in selecting and training appropriate staff and providing professional supervision and consultation regarding routine and emergency care of the student with seizures.

In Michigan, school districts may train school personnel to provide daily care and emergency medical assistance including the administration of Vagus Nerve Stimulation (VNS) and rescue medications to students with seizures, in accordance with a health care provider's written statement. Best practice is set forth by the [CDC: Epilepsy in Schools: Tools to Help Schools Manage Epilepsy](#) and the [Epilepsy Foundation](#)

This toolkit is designed to guide the School Nurse or other medical professional in providing the most complete training according to standards set by the Supporting Students with Seizures in School Standard of Care and Training Standards.

The training standards outline the steps for supporting students with seizures in school. These steps follow the [Safe and Legal Support for Students with Health and Medication Needs in School](#) guidance developed by the Michigan Association of School Nurses for medication administration Training. Once *Steps 1-3* of this toolkit are complete, the staff training, and ongoing management and support can be implemented.

All school personnel should be given training about seizures and how to manage it in *Step 4*. This training should be broken down into different levels depending on the responsibility of each staff member towards the student with seizures. The training should be administered by a school nurse or a qualified medical professional. Training should take place at the beginning of each school year and should be repeated when a current student is newly diagnosed with seizures or a student with seizures enrolls in the school. Refresher training is done as needed to support the student as his/her condition or needs change, as outlined in *Step 5*.

The Performance Standards included in this kit outline the support that should be provided to students with seizures in school in compliance with the law and best practice. Training

must be documented and these records must be saved according to the [Michigan Records Retention and Disposal Schedule for Michigan Public Schools](#).

Training Presentations for the 3 tiers of training are *linked*. Additional resources for training are provided in the appendices and marked in the training outline with a ►.

Steps to Supporting Students with Seizures in School

1. Review the Legal Considerations
 - a. [Michigan School Code](#)
 - b. [Michigan Public Health Code](#)
 - c. [FERPA](#)
2. Assemble the Student's Health Care Plans (Samples included in the appendices)
 - a. ► **SAP** Seizure Action Plan can be considered the **MMP** or Medical Management Plan including the **MAA** Medical Authorization (Prepared by the Student's Personal Seizures Health Care Team)
 - b. ► **IHP** Individualized Health Care Plan (Prepared by the School Nurse)
3. Coordination of Care: School Health Team/Seizures Health Care Team
 - a. Meet with student's parent(s)/guardian(s) to review Health Care Plans and identify the support that will be provided according to the student's specific needs.
4. Train School Personnel

The three tiers of support build on each other.

 - a. Tier 1- General Staff Awareness (All staff members)
 - i. 15-20 minutes in length
 - b. Tier 2- Emergency Care (MERT Team and Daily Support Staff)
 - i. 1-3 hours in length
 - c. Tier 3- Daily Support (Daily Support Staff)
 - i. 1-3 hours in length
5. Ongoing Seizures Management and Support

The checklist on Page 8 is the seizure specific Standard of Care tool that can be used to ensure that all steps are completed when providing care to students with Seizures in schools.

Safe & Legal Support of Students with Seizures in School

Checklist:

- Non-Emergent Health Need Identified- **Student with Seizures**
- If Emergency is suspected, Call 9-1-1 immediately**
- Parent Provides:
 - SAP/MMP; includes routine/daily care and emergency action steps
- DSP/RN verifies forms are complete
- Student specific meeting with parent, administrator, teacher, DSP and RN/Trainer to provide input to the POC based on the SAP/MMP, MAA, and student needs (i.e., student's daily schedule)
- Building administrator identifies and designates school personnel to be trained
- DSP determines training needs and arrange skill-based training for SSH Team *
- SSH Team participates in skill-based training**
- STOP**: Verify all forms are appropriately signed and training is complete before DSP assume responsibility for provision of care
- DSP establishes student-specific health file and medication administration record.
- DSP distributes SAP/MMP to SSH Team members and other school staff per FERPA guidelines
- DSP provides care to student as outlined in SAP/MMP
- DSP documents in student health records all care (including student responses to care)
- In the event of non-urgent unexpected response or error, follow school procedure.
- Inform parent in a timely manner
- In the event of **suspected emergency, always call 9-1-1 first**, then call parent
- Follow SAP/MMP emergency plan
- Follow school policy for responding to emergencies (See sample Seizures MERT protocol)
- DSP maintains regular communication with SSH Team. If appropriate, evaluate for eligibility for a Section 504 Academic Accommodations Plan
- DSP secures updated SAP/MAA, and training before the start of each school year or more frequently if student and/or school personnel needs dictate

Key:

DSP: Designated School Personnel

SAP/MMP: Seizure Action Plan/Medical Management Plan

PA: Physician's Assistant

NP: Nurse Practitioner

RN: Registered Nurse

MAA: Medication Administration Authorization

MERT: Medical Emergency Response Team

SSH Team: Student-specific Health Team

****SSH Team includes:** Parent(s), Student, Designated School Personnel AND

Registered Nurse/Physician/Physician's Assistant

****Based on Michigan law and current best practices**

Please note: Timely completion of each step is an expectation for all members of SSH Team

Performance Standard 1: LEGAL CONSIDERATIONS

The [Michigan School Code](#) and [Public Health Code](#) (applicable for schools with school nurses) dictate the legal requirements for support provided in schools to students with health and medication needs. Three laws apply to students with seizures. The Americans with Disabilities Act (ADA), the Individuals with Disabilities Education Act (IDEA) and Section 504 of the Rehabilitation Act of 1973 require schools to provide accommodations for students if their health condition affects their education. Students with seizures may qualify for reasonable accommodations in the school setting so they are successfully supported, and their schooling is not adversely affected by their disability or perceived disability.

Performance Standard 2: COORDINATION OF CARE

Collaboration and cooperation are key elements in creating a Circle of Support for planning and implementing successful support for students with seizures at school. To work collaboratively, a school health team should be assembled to include people who are knowledgeable about seizures, the school environment, Federal, State, Education and Nursing laws. The school health team is distinct from the student's personal health care team.

The school health team members work together to implement the medical orders in the Seizure Action Plan (SAP/MMP) developed by the student's personal health care team, using the strategies outlined by the school nurse in **the Individualized Health Care Plan (IHP)**.

In addition, the school health team should be part of the group that develops and implements the student's Section 504 Plan, if there is a need for one.

School Health Team

- Student with Seizures
- Parent/guardian
- School nurse or other qualified personnel
- Other school health care personnel
- Trained Seizures personnel
- Principal and other administrators
- 504/IEP Coordinator
- Office Staff
- Teacher(s)
- Guidance counselor
- Coach(es) and other school staff members responsible for the student

Personal Health Care Team

- Student with Seizures
- Parent/guardian
- Medical Provider
- Nurse
- Registered Dietician (if available)
- Seizures Educator (if available)
- Clinic Social Worker (if available)

Performance Standard 3: STUDENT HEALTH PLANS

► **SAP/MMP Seizure Action Plan/Medical Management Plan**

Information in the SAP/MMP will include:

- Date of diagnosis; what type(s) of seizure the student has, what they look like, how often they occur and when they are most likely to occur
- Contact information (parents/guardians and student's health care provider)
- Specific medical orders for avoiding seizure triggers, administering VNS (Vagus Nerve Stimulation) and rescue medications, and supporting a ketogenic diet
- Assessment of student's self-care skills for identifying seizure warning signs or auras
- What first aid may be needed
- Use of magnets for Vagus Nerve Stimulator
- When and how to administer rescue medications, post-administration monitoring requirements
- How to document seizures and side effects and share this information with medical providers and parents
- Activity restrictions
- 72-hour disaster, lockdown, or emergency plan

► **Medication Administration Authorization (MAA)** Provides the health care provider's orders that allow for medication to be on school property and to be administered to students according to Physician's, Physician's Assistant's (PA) or Nurse Practitioner's (NP) instructions and written parent/guardian permission.

► **Seizures Observation Record Provides** a template to document the suspected seizure activity for students who are in the process of being diagnosed with epilepsy, have recently been diagnosed, have experienced a recent change in seizure type or patterns, or have infrequent seizures.

► **Seizure Action Plan/Medical Management Plan (SAP/MMP)** Provides explicit steps for how to respond to a seizure.

► **IHP Individualized Health Care Plan (Prepared by the School Nurse)** sometimes called the nursing care plan, is based on the medical orders in the student's SAP/MMP and MAA and incorporates an assessment of the school environment as well as student-specific information (e.g., familial, psychosocial, and developmental information).

Information in the IHP may include:

- Plan for supporting the student daily (including avoidance of known seizure triggers, adhering to the student's meal plan, and promoting physical activity)
- Supplies needed and where they will be kept

- Participation in all school-sponsored activities and field trips, with coverage provided by the school nurse or trained seizure personnel
- Guidelines for communicating with the family and the student's personal health care team
- List of trained seizure personnel
- Plan and timeline for training and supervising trained seizure personnel and other school personnel.
- Timeframe for ongoing review of student outcomes
- Strategies to ensure the student is not subject to inappropriate penalties for health care appointments and to provide accommodations during the school day
- Maintenance of confidentiality and the student's right to privacy

Performance Standard 4: TRAINING

Seizure care must be carried out as specified in the student's Seizure Action Plan/Medical Management Plan (SAP/MMP).

Nonmedical school personnel, called "trained seizure personnel" or "designated school personnel" can be trained and supervised to safely support students with seizures in the school setting. In addition to learning how to perform general seizure care tasks, trained seizure personnel should receive student-specific training and be supervised by the School Nurse or Epilepsy Care and Education Specialist. [Epilepsy Foundation of Michigan](#)

Care tasks performed by trained seizure personnel may include vagus nerve stimulation, and basic ketogenic diet support.

The school nurse has a critical role in training and supervising trained seizure personnel to ensure the health and safety of students with seizures. In addition, a student's health care provider or an Epilepsy Care and Education Specialist may assist in training nonmedical personnel in seizure care. Given the rapid changes in technology, therapies, and evidence-based practice, the school nurse who provides care to students with seizures and facilitates training for school personnel has a professional responsibility to acquire, maintain knowledge and competency related to seizures.

All school personnel should be given training about seizures. Training should be broken down into different levels depending on the responsibility of each staff member towards the student with seizures. The training should be administered by a School Nurse or an Epilepsy Care and Education Specialist. [Epilepsy Foundation of Michigan.](#)

Training should take place at the beginning of each school year and should be repeated when a current student is newly diagnosed with Seizures or when a student with Seizures enrolls in the school. Refresher training is to be done as the needs of the student change.

The trainer shall document the training.

Seizure Training Documentation should include student specific training.

Tier 1 Training Outline

Administered to all school personnel at the beginning of the year. This training may be provided at a staff meeting and could consist of viewing the Overview of Seizures video or providing the Level1 PowerPoint Presentation.

Tier 1 training content options:

1. [Epilepsy Foundation](#) 13:39 minutes
2. [On-Demand Training](#) Available 24/7 60 minutes
 - Certificate available upon completion of the program
 - By completing the course, school personnel will be able to:
 - Recognize 3 common seizure types
 - Describe 3 seizure first aid steps to assist a student having a seizure
 - Recognize 3 key factors that would make a seizure a medical emergency
 - Describe 3 ways to support student living with epilepsy
3. Tier 1 PowerPoint Presentation '[Keeping Students with Seizures Safe at School](#)'
 - General training on seizure management and response:
 - Observing, recognizing and responding to seizures
 - Documenting
 - Roles and responsibilities of individual staff members
 - Who to contact for help in an emergency?

► Handouts

Seizure First Aid

Tier 2 Training Outline

Designed for school personnel who have responsibility for the student with seizures throughout the school day, including but not limited to: classroom, physical education, music, and art teachers, as well as other personnel such as lunchroom staff, coaches, and bus drivers.

Tier 2 training content:

- Tier 2 [Emergency Care PowerPoint](#)
 - Content from Tier 1 with specific instructions for responding to an emergency
 - Roles and responsibilities of individual staff members
 - Expanded overview of seizures
 - Procedures and brief overview of the operation of devices (or equipment) commonly used by students with seizures
 - Impact of seizures on behavior, learning, and other activities
 - ► Seizure Action Plan or Medical Management Plan and how to activate Emergency Medical Services in case of a seizure emergency
 - Tips and planning needed for the classroom and for special events
 - What to do during a schoolwide emergency (e.g., lockdown or evacuation)
 - Overview of the legal rights of students with seizures in the school setting
 - Seizure Response Protocol

Sample Seizure Emergency Response Protocol

Seizure activity identified → Protect student from injury, note the time, and initiate actions below:

- ❖ Call 9-1-1 immediately:
 - Make call from location of incident, if possible.
 - Use speaker mode on phone, if possible.
 - Be prepared to provide EMS Dispatcher with location name and address and the entrance door number nearest to the emergency situation.
 - Don't hang up the phone until instructed to do so by the EMS Dispatcher.
- ❖ Notify front office of Medical Emergency.
- ❖ **Announcement** (□ OVER-HEAD; □ WALKIE-TALKIE) to alert trained Medical Emergency Response Team (MERT) members:

“Attention Staff and Students, We are now going into Lock-in (Verbiage for all to stay in place) for a medical emergency in Room _____. MERT team please respond.”

- ❖ Available MERT members immediately carry out assigned tasks.
 - Take AED and any emergency medical supplies and medication (if ordered) to location.
 - Inform Central Administration of Emergency.
 - Contact parents. Meet them in the parking lot.
 - Meet the ambulance. Unlock the gate/door/ direct traffic
 - Copy the medical records of the student. Provide to EMS.
 - Control the scene. Clear the area by directing uninvolved students to alternate location
 - Document emergency situation and response on Emergency Response/Incident Report form
 - Conduct debriefing session of incident and response following the event.
- ❖ Response Team members will immediately initiate the student's specific Seizure Action Plan (SAP) or “Basic First Aid for Seizures” if no SAP on file:
 - Cushion Head
 - Loosen Clothing
 - Turn on Side
 - Keep airway open, monitor breathing –
If no breathing/ineffective breathing, start CPR and use AED when appropriate
 - Don't hold down or restrict movement
 - Don't put anything in mouth
 - Time the seizure

- Administer emergency medication (if ordered) per student's SAP
- Ensure that 9-1-1 has been called
- Also, remember to Document seizure activity on the "Seizure Observation Record"

PLEASE NOTE: Regardless of any other instructions or requests you have received,

always call 9-1-1 if:

- You are unsure of what to do
- It is a first- time seizure
- The seizure lasts more than 5 minutes
- The student is having difficulty breathing
- The student is injured, pregnant, or has diabetes; or
- There is a slow recovery or more than one seizure event

Tier 3 Training Outline

For two or more (ideally four staff members should be trained) school staff members designated as trained seizure personnel who will perform or assist the student with seizure care tasks.

Tier 3 training content:

- Tier 3 [Daily Support PowerPoint Presentation](#)
- Content from Tier 1 and Tier 2+
 - Student-specific training, when addressing each seizure care task, including:
 - ► Seizures Medical Management Plan (MMP), 504 Plan, IEP, or other education plan
 - Clear identification and understanding of the task as outlined in the student's MMP
 - VNS administration
 - Rescue medication administration
 - ► Basic dietary therapy information
 - Each student's specific trigger and symptoms for seizures
 - Prodrome
 - Aura
 - Ictus
 - Postictal
 - Step-by-step instruction on how to perform the task using the student's equipment and supplies
 - How to document all care tasks provided
 - Plan for ongoing evaluation

Ideally, at least four adults should be trained as a Tier 3. Monitoring all employees who assist students with seizures is the responsibility of each school.

All supplies for treatment, including the materials necessary to administer rescue medications, are provided by the parent/guardian.

TRAINING: Content and Resources

Understanding Seizures

Seizures Overview [1. Epilepsy Foundation 13:39 minutes](#)

Epilepsy is the general term for a variety of neurological conditions characterized by recurrent unprovoked seizures. A seizure is a brief disturbance in the electrical activity of the brain that causes temporary changes in movement, awareness, feelings, behavior, or other bodily functions.

Prevalence and Incidence

Epilepsy is the fourth most common neurological disorder in the United States after migraine, stroke, and Alzheimer's disease. About one percent of Americans have some form of epilepsy, and nearly four percent (1 in 26) will develop epilepsy at some point in their lives. The number of Americans who have epilepsy is greater than the number who have multiple sclerosis, Parkinson's disease, and cerebral palsy combined. 10% of Americans will have at least one seizure at some point in their lives.

For many children with epilepsy, seizures are well controlled, and the condition has little or no impact on school performance. For others, however, seizures, medication side effects, learning difficulties, and other disabilities associated with epilepsy can interfere with school performance and social integration.

Seizure Types and Epilepsy Types

There are about 30 different [types of seizures](#) and over 60 different [types of epilepsy](#). It's important for patients to ask their neurologists what type of seizures they are experiencing and what type of epilepsy is suspected. While most people are familiar with tonic-clonic or "grand mal" seizures, there are many types which are more subtle and can be easily confused with other conditions or behaviors. This can lead to misunderstanding or inappropriate reactions by onlookers and can also delay necessary diagnosis and treatment.

The following are some of the more common types of seizures: [Seizure Types and Classifications](#), featuring Erica Austin, DO (2017).

- **Generalized Tonic-Clonic Seizure (formerly called grand mal):** sudden fall and period of rigidity followed by muscle jerks, shallow breathing, pale or bluish skin, and possible vomiting or loss of bowel or bladder control; usually lasts a couple of minutes; normal breathing and complexion return promptly; some confusion and/or fatigue may occur, followed by a return of full consciousness.
- **Generalized Absence Seizure (formerly called petit mal):** most common in children; looks like a blank stare; lasts for only a few seconds; may be accompanied by rapid blinking or chewing movements; person will be unaware of what happened during seizure, but will quickly return to full consciousness once the seizure has stopped; seizures often occur frequently throughout the day; atypical absence seizures begin and end more gradually and may last a bit

longer; absence seizures may be mistaken for ADHD, behavior problems, or learning disabilities.

- **Atonic Seizure:** sudden loss of muscle tone that may cause a drop of the head or fall to the ground; if consciousness is lost, the person usually regains it promptly with little or no confusion; typically lasts less than 15 seconds; because people with these seizures fall so suddenly, many have to wear helmets.
- **Tonic Seizure:** sudden stiffening of the body, which may cause a fall if standing; most often occurs during sleep; if consciousness is lost, the person usually regains it promptly with little or no confusion; typically lasts less than 20 seconds
- **Myoclonic Seizure:** sudden, involuntary, brief, shock-like bodily jerk caused by contractions of one or more muscles or muscle groups; often occur in clusters
- **Focal Impaired Awareness Seizure (Complex Partial Seizure):** usually starts with blank stare, followed by chewing, walking about, random movements, vocalizations, picking at clothing, or other actions that the individual cannot control (automatisms); person is unresponsive and awareness of surroundings is clouded; usually lasts 1-2 minutes; person will have no memory of what happened during the seizure and may be confused for several minutes after the seizure has stopped; in some cases, complex partial seizures may simply look like prolonged absence seizures; may be mistaken for mental illness, drug use, intoxication, aggression, or behavior problems.
- **Focal Aware Seizure (Simple Partial Seizure):** person is fully aware during the seizure; may involve jerking or other body movements, sensory distortions or hallucinations, unusual physical or emotional feelings, changes in bodily functions, or other symptoms that are not obvious to the onlooker; referred to as an aura if it precedes another seizure
- **Focal to Bilateral Tonic-Clonic Seizure (Secondarily Generalized Seizure):** seizure that begins in one part of the brain and spreads to both sides of the brain to become a tonic-clonic seizure.

Treatment

Daily [medication](#) is the standard treatment for epilepsy. Unfortunately, though, 30 - 40% of people with epilepsy continue to have seizures despite treatment. The goal of treatment should always be “no seizures and no side effects.” With this in mind, patients who continue to have seizures or side effects after having tried two to three medications should see an epileptologist (a neurologist who specializes in epilepsy) to review their current diagnosis and treatment regimen and to explore other treatment options.

Other treatment options include [brain surgery](#), [vagus nerve stimulation](#), [responsive neurostimulation](#), [deep brain stimulation](#), and the [ketogenic diet](#). There are also a number of complementary therapies that may be considered.

What Happens During a Seizure?

[Seizures](#) can take on many different forms, and seizures affect different people in different ways. Anything that the brain does normally can also occur during a seizure when the brain is activated by seizure discharges. Some people call this activity “electrical storms” in the brain.

Seizures have a beginning, middle, and end. Not all parts of a seizure may be visible or easy to separate from each other. Every person with seizures will not have every stage or symptom described below. The symptoms during a seizure usually are stereotypic (occur the same way or similar each time), episodic (come and go), and may be unpredictable.

Beginning:

Some people are aware of the beginning of a seizure, possibly as much as hours or days before it happens. On the other hand, some people may not be aware of the beginning and therefore have no warning.

Prodrome:

Some people may experience feelings, sensations, or changes in behavior hours or days before a seizure. These feelings are generally not part of the seizure, but may warn a person that a seizure may come. Not everyone has these signs, but if they do, the signs can help a person change their activity, make sure to take their [medication](#), [use a rescue treatment](#), and [take steps to prevent injury](#).

Aura:

An aura or warning is the first symptom of a seizure and is considered part of the seizure. Often the aura is an indescribable feeling. Other times it's easy to recognize and may be a change in feeling, sensation, thought, or behavior that is similar each time a seizure occurs.

- The aura can also occur alone and may be called a [focal onset aware seizure](#), simple partial seizure or partial seizure without change in awareness.
- An aura can occur before a change in awareness or consciousness.
- Yet, many people have no aura or warning; the seizure starts with a loss of consciousness or awareness.

Common Symptoms Before A Seizure:

Awareness, Sensory, Emotional or Thought Changes:

- Déjà vu (a feeling that a person, place or thing is familiar, but you've never experienced it before)
- Jamais vu (feeling that a person, place or thing is new or unfamiliar, but it's not)
- Smells
- Sounds
- Tastes

- Visual loss or blurring
- “Strange” feelings
- Fear/panic (often negative or scary feelings)
- Pleasant feelings
- Racing thoughts

Physical Changes:

- Dizzy or lightheaded
- Headache
- Nausea or other stomach feelings (often a rising feeling from the stomach to the throat)
- Numbness or tingling in part of the body

Middle:

The middle of a seizure is often called the ictal phase. It’s the period of time from the first symptoms (including an aura) to the end of the seizure activity, this correlates with the electrical seizure activity in the brain. Sometimes the visible symptoms last longer than the seizure activity on an EEG. This is because some of the visible symptoms may be aftereffects of a seizure or not related to seizure activity at all.

Common Symptoms During A Seizure:

Awareness, Sensory, Emotional or Thought Changes:

- Loss of awareness (often called “black out”)
- Confused, feeling spacey
- Periods of forgetfulness or memory lapses
- Distracted, daydreaming
- Loss of consciousness, unconscious, or “pass out”
- Unable to hear
- Sounds may be strange or different
- Unusual smells (often bad smells like burning rubber) or tastes
- Loss of vision or unable to see
- Blurry vision
- Flashing lights
- Formed visual hallucinations (objects or things are seen that aren’t really there)
- Numbness, tingling, or electric shock like feeling in body, arm or leg
- Out of body sensations

- Feeling detached
- Déjà vu or jamais vu
- Body parts feels or looks different
- Feeling of panic, fear, impending doom (intense feeling that something bad is going to happen)
- Pleasant feelings

Physical Changes:

- Difficulty talking (may stop or keep talking, make nonsense or garbled sounds, or speech may not make sense)
- Unable to swallow, drooling
- Repeated blinking of eyes, eyes may move to one side or look upward, or staring
- Lack of movement or muscle tone (unable to move, loss of tone in neck and head may drop forward, loss of muscle tone in body/person may slump/fall forward)
- Tremors, twitching or jerking movements (may occur on one or both sides of face, arms, legs or whole body; may start in one area then spread or stay in one place)
- Rigid or tense muscles (part of the body or whole body may feel very tight or tense and if standing, may fall “like a tree trunk”)
- Repeated non-purposeful movements, called **automatisms**, such as
 - lip smacking or chewing movements
 - repeated movements of hands, like wringing, playing with buttons or objects in hands, waving
 - dressing or undressing
 - walking or running
- Repeated purposeful movements (may continue activity that was going on before seizure)
- Convulsion (person loses consciousness, body becomes rigid/tense, then fast jerking movements occur)
- Losing control of urine or stool unexpectedly
- Sweating
- Change in skin color (looks pale or flushed)
- Pupils may dilate or appear larger than normal
- Biting of tongue (from teeth clenching when muscles tighten)
- Difficulty breathing
- Heart racing

Ending:

As the seizure ends, the postictal phase occurs - this is the recovery period after the seizure. Some people recover immediately while others may take minutes to hours to feel like their usual self. The type of seizure, as well as what part of the brain the seizure impacts, affects the recovery period – how long it may last and what may occur during it.

Common Symptoms After A Seizure:

Awareness, Sensory, Emotional, or Thought Changes:

- Slow to respond or not able to respond right away
- Sleepy
- Confused
- Memory loss
- Difficulty talking or writing
- Feeling fuzzy, lightheaded, or dizzy
- Feeling depressed, sad, upset
- Scared or anxious
- Frustrated, embarrassed, ashamed

Physical Changes:

- May have injuries, such as bruising, cuts, broken bones, or head injury if fell during seizure
- May feel tired, exhausted, or sleep for minutes or hours
- Headache or other pain
- Nausea or upset stomach
- Thirsty
- General weakness or weak in one part or side of the body
- Urge to go to the bathroom or lose control of bowel or bladder

Rescue Medications

Types of Rescue Therapies

Used 'off-label'

An oral rescue medicine may be recommended by a health care provider. Oral medicines can be pills, liquids, or dissolvable tablets. Rescue medicines can be given by mouth in 1 of 3 ways.

Oral

If a prescription just says, “take by mouth,” it usually means swallowing the medicine with water. The medical abbreviation P.O. (per os) may be on the prescription.

- An oral rescue medicine should only be given if the person is awake and alert and is not at risk for choking on the pill or water.
- If the medicine is in a tablet form, you may be told to chew it before swallowing. Chew medicine first only if your provider recommends it.
- One medicine, [clonazepam](#), may come as a wafer that can dissolve on the tongue. Another form of benzodiazepine is being developed to dissolve in the mouth too.

Sublingual

This means that the medicine is placed under the tongue where it will dissolve and be absorbed into the bloodstream. The person should not drink or eat anything until the medicine is gone.

Buccal

This means that the medicine can be placed in the mouth between the cheek and the gum. The medicine dissolves and is then absorbed into the bloodstream. Usually, medicines that can be taken under the tongue can also be placed between the cheek and the gum. The person should not drink or eat anything until the medicine is gone.

Who Should Get Oral Medicines That Are Not Swallowed?

Swallowing pills is easier for most people. Yet there are situations where it is not safe or possible for a person to swallow a pill. These may include

- An infant or young child who cannot swallow
- A person who is too sleepy or not able to cooperate
- Someone who cannot keep the medicine in their mouth (for example, a person who drools or has vomited)
- A person who has a medical or neurological condition that makes swallowing unsafe
- A person who is having too many seizures

In these situations, talk to your provider about other forms of rescue medicine, such as a nasal or rectal one.

What Are Lorazepam and Diazepam Used For?

Some fast-acting medicines (such as diazepam, [lorazepam](#), or midazolam) can be used as a rescue medicine to stop seizures.

Both diazepam and lorazepam can be used to help stop seizures on an “as needed” or rescue basis. However, if they are used every day, they may not work as well. They are NOT intended to take the place of daily seizure medicine. Sometimes a small amount of one of these medicines may be prescribed to take daily with another seizure medicine, but for most people, lorazepam and diazepam are not used regularly.

Lorazepam is available under the brand name *Ativan*® or the generic name of lorazepam in pill form with different dosage strengths. It also comes as a concentrated liquid solution under the name Lorazepam or *Ativan Intensol*®. The liquid form has to be refrigerated, which makes it hard to carry with you. Lorazepam in an injection is only used in a hospital.

Diazepam for use in the mouth is available in pill form under the brand name of *Valium*®, in liquid form as *Diazepam Intensol*®, or in generic form. The injectable form is usually given only in a hospital.

How Are Lorazepam Or Diazepam Given?

- Either medicine may be swallowed whole with water or another liquid.
- Pills or tablets can be dissolved under the tongue or between the cheek and the gum. They may get into the bloodstream quickly, up to 3 to 5 minutes.
- The liquid intensol form is usually given between the gum and the cheek. Use a specially marked dropper that comes with the solution to measure the correct dose. It could also be mixed with liquid or soft food to swallow.
- It's important to follow the health care provider's directions.

How Long Does It Take to Work?

Lorazepam and diazepam act quickly in the brain to stop seizures. It may take up to 15 to 30 minutes to start working when put under the tongue or between the cheek and the gum.

Diazepam gets into the brain quicker, but lorazepam tends to last longer and will help seizures over a longer period of time.

Approved by FDA

Rectal

[Rectal Diastat](#) (rectal diazepam)

- Common rescue therapy in children
- Used for prolonged seizure activity, seizure clusters, or breakthrough seizures

- Pre-packaged syringe: dose should be locked in place by pharmacist
- Begins to work within 15 minutes
- Can be used ages 2 years and older
- Usually tolerated well
- Student may fatigue after administered

Nasal

Nayzilam – (midazolam)

- Indicated for acute treatment of intermittent stereotypic episodes of frequent seizure activity (seizure clusters, acute repetitive seizures)
- Approved for use in people 12 years and older
- Intended to be given by patient or caregiver
- Each spray for one time use, 5mg/0.1ml spray in one nostril
- Second spray used in opposite nostril if seizure continues after 10 minutes

Valtoco (diazepam)

- Indicated for acute treatment of intermittent stereotypic episodes of frequent seizure activity (seizure clusters, acute repetitive)
- Approved for children age 6 >, adults with epilepsy
- Intended to be given by patient or caregiver
- Each spray for one time use (5 mg, 7.5 mg, 10 mg 0.1ml)
- Second spray used if needed in 4 hours after first dose

Common Side Effects

Side effects may occur, such as weakness, dizziness, headache, memory problems, fatigue, sleepiness or sedation, unsteady walking, respiratory depression, or low blood pressure.

In children, side effects may include sleepiness or sedation, irritability, silliness, hyperactive behaviors, or unsteady walking. Rarely respiratory depression or slowed breathing happens.

Is Special Monitoring Needed?

When rescue medicines are prescribed to help treat seizures, respiratory status must be monitored.

Watch the person to make sure the seizures have stopped. How long this may take will depend on their seizure frequency before the medicine was given and their usual seizure pattern.

The most important monitoring is to time the seizure. If the seizure lasts longer than usual, follow the Seizure Action Plan for what to do next and when to call for emergency help.

Magnet for VNS

- May stop seizure for people with VNS

Impact on Daily Life

Living with epilepsy is often associated with fear: fear of having a seizure in public, fear of injury, fear of losing one's job, fear of dying, and many other legitimate fears. This feeling can be pervasive, even among those with well-controlled seizures. Persistent stigma and public misunderstanding about epilepsy only compound these fears.

Driving restrictions pose a major barrier to employment, independence, and social activity. Without a driver's license, people who continue to have seizures are dependent upon family members, friends, walking, biking, or using public transportation to get around in their communities. In most cases, none of these options fully meet the individual's needs. This lack of transportation, when combined with fear of seizures and other symptoms associated with epilepsy, often leads to social isolation.

Lack of transportation, along with cognitive problems, continued seizures, and employer misunderstanding, can also make finding and keeping a job very difficult. Without employment, people with epilepsy are often unable to get private health insurance, and in all too many cases, they are denied Medicaid, Medicare, and Social Security disability benefits. Without adequate insurance, seizure control gets worse, and epilepsy's impact on daily life grows.

Most people with epilepsy are able to lead productive and fulfilling lives, but for many, epilepsy can be a devastating condition. Additional funding and support for research, improved public services and benefits, and increased awareness are all needed to minimize the impact of epilepsy.

Risks

People with epilepsy are at increased risk of developing a number of physical and mental health conditions, including [depression](#), [memory problems](#), heart disease, stroke, arthritis, asthma, and cancer. Epilepsy also carries an increased risk of injury and death from a variety of causes. Most seizures are benign, but a prolonged seizure can evolve into [status epilepticus](#), a condition that sometimes leads to brain injury and, occasionally, death.

People with epilepsy also have a greater than average risk for suicide, [sudden unexpected death in epilepsy](#) (SUDEP), and accidental death, especially drowning. It's important for patients to talk with their doctors about these risks and what can be done to reduce them.

Epilepsy and School Performance

Many children with epilepsy have normal intelligence, perform well in school, and have a smooth transition into adulthood, without the need for any of the services offered through IDEA. Others have additional disabilities (e.g., intellectual disability, traumatic brain injury, autism, learning disability, etc.) that affect school performance more than the epilepsy itself.

For others, however, school performance problems relate directly to epilepsy and its treatment. The following are just some of the epilepsy-related factors that can affect school performance:

- **Seizures** – Seizures can result in missed information, particularly if the seizures are brief and not noticed by teachers. They can also disrupt memory function so that information provided prior to the seizure is not properly stored.
- **Postictal Effects** – The period after some seizures can be associated with memory dysfunction, sleepiness, and confusion...all of which can interfere with learning.
- **Interictal Epileptiform Discharges** – Abnormal electrical activity in the brain that takes place between seizures can cause temporary changes in cognitive functions like alertness and processing speed.
- **Structural Brain Abnormalities** – The effects of intractable epilepsy on a region of the brain called the hippocampus can result in problems with memory and other cognitive functions. In addition, underlying structural abnormalities responsible for the epilepsy are often the primary cause of learning problems.
- **Medication Side Effects** – Any antiepileptic medication has the potential for cognitive side effects. Such effects are more likely in children on high doses or multiple medications.
- **Sleep Disruption** – Epilepsy and its treatment can interfere with sleep. Not getting enough high-quality sleep can have a major impact on cognitive function.
- **Depression and Anxiety** – Both depression and anxiety disorders are more common in children with epilepsy than the general population. Both can affect concentration and other cognitive functions, and both can reduce a child's motivation and confidence.

These epilepsy-related effects are easily overlooked by school staff. They are often attributed to lack of motivation because the child's learning difficulties are not obvious or consistent. Parents often need to be strong advocates to ensure that the impact of epilepsy on school performance is well understood by school personnel and taken seriously.

Dietary Therapy

Dietary therapy is an approach to help control seizures, usually in conjunction with [seizure medications](#).

- The [classic ketogenic diet](#), a special high-fat, low-carbohydrate diet, is prescribed and monitored by a physician and nutritionist and can help control seizures in some people. It can help both children and adults with refractory seizures.
- Additionally, the [modified Atkins Diet](#), which has some similar components to the traditional ketogenic diet, can be effective.

This section presents information and monthly updates about these dietary therapies and others (like the [Low Glycemic Index treatment](#)) and how they might be helpful to people with epilepsy.

► Basic dietary therapy information

KetoNews [Ketogenic Diet](#)

Epilepsy.com

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Resources

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