

# Utah guidelines for seizures in schools

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# Guidelines for seizures in schools

# Introduction

Epilepsy is a broad term used for a brain disorder that causes seizures. There are many different types of epilepsy. There are also different kinds of seizures. About 0.6% of children ages 0 to age 17 have active epilepsy in the United States (Zack & Kabou, 2017).

Students with epilepsy are more likely to have difficulties in school (such as problems communicating), use special education services, and have activity limitations (such as less participation in sports or clubs) compared with students with other medical conditions (CDC 2017).

The purpose of this guide is to assist local education agency (LEA) personnel in providing a safe learning environment for students with epilepsy.

#### Seizure classifications

Seizures are classified into 2 groups: generalized seizures that affect both sides of the brain, and focal seizures which are located in just one area of the brain (CDC, 2020).

Examples of generalized seizures are:

- Absence seizures which can cause rapid blinking or a few seconds of staring into space.
- Bilateral tonic-clonic seizures that may make a person
  - Cry out
  - Lose consciousness
  - o Fall to the ground
  - Have muscle jerks or spasms
  - Lose bowel or bladder control
  - o Change from normal breathing pattern

The person may feel tired after a bilateral tonic-clonic seizure.

Focal seizures are also called partial seizures.

- Simple focal seizures affect a small part of the brain. These seizures can cause twitching or a change in sensation, such as a strange taste or smell.
- Focal seizures with impaired awareness, also known as complex focal seizures can make a person with epilepsy confused or dazed. The person will be unable to respond to questions or direction for up to a few minutes.
- Secondary generalized seizures begin in one part of the brain, but then spread to both sides of the brain. In other words, the person first has a focal seizure, followed by a generalized seizure.

Most seizures last from 30 seconds to 2 minutes. A seizure that lasts longer than 5 minutes is a medical emergency.

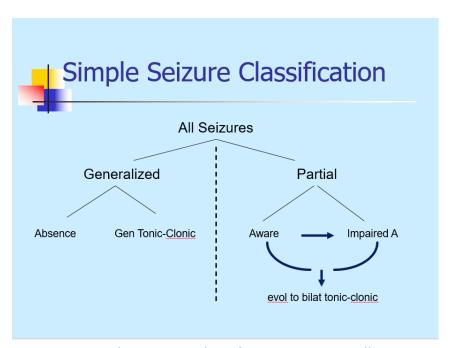


Figure 1. Simple Seizure Classification. (Dr. F. Filloux, 2020)

# Health-related forms

All students with a chronic health condition should have a healthcare plan on file if there is a chance the condition might result in a health crisis while at school. This can be an individualized healthcare plan (IHP) or an emergency action plan (EAP). A healthcare plan is written by the school nurse. It outlines how to manage the student's chronic health

condition. A medication authorization must be on file with the LEA if a student requires medication to be available at school. This form must be signed by a parent and the student's healthcare provider every year.

The following are forms that a student with seizures may have:

- Individualized healthcare plan (IHP): The IHP is written by the school nurse
  with input from the family. The IHP outlines the plan of care necessary to
  keep the student safe at school (National Association of School Nurses
  [NASN], 2020). The student must have a confirmed medical diagnosis by a
  licensed healthcare provider before an IHP can be written (DOPL 2023).
- Emergency action plan (EAP): an EAP is a type of individualized healthcare plan that instructs school staff how to manage a specific student's medical emergency. The EAP is written by the school nurse with input from the family but is designed for staff without any medical training. The EAP is usually in an "if you see this do this" format.
- Medication authorization: This form must be submitted to the LEA if emergency medication is required at school. It should be submitted to the school every year and must be signed by a parent and the student's healthcare provider.
- Section 504 of the Rehabilitation Act of 1973 (Section 504 Plan): A written plan to direct the team on accommodations necessary for the student to have free and appropriate public education (regular education students). The section 504 plan does not replace an individualized healthcare plan but should be used together with an individualized healthcare plan if the student requires certain accommodations for their chronic health condition.
- Individualized education plan (IEP): A written plan for students in special education who are protected by the Individuals with Disabilities Education Act (IDEA, 2004). Accommodations for students with health conditions who are served by special education can be outlined in their IEP, but may also require a separate individualized healthcare plan or emergency action plan.

The Utah Department of Health and Human Services DHHS) has created a separate seizure action plan and a seizure medication management order (SMMO) form. These forms can be found at <a href="heal.utah.gov">heal.utah.gov</a>.

# Medication

Daily seizure control medications are the mainstay of epilepsy treatment, but there are other approaches used to treat epilepsy including surgery, neurostimulation devices, and dietary therapy.

Sometimes additional medications are needed during a seizure emergency. These are called rescue medications. Rescue medications are typically used for seizure clusters, or when seizures are different from a person's typical pattern, such as more frequent, longer, or more severe. Rescue treatments are taken "as needed" to try and prevent a seizure emergency from occurring. Rescue medications are not used instead of daily seizure medications.

# **Devices**

In at least 3 out of 10 people with epilepsy, seizure medications do not control seizures or can cause bothersome side effects. For some of these people surgery may be possible to remove the area of the brain causing the seizures.

Neuromodulation is another option. This therapy involves using a device to send small electric currents to the nervous system. There are different models of stimulators. They can deliver stimulation in response to heart rate changes and time of day.

Vagus nerve stimulation, also called VNS therapy, uses a device to help control seizures. While it does not work for everyone and is not a cure for epilepsy, it can help control seizures in some people.

VNS therapy prevents seizures by sending regular, mild pulses of electrical energy to the brain via the vagus nerve. It's sometimes referred to as a "pacemaker for the brain". A stimulator device is implanted under the skin in the chest. A wire from the device is wound around the vagus nerve in the neck. If a person is aware of when a seizure happens, they can swipe a magnet over the generator in the left chest area to send an extra burst of stimulation to the brain. Some vagus nerve stimulators work automatically in response to an increased heart rate. Staff should swipe the

magnet if they see seizure activity regardless of whether the VNS is set to automatically respond.

Responsive neurostimulation is known as RNS therapy. The RNS system is like a heart pacemaker. It can monitor brain waves, then respond to activity different from usual activity or that looks like a seizure. The neurostimulator device is secured into the skull and is fixed so it cannot move. It lies flat under the skin. People cannot feel the stimulation once it's programmed. It doesn't cause pain or any unusual feelings. The RNS system is approved for use in people ages 18 and older.

Deep brain stimulation (DBS) requires a neurosurgeon to place electrodes in a specific area of the brain. The electrodes provide stimulation directly to the brain to help stop the spread of seizures. DBS is approved for use in adults ages 18 and older.

# Training resources

School employees should have training on seizures to include the following (where appropriate):

- General seizure recognition recommended for all school staff.
- Seizure rescue medication initial and annual refresher training required if the school has employee volunteers trained to administer rescue medication.
- Student specific training for individual students (which may or may not include seizure rescue medication).

During the 2022 general legislative session, a bill was passed that requires LEAs to provide seizure training to all administrators, teachers, classroom aides, and other individuals who interact with or supervise students (<u>UCA 53G-9-213</u>). Training must be offered every 2 years and include recognizing signs and symptoms of seizures, and appropriate steps for seizure first aid. The statute requires the Utah State Board of Education and Utah Department of Health and Human Services to adopt guidelines that will be used for this training. Links to approved trainings can be found on the <u>HEAL website</u> and the <u>USBE Safe and Healthy Schools website</u>.

# First aid for seizures

First aid for seizures involves keeping the person safe until the seizure stops and observing them afterward. The Epilepsy Foundation (2020) has a <u>seizure first aid poster</u> that is available at no cost to download.

### General care for all types of seizures

There are many types of seizures, and most end in a few minutes. These are general actions to help someone who is having any type of seizure (CDC, 2022).

- Stay with the person until the seizure ends and he or she is fully awake.
- Check to see if the person is wearing a medical bracelet or has other emergency information.
- Keep yourself and other people calm.
- If this is a student, check to see if there is a healthcare plan for more information.
- When the seizure ends, help the person sit in a safe place.
- Once they are alert and able to communicate, tell them what happened in very simple terms.
- Comfort the person and speak calmly.

# Seizures requiring first aid

Types of seizures that might require first aid are: bilateral tonic-clonic, complex partial (which may progress to a generalized seizure), status epilepticus or prolonged seizures, and clusters of seizures. Seizures that do not generally need first aid but should be monitored and reported are: absence, infantile spasms, atonic, or myoclonic.

CPR is not necessary during a seizure. Only follow the protocol for CPR/AED if the person does not start breathing after the seizure or their breathing stops after a seizure. Always call 911 if the person stops breathing.

#### Call 911 if:

- The person has never had a seizure before.
- The person has difficulty breathing or waking after the seizure.
- The seizure lasts longer than 5 minutes.
- The person has another seizure soon after the first one.
- The person is seriously hurt during the seizure.
- The seizure happens in water.

• The person has a health condition such as diabetes, heart disease, or is pregnant.



What NOT to do during a seizure:

- DO NOT restrain the person.
- DO NOT put any objects in the person's mouth.
- Do NOT offer the person water or food until fully alert.

Rescue medications can be given if prescribed by the student's healthcare provider, the required paperwork has been submitted to the school, and training has been completed by the employee volunteer.

### Seizure rescue medication

This guide will assist LEA personnel with the management, response, and administration of seizure rescue medication under certain conditions for students with epileptic seizures. Epilepsy can be a life-threatening condition. Some people with epilepsy are at special risk for abnormally prolonged seizures called status epilepticus.

Utah statute <u>53G-9-505</u> pertains to the administration of seizure rescue medication by trained volunteers who are non-medical school personnel. This law authorizes LEA employee volunteers to be trained to administer a seizure rescue medication under certain conditions, upon request by a parent or guardian.

Disclaimer: the Utah Department of Health and Human Services (DHHS) has developed this training in conjunction with input from the Utah State Board of Education, Primary Children's Hospital (Pediatric Neurology clinic), and several other stakeholders. If the trainer or volunteer modifies the training program or application in any way they may not be protected from legal action.

Pursuant to UCA 53G-9-505, a student's parent or legal guardian can request the LEA identify and train employees who are willing to volunteer to receive training to administer a seizure rescue medication. If the LEA receives a qualified request from a parent or guardian, meaning one that meets the conditions set forth in the law, the LEA must attempt to recruit for and subsequently provide the LEA employee

volunteer with medical training from a licensed healthcare professional such as a physician, physician assistant, school nurse, registered nurse, or certificated public health nurse, who has been approved to do the training set up per UCA <u>53G-9-505</u>. It is imperative this solicitation is not a factor in any employee's condition of employment. This is strictly on a volunteer basis and must be presented as such. Until the LEA finds an employee to function in this trained volunteer capacity or if, for any reason, the trained person is unavailable, and the need for seizure rescue medication arises, the school will follow the healthcare plan, except for the administration of the medication, and call 911 and first responders.

#### Points from the law:

- The student's parent or guardian must have previously administered the student's seizure rescue medication in a non-medically supervised setting without a complication, and the student must have previously stopped having a full body prolonged convulsive seizure.
- Trained employee volunteers must be age 18 or older, complete the training program, demonstrate competency, and complete refresher training.
- The student's parent or guardian and 911 must be called if medication is administered at school.
- The LEA cannot compel an employee to become a trained employee volunteer.

#### Local education agencies must have a plan to:

- Identify existing staff within the district or region who could be trained in the administration of a seizure rescue medication, and would be available to respond to an emergency need to administer the seizure rescue medication.
- Identify students whose parents or guardians have requested seizure rescue medication be available at school.
- Maintain a seizure medication management order (SMMO) and an individualized healthcare plan (IHP) from the student's healthcare provider authorizing the administration of the seizure rescue medication. A Section 504 Accommodation Plan or individualized education plan (IEP) may also be necessary.
- Require a parent or guardian to notify the LEA if the student has had any seizure rescue medication administered within the past 4 hours on a school day.
- Notify the parent or guardian that a seizure rescue medication has been administered at school.

# Standard procedures

The school nurse must always be notified if any seizure rescue medication is brought to the school. Before any seizure rescue medication can be administered or stored at school, there must be a current individualized healthcare plan and seizure medication management order. These must be signed by the student's healthcare provider and parent or guardian and submitted to the school (as per LEA policy). A section 504 accommodation plan or individualized education plan may also be necessary. The school nurse should review these forms to make sure they are complete.

- It is the responsibility of the parent or guardian to make sure the proper forms (as required by LEA policy) are submitted to the school, and the forms have the required signatures from the prescriber and parent or guardian.
- All seizure rescue medication must be locked up, but easily accessible for use during a seizure. The exact location of the locked medication can be determined by the school, after evaluating the student-specific situation (office or classroom).
- Seizure rescue medication should be given if a seizure lasts 5 minutes or longer.
- Trained employee volunteers may only give seizure rescue medication for full body or prolonged, or full body convulsive seizures. For any other type of seizure, rescue medication can only be given by a registered nurse, parent, or emergency medical services (EMS) responder. See the student's individualized healthcare plan for information on student specific instructions.
- Seizure rescue medication cannot be administered as a first dose at school, and it cannot be given if it is the first dose after a dosage change (will be treated as a first dose). Any change in medication must be handled the same way and may not be administered if the new dose has not already been given.
- In the case of a dosage change, new paperwork reflecting the change must be filled out and signed appropriately and reviewed by the school nurse. The employee volunteer will be trained regarding the change in dosage. Any paperwork with old dosage information must be removed and replaced with new paperwork. A parent or guardian must bring the updated medication with the appropriate dose and label to the school.
- Seizure rescue medication must be labeled with the student's name and dosage. Any medication not received as described above must be returned to the parent or guardian. A parent or guardian must transport the medication to and from school. Medication cannot be carried by the student.

- The student's parent or guardian must have previously administered the student's seizure rescue medication in a non-medically supervised setting without complication.
- The student must have previously ceased having full body prolonged or full body convulsive seizure activity as a result of receiving the seizure rescue medication.
- The parent or guardian, school nurse, and 911 must always be called if seizure rescue medication is administered at school. The LEA administrator must also be notified.
- A parent or guardian, registered nurse, or 911 responder must give the seizure rescue medication if an employee volunteer has not or cannot be identified at an LEA.
- If oxygen is ordered by the physician, the parent or guardian must provide all the equipment necessary, including a signed medication authorization signed and a way to safely store the oxygen. A parent or guardian is responsible for maintaining oxygen. The LEA does not provide oxygen, nor are they required to provide oxygen.
- The student cannot be excluded from attending a field trip, or a before or after school activity because of the need for seizure rescue medication.
- Each LEA should develop protocols on how to contact the trained employee volunteer immediately if the student with the seizure rescue medication has a seizure at school. The trained employee volunteer must be allowed to leave their current location immediately to attend to the needs of the student having a seizure. If no trained employee is available to give the medication, it cannot be given and the school must call 911 and the LEA first responders.

# Solicitation for trained LEA employee volunteers:

LEAs that receive a request for an employee volunteer to administer a seizure rescue medication to a student shall solicit volunteers to be trained to do so. It is imperative this solicitation is not a factor in an existing employee's condition of employment. This is strictly on a volunteer basis and must be presented as such. If the LEA is unable to find an employee to function in this trained employee volunteer capacity—or the trained employee volunteer is unavailable and the need for seizure rescue medication arises—the LEA will follow the IHP, without giving the medication, and call 911, school first responders, and the student's parent or guardian.

 Each LEA should develop protocols on how to find an employee volunteer, such as an email to all staff or a general announcement at a staff meeting.
 No potential employee volunteer should be coerced.

- The LEA and parent or guardian cannot solicit trained employee volunteers other than as described above.
- The request for a trained employee volunteer should include the expected time required to complete the training. The trained employee should also be notified that they will need to attend field trips with the student (unless a parent or guardian chooses to attend).
- Each LEA should provide a description of the training to the employee volunteer.
- No person (staff, parent or guardian, etc.) may coerce, intimidate, or threaten staff regarding their decision to take or not take this trained employee volunteer position.
- Each school that has an order for seizure rescue medication should attempt to find at least 3 employee volunteers in the event of staff absence.

# Seizure rescue medication training for employee volunteers

A school employee volunteer must be informed of the following:

- Trained employee volunteers should be trained in seizure first aid. At least 2
  people at the school should be CPR certified including rescue breathing
  (R392-200-9).
- The LEA cannot force someone to be a trained employee volunteer. The agreement to administer a seizure rescue medication is voluntary.
- Training must be documented with the training date and signature of both the trainer and employee volunteer.
- The employee volunteer will not administer a seizure rescue medication until they have completed the required training and documentation of completion is recorded.
- The trained employee volunteer may withdraw from the agreement at any time.
- The trained employee volunteer should be paid at least their hourly rate if they are required to work beyond their normally scheduled hours in this capacity.
- The trained employee volunteer must review administration procedures with the school nurse at least once every year.
- All required training materials should be maintained at the school where there is an order for seizure rescue medication.
- If a trained employee volunteer gives the rescue seizure medication it must be reported to the school administrator, the school nurse, and the parent or guardian.

- The trained employee should be notified that they will need to attend field trips with the student (unless a parent or guardian chooses to attend). If the parent or guardian cannot attend a school-sponsored overnight trip, the school should make every effort to have a trained employee volunteer accompany the student.
- A trained employee volunteer who administers a seizure rescue medication in accordance with UCA <u>53G-9-505</u> in good faith is not liable in a civil or criminal action for an act taken or not taken.

### Training content:

The training provided by an authorized licensed healthcare professional must be provided in accordance with the seizure rescue medication manufacturer's instructions, the student's healthcare provider, and in accordance with UCA <u>53G-9-505</u>. The training shall include, but not be limited to, all of the following:

- Recognition and treatment of different types of seizures, including techniques to recognize symptoms that warrant the administration of a seizure rescue medication.
- Procedures for the administration of commonly prescribed seizure rescue medication.
- Basic emergency follow-up procedures, including a requirement for the school administrator or another school staff member to call 911 and the school nurse (if available), and to contact the student's parent or guardian.
- Calling 911 does not mean a student is required to be transported to an emergency room unless the parent or guardian is not available.
- Techniques and procedures to make sure student's information remains private.
- Standards and procedures for the storage of a seizure rescue medication.
- An assessment to determine if the trained employee volunteer is competent to administer a seizure rescue medication.
- Record-keeping and record retention, including documenting each time a seizure rescue medication is administered, the student's name, the name of the medication administered, the dose given, the date and time of administration, the length of the seizure, and observation and action taken after the seizure.
- A refresher component. School nurses should follow up with the trained employee volunteer at least once every 3 months (quarterly) to determine if additional training is needed.

# Disposal of medication and supplies

All expired and used medication and supplies should be disposed of according to manufacturer's instructions and LEA policy.

# **Definitions**

Atomizer: a device for reducing liquids to a fine spray.

Bilateral tonic-clonic seizure: a seizure where the person loses consciousness, muscles stiffen, and jerking movements are seen. These types of seizures usually last 1 to 3 minutes. Seizures that last more than 5 minutes are a medical emergency.

Emergency action plan (EAP): a written document that guides actions during an emergency. For our purposes, this document gives guidance for actions to be taken for a specific student having a seizure at school. An individualized healthcare plan may also be necessary.

Full body prolonged convulsive seizure: this terminology is used in UCA <u>53G-9-505</u> as those seizures where seizure rescue medication can be administered. For purposes of this training, these are defined as bilateral tonic-clonic seizures.

Individualized education plan (IEP): a plan or program developed to make sure that a student who has a disability (identified under the law and attending school) receives specialized instruction and related services.

Individual healthcare plan (IHP): The IHP outlines the nurse's plan of care necessary to keep the student safe and healthy at school.

Non-medically supervised setting: this refers to any setting outside a hospital or clinic where there are no medical professionals available to respond in the event of an emergency, such as a home or school.

Section 504 plan: a federal law that protects students with disabilities from being discriminated against at school. It requires the school to make "reasonable" accommodations for all students, even those without an IEP.

Seizure medication management order (SMMO): this is the form created by the team that developed this training. This form is taken to the prescribing provider to

authorize the use of a seizure rescue medication at school in the event of a full-body prolonged convulsive seizure during school hours. This form specifies the student to be given the medication, and under what circumstances the medication can be given. This form must be signed by the prescribing provider and parent to be valid and must be re-signed and re-submitted to the school each year.

Status epilepticus: this occurs when a seizure lasts too long or when seizures occur close together and the person doesn't recover between seizures. Status epilepticus is dangerous and can lead to brain injury or even death. Seizure rescue medication can often decrease the chance of a student progressing into status epilepticus.

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