This guide is intended to provide school nurses with information on epilepsy. Laypersons who read this material are warned against making any changes in their treatment approaches without consulting their healthcare providers. Approaches for diagnosing and treating epilepsy are improving constantly. For more information, visit the Epilepsy Foundation’s Web site at www.epilepsyfoundation.org.

Great care has been taken to maintain the accuracy of the information contained within this volume. However, the Epilepsy Foundation cannot be held responsible for errors or for any consequences arising from the use of the information contained herein.
A school nurse can have a significant impact on the wellbeing of students with epilepsy. This guide is an invaluable tool to help school nurses manage students’ seizure conditions in school. It is easy to use, provides current findings and recommendations on the treatment and management of students with seizures and discusses school nursing best practices. By applying the practices discussed in this guide the school nurse can support positive treatment outcomes, maximize educational and developmental opportunities, and create a safe and supportive environment for the student with seizures.

Although research has advanced our understanding and treatment of epilepsy, there are still unfounded prejudices that negatively impact students. The school nurse can play a pivotal role in changing these attitudes. Through positive example and educational efforts, the school nurse helps to demystify epilepsy and positively influence the attitudes of others toward those with this condition.

The care of children with epilepsy is a mutual concern of many parents, educators, health care providers, health organizations and students. Therefore, a collaborative effort between school nurses, epilepsy specialists, and other vested partners is vital to ensure accurate and up-to-date information is available to support the work of school nursing.

The Epilepsy Foundation continues to provide educational opportunities for school nurses and current medical information about epilepsy. For additional information on further educational opportunities please contact the Epilepsy Foundation or your state school nurse organization.

We gratefully acknowledge all the contributions to this manual. The clinical expertise and professional commitment dedicated to the delivery of quality, specialized school health services is a commendable legacy for the health and safety of our children.

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As parents, grandparents and healthcare professionals, we can agree that all children should be afforded every opportunity to learn and to play, exploring life both at home and at school. This is how youngsters acquire both the cognitive and social skills, in conjunction with neurodevelopmental growth, needed to function in today’s increasingly complex and demanding society. As William Wordsworth noted, “The child is father of the man,” so the legacy of lessons learned in childhood — both positive and negative — play a pivotal role in the quality of life each child will eventually enjoy as an adult.

While most seizures last from a few seconds to a minute or two, the child who experiences them in school is often compromised on several levels. Cognitive function is often affected. But it is not the only complicating factor. These students must often cope with added challenges related to the adverse effects of drug therapy. There can be emotional and behavioral consequences as well. This multiplicity of issues adds to the complexity of managing the student’s needs and safeguarding the student both physically and emotionally in the school setting.

For those working with students with epilepsy, there are many challenges. These include coping with the unpredictability of seizures and learning how to respond to a seizure.

Perhaps most importantly, however, is the school nurse’s ability to help create a positive atmosphere among teachers, staff and fellow students with respect to the student with seizures. This helps to minimize stigmatizing behaviors and to support a positive self-image for the student. The school nurse can facilitate this understanding and enhance awareness and sensitivity by educating everyone in the school setting about the nature and management of seizures. By example, the school nurse can reinforce the need for compassion, patience and understanding for the student who has seizures.

While the school nurse is clearly important in influencing positive societal attitudes that we hope will prevail in the future, his/her intervention is especially crucial for the here and now. All of the school nurse’s activities assist the student with epilepsy in achieving success in school life and in social relationships. The school nurse can help educators recognize the causes of behavior problems, if these occur, and can help diminish the educational and social impacts often associated with childhood epilepsy. The school nurse can also assist in early diagnosis by alerting parents and healthcare providers about possible seizure-related behaviors and offer guidance on obtaining information and services that will benefit students and their families.

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Epilepsy is a chronic disorder, the hallmark of which is recurrent, unprovoked seizures."
Section 1
SEIZURE AND EPILEPSY BASICS

Epilepsy is clinically defined as two or more unprovoked seizures occurring more than 24 hours apart in someone older than one month of age. It is the most common treatable serious neurological disorder in children and is the third most common of all serious neurological disorders in childhood, with mental retardation and cerebral palsy being the most common (Shinnar and Pellock, 2002). It affects from four to ten school-aged children per 1,000.

A seizure is the clinical manifestation of an abnormal and excessive synchronized discharge of cerebral neurons. It is sudden and transient and can include a wide variety of motor, psychic and sensory phenomena. There may or may not be an alteration in consciousness or awareness. The location of the initial electrical disruption, the extent of its spread within the brain and its duration determine the clinical manifestations of the seizure and its impact on the student.

A seizure can include jerking movements of the limbs, falling down, staring, automatisms (purposeless repetitive actions) such as lip smacking or hand wringing or even strange feelings in one’s stomach. Seizures are usually unprovoked and unpredictable. The child can’t control his or her behavior during a seizure.

About 10 percent of all individuals will experience a seizure during their lifetimes. These seizures may be related to acute medical, neurological or neurosurgical conditions and do not recur once the underlying cause is resolved. Some children have a single seizure, the cause of which is never identified. These acute episodes are not considered to be epilepsy.

Epilepsy Etiology and Prognosis

Epilepsy is a brain disorder characterized by the tendency to have recurrent unprovoked seizures. It may or may not be associated with damage in brain structure. In some cases, usually the more benign forms, genetics seem to play a role. Sometimes epilepsy is related to a congenital malformation in brain structure or an inborn error in brain metabolism. About 30 percent of cases of epilepsy can be attributed to trauma, infection, postnatal vascular lesions or CNS degenerative conditions. About 20 percent of cases are associated with neurological conditions presumed to be present from birth, such as mental retardation and/or cerebral palsy (see Table 3). About 70 percent of all new cases in children are considered idiopathic (assumed to be genetic) or cryptogenic (see Table 2) and have no apparent cause (Hauser, 2001).

### TABLE 1: Epilepsy Statistics

- Epilepsy affects up to 1 percent of all children age 16 or younger.
- As many as 325,000 school-aged children (ages 5 to 14) have epilepsy (Shinnar and Pellock, 2002).
- Up to 45,000 new cases of epilepsy are diagnosed annually in children (200,000 total new cases are diagnosed annually in the United States).
- Incidence is highest in those under age 2 and over age 65.
- In children, the median age of onset is between 5 and 6 years old.
- Incidence is greater in African-American and socially-disadvantaged populations.
- In more than 70 percent of those with epilepsy, no specific cause for the disorder can be identified.
In general, those who experience idiopathic seizures have a better prognosis in terms of both seizure control and eventual remission than do those with epilepsy symptomatic of underlying brain damage or disease. About 70 percent of those children who are otherwise normal will outgrow epilepsy and be seizure-free as adults (Shinnar and Pellock, 2002).

In childhood, the majority of seizures are partial in nature, with specific epileptic syndromes, such as benign rolandic epilepsy and childhood absence epilepsy, accounting for a large proportion of cases (Shinnar and Pellock, 2002).

Some forms of childhood epilepsy are defined as benign. They are self-limiting and often remit by adolescence. The child’s development and intellect will most likely be normal. In other cases, although development and intellect do not appear to be affected, seizures persist despite treatment. Others are more serious and can be associated with developmental delay or cognitive impairment and persistent seizures. The prognosis depends upon a variety of factors as listed in Tables 4 and 5.

**Risk of Epilepsy in Special Populations**

The basic underlying risk of developing epilepsy is about 1 percent. Individuals in certain populations are, however, at greater risk. Epilepsy can be expected to develop in:

- 10 to 15 percent of children with mental retardation
- 13 percent of people with Cerebral Palsy (McDermott, 2005)
- 8.7 percent of children of mothers with epilepsy
- Up to 50 percent of children with both mental retardation and cerebral palsy
- 2.4 percent of children of fathers with epilepsy
- 33 percent of children who have had a single seizure

(Hauser, 1990)

**Classifying Seizures**

Seizures are classified by their clinical symptoms, supplemented by electroencephalographic (EEG) data. Accurate classification of seizures has been greatly improved by the simultaneous use of EEG and videotape recordings. However, since most children experience seizures in a non-medical setting, the most important basis for classification is still an eyewitness account.

The International League Against Epilepsy (ILAE) Commission on Classification and Terminology first proposed a classification system for epileptic seizures in 1981. Today, it is the most widely used classification system. It divides seizures into two major groups — **partial** and **generalized** (see Table 6).

**Partial Seizures**

Partial seizures are the most common type of seizure experienced by children with epilepsy. Virtually any movement, sensory or emotional symptom can occur as part of a partial seizure, including complex visual, auditory or olfactory hallucinations.

**TABLE 3: Causes of Symptomatic Seizures**

- Brain trauma (auto accidents are #1)
- Brain lesions (e.g. tumors, tubers)
- Brain injury at birth
- Congenital malformations
- Infections of the brain (e.g. meningitis, encephalitis)
- High fever
- Metabolic abnormalities (e.g. hypoglycemia, hypocalcemia, hyponatremia)
- Poisoning
In partial seizures the electrical disturbance is limited to a specific area of one cerebral hemisphere (side of the brain). Partial seizures are subdivided into simple partial seizures (in which consciousness is retained) and complex partial seizures (in which consciousness is impaired or lost). Partial seizures can spread to cause a generalized seizure, in which case the classification category is partial seizures secondarily generalized.

**Simple Partial Seizures**

Simple partial seizures result from abnormal neuronal activity in specific, limited areas of the brain that affect movement, sensation or emotion. Partial seizures can progress through several stages that reflect spread of the abnormal neuronal firing to different areas of the brain. For example, a seizure that begins in a motor area can cause focal twitching of the hand or the face.

This explains why simple partial seizures do not affect consciousness. The child remains aware of the environment, remembers the seizure experience, but may be limited in how he or she can interact while it is in progress. Speech, for example, may be arrested.

A simple partial seizure can also be manifested as tingling in the hand or face, visual distortions or hallucinations, a feeling of sudden fear, a sense of unexpected familiarity (déjà vu) or unfamiliarity (jamais vu), a breeze on the skin, a sudden rising feeling in the stomach or sudden unexplained pain. Simple partial seizures of this type are also referred to as *auras*, internal experiences that may herald more extensive seizures to come and serve as warnings to the affected individual.

**Complex Partial Seizures**

Complex partial seizures, like simple partial seizures, begin in one area of the brain, but usually involve larger portions of the brain and are associated with an alteration in consciousness. In practical terms, this means that the person experiencing the seizure cannot interact normally with his environment, has impaired responsiveness and usually does not remember what happened during the episode.

Automatisms are a common characteristic of complex partial seizures. These are repetitive, complex movements that are purposeless, undirected and inappropriate. Common examples of automatisms include lip smacking, repetitious swallowing or chewing, fidgeting with fingers or hands and repeated clumsy movements of a preceding motor act. Automatisms are likely to be stereotyped — that is, the same type of movement occurs each time the student has a complex partial seizure.

In some cases, complex partial seizures generate activities that cause social distress — disrobing, running, screaming, flailing and exhibiting excessive fear. These phenomena, while far less common than the facial and fumbling automatisms described above, nevertheless create major social difficulties for children who experience them and for their families.

### TABLE 4: Factors Predictive of Good Prognosis

- Normal neurological exam
- Normal intellectual functioning
- Absence of brain lesions
- Late onset of seizures (child is older than 3 or 4 years)
- Normal EEG
- Infrequent seizures
- Only one type of seizure
- Early response to a single medication
- No tonic and/or atonic seizures
- No status epilepticus

### TABLE 5: Factors Predictive of Seizure Persistence

- Abnormal neurological exam
- Brain abnormality
- Abnormal EEG
- Multiple seizure types
- Frequent seizures
**Generalized Seizures**

Generalized seizures affect both cerebral hemispheres (sides of the brain) from the beginning of the seizure. They produce loss of consciousness, either briefly or for a longer period of time.

**Absence Seizures**

Absence seizures typically last just several seconds. There is no warning before the seizure and the child typically resumes whatever activity he or she was involved in before the seizure occurred. For example, if a student is reading he or she will stop. The child will usually blink his eyes a few times and the eyes may even roll up a bit. They may also have associated automatisms. When the seizure is over the student will continue to read. These seizures are extremely brief in duration and are typically not associated with the risk of injury. These seizures can occur many times a day or in clusters, both of which interfere with a child’s ability to learn and function.

**Atypical Absence Seizures**

Atypical absence seizures are different from typical absence seizures. They last longer, onset is not as abrupt and incomplete loss of awareness and muscle tone changes are more severe. There may be associated head drops (atonic seizures) or myoclonic seizures (see below). Atypical absence seizures usually occur as part of a mixed seizure disorder.

**Atonic Seizures**

Atonic seizures produce an abrupt loss of muscle tone. Other names for this type of seizure include drop attacks, astatic or akinetic seizures. They produce head drops, loss of posture or sudden collapse. Because they occur abruptly without warning, and because those who experience them fall with force, atonic seizures can result in injuries to the head and face. Children with this type of seizure sometimes wear protective headgear to avoid injury. These seizures tend to be resistant to drug therapy.

---

**TABLE 6: Classification of Epileptic Seizures**

<table>
<thead>
<tr>
<th>I. Generalized Seizures (Convulsive or nonconvulsive)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Absence</td>
</tr>
<tr>
<td>b. Atonic/akinetic</td>
</tr>
<tr>
<td>c. Myoclonic</td>
</tr>
<tr>
<td>d. Tonic, clonic and tonic-clonic</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>II. Partial (Focal Seizures)</th>
</tr>
</thead>
<tbody>
<tr>
<td>a. Simple partial seizures (consciousness is not impaired)</td>
</tr>
<tr>
<td>i. With motor symptoms</td>
</tr>
<tr>
<td>ii. With sensory symptoms (including vision changes, bodily sensations, dizziness and imagined sounds, smells and tastes)</td>
</tr>
<tr>
<td>iii. With autonomic symptoms</td>
</tr>
<tr>
<td>iv. With psychic symptoms (including dysphasia, dysmnesia, hallucinatory and affective changes)</td>
</tr>
<tr>
<td>v. Compound (i.e., mixed) forms</td>
</tr>
<tr>
<td>b. Complex partial seizures (consciousness is impaired)</td>
</tr>
<tr>
<td>i. Simple partial seizures followed by loss of consciousness</td>
</tr>
<tr>
<td>ii. With impairment of consciousness at the outset</td>
</tr>
<tr>
<td>iii. With automatisms</td>
</tr>
</tbody>
</table>

| III. Unclassified                                      |
| IV. Prolonged or repetitive seizures (status epilepticus) |

*Summarized from the International Classification of Epileptic Syndromes, 1981*
Clonic Seizures
Clonic seizures are always symptomatic of underlying brain disease. They involve rhythmic jerking movements of the arms and legs, sometimes on both sides of the body. They are uncommon and occur most frequently in neonates, infants and younger children.

Myoclonic Seizures
Myoclonic seizures are characterized by rapid, brief muscle contractions that usually occur at the same time on both sides of the body. Occasionally, they involve one arm or foot. Observers usually see them as sudden jerks or clumsiness. A variant of the experience, common to many individuals who do not have epilepsy, is the sudden jerk of a foot during sleep (sleep myoclonus).

Tonic Seizures
Tonic seizures are particularly common in children who have Lennox-Gastaut syndrome, but they can occur in anyone. They involve tensing or stiffening of muscles in the body, arms or legs. The limbs may extend and maintain this posture for seconds to a minute or so. Consciousness is usually preserved.

These seizures occur most often during sleep. However, because they usually involve all or most of the brain and affect both sides of the body, a child who is standing when the seizure starts will often fall.

Tonic-Clonic Seizures
These seizures are the most common and best known type of generalized seizure. They begin with stiffening of the limbs (the tonic phase), followed by jerking of the limbs and face (the clonic phase).

During the tonic phase, breathing may decrease or cease altogether, producing cyanosis (bluing) of the lips, fingernail beds and face. Breathing typically returns during the clonic (jerking) phase, but it may be irregular. The clonic phase usually lasts less than a minute. Incontinence can occur. The child may bite his/her tongue or inside of the mouth during the episode. Breathing afterward may be noisy and appear to be labored.

Contrary to popular belief, nothing should be placed in the student's mouth during a seizure. It is best to turn the student on one side to help prevent choking and keep the airway clear. Following the seizure, the student will be lethargic, possibly confused, and want to sleep. Headaches sometimes occur. Full recovery takes minutes to hours, depending on the individual.

Epileptic Syndromes
Using seizure type alone to classify the type of epilepsy often overlooks other important information about the student and the seizure episodes. Classifying into syndromes takes a number of these identifying characteristics and symptoms into account, including the following:

- Seizure type
- Typical EEG recordings
- Clinical features such as behavior during the seizure
- The expected course of the disorder
- Precipitating features
- Expected response to treatment
- Genetic factors

Epileptic syndromes can be either idiopathic or symptomatic of underlying brain damage or disease. In general, idiopathic forms have a better prognosis in terms of both seizure control and eventual remission than do symptomatic forms.

Benign Rolandic Epilepsy
Benign rolandic epilepsy is the most common epilepsy syndrome in children. It usually begins between ages three and thirteen in neurologically normal children. Also known as benign partial epilepsy of childhood, it accounts for more than one-third of all cases of epilepsy that begin in middle childhood. There is a family history of this syndrome in 18 percent of cases and the condition is thought to be genetically determined.

Seizure episodes begin as simple partial seizures, usually with twitching in the face, tongue, pharynx
and larynx. Most of the seizures are nocturnal, occurring within a few hours after falling asleep. Seizures are usually accompanied by gurgling sounds, profuse drooling and temporary inability to speak. Consciousness is generally preserved, unless the seizure generalizes to tonic-clonic seizure, which happens often. If the child experiences these seizures only during sleep, the decision is often made not to treat with medication.

The child’s neurological and other functioning is usually normal. However the EEG readings most often show a dramatic focal spike in the centrotemporal regions of the brain. Most children are seizure-free five years after onset and 95 percent of them will have undergone permanent remission by age 14 (see Table 7).

**Childhood Absence Epilepsy**

Absence seizures account for 2 to 4 percent of all cases of epilepsy in children. These seizures are non-convulsive and tend to occur in clusters.

**TABLE 7: Benign Rolandic Epilepsy**

- Onset usually before age 15
- Characterized by partial seizures resulting in temporary inability to speak
- Seizure often generalizes to tonic-clonic
- Most seizures are nocturnal
- 95 percent of children experience remission by age 14

Seizure onset usually occurs between ages four and eight.

Children with this syndrome are otherwise normal. About 40 percent outgrow the seizures. The syndrome has a strong genetic component which is not well understood at this time. Despite its overall benign nature, approximately half of the children with absence epilepsy can expect to have a generalized tonic-clonic seizure during adolescence. The risk is reduced if seizures are quickly controlled with medication.

The prospects for remission of childhood absence epilepsy are more likely when the child is younger at onset, the seizures are easily controlled with medication, the child does not have generalized tonic-clonic seizures and there are no other neurological problems (see Table 8).

**TABLE 8: Childhood Absence Seizures**

- 40 percent outgrow seizures
- Probably inherited
- Half of these children also experience generalized tonic-clonic seizures

**Juvenile Myoclonic Epilepsy**

Juvenile myoclonic epilepsy is also called Janz’s syndrome and myoclonic epilepsy of adolescence. It is characterized by myoclonic, tonic-clonic and absence seizures. These seizures often occur upon awakening.

Juvenile myoclonic epilepsy generally appears at puberty (between ages 10 and 20), but may have existed prior to that time. Seizures may be precipitated by sleep deprivation, early awakening, alcohol and drug use, stress, strong emotion, photic stimulation and menstruation. This is often a lifelong condition (see Table 9).

**TABLE 9: Juvenile Myoclonic Epilepsy**

- Appears at or around puberty
- Is characterized by generalized tonic-clonic, myoclonic and absence seizures
- Seizures are primarily jerking of arms and legs
**Lennox-Gastaut Syndrome**

The Lennox-Gastaut syndrome (also known as myoclonic astatic epilepsy) is characterized by a combination of factors, usually including atypical absence seizures, tonic seizures, atonic seizures and mental retardation with a distinctive slow spike-and-wave EEG. Students with this syndrome are prone to convulsive and nonconvulsive status epilepticus both requiring a medical intervention. Onset is usually between ages one and five.

Some children with this epilepsy syndrome are developmentally normal when the syndrome begins, but then lose ground, sometimes dramatically. Episodes of status epilepticus contribute to this decline. By age six most of these children have some degree of mental retardation.

Children with Lennox-Gastaut syndrome typically experience more than one type of seizure. The atonic astatic (drop attack) seizures are potentially the most troubling because of injuries caused by repeated falls. As a result, many children with this syndrome must wear protective helmets. The tonic seizures are most common during sleep, including nap time, whereas generalized tonic-clonic seizures occur most often on awakening. As children with the Lennox-Gastaut syndrome grow older, the types of seizures change. Among teenagers with Lennox-Gastaut, complex partial seizures are the most-common form.

**Temporal Lobe Epilepsy**

The temporal lobes, one on each side of the head, just above the ears, are the sites of one of the most-common forms of epilepsy. Complex partial seizures with automatisms, such as lip smacking or rubbing the hands together, are the most-common seizures in temporal lobe epilepsy.

Seventy-five percent of patients with this form of epilepsy also experience simple partial seizures which may include features such as: a mixture of thoughts, emotions and feelings that are hard to describe; sudden emergence of old memories or feelings of strangeness in familiar surroundings; hallucinations of voices, music, smells or tastes and feelings of unusual fear or joy and; gastric sensations (e.g. pain, nausea, emesis). While partial seizures dominate, approximately half the people with temporal lobe epilepsy have generalized tonic-clonic seizures as well.

The seizures characteristic of temporal lobe epilepsy often begin in the deeper parts of the temporal lobe (part of the limbic system) which control emotions and memory. Memory problems may develop over time in people with this syndrome.

**Frontal Lobe Epilepsy**

Partial seizures beginning in the frontal lobe may produce weakness or the inability to use certain muscles, including the muscles that make it possible to talk. Sudden thrashing movements during sleep are also characteristic of frontal lobe epilepsy, as is posturing with the head jerking to one side and the arm rising with it into a brief, frozen state. Sometimes a generalized convulsion follows the slow march of these movements.

Complex partial seizures in the frontal lobe have some distinct features in contrast to those in the temporal lobes. They usually last less than a minute, are less likely to be followed by confusion or fatigue and often occur in a series or cluster. They often occur during sleep and may occur many times during the night and disrupt the normal sleep cycle. This can result in daytime sleepiness, behavioral problems and poor school performance.

Frontal lobe epilepsy has significant social effects because the seizures it generates are more likely to involve brief episodes of screaming, bicycling movements or even movements suggestive of sexual activity.

**Progressive Myoclonic Epilepsy**

Progressive myoclonic epilepsy is a rare, genetically based form of epilepsy marked by myoclonic and tonic-clonic seizures. People with this disorder also experience difficulties with balance, muscle rigidity and progressive loss of mental abilities. A gene associated with this disorder has recently been identified.
Landau-Kleffner Syndrome

Landau-Kleffner syndrome, also a rare disorder, causes the sudden or gradual loss of the ability to understand spoken language in addition to a seizure disorder. Speech in children with this syndrome slowly declines over time. There are always epilepsy-related abnormalities on the EEG, even though some children with this syndrome do not have seizures. Parents often think that the child is developing a hearing problem or has become suddenly deaf. Hearing tests, however, show normal hearing. Children may also be initially diagnosed as autistic or developmentally delayed.

The syndrome typically begins between ages three and seven. Seizures generally occur while the child is asleep and may be quite infrequent. Simple partial and tonic-clonic seizures may occur. Treatment with standard antiepileptic drugs is not very effective, but treatment with steroids has been tried with some success.

Reflex Epilepsy

Reflex epilepsy is the name given to seizures which are triggered by individual sensitivity to sensory stimulation in the environment. The most-common form is photosensitive epilepsy — seizures caused by exposure to intense or fluctuating levels of light.

Seizures in photosensitive people may be triggered by exposure to television screen flicker or rolling images, certain video games, computer monitors, alternating patterns of different colors or the intense strobe lights in fire alarms. Also, some people have reported having seizures triggered by natural light, such as sunlight flickering through trees, light glancing off water or through the slats of Venetian blinds. The condition usually begins in childhood and may be outgrown by adulthood.

The reflex response is usually absence seizures but may generalize to myoclonic seizures or generalized tonic-clonic seizures. Wearing polarized sunglasses with blue lenses has been cited as good protection against photosensitive reflex seizures.

While flashing or flickering light is the most common trigger for reflex epilepsy, rare triggers include certain sounds, music, tone of voice, reading, immersion in hot water or even eating.

Seizure-Like Phenomena: Medical Conditions that Mimic Epilepsy

Differential diagnosis of epilepsy is sometimes confounded by a variety of medical conditions that produce sudden symptoms resembling epileptic seizures. Some of these episodes can be caused by other medical conditions that mimic epilepsy. These include:

- Migraine and transient ischemic attacks that produce visual disturbances
- Hyperventilation, which produces tingling, lightheadedness and occasionally loss of consciousness
- Syncope (see Table 10)
- Breath-holding spells that lead to cyanosis (bluing) of the lips and jerking (usually in children under age five)
- Tics that produce jerking
- Sleepwalking and other sleep disturbances that mimic seizure symptoms
- Episodic dyscontrol syndrome (rage attacks) that are erroneously identified as epileptic seizures
- Narcolepsy, characterized by intermittent, uncontrollable episodes of falling asleep during the daytime which can produce cataplexy (short-lived intermittent muscle weakness) and sleep paralysis (paralysis while falling asleep or waking)
- Certain paroxysmal movement disorder — with chorea or dystonia

“About 70 percent of those children who are otherwise normal will outgrow epilepsy and be seizure-free as adults.”
### TABLE 10: Differentiating Syncope from Epileptic Seizures

<table>
<thead>
<tr>
<th>CLINICAL DATA</th>
<th>SYNCOPE</th>
<th>SEIZURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Precipitating factors</td>
<td>Almost always</td>
<td>Occasional</td>
</tr>
<tr>
<td>Warning</td>
<td>Lightheaded, dizzy, queasy</td>
<td>May have aura</td>
</tr>
<tr>
<td>Fall</td>
<td>Often slumps to the floor</td>
<td>May be violent</td>
</tr>
<tr>
<td>Motor component</td>
<td>Rare</td>
<td>Frequent</td>
</tr>
<tr>
<td>Incontinence</td>
<td>Rare</td>
<td>Occasional</td>
</tr>
<tr>
<td>Self-injury</td>
<td>Rare</td>
<td>Common</td>
</tr>
<tr>
<td>Appearance</td>
<td>Pale, clammy</td>
<td>Rubor, cyanosis, diaphoresis</td>
</tr>
<tr>
<td>Pulse</td>
<td>Decreased, irregular</td>
<td>Usually increased</td>
</tr>
<tr>
<td>Degree of postictal</td>
<td>Mild</td>
<td>Often marked</td>
</tr>
<tr>
<td>Family history</td>
<td>Often positive for syncope</td>
<td>Often positive for seizures</td>
</tr>
<tr>
<td>Intercital EEG</td>
<td>Usually normal</td>
<td>Often abnormal</td>
</tr>
</tbody>
</table>

### Psychogenic Seizures

Psychogenic seizures, also called pseudoseizures, are non-epileptic, episodic, paroxysmal events not related to abnormal electrical activity in the brain. Considered to be of psychological rather than physical origin, they offer a major challenge to diagnose and treat.

While these episodes do resemble true epileptic seizures, they are different from them in several important ways:
- Students have repeatedly normal EEG readings during seizure-like events.
- There is a lack of any response to therapeutic levels of antiepileptic drugs.

### TABLE 11: Differentiating Epileptic Seizures from Psychogenic Seizures

<table>
<thead>
<tr>
<th>CLINICAL DATA</th>
<th>PSYCHOGENIC SEIZURES</th>
<th>GENERALIZED TONIC-CLONIC SEIZURES</th>
<th>COMPLEX PARTIAL SEIZURES</th>
</tr>
</thead>
<tbody>
<tr>
<td>Changes in seizure frequency</td>
<td>Rare</td>
<td>Common</td>
<td>Common</td>
</tr>
<tr>
<td>with medication change</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Increased seizure frequency with stress</td>
<td>Frequent</td>
<td>Occasional</td>
<td>Occasional</td>
</tr>
<tr>
<td>Combativeness</td>
<td>Common</td>
<td>Rare</td>
<td>Rare</td>
</tr>
<tr>
<td>Vulgar language</td>
<td>Frequent</td>
<td>Rare</td>
<td>Rare</td>
</tr>
<tr>
<td>Self-injury</td>
<td>Rare</td>
<td>Occasional</td>
<td>Rare</td>
</tr>
<tr>
<td>Incontinence</td>
<td>Rare</td>
<td>Common</td>
<td>Rare</td>
</tr>
<tr>
<td>Tongue biting</td>
<td>Rare</td>
<td>Common</td>
<td>Rare</td>
</tr>
<tr>
<td>Nocturnal occurrence</td>
<td>Rare</td>
<td>Common</td>
<td>Occasional</td>
</tr>
<tr>
<td>Stereotype of attacks</td>
<td>Often variable</td>
<td>Little variation</td>
<td>Not identical but usually have similar patterns</td>
</tr>
<tr>
<td>Postictal confusion, lethargy, sleepiness</td>
<td>Rare</td>
<td>Always</td>
<td>Frequent</td>
</tr>
<tr>
<td>EEG, Intercital</td>
<td>Often normal</td>
<td>Frequently abnormal</td>
<td>Frequently abnormal</td>
</tr>
<tr>
<td>EEG, During attack</td>
<td>Normal</td>
<td>Always abnormal</td>
<td>Usually abnormal</td>
</tr>
</tbody>
</table>
• The seizures may be marked by violent thrashing of all four limbs, with typically asynchronous and arrhythmic movement, without losing consciousness. It is unusual in epilepsy for someone to remain conscious in the presence of sustained motor activity of the arms and legs.

Psychogenic seizures are best dealt with on an individual basis. Once identified through video-EEG monitoring, the problem can be addressed through individual and family counseling and psychotherapy. Occasionally treatment may include psychiatric medication. Sometimes the seizures abate when the person is informed that they are psychological in nature.

**Intractable Epilepsy**

Students with intractable epilepsy fail to respond to standard antiepileptic drug therapy. Often, they have underlying structural brain or neurological conditions, head injury or cognitive problems. These children continue to experience seizures and are usually on large amounts of multiple antiepileptic medications. They must endure not only the ongoing seizures but also the side effects of the drug therapy. Of the 326,000 children under age 15 with epilepsy, approximately 90,000 have severe seizures that cannot be adequately treated.

Students with intractable epilepsy are the greatest challenge for school nurses. They are more likely to experience seizures during school and, therefore, require more time and attention. They may require onsite emergency interventions by the nurse or a trained designee.

Although single seizures do not permanently impair intellectual or behavioral functions, multiple and uncontrolled seizures can have significant consequences. The long-term effects of numerous or recurrent seizures are the subject of studies and controversy and should never be underestimated.

Intractable seizures also significantly impact the student’s quality of life, with limitations on participation in sports, schoolyard games and class outings. Students with more severe seizures may need an aide with them at all times and/or must wear a protective helmet. This can further stigmatize and shame the student and have deleterious effects on the student’s self esteem.

These students are at high risk of becoming isolated and withdrawn. The school nurse should facilitate the student’s ability to participate safely in school activities and counsel the family whenever there are concerns about the student’s emotional well-being.

**Status Epilepticus: Prolonged or Serial Seizures**

Most seizures end after a few seconds or a few minutes. If they are prolonged or occur in a series, there is an increased risk of status epilepticus. Traditionally, status epilepticus is medically defined as 30 minutes or more of uninterrupted seizure activity or more than one seizure without regaining baseline within 30 minutes. Many believe, however, that much shorter periods of continuous seizure activity may cause neuronal injury and that seizure self-termination is unlikely after as few as five minutes. More recent medical definitions consider 10 minutes, rather than 30 minutes, as the defining time. The Epilepsy Foundation advises calling for emergency assistance whenever a convulsive seizure continues for more than five minutes without signs of stopping.

Although rare, death or brain damage can occur as a result of status epilepticus. During status seizures problems can arise if there is pulmonary or cardiac arrest that is not promptly treated. More often, however, serious negative consequences occur hours or days after the onset of status as a result of prolonged stress, oxygen deprivation and systemic complications such as organ failure.

**TABLE 12: Status Epilepticus Facts**

- 10 percent of patients who develop epilepsy have status as their first seizure
- Of all of those who experience status, 25 percent are individuals with epilepsy
- 15 percent of persons with epilepsy experience an episode of status epilepticus
In children, the most common precipitating factors for status epilepticus are fever/infection and withdrawal from medication or noncompliance with the prescribed regimen (DeLorenzo, 1992). There may, however, be no obvious cause for the episode. Ten percent of children who later progress to epilepsy have experienced their first seizure as a status episode.

In all cases, prompt treatment is the key to preventing serious negative outcomes. The goal of treatment is to stop the seizure activity as quickly as possible and treat any underlying precipitant (Delorenzo, 1992). Mortality in children and adults is minimized when status lasts less than one hour. After an hour, however, mortality increases slightly in children but jumps dramatically to close to 38 percent in adults.

Any type of epileptic seizure can progress to status epilepticus, but convulsive status has the greatest potential for causing long-term damage.

Treatment of convulsive status epilepticus generally includes use of such drugs as diazepam, lorazepam, phenytoin and phenobarbital administered in a planned sequence. Rectal diazepam gel may be prescribed for at-home or non-hospital use to stop bouts of prolonged seizures or clusters of acute repetitive seizures in children with a history of this type of seizure.

**Nonconvulsive Status Epilepticus**

Nonconvulsive status can present in various ways, including loss of speech, automatisms and alteration of consciousness. It includes continuous absence seizures and partial status epilepticus, as well as status involving simple partial seizures called epilepsia partialis continua.

Although nonconvulsive status epilepticus is not usually a dangerous or life-threatening condition it may have an adverse effect on a child's memory and intellectual abilities, particularly if it is not recognized early. The treatment of nonconvulsive status epilepticus, whether absence or complex partial status epilepticus, is similar to the treatment of convulsive status epilepticus.

**Epilepsy in Female Students**

More than one million women and girls in the United States have epilepsy. While many of the issues they face are common to both genders, women with epilepsy must deal with unique levels of uncertainty at various points in their reproductive lives from puberty onward because of the influence of hormones associated with menstrual cycles. Epilepsy related to the menstrual cycle is called catamenial epilepsy. While research in this area is just beginning, it is already yielding important new information.

Antiepileptic drugs that induce the hepatic microsomal enzyme system that clears drugs through the liver can, in some women, lower the effectiveness of birth control pills, requiring higher doses to prevent conception. This is important for older female students to know, especially if they are sexually active.
"Understanding where a child is on the spectrum of severity helps in determining the extent of intervention necessary at given points in time."
The many variables in epilepsy add to the complexity of its impact on students. Seizures may be controlled or uncontrolled. They can lead to disabling events or simply minor challenges. Medications can have mild or severe side effects. The stigma of epilepsy impacts self-concept and socialization skills. Therefore, when evaluating the consequences of epilepsy, it is important to recognize that the conjoined impact of all of these factors — seizures, medications and external and/or internalized stigma — can be significant. Each variable, alone or in combination, can dramatically affect the child and define the extent to which he/she is disabled by epilepsy.

Impact of Epilepsy on Learning

While most children with epilepsy are otherwise normal, as a group, their risk for learning problems is significantly increased. Research suggests that about half of children with epilepsy meet the criteria for a learning disability in at least one area (Fastenau et al., 2008). In this study, learning disabilities were found in all three areas: writing (38%), mathematics (20%), and reading (13%). Underachievement often occurs in language skills, reading and mathematics. The long-term adverse impact of these deficits may extend beyond education to employment, marriage and fertility (Shinnar and Pellock, 2002).

Children who achieve seizure control relatively quickly, with few medication side effects and no cognitive impairments, generally have the best chance for average or above-average educational achievement. However, it is worth noting that children with epilepsy with average IQs may not achieve up to their potential, and attention problems are identified in many children with epilepsy. Loss of school time, because of seizures or medical tests, may also affect performance, even among students who are otherwise doing well.

Not surprisingly, students with uncontrolled seizures have difficulty with learning, memory, concentration and attention, arising from the underlying cause of the epilepsy itself or from recurrent and/or uncontrolled seizures (Sperling 2004, Hermann 1993). Antiseizure medicines sometimes compound these challenges but are not completely to blame (Prevey, 1998).

Other findings and observations about the impact of epilepsy on learning and behavior in children include:

- As many as a third of children with epilepsy require special education (Zelnick et al, 2001).
- Young age at onset, poor seizure control, underlying brain lesions and mixed EEG patterns are some of the predictors of the need for special education (Zelnick et al, 2001).
- When intellectual disability and seizures coexist, a higher rate of disturbed behavior is found (Sabaz, 2001).
- In a quality of life survey, intellectually normal children with refractory (uncontrolled) epilepsy had difficulty with school performance and experienced socialization problems and a reduced quality of life (Sabaz, 2001).

**TABLE 13: Factors that May Increase the Risk of Learning, Psychosocial and Behavioral Problems**

- Early age of onset
- Frequent seizures
- High seizure frequency
- Multiple lifetime seizures
- Seizures in school
- Memory deficit
- Slowed motor speed
Educational achievement is influenced by several factors: neurological and cognitive impairments, psychiatric problems, underlying pathology and social and cultural influences, as well as the degree of seizure control (Sperling, 2004; Hermann, 1993).

Assessing Learning and Behavioral Disorders

Students with seizures may exhibit behaviors and have learning consequences that should be assessed while determining eligibility for an Individualized Education Plan (IEP) and completing the Individualized Healthcare Plan (IHP). These may include:

• Attention deficit disorder (ADD) or attention deficit hyperactivity disorder (ADHD)
• Learning disorders
• Adjustment disorders — psychological and social adjustment to epilepsy
• Mood disorders — anxiety and depression are most common
• Mobility problems — motor deficits such as hemiparesis or spastic paresis, which are most likely caused by underlying etiology. Episodic weakness or incoordination may be due to postictal effects of seizures or side effects of medications
• Injuries — from seizures or falls, are usually minor, but may include head injuries, fractures, lacerations and bruises
• Developmental delay — seizures are often a symptom of neurological dysfunction for children with developmental delay or mental retardation

Impact of Epilepsy on the Brain

Different types of seizures can have a variable impact on the brain, lifestyle and safety. Research suggests that uncontrolled seizures can become part of a progressive disorder (Sutula, 2003), with persistent seizures resulting in increasing cognitive dysfunction and changes in the brain tissue as a part of disease progression. These problems are not seen in individuals with controlled epilepsy, which reinforces the importance of early diagnosis and effective treatment of seizure disorders.

Impact of Epilepsy on Social Development and Quality of Life

One leading expert refers to epilepsy as “unique among illnesses for the extent and degree of psychosocial disability it causes” (Sperling, 2004). Others confirm this, reporting:

• The unpredictable and incapacitating nature of seizures can cause stress and embarrassment.
• Behavior problems in children with epilepsy are frequently the result of a combination of factors, including family stress and seizure frequency (Hermann and Austin 1993). Family stress is often more significant than the number of seizures and may be negatively impacted by lack of support from the extended family, financial problems and low self esteem. Accordingly, family issues and attitudes must be addressed as part of any treatment plan.

Students with epilepsy are more likely to experience impaired self-image, behavior problems and psychiatric co-morbidities than are students with other chronic medical problems, such as asthma. Those with frequent or uncontrolled seizures may also face social rejection by peers.

Epilepsy still carries much stigma. This often affects psychological well-being and, for many children, it influences their ability to make and keep friends and to feel confident in social settings away from their parents. The impact of epilepsy on adolescent growth and development can be dramatic. The normal transition from dependence to independence is often disrupted. Families report concerns about safety, social isolation, frequently missed school days, grades and, eventually, driving (Swartztrauber K, 2003).

Epilepsy has measurable effects on most primary areas of life including education, marriage and family and emotional adjustment. It is to be expected that the more severely affected an individual student or adult, the greater the social and psychosocial difficulties they will experience. For many, however,
the negative reactions of others far outweigh the impact of the condition itself, no matter how well they are doing or how much they have achieved. It is not surprising then, that while some successful individuals with epilepsy are willing to acknowledge their condition, many in a position to help change social attitudes prefer to keep their seizure disorder private.

Assessing the Impact of Epilepsy: The Spectrum of Severity

Epilepsy affects individuals to varying degrees, creating a spectrum of disability that is broad and ranges from having a very limited effect on the individual to having a devastating impact on all aspects of life. For the majority (perhaps as high as 80 percent) of those with epilepsy, seizures can be substantially reduced or completely controlled, enabling children to live normal or close to normal lives.

For the remaining 20 percent, epilepsy is truly disabling, marked by frequent seizures, other impairments, memory and other cognitive effects and a highly compromised standard of life. Children whose seizures are not well controlled often experience social, emotional and academic problems that affect various stages of development.

These problems commonly extend into adult life, where the same issues become chronic barriers to employment and independence. For many other children and adults, the level of functioning actually falls somewhere between these extremes.

Marshall and Cupoli (1986) have identified three categories of severity among students with seizure disorders. The severity of the seizures, the effects of the medication and the neurological status of patients all interact to produce these characteristic levels of functioning.

The categories are defined as:

- **Uncomplicated**, because the seizures are controlled with medication
- **Compromised**, because of social, emotional and educational (cognitive) problems
- **Devastated**, by virtue of multiple problems

While social issues based on society’s reaction to epilepsy also affect children across all severity measures, epilepsy is less disabling for children with uncomplicated epilepsy. Educational/employment problems among this group may occur, but their impact is less than those with complicated epilepsy.

**Uncomplicated**

Children in this category are likely to have gained control of seizures fairly rapidly and have no, or infrequent, seizures. They have limited, if any, side effects from medication and are cognitively intact (although memory problems are commonly cited across all levels of severity). They have no additional physical or mental impairments.

**Compromised**

Children in this category have seizures that are usually controlled and do not have serious mental or motor deficits. However, they take higher doses of medication to maintain control and are more likely to experience side effects. They are also more likely to experience a greater level of social, emotional and educational/employment problems during their lives.

**Devastated**

Children and adults whose lives are devastated by epilepsy often have seizures as a result of brain disease or injury that also impairs learning, memory, attention and motor and emotional function. Their seizures start early in life and may never be controlled, despite the use of multiple and combined medications. They are likely to be heavily medicated and may experience some slowing or retardation. They have difficulty in maintaining family support and social relationships and require help in everyday living. They are more susceptible to bouts of continuous seizure activity (flurries) and status epilepticus. Individuals of all ages in this category have a lifelong need for services and are substantially limited in their ability to function independently.

Understanding where a child is on the spectrum of severity helps in determining the extent of intervention necessary at given points in time. It can also be a useful reference tool in determining when added assistance may be needed for a child whose epilepsy is destabilized by medication changes, puberty or other factors.
Basic first aid (care and comfort) is the responsibility of all school personnel who interact with a child who has seizures.
Section 3
FIRST AID

The school nurse should be informed by parents or guardians if there is a history of any type of seizure for any student in his/her care. A seizure action plan should be developed that includes plans for both basic first aid and acute intervention, should these ever be needed. See Section 5 for more information about seizure action plans.

First aid can be broken down into two steps:
1. Basic First Aid — Care and Comfort
2. Acute Interventions and Emergency Response

Basic First Aid: Care and Comfort
Seizures can last from a few seconds to a few minutes, depending on the type of seizure. They may affect awareness, but are rarely medical emergencies and usually require only basic care and comfort. If a student has more frequent seizures than is usual for that student, or if seizures appear different than usual, the school nurse or a delegate should follow the seizure action plan and contact the parents or other designated emergency contact.

Basic first aid (care and comfort) is the responsibility of all school personnel who interact with a child who has seizures. The school district should provide a training opportunity to all relevant staff according to the student’s IHP and seizure action plan so they can respond appropriately to routine seizures. Basic first-aid training can be performed by the school nurse or by staff from a local Epilepsy Foundation affiliate. Basic first aid does not need to be made complicated. Most people, with instruction, can safely provide basic first aid.

Basic first-aid measures for seizures have common elements. However, the type of assistance provided to the student who loses consciousness because of a primary or secondarily generalized seizure (see Table 15) is different than that for students who experience states of altered awareness as seen with complex partial seizures (see Table 14).

Care of Students with No Change in Consciousness
When seizures do not alter the student’s awareness or consciousness, as in simple partial seizures, school personnel who are assisting the student should focus on ensuring the student is safe. Make sure the school nurse or trained school personnel is with the student during the event, observing and recording what transpires. After the seizure, the school nurse or trained school personnel should ensure that the student is fully oriented and able to resume prior activities. If needed, the student should also be provided with a comfortable, safe and supervised place to rest until he/she feels able to actively and appropriately participate.

Care of Students with Altered Awareness
Absence seizures are characterized by brief lapses in awareness. A typical seizure lasts five to ten seconds. No specific first aid is required for absence seizures. However, when these occur in clusters, the student may experience a longer period of feeling spacey, out of contact or confused. In these instances the educator/school personnel should ensure that the student is fully oriented and able to resume prior activities.

Complex partial seizures last longer than absence seizures and can affect the student’s awareness of what is occurring and cause confusion. Some children report that they can hear but cannot talk. Others can talk, but may not remember what they have said or their speech does not make sense.
If a complex partial seizure lasts more than five minutes beyond its usual duration for that student, or if another seizure begins before the student fully regains consciousness, call EMS or another predetermined emergency assistance provider as noted in the student’s seizure action plan.

**Care of Students with Seizures that Cause Loss of Consciousness**

*Generalized tonic-clonic seizures*, whether primary or secondarily generalized, are often called major motor seizures. Observers often believe that these seizures last longer than they actually do. For example, while the student may not be able to respond appropriately for 20 minutes or more, the actual seizure, with stiffening and/or jerking movements of the arms or legs, may last one to two minutes or less.

**After a Seizure Episode**

A written protocol dictating what happens after a student has a seizure should be included in the student’s seizure action plan. This protocol should be a collaborative effort between the school nurse, parent(s) and the healthcare team. The majority of students will not need to leave the classroom or

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**TABLE 14: Care and Comfort for a Complex Partial Seizure**

<table>
<thead>
<tr>
<th>Caregivers responding to a complex partial seizure should:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Stay calm and reassure the student that he/she is safe</td>
</tr>
<tr>
<td>• Reassure the other students</td>
</tr>
<tr>
<td>• Speak softly and calmly, keeping in mind that the student may not be able to obey verbal instructions</td>
</tr>
<tr>
<td>• Protect the student’s privacy whenever possible</td>
</tr>
<tr>
<td>• Direct the student away from potentially harmful objects such as tables, chairs and doors</td>
</tr>
<tr>
<td>• Allow a wandering student to walk in a contained area</td>
</tr>
<tr>
<td>• Stay with the student until complete awareness of the environment is maintained</td>
</tr>
<tr>
<td>• After the event, reorient the student to the surroundings and provide a comfortable, safe and supervised place to rest, if needed</td>
</tr>
</tbody>
</table>

Caregivers should NOT:

• Restrain the student’s movements
• Expect instructions to be followed
• Shout

**TABLE 15: Care and Comfort for a Generalized Tonic-Clonic Seizure**

<table>
<thead>
<tr>
<th>If a student is having a generalized tonic-clonic seizure:</th>
</tr>
</thead>
<tbody>
<tr>
<td>• Stay calm and reassure the student that he/she is safe</td>
</tr>
<tr>
<td>• Reassure the other students</td>
</tr>
<tr>
<td>• Help the student to lie down, if necessary</td>
</tr>
<tr>
<td>• Observe and time events</td>
</tr>
<tr>
<td>• Turn the student on one side</td>
</tr>
<tr>
<td>• Protect the student’s head and remove eyeglasses</td>
</tr>
<tr>
<td>• Loosen any tight clothing from around the neck</td>
</tr>
<tr>
<td>• Remove potentially harmful objects from the surrounding area</td>
</tr>
<tr>
<td>• Follow the seizure action plan</td>
</tr>
</tbody>
</table>

**Caregivers should NOT:**

• Restrain the student’s movements
• Put anything in the student’s mouth
• Expect instructions to be followed
• Shout
school after a seizure. Whether a student leaves school after a seizure is often dependent upon the final assessment of a professional school nurse. Some students will need to rest in the school nurse’s office or another comfortable, safe and supervised area until they are able to return to normal activities. If the student is not able to resume scheduled activities within a reasonable period of time, as documented in the seizure action plan, the school nurse or other trained school personnel should contact the student’s parent(s) or healthcare professional(s) to determine the best course of action.

**Acute Interventions and Emergency Response**

The school nurse should develop a seizure action plan for every student with a known seizure condition. This should include a detailed description of recommended seizure abortive therapy and appropriate emergency responses to ensure the student remains safe in the event of an acute seizure emergency, including status epilepticus.

Each school typically has a system in place for school nurses and other personnel to call for emergency medical assistance. In some school districts, 911 is available. In others, the school may have arrangements with local hospitals or healthcare systems. The school nurse should inform parents of students with seizures about emergency system options and discuss when these systems would be needed. She/he can then develop guidelines in concert with the parents and healthcare team, defining specifically what constitutes an emergency for that student and how to respond appropriately. All of this information should be included in the seizure action plan.

Currently the Epilepsy Foundation recommends initiating acute interventions after five minutes of continuous seizure activity. The school nurse or other trained school personnel should also be prepared to administer (within the state law) PRN medications as prescribed and incorporated into the seizure action plan.

**When is a Seizure Considered an Emergency?**

*Call 911 and seek emergency assistance immediately when a seizure occurs in a student who:*

- Has no previous history of seizures
- Has a convulsive (generalized tonic-clonic) seizure that lasts longer than five minutes
- Experiences repeated seizures with loss of consciousness or a second seizure occurs before the student regains consciousness
- Has more seizures (of any kind) than usual or has a different kind of seizure than normally experienced as noted in student’s seizure action plan
- Has an actual injury (or a suspected one) as a result of a seizure or if parents or guardians request emergency help or an evaluation
- Has diabetes, is pregnant or has another medical condition
- Does not resume normal breathing at the conclusion of the seizure

**IMPORTANT:** If a student is not breathing at the conclusion of the seizure, begin mouth-to-mouth resuscitation immediately and call 911 or the local emergency medical personnel.

**Use of Medications for Prolonged or Cluster Seizure**

Physicians sometimes prescribe an antiepileptic medication for PRN use for children who have clusters of seizures (multiple seizures within a defined period of time), prolonged seizures (status epilepticus) or a tendency to have seizure emergencies. The administration of oral medications during a seizure should be avoided, but if the student is alert between seizures, a fast-acting antiepileptic drug, such as lorazepam (Ativan®) or midazolam can be given buccally or sublingually, as prescribed by the student’s physician. If a student is not alert or if other routes cannot be used, diazepam rectal gel (Diastat® AcuDial™) may be used.
Medication administration for acute or prolonged seizures may be accomplished in different ways depending on a state’s nurse practice act, school district policy, school policy, state laws, physician order and parent preference and should be noted in the seizure action plan. In many states, the school nurse has the primary responsibility for administering medications, but this is not always the case. Good nursing practice requires the school nurse to work proactively with the student’s parents and healthcare providers to clarify indications and instructions for the medication’s use.

The student’s seizure action plan should incorporate instructions for medications to be used during prolonged seizures or seizure emergencies. Seizure medication and treatment instructions should include:

- Brand and generic name of the antiepileptic medication
- Dosage
- Dosing regimen
- Special instructions for administration
- How to monitor responses
- Potential side effects
- Possible drug interactions
- What to do if a dose is missed
- What to do if side effects are observed

**Vagus Nerve Stimulation and Magnet Use**

Vagus nerve stimulation therapy delivers preprogrammed electrical impulses to the vagus nerve on an ongoing basis. A Vagus Nerve Stimulator (VNS), usually implanted in the upper left chest or under the arm, stimulates the vagus nerve, which in turn transmits electrical impulses to critical brain areas that are involved in seizure generation or spread.

A VNS device may be stimulated manually with the use of a magnet, typically worn on the wrist or belt. If the student has a seizure warning sign (aura), or at the onset of a seizure, the student, school nurse or trained school personnel may swipe the magnet over the VNS device to trigger an extra burst of stimulation. Many people with epilepsy report that activating the VNS device in this manner helps to abort the seizure or lessens its intensity. The magnet may be used as often as needed with at least a minute between swipes.

If the magnet is held over the VNS device for six seconds it will turn it off temporarily. The student may consciously do this to avoid certain side effects, such as changes in voice or coughing during activities involving public speaking or singing or when stimulation is uncomfortable.

The most common side effect of vagus nerve stimulation is mild hoarseness and slight tingling in the neck when the signal is activated. Other reported side effects include dyspepsia, insomnia and difficulty swallowing.

A magnet should be with the student at all times. However, the student should be reminded to keep the magnet away from anything that is sensitive to magnetic fields including computers, cards with magnetic strips (e.g. credit cards) and videotapes.

Instructions for VNS magnet use should be incorporated into the seizure action plan for students with a VNS device as a first-aid intervention that can be administered by the student, school nurse or trained school personnel. Students with a VNS implant should also carry VNS identification cards.

Videos that demonstrate the use of the Vagus Nerve Stimulator are available from the manufacturer, as are magnets. Visit www.vnsterapy.com to obtain ordering information (please see page 39 for additional information on VNS therapy).

**Delegation of Acute Intervention Responsibilities**

Federal laws like Section 504 of the Rehabilitation Act of 1973, the 1990 Americans with Disabilities Act (ADA) and the 2004 reauthorized Individuals with Disabilities in Education Act (IDEA) mandate that reasonable accommodations be enacted in schools to ensure that a student with a disability has full access to all school activities in the least restrictive environment and that each student has educational opportunities equal to his/her non-disabled peers.
This mandate requires that both public and private schools make appropriate arrangements to accommodate a student who may need to receive PRN medications while at school or during school activities such as routine school bus rides, field trips and sporting or fine arts events. Whether this administration is accomplished by a licensed professional school nurse or a delegate depends on state laws, a state’s nurse practice act, school district and school policy and finally, parent and child preference. Where state laws restrict the delegation of medications, the school nurse, individual school, school district and student’s parent(s) must discuss this issue and develop a plan for how to provide the student who may require these medications with full access to all activities.

Unfortunately, even when it is determined that delegation of acute intervention responsibilities is legal and necessary, there may be no one immediately available or willing to perform this function. When this occurs, the school nurse, parents and school administrators must seek (within state law) a workable solution to ensure that an appropriately trained individual is delegated the authority and is available to perform this function.

When delegation of an acute intervention is considered, the school nurse should make certain that all involved in the delegation process (i.e. teachers, parents, school staff, classmates or other students) understand that the school nurse must:

- Put the health, safety and welfare of the student above all other considerations
- Abide by the state nurse practice act
- Abide by the school and school district policies
- Abide by applicable state and federal mandates
- Abide by state education, public health and pharmacy laws and regulations
- Determine if a nursing task can be delegated under her nursing license

If a determination is made that a school nurse can delegate a task under her nursing license, depending on state law, the nurse is then responsible for the following:

- Ensuring that the chosen delegate is appropriate
- Providing training and ongoing assessment and documentation of the competence of the delegate
- Providing ongoing assessment of the student’s health

Note: In situations where a professional school nurse is not available, the training and supervision of approved delegates may fall on the student’s prescribing physician.
The goal of treatment for the student with epilepsy is no seizures and no medication side effects.
When treatment is indicated for the student with epilepsy, there are a variety of options which, used alone or in combination, can help prevent seizures and minimize their impact and severity. These include:

- **Antiepileptic drugs** (AEDs) are the cornerstone of epilepsy treatment and the most common approach. (Please see Appendix C for medications used in the United States along with dosage information and the most common side effects.) PRN AEDs are essential in managing acute seizures and status epilepticus.

- **Surgery** is an option when there is a brain lesion or abnormality that can be identified as the origin of seizure activity and can be removed safely.

- The **ketogenic diet** is high in fat and low in protein, carbohydrates and fluids. It produces a ketotic state that is beneficial in reducing seizures in some individuals with epilepsy.

- **Vagus nerve stimulation** therapy sends an electric stimulus to the brain, averting seizures.

- **Alternative therapies**, while not well studied, are currently under investigation by researchers.

### Antiepileptic Drugs (AEDs)

Before 1990, antiepileptic medication choices were limited, but since then, nine new products have been introduced. Some work well for some individuals, so it is important for the student’s healthcare providers and parents to determine the best course of treatment. (See Appendix C for more information on drug therapies.)

### Initiating Drug Treatment

The decision to begin drug treatment is based upon many factors, including the risk of having recurrent events. Clinical experience and research findings demonstrate that monotherapy is effective for controlling seizures in approximately 65 percent of patients. Treatment with two AEDs controls seizures in another 10 percent.

It is common practice today to start treatment with one antiepileptic drug after the child has had two unprovoked seizures. If the child does not respond to one drug, a second drug is often added. In more resistant seizures, multiple medications are added and may control seizures. Unfortunately, multiple medications can also have negative side effects. There is frequently an effect on attention, somnolence and/or cognition when medications are used in high doses or in combinations.

### Antiepileptic Drugs in Use

There are many antiepileptic drugs in use today. The oldest of these are Dilantin® (phenytoin), phenobarbital, Tegretol® (carbamazepine), Zarontin® (ethosuximide) and Depakote® (valproic acid).

The newer AEDs are Felbatol® (felbamate), Gabitril® (tiagabine), Topamax® (topiramate), Zonegran® (zonisamide), Keppra® (levetiracetam), Lamictal® (lamotrigine), Trileptal® (oxcarbazepine), Lyrica® (pregabalin) and Neurontin® (gabapentin). Many of these products are available in different formulations for ease of administration.

The student’s healthcare provider, along with his/her parents, will decide when treatment is necessary and which medication should be used. The prescribed treatment and medications are usually based on seizure type, frequency and severity and the ability to perform daily living tasks at home and school as appropriate to the child’s age and stage of development. Titration of medication in epilepsy is routinely needed, because dosages are adjusted for weight, side effects and efficacy. When new medications are being introduced and/or current medications are being weaned, flexibility is needed. These processes can be time-consuming and can put the student at risk for seizures during the period of adjustment.
Approximately 25 percent of those with epilepsy have seizures that are not completely controlled with medications alone. It is important to make early determinations of treatment intractability and promptly refer the child to an epilepsy specialty center to minimize both the psychosocial consequences of uncontrolled epilepsy and the potential for physical sequela (Wiebe, 2004).

The primary risks related to drug therapy range from common side effects (dizziness, drowsiness or nausea) to toxicity from medication, which can be idiosyncratic, dose-related or chronic. Conversely, allowing a child to have seizures also has risks. These include physical injury associated with falls and psychosocial issues associated with restrictions placed on the child because of epilepsy, the social stigma of seizures and the child’s ongoing concerns about having another seizure.

**PRN Medications for Prolonged or Acute Repetitive Seizures**

Several fast-acting AEDs are currently prescribed for PRN use for students who have clusters of seizures (multiple seizures within a defined period of time), prolonged seizures (status epilepticus) or a tendency to have seizure emergencies. These include AEDs such as lorazepam (Ativan®) and midazolam (Versed®), both of which may be given buccally or sublingually, and diazepam rectal gel (Diastat® AcuDial™).

Diazepam rectal gel, often referred to as a seizure rescue medication, is the most commonly prescribed medication for out-of-hospital use to stop acute or cluster seizures. It is approved by the U.S. Food and Drug Administration for use by family members or other non-medical caregivers. It is supplied in pre-packaged syringes for rectal administration, with dosages tailored to the child’s weight. Remember that medication administration in the school setting depends on state laws, the state’s nurse practice act, school district and school policy and finally, parent and child preference.

Diazepam rectal gel is usually well tolerated. Some students may be tired after the drug is given and need to rest, while others can resume their usual activity immediately. Primary concerns about diazepam rectal gel include student privacy during administration, the ability to assess when to administer and respiratory depression. Despite concerns, respiratory depression is not a common side effect of this medication.

Videos demonstrating the use of the diazepam rectal gel are available from the manufacturer, as are rectal syringes. Visit www.diastat.com to obtain ordering information.

Midazolam treatment by intranasal routes is also indicated for the treatment of prolonged seizures in children. Although this nasal spray is not currently indicated for out-of-hospital use in the United States it shows promise as an effective seizure rescue medication in the future. In preliminary studies intranasal midazolam has been shown to be at least as effective as diazepam rectal gel in stopping prolonged and cluster seizures in children (Harbord, 2004).

**The Cognitive and Behavioral Effects of Antiepileptic Drugs**

In children, the side effects from AEDs can be unpredictable and must be weighed against the

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**TABLE 16: Drug Reaction Warning Signs**

- Rash
- Prolonged fever
- Severe sore throat
- Mouth ulcers
- Easy bruising
- Pinpoint bleeding
- Weakness
- Excessive fatigue
- Swollen glands
- Lack of appetite
- Increased seizures
benefits. Some common adverse effects include double vision, sedation, dizziness and ataxia. Other effects, like depression and psychosis, are dose dependent. Carbamazepine can induce anxiety, agitation and insomnia. Valproate can produce increased appetite and weight gain. Barbiturates can produce hyperactive responses. Phenytoin and phenobarbital have been associated with alterations in personality and changes in intellectual functioning. Although the newer agents (Lamotrigine®, Topiramate® and Gabapentin®) are less well studied than older medications, they appear to have fewer cognitive side effects.

The long term effects of AEDs in children are not clear but, given the developmental challenges of a normal childhood and adolescence, even mild drug effects can have an adverse impact (Drone, 2002).

**Discontinuing Treatment**

Antiepileptic medications prevent seizures but do not change the status of the underlying epilepsy. Research has shown that if a child is seizure-free for two years on medication, he/she is likely to remain seizure free without medication. With that in mind, children can be weaned off AEDs in a process that is usually accomplished over a period of several weeks.

During the drug withdrawal process and for some time thereafter, school personnel should be especially observant for signs of recurrent seizures. The majority of seizures recur within six months of having medication withdrawn. For children with no major risk factors for recurrence, the rate of recurrence following withdrawal of drug therapy is less than 15 percent (Shinnar and Pellock, 2002).

**Surgery**

About 25 percent of children have seizures that are not well controlled, even with medications. Those who have not responded to the first drug, or even a second one, have a reduced chance of obtaining control of their seizures through standard medication therapy. In these situations, the addition of third and fourth medicines is unlikely to be successful. Some of these children are candidates for surgery.

Several different surgical procedures have been shown to control seizures. The more common include focal resection, temporal lobectomy, lesionectomy and corpus callosotomy. Surgery typically offers relatively high post-surgical cure rates. Some studies suggest that post-surgical seizure-free rates are as high as 75 percent one year after surgery.

Evaluation prior to a surgical procedure is rigorous and generally includes inpatient video/EEG monitoring for five to ten days. The goal is to locate the area of the brain from which seizures are emanating as well as areas affected by seizures. Besides noninvasive and invasive EEGs, the workup often includes diagnostics such as magnetic resonance imaging (MRI), positron emission tomography (PET) and/or single photon emission computed tomography (SPECT). Neuropsychological testing may also be conducted.

Side effects can take several weeks or months to completely disappear. Typical side effects include headaches, dizziness, unsteadiness, jaw aches, swelling or bruising of head and face, blurred vision and sensation changes, especially numbness around the operation site. Depression or mood changes may also occur, but are generally temporary. Headaches often worsen with coughing, sneezing or straining. Jaw aches occur because the muscles controlling the jaw may need to be cut. Blurred vision can last for several weeks.

A child will usually go home after seven days in the hospital and will likely miss several weeks or months of school. Therefore, it is advisable to discuss post-surgical academic needs with a student and their parents prior to the surgery and develop a plan for re-entering the school environment.

**Ketogenic Diet**

The ketogenic diet was first introduced as a treatment for intractable seizures in the late 1920s. This diet, which is high in fat and low in protein, carbohydrates and fluids, produces a ketotic state in the child. It appears to be most effective for myoclonic seizures which involve brief, shock-like jerks of a muscle or a group of muscles. It may also be helpful for other seizure types, such as tonic-
clonic and complex partial seizures. The precise mechanism of action is not completely understood.

The physician, nutritionist and nurse must collaborate to supervise elements of this dietary therapy. The child is usually hospitalized when the diet is initiated, because two to three days of fasting are needed to produce the initial ketotic state. Afterward, the diet must be strictly followed. Even a minute amount of sugar can disrupt the ketosis and jeopardize the child’s seizure-free state.

Parents need to provide prepared meals and snacks for the child, who is not allowed to eat anything else. Each item provides nutrients mathematically calculated to keep the child in a state of ketosis. The diet also includes fluid restrictions. Supplemental vitamins and minerals are given in sugar-free form.

Not surprisingly, compliance is the main problem that school nurses see with students on this regimen. If an older student is doing well on the diet, the school nurse can often promote compliance by emphasizing its benefits. Younger students need to be observed carefully to prevent them from eating and drinking another student’s food. Teachers and other school personnel and volunteers need education on the importance of maintaining the student’s dietary restrictions.

As with other forms of treatment, the ketogenic diet does have side effects. Renal calculi and cardiomyopathy can occur. Blood abnormalities may occur but are not common.

**Vagus Nerve Stimulator (VNS)**

Vagus nerve stimulation therapy is usually reserved for adjunctive treatment in refractory epilepsy. This approach to managing seizures consists of implanting a generator subcutaneously in the left upper chest or under the arm. A wire conducts the electric impulse from the generator to the left vagus nerve in the neck. When the generator sends an electric signal through the wire, the vagus nerve sends this stimulation to the brain. Although the exact mechanism of action is not completely understood, these intermittent electrical signals interrupt epileptiform activity for some people.

The generator is programmed to automatically deliver intermittent stimulation to the vagus nerve. The frequency and amount of stimulation can be controlled with a programming device. Initially, the child is started on a low level of current that is increased gradually. Periodic reprogramming of the generator is generally needed, based upon seizure control and patient response to treatment. A VNS device may also be stimulated manually with the use of a magnet, typically worn on the wrist or belt. Many people with epilepsy report that activating the VNS device in this manner helps to abort the seizure or lessens its intensity. (See page 33 for more information on VNS magnet use as a seizure first-aid intervention.)

**Alternative Therapies**

Alternative therapies for treating epilepsy have not been validated by rigorous scientific studies and their usefulness has not been established. It is important to question parents about the use of any alternative therapies, since these approaches might interfere with the effects of medical treatment.

Some complementary therapies that have been used for seizure control include acupuncture, aromatherapy, biofeedback and stress management techniques. Research regarding the effectiveness of these approaches is underway.

**Advances in Treatment**

Clinical testing of new medications continues and many of the more recently approved medications are only now being used often enough in children to provide insight into their pharmacological properties and potential. In addition, technological advances in radiology and imaging are helping to better define the anatomy and physiology of the brain.

Knowledge gained from this research will promote more precise diagnoses and create greater potential for surgical solutions for certain types of epilepsy. Research will also help provide clues to the pathogenesis of epilepsies, which in turn will aid in developing new AEDs.
To ensure the student’s needs are met, a seizure action plan must be student-centered and identify strategies to overcome barriers within school settings.
Section 5
SEIZURE ACTION PLANS

A seizure action plan is a tool used by school nurses and other school personnel to organize, communicate and tailor the healthcare and educational needs of the student with seizures. The plan helps ensure a safe environment for students, while maximizing opportunities for learning and development. In addition to documenting seizure type and treatment, this plan should document basic and emergency first-aid procedures and list specific interventions and strategies that will minimize the potential for stigmatization, while maximizing learning and social development opportunities. A seizure action plan is specific for each student with a known seizure condition and should also include the date of last seizure, aura, length of a typical seizure for that student, frequency and how the student responds after a seizure.

Crafting the plan requires collaboration among the school nurse, student, parents/guardians, school personnel and the student’s treating physicians. To ensure the student’s needs are met, a seizure action plan must be student-centered and identify strategies to overcome barriers within school settings. This information may be incorporated into Individual Healthcare Plans (IHPs), 504 Plans or Individualized Education Plans (IEPs). The seizure action plan may also serve as the basis of the training curriculum for other school personnel (see Table 17).

Assessing the Student’s Needs

The first steps for the school nurse in assessing a student are to gather, document and review information from the student, parents, teachers and the student’s treating physician. These steps also help

TABLE 17: Key Components of a Seizure Action Plan

<table>
<thead>
<tr>
<th>Assess the Student’s Needs</th>
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<tbody>
<tr>
<td>• Gather information from parents, teachers, healthcare professionals and others.</td>
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<tr>
<td>• Observe and document seizures and circumstances (seizure precipitants and precautions).</td>
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<tr>
<td>• Observe and document responses to medications.</td>
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<tr>
<td>• Observe and document impact on learning, behavior, socialization and mood.</td>
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<table>
<thead>
<tr>
<th>Customize an Action Plan</th>
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<tbody>
<tr>
<td>• Document treatment.</td>
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<tr>
<td>• Detail first aid (care, comfort, emergency).</td>
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<tr>
<td>• Detail strategies for managing seizures in special circumstances.</td>
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<tr>
<td>• Document strategies and accommodations to address learning, behavioral and psychosocial issues.</td>
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<table>
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<tr>
<th>Teach and Tailor Interventions as Needed</th>
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</thead>
<tbody>
<tr>
<td>• Teach all relevant school personnel and students (first aid, relevant accommodations, myths).</td>
</tr>
<tr>
<td>• Tailor and test interventions and accommodations.</td>
</tr>
<tr>
<td>• Provide supportive counseling and referrals, as necessary.</td>
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</tbody>
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identify coexisting learning, behavior, mood or mobility problems that occur as a consequence of the epilepsy, the medications and any associated stigma. Completing a thorough assessment helps predict and address issues before they arise. (Please see Appendix A for forms and questionnaires that school nurses can use to collect data and structure interventions.)

**Medication Documentation and Administration**

The school nurse or her delegate is responsible for documenting and administering medications. Fortunately, many of the newer seizure medications can be given once or twice a day, often eliminating the need for the student to take medications during school hours. However, detailing daily AED administration procedures is still a critical function of the seizure action plan for most students with seizures (see Table 17).

**Documenting Seizures and Circumstances**

Managing seizures in school settings begins with observing, recognizing and documenting seizure behaviors that are occurring. This can be challenging, because many symptoms are subtle, difficult to detect or occur without warning. Many are easily confused with other behavioral symptoms or problems. For example, brief staring episodes during absence seizures are often mistaken for attention disorders or daydreaming. Confusion, headaches, dizziness and language problems can also be symptoms of seizures that are often overlooked in school-aged children. (Please see page 21 for more details on conditions that might mimic epilepsy.)

Parents of students already diagnosed with epilepsy can help school personnel to observe and recognize possible seizure behaviors. They should provide the name and seizure type, detailed descriptions of the student’s typical seizure(s), the date of the last seizure, the aura, usual length of a seizure, frequency and how the student responds after the seizure and first-aid measures used at home.

Non-medical school personnel need to be enlisted to help observe the student and gather information and insights into his/her seizure behaviors. Information should be gathered about what happens before, during and after the seizure.

**TABLE 19: Documenting Seizure Activity**

When a seizure is suspected, school personnel should:

- Observe in detail the student’s behaviors
- Time the length of the seizure
- Keep a written log of seizure descriptions in a communication book or flow sheet that can be shared with the school nurse, parents/guardians and healthcare team
- Recall and document what behaviors occurred before the seizure
- Determine if there is a pattern in the timing of the seizure and/or if there are triggers involved

**Behaviors Before a Seizure**

Children may experience changes in mood hours — or even days — before a seizure event. Some children have a warning, or aura, such as a strange feeling,
tingling, numbness or nausea that immediately precedes a seizure. Children may also report strange tastes or smells, ringing in their ears, vision changes or a headache. Sudden changes in emotion (fear, anxiety, unpleasant feelings) should also be documented.

Is There a Pattern?
School personnel who observe a seizure should be instructed to look for a pattern in the timing of the seizure and possible seizure triggers. They should first note the date and time of day of each seizure. Noting and reporting all possible environmental triggers is helpful and serves to inform the seizure action planning process.

For a small number of students a specific seizure trigger may be identified. Flashing lights (photosensitivity) and hyperventilation are two documented seizure triggers.

Many other factors not considered to be true seizure triggers are also known to increase the likelihood of a seizure in students with epilepsy. These include the following:

• Missed or late medication (#1 reason)
• Overheating/overexertion
• Stress/anxiety
• Lack of sleep or fatigue
• Poor diet/missed meals
• Hormonal changes, particularly in adolescent girls
• Alcohol use
• Drug interactions

A school safety evaluation should be done to assess possible seizure triggers. During this assessment it is important to ask parents about seizure triggers in their child. The assessment may reveal that activities in which the child engages may need to be modified to reduce exposure to situations that trigger seizures. For example, flashing lights in movies, television and computers may be seizure triggers. In many cases, however, there is no identifiable trigger or precipitating factor.

What Happens to the Student During a Seizure?
Teachers and others should observe and make note of the following:

• Awareness/consciousness – Is the student confused, disoriented, not responsive, unconscious?
• Speech – Is the student able to talk clearly? Does he/she respond with only a few words or sounds? Is his/her speech nonsensical or incoherent? Is there speech arrest?
• Facial expression – Is the student staring blankly? Are eyes blinking in an unusual way? Is there facial droop or drooling?
• Turning – Is the student turning his/her head, eyes or body in an unusual way?
• Muscle tone – Is the student’s body stiff or limp?
• Twitching – Is the student jerking, with movements of face, arms or legs?
• Automatisms – Is the student aimlessly lip smacking, chewing, swallowing, picking at clothes, rubbing hands or tapping his/her feet?
• Walking, running or wandering – Is the student moving about without awareness of activity?
• Falling – Is the student walking unsteadily?
• Skin color – Is skin pale, cyanotic, sweating?
• Respiration – Are there breathing changes?
• Control of urine or bowels – Is the student incontinent?

What Was the Length of the Seizure?
Observers should accurately record the time from the beginning of the seizure to cessation of movement or altered behavior (ictal phase) and from the end of the seizure to the point in time when the student resumes normal activity (postictal phase). If the student transitions directly into postictal sleep, record the length of sleep.

Behavior After the Seizure?
Important observations after a seizure include:

• Is the student able to respond to voice or
touch?
• Is the student aware of person, place or time?
• Is there memory of the seizure event?
• Can the student talk?
• Is there weakness or numbness in the arms or legs?
• What is the student’s mood?
• Is he/she fatigued or sleepy?

**Observing Responses to Treatment**

The school nurse needs to gather detailed information about the student’s AED regimen and the potential side effects of medication. He/she should also be aware whenever medication changes are being made. When appropriate, the school nurse should educate the student’s teachers on behavioral or mood changes they may observe and establish a means of communicating these observations back to the school nurse, parents/guardians and the student’s healthcare provider(s) as needed.

**Assessing Learning and Psychosocial Issues**

Children with seizures often experience problems with learning, behavior, mood and mobility as a consequence of the epilepsy or its underlying etiology. These consequences may impact the child in the school setting more than occasional seizures themselves. Recognition and treatment of these issues are critical to successful school experiences.

The school nurse’s role in identifying and managing consequences of seizures will vary depending upon the severity of the student’s condition. For example, the student with intractable seizures who experiences many injuries will need help from the school nurse to ensure that appropriate safety precautions are in place to prevent injury and allow him/her to participate fully in activities.

Evaluating the impact of seizures and medications on each student’s learning and educational achievement will help identify learning or mood problems in students with seizures. The school nurse’s role should focus on communicating concerns with the parents and healthcare professionals and on encouraging additional educational and medical evaluations. Strategies and accommodations to address learning deficits, mood issues and other identified disabilities should be included in both the student’s seizure action plan and the IEP.

**Customizing an Action Plan**

Once an assessment and the collection of key information are complete the school nurse must write a customized seizure action plan for each student with seizures. The plan should be distributed to relevant school personnel. In addition to documenting seizure type and treatment, this plan should document basic and emergency first-aid procedures and list specific interventions and strategies that will minimize the potential for stigmatization while maximizing learning and social development opportunities.

Seizure first aid used to be thought of as protecting a student during a seizure or calling for emergency help. Seizure action plans, however, recognize that more can be done to help a student during a seizure and, in some circumstances, to intervene to help prevent, stop or lessen part or all of a seizure.

**Educational Accommodations**

The school nurse should work with teachers to make sure that they understand the dynamics of seizure disorders and their impact on the educational process for each student. Teachers should be

**TABLE 20: Simple Educational Accommodations**

- Extra test time or untimed tests
- Verbal responses on tests
- Moving chair closer to the front of the room
- Tutoring or peer assistance
- Dimming fluorescent lights
- Allowing student to wear a hat if needed to dim lights
- Limit computer time
encouraged to make accommodations to assist the student through easy-to-implement classroom practices. These accommodations may also need to be included in the student’s IHP, IEP and/or 504 Plan.

**Special Circumstances and Precautions**

Students with seizures should be allowed to participate in field trips, recesses and after-school activities. To ensure full participation, the school district should provide a training opportunity to all relevant staff so they can respond appropriately to seizures. The school nurse should incorporate procedures and strategies to address special needs identified by the student and his/her parents during the assessment. For example, when students with frequent seizures, a tendency to seizure clusters or long seizures participate in a field trip or after-school activity, the school nurse may need to work creatively with the student and his/her parents to provide training for teachers and chaperones in seizure recognition and first aid so they can respond appropriately until additional help is available. Other circumstances that may require special precautions include:

- Students involved in school sports, especially swimming and contact sports
- Students in wheelchairs
- Students who have specific, identified seizure triggers

**Teaching and Tailoring Interventions**

It is essential that the school nurse teach other school personnel how to respond to seizures in school settings and help to implement any special strategies and classroom or extracurricular accommodations. It is advisable to conduct a thorough assessment of the needs of the student with seizures, as well as those of teachers and other school personnel prior to implementing a training program. This will help ensure that training is focused on the most
important issues. For example, teachers and other school personnel who have a student who uses a Vagus Nerve Stimulator and is going through medication changes, or has a tendency to have seizure clusters, may require special training. In addition, teachers and other school personnel who express significant fears and concerns about having a student with seizures in their classrooms may need additional training or counseling assistance.

Training protocols for school personnel must focus on dispelling myths and fears and teaching basic first aid. The training should emphasize that, while most students will not have seizures at school, they may still experience social, emotional and cognitive problems that interfere with school performance. (For more information on training school personnel, please see Section 6 of this guide.)

Interventions, whether they include training, specific accommodations or ongoing counseling, must be tailored to address the special circumstances of the student. These should be monitored and adjusted regularly to allow for medication changes and natural hormonal and growth-related shifts that can impact seizure control. Over time, additional interventions and precautions may be needed, as the original guidelines for managing each student’s situation change.

This type of proactive, caring approach helps students with epilepsy to grow up to be successful, well-adjusted individuals.

**Supportive Counseling and Referrals**

Students with epilepsy and their families may need supportive counseling and referrals. A thorough assessment of psychosocial, learning and behavioral risk factors will help determine the best course of action. Understanding where the student is on the spectrum of severity will also help predict the likelihood of the student's developing a truly disabling condition.

The school nurse, in collaboration with a school counselor, social worker and/or school psychologist may choose to address basic behavioral, social and learning issues directly through supportive and educational counseling with the student and his/her parents. Some issues that can be addressed include:

- Medication compliance
- Dating, driving and disclosure
- Parental over-protectiveness
- Minor memory and learning impairments
- Socialization issues (anger, withdrawal, embarrassment)
- Career choices and possible work limitations

**When to Refer to a Specialist**

Students with more significant and severe consequences, who are not currently under the care of a specialist, may require additional referrals to medical specialists or mental health professionals. Referrals should be considered for the following:

- Uncontrolled seizures and status epilepticus
- Significant mood and anxiety disturbances
- Major memory and learning deficits
- Sudden change in seizure type
- Signs of medication toxicity or allergy
Section 6
TRAINING TEACHERS AND OTHER SCHOOL PERSONNEL

“ There is a real need to share facts, dispel myths and reduce fears about seizures. ”
The attitude and full cooperation of teachers and other school personnel are key factors in promoting positive social and educational outcomes for the student with epilepsy. Appropriate training optimizes seizure management strategies and helps ensure the full integration of the student with epilepsy into all school activities while minimizing further stigmatization.

**General Curriculum for Training Others in the School Setting**

Since seizures only last a few seconds to a few minutes, the seizure is often over by the time the school nurse arrives. Therefore it is important that all of those who may be in a position to assist the student with epilepsy receive information about seizure recognition, seizure first aid and the impact of seizures and epilepsy on learning and psychosocial development. This includes, but is not limited to, teachers, secretaries, athletic coaches, bus drivers, foodservice workers, administration personnel, counselors, volunteer parents and classmates.

The school nurse, the student’s physician or an Epilepsy Foundation staff member or volunteer can conduct seizure recognition and first-aid training for teachers and students. A variety of training aids are available from the Epilepsy Foundation to assist with this training. These include, but are not limited to, the following:

- Seizure Training for School Personnel: A Presentation Guide and Toolkit
- Be Seizure Smart! – Teacher Information Kit
- Seizures and You: Take Charge of the Facts – An epilepsy awareness program for teens
- Brochures, videos, books and pamphlets targeting teens, parents, teachers and siblings
- Fact sheets on various subjects related to epilepsy and seizures, including specific treatments and classroom accommodation issues (visit www.epilepsyfoundation.org/schoolnurse to access these fact sheets)

**Training Objectives**

After training, school personnel should be able to:

- Recognize seizures
- Provide appropriate first aid
- Recognize when a seizure is a medical emergency
- Provide appropriate social and academic support

**Considerations in Curriculum Development**

Seizure recognition and first aid should be provided for all school personnel who interact with students with seizures. Training should include at least the following information:

- What is a seizure? What is epilepsy?
- Who has epilepsy? (incidence and prevalence)
- What do seizures look like?
- What are common myths about epilepsy?
- How might seizures and epilepsy impact learning?
- What is appropriate first aid for seizures?
- When is a seizure an emergency?
- What causes seizures?
- What are common seizure triggers?
- What can be done to prevent stigma?
- What is a seizure action plan?

The following optional topics might be included if relevant:

- Use of “rescue” medication including Diastat® AcuDial™
- Use of the Vagus Nerve Stimulator magnet
• Use of the ketogenic diet
• Seizures in a wheelchair
• Seizures in the water
• Seizures on a bus
• Seizures in a non-classroom area

Dispelling Myths and Reducing Fears
All school personnel should be taught the following information to dispel myths and reduce their fear of students with seizures:
• Most seizures are not medical emergencies.
• Children are usually not aware they are having a seizure and will not remember what happened.
• Epilepsy is not contagious.
• Epilepsy is not a form of mental illness.
• It is extremely unlikely that a child will die or have brain damage during a seizure.
• It is very rare for a child to become violent during a seizure.
• It is not possible to swallow one’s tongue during a seizure or at any other time.

Teaching About the Impact of Epilepsy on Learning
Input from school nurses can help explain the need to modify the educational plan for some students with epilepsy. Teachers should be aware of the following information:
• Seizures often cause short-term memory problems. After a seizure event, coursework must be re-taught.
• Seizure activity in the brain, without obvious physical symptoms, can still affect learning.
• Learning will occur more easily on some days than on others.
• Medication may cause drowsiness, inattention, concentration difficulties and behavior changes.
• Children with epilepsy are more likely to suffer from depression and low self-esteem than children with diabetes or asthma.
• Children are not always aware of their seizures.
• School difficulties are not always epilepsy related.
• Each student’s seizure action plan, IHP, 504 Plan and/or IEP should address these issues.

Managing Seizures in the Classroom
Teachers play a special role in setting the tone when a student experiences a seizure. If the teacher is calm and matter-of-fact and it’s clear that he/she knows what to do, the student’s classmates are reassured by both actions and words. The teacher should also note key information about the seizure so these details can be shared with the school nurse, the student’s parents and the student’s treating physician.

If the student with epilepsy and his/her parents agree to share information about the seizure with other students, then it is important that the class be able to discuss the event afterward and have a clear explanation of what happened. The following list provides key messages a nurse or teacher should convey to students who have witnessed a seizure in the classroom:
• What happened is called a seizure.
• Having a seizure is part of a health condition called epilepsy.
• No one knows exactly what causes epilepsy in some children. Fortunately, most will outgrow it.
• The seizure happened because, for just a very short time, the electrical impulses in the student’s brain did not work properly and sent mixed messages to the rest of the body. Now that the seizure is over, his/her brain is working properly again.
• Epilepsy is not a disease and it cannot be caught from or given to other students.
• Epilepsy is not a mental illness or a psychological problem.
• Children who have this condition take medicine to prevent seizures, but sometimes seizures occur anyway (Even taking cough medicine does not always stop a cough).
• Seizures stop by themselves, but it is important to know first-aid steps that will keep the student safe while the seizure is happening.

Managing Seizures Under Special Circumstances

On the School Bus
The school district should allow time for the school nurse to provide basic training to all school personnel,
including school bus drivers, so that they are equipped to deal with a student who experiences a seizure.

A seizure occurring on a school bus can be challenging for the school bus driver, who must safely navigate in traffic while directing students to provide first aid. During a generalized tonic-clonic seizure, the bus driver should attempt to pull over and stop the bus. The student should be placed on one side across a seating section with his/her head toward the aisle and facing away from the seat back. Alternatively, the student can be placed on one side in the aisle. Basic first-aid measures should be provided until the seizure abates and the student regains full awareness and consciousness.

Once the seizure has passed the bus driver may return to driving the bus. The bus driver’s decision to return to school or proceed to the final destination should be based on school policy and the seizure action plan.

**For a Student in a Wheelchair**
A student in a wheelchair should remain in the chair if at all possible. First-aid responders should secure the wheelchair to prevent it from moving and gently support the student’s head and body to prevent injury. Fasten the student’s seatbelt (loosely) to prevent the student from falling from the wheelchair. Allow for unobstructed movement and breathing and for secretions to flow out of the mouth. If possible, pad the wheelchair to prevent injury to the student’s limbs. Follow the relevant first-aid protocol. The student’s seizure action plan should be reviewed for specific first aid and emergency treatment procedures.

**When Seizures Occur in Water**
Remove the student from the water immediately, supporting the head so that both the mouth and nose are always above the water. If the student is not breathing, begin rescue breathing. Always transport the student to the emergency room even if he or she appears fully recovered.

**In Non-Classroom Areas of the School**
For each area of the school (hallway, cafeteria, gymnasium, playground, playing field, auditorium, restroom), there should be a trained first responder and a backup first responder listed in the seizure action plan procedures for seizure response. Responsible students as well as adults can be trained as first responders.
School nurses and educators should act as role models for other school personnel and students, helping them see that seizures are a medical problem that can be treated easily.
The resources listed in this section will be of value to the school nurse dealing with students with seizures. For more details and an up-to-date list of resources, school nurses can visit a special section on the Epilepsy Foundation Web site at the following: www.epilepsyfoundation.org/schoolnurse.

Community Resources
At the time of this publication, there are 52 Epilepsy Foundation affiliates serving local communities throughout the United States. To locate the affiliate nearest you, please call the national office of the Epilepsy Foundation at (800) 332-1000 or visit www.epilepsyfoundation.org/aboutus/AffiliateLookup.cfm

Internet Resources
Below is a short list of valuable Internet resources. For a more exhaustive and updated list please visit www.epilepsyfoundation.org/schoolnurse.

The Epilepsy Foundation
www.epilepsyfoundation.org
The Epilepsy Foundation is the national voluntary agency solely dedicated to the welfare of the 3 million people with epilepsy in the U.S. and their families. The organization works to ensure that people with seizures are able to participate in all life experiences; and to prevent, control and cure epilepsy through research, education, advocacy and services.

American Epilepsy Society
www.aesnet.org
The American Epilepsy Society promotes research and education for professionals dedicated to the prevention, treatment and cure of epilepsy.

Epilepsy.com
www.epilepsy.com
Epilepsy.com is an online resource provided by The Epilepsy Project. Its mission is to inform and empower two groups of patients and their families: those facing newly diagnosed epilepsy and those struggling with epilepsy that has resisted the usual treatments.

American Academy of Neurology
www.aan.com
The American Academy of Neurology provides valuable resources for medical specialists worldwide who are committed to improving the care of patients with neurological diseases.

American Clinical Neurophysiology Society
www.acns.org
The ACNS is a professional association dedicated to fostering excellence in clinical neurophysiology and furthering the understanding of central nervous system function in health and disease through education, research and the provision of a forum for discussion and interaction.

American Neurological Association
www.aneuroa.org
The American Neurological Association is a professional society of academic neurologists and neuroscientists devoted to advancing the goals of academic neurology, to training and educating neurologists and other physicians in the neurological sciences and to expanding both our understanding of diseases of the nervous system and our ability to treat them.

Centers for Disease Control and Prevention Epilepsy Web Site
www.cdc.gov/epilepsy/index.htm
The national Centers for Disease Control and Prevention is recognized as the lead federal agency for protecting the health and safety of people at home and abroad, providing credible information to enhance health decisions and promoting health through strong partnerships. Its epilepsy Web site details current partnerships and health promotion activities being supported by the agency’s epilepsy program.
The Charlie Foundation  
www.charliefoundation.org  
The Charlie Foundation was established in 1994 to raise awareness about the ketogenic diet as a treatment for childhood epilepsy. It facilitates basic and clinical research, educates professionals and informs families about the current status of the ketogenic diet.

The Child Neurology Society  
www.childneurologysociety.org  
The Child Neurology Society is the preeminent non-profit professional association of pediatric neurologists in the United States, Canada and elsewhere in the world.

The Child-Neuro Web Site  
www-personal.umich.edu/~leber/c-n/  
The main purpose of this site is to coordinate the available internet resources in child neurology for professionals and patients.

The Epilepsy Center  
www.epilepsycenter.org  
The Epilepsy Center is a non-profit organization dedicated to providing resources for better living to those persons with epilepsy and/or developmental disabilities, as well as to their families and friends.

The International Bureau for Epilepsy  
www.ibe-epilepsy.org  
The International Bureau for Epilepsy was established in 1961 as an organization of laypersons and professionals interested in the medical and non-medical aspects of epilepsy. The IBE addresses such social problems as education, employment, insurance, driver’s license restrictions and public awareness.

The International League Against Epilepsy  
www.ilae-epilepsy.org  
The International League Against Epilepsy works to advance and disseminate knowledge concerning epilepsy. Membership is comprised of national professional organizations and individuals involved in research and those interested in the exchange of scientific information concerning epilepsy.

The National Institute of Neurological Disorders and Stroke  
www.ninds.nih.gov  
The National Institute of Neurological Disorders and Stroke supports and conducts research on brain and nervous system disorders. By supporting and conducting neurological research, the NINDS seeks better understanding, diagnosis, treatment and prevention of these disorders.

Neuroscience for Kids  
faculty.washington.edu/chudler/neurok.html  
Neuroscience for Kids was created for all students and teachers who would like to learn about the nervous system.

PACE (Parents Against Childhood Epilepsy, Inc.)  
www.paceusa.org  
PACE was founded in 1996 by a group of parents in response to their experiences in caring for the medical, physical, social, educational, developmental and emotional needs of their children who have epilepsy and severe seizure disorders.

Books, Kits, Pamphlets and Videos

Many books, kits, manuals, pamphlets, posters and videos targeting health professionals, parents, children, teens and other populations are available for sale through the Epilepsy Foundation Marketplace. These items can be purchased online at www.epilepsyfoundation.org/marketplace or ordered by phone at (866) 330-2718. For a complete and current list of all products and prices, please visit the Epilepsy Foundation Marketplace Web site. For questions about specific products, call the Epilepsy Foundation Marketplace.

Materials for Training Teachers and Other School Personnel

A tool kit titled Seizure Training for School Personnel is available to assist school nurses in training teachers and other school personnel. This kit includes overhead slides, a video/DVD program and a facilitator’s
guide. For questions about this product and its current availability, call the Epilepsy Foundation Marketplace at (866) 330-2718.

Information packets designed specifically for teachers, parents and students are available. A small quantity may be ordered by contacting the Epilepsy Foundation’s Answer Place at (800) 332-1000. For larger quantities, please call the Epilepsy Foundation Marketplace at (866) 330-2718.

**Fact Sheets on Epilepsy**

The Epilepsy Foundation has fact sheets on a variety of epilepsy-related topics including seizure-specific information, treatment, education, insurance and employment. A complete list of fact sheets can be accessed from the school nurse web page at www.epilepsyfoundation.org/schoolnurse. Many of the fact sheets can be downloaded for your immediate use. Please check the Web site regularly as this list is periodically updated.

Below is a partial list of topics covered:

- Alcohol and Drug Abuse
- Blood-Level Monitoring of Antiepileptic Medication
- Diagnosing Epilepsy and Seizure Disorders
- Effects of Epilepsy on Learning and Memory
- Financial Aid: Scholarships, Grants and Fellowships
- IDEA: Elementary and Secondary Education
- Insurance Issues in Epilepsy and Seizure Disorders
- Nonepileptic Seizures
- Patterns of Seizure Frequency
- Photosensitivity and Seizures
- Prognosis in Epilepsy and Seizure Disorders
- Remission vs. Cure for Epilepsy
- Seizure Classifications: Absence Seizures
- Seizure Classifications: Complex Partial Seizures
- Seizure Classifications: Tonic-Clonic Seizures

**Driving and Epilepsy**

Every state regulates driver’s license eligibility for those with certain medical conditions. The most common requirement for those with epilepsy is that they be seizure-free for a specific period of time and submit a physician’s evaluation of their ability to drive safely. Another common requirement is the periodic submission of medical reports. In some states, this is for a specified period of time, while other states require routine reporting as long as the person remains licensed. To determine the regulations for your state, visit www.epilepsyfoundation.org/schoolnurse.
BIBLIOGRAPHY

Section 1


Section 2


**Section 4**

Appendix A:
SEIZURE ACTION PLANNING FORMS

The sample forms that follow provide guidelines for collecting data relevant to educational and seizure action planning for students with epilepsy. They can be adapted to meet individual and institutional needs. Each form provides a framework for collecting and sharing information critical to appropriate health management planning, which can occur only if the data are used collectively. Editable copies of these forms can be accessed through the following Web site: www.epilepsyfoundation.org/schoolnurse.

1. Questionnaire for Parent of a Student with Seizures
This form should be completed by the student’s parent(s). In some cases the school nurse may need to interview the parent(s) to clarify and complete the information requested on this form. The form should be updated annually or when any changes occur in the student’s health status. This information will assist school personnel in recognizing a student’s seizure(s) and responding appropriately.

2. Seizure Observation Record
This form should be completed by school personnel when reporting a seizure.

3. Seizure Action Plan
This form is designed to provide basic information about a student’s seizure(s) and medication. A completed seizure action plan should be distributed to all relevant school personnel at the beginning of a school year, when a diagnosis is made or when a change in health status occurs. This should generally be signed and approved by the treating physician.
**Questionnaire for Parent of a Student with Seizures**

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

<table>
<thead>
<tr>
<th><strong>Contact Information</strong></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Student’s Name</strong></td>
<td><strong>School Year</strong></td>
</tr>
<tr>
<td><strong>School</strong></td>
<td><strong>Grade</strong></td>
</tr>
<tr>
<td><strong>Parent/Guardian</strong></td>
<td><strong>Phone</strong></td>
</tr>
<tr>
<td><strong>Parent/Guardian Email</strong></td>
<td></td>
</tr>
<tr>
<td><strong>Other Emergency Contact</strong></td>
<td><strong>Phone</strong></td>
</tr>
<tr>
<td><strong>Child’s Neurologist</strong></td>
<td><strong>Phone</strong></td>
</tr>
<tr>
<td><strong>Child’s Primary Care Doctor</strong></td>
<td><strong>Phone</strong></td>
</tr>
</tbody>
</table>

**Significant Medical History or Conditions**

**Seizure Information**

1. When was your child diagnosed with seizures or epilepsy? __________________________

2. Seizure type(s)

<table>
<thead>
<tr>
<th>Seizure Type</th>
<th>Length</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
</table>

3. What might trigger a seizure in your child? __________________________

4. Are there any warnings and/or behavior changes before the seizure occurs? [ ] YES [ ] NO

   If YES, please explain: __________________________

5. When was your child’s last seizure? __________________________

6. Has there been any recent change in your child’s seizure patterns? [ ] YES [ ] NO

   If YES, please explain: __________________________

7. How does your child react after a seizure is over? __________________________

8. How do other illnesses affect your child’s seizure control? __________________________

**Basic First Aid: Care & Comfort**

9. What basic first aid procedures should be taken when your child has a seizure in school? __________________________

10. Will your child need to leave the classroom after a seizure? [ ] YES [ ] NO

   If YES, what process would you recommend for returning your child to classroom? __________________________

**Basic Seizure First Aid**

- Stay calm & track time
- Keep child safe
- Do not restrain
- Do not put anything in mouth
- Stay with child until fully conscious
- Record seizure in log

For tonic-clonic seizure:

- Protect head
- Keep airway open/watch breathing
- Turn child on side
Seizure Emergencies

11. Please describe what constitutes an emergency for your child? (Answer may require consultation with treating physician and school nurse.)

12. Has child ever been hospitalized for continuous seizures?  □ YES  □ NO
   If YES, please explain:

Seizure Medication and Treatment Information

13. What medication(s) does your child take?

<table>
<thead>
<tr>
<th>Medication</th>
<th>Date Started</th>
<th>Dosage</th>
<th>Frequency and Time of Day Taken</th>
<th>Possible Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
<td></td>
<td></td>
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<td></td>
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<td></td>
<td></td>
</tr>
</tbody>
</table>

14. What emergency/rescue medications are prescribed for your child?

<table>
<thead>
<tr>
<th>Medication</th>
<th>Dosage</th>
<th>Administration Instructions (timing* &amp; method**)</th>
<th>What to Do After Administration</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td></td>
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<td></td>
</tr>
</tbody>
</table>

* After 2nd or 3rd seizure, for cluster of seizures, etc.  ** Orally, under tongue, rectally, etc.

15. What medication(s) will your child need to take during school hours?

16. Should any of these medications be administered in a special way?  □ YES  □ NO
   If YES, please explain:

17. Should any particular reaction be watched for?  □ YES  □ NO
   If YES, please explain:

18. What should be done when your child misses a dose?  

19. Should the school have backup medication available to give your child for missed dose?  □ YES  □ NO

20. Do you wish to be called before backup medication is given for a missed dose?  □ YES  □ NO

21. Does your child have a Vagus Nerve Stimulator?  □ YES  □ NO
   If YES, please describe instructions for appropriate magnet use:

Special Considerations & Precautions

22. Check all that apply and describe any consideration or precautions that should be taken:
   □ General health
   □ Physical education (gym/sports)
   □ Physical functioning
   □ Recess
   □ Learning
   □ Field trips
   □ Behavior
   □ Bus transportation
   □ Mood/coping
   □ Other

General Communication Issues

23. What is the best way for us to communicate with you about your child’s seizure(s)?  

24. Can this information be shared with classroom teacher(s) and other appropriate school personnel?  □ YES  □ NO
   Dates
   Updated

Parent/Guardian Signature ___________________________ Date ___________________________
### Seizure Observation Record

<table>
<thead>
<tr>
<th>Student Name:</th>
<th></th>
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<tbody>
<tr>
<td>Date &amp; Time:</td>
<td></td>
</tr>
<tr>
<td>Seizure Length:</td>
<td></td>
</tr>
<tr>
<td>Pre-Seizure Observation (Briefly list behaviors, triggering events, activities):</td>
<td></td>
</tr>
<tr>
<td>Conscious (yes/no/awakened):</td>
<td></td>
</tr>
<tr>
<td>Injuries? (briefly describe):</td>
<td></td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Muscle Tone/Body Movements</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Rigid/clenching</td>
<td></td>
</tr>
<tr>
<td>Limp</td>
<td></td>
</tr>
<tr>
<td>Fell down</td>
<td></td>
</tr>
<tr>
<td>Rocking</td>
<td></td>
</tr>
<tr>
<td>Wandering around</td>
<td></td>
</tr>
<tr>
<td>Whole body jerking</td>
<td></td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Extremity Movements</th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>(R) arm jerking</td>
<td></td>
</tr>
<tr>
<td>(L) arm jerking</td>
<td></td>
</tr>
<tr>
<td>(R) leg jerking</td>
<td></td>
</tr>
<tr>
<td>(L) leg jerking</td>
<td></td>
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<tr>
<td>Random Movement</td>
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<table>
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<tr>
<th>Color</th>
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<tbody>
<tr>
<td>Blush</td>
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<tr>
<td>Pale</td>
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<tr>
<td>Flushed</td>
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<table>
<thead>
<tr>
<th>Eyes</th>
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<tbody>
<tr>
<td>Pupils dilated</td>
<td></td>
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<tr>
<td>Tumed (R or L)</td>
<td></td>
</tr>
<tr>
<td>Rolled up</td>
<td></td>
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<tr>
<td>Staring or blinking (clarify)</td>
<td></td>
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<tr>
<td>Closed</td>
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<table>
<thead>
<tr>
<th>Mouth</th>
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<tbody>
<tr>
<td>Salivating</td>
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<tr>
<td>Chewing</td>
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<tr>
<td>Lip smacking</td>
<td></td>
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<table>
<thead>
<tr>
<th>Verbal Sounds (gagging, talking, throat clearing, etc.)</th>
<th></th>
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</table>

<table>
<thead>
<tr>
<th>Breathing (normal, labored, stopped, noisy, etc.)</th>
<th></th>
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</table>

<table>
<thead>
<tr>
<th>Incontinence (urine or feces)</th>
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<tbody>
<tr>
<td>Confused</td>
<td></td>
</tr>
<tr>
<td>Sleepy/tired</td>
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<tr>
<td>Headache</td>
<td></td>
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<tr>
<td>Speech stuttering</td>
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<tr>
<td>Other</td>
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<table>
<thead>
<tr>
<th>Post-Seizure Observation</th>
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<tr>
<td>Confused</td>
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<td>Sleepy/tired</td>
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<td>Headache</td>
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<tr>
<td>Speech stuttering</td>
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<tr>
<th>Length to Orientation</th>
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<table>
<thead>
<tr>
<th>Parents Notified? (time of call)</th>
<th></th>
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<tbody>
<tr>
<td>EMS Called? (call time &amp; arrival time)</td>
<td></td>
</tr>
<tr>
<td>Observer’s Name</td>
<td></td>
</tr>
</tbody>
</table>

*Please put additional notes on back as necessary.*
# Seizure Action Plan

**Effective Date**

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

<table>
<thead>
<tr>
<th>Student's Name</th>
<th>Date of Birth</th>
</tr>
</thead>
<tbody>
<tr>
<td>Parent/Guardian</td>
<td>Phone</td>
</tr>
<tr>
<td>Other Emergency Contact</td>
<td>Phone</td>
</tr>
<tr>
<td>Treating Physician</td>
<td>Phone</td>
</tr>
</tbody>
</table>

**Significant Medical History**

**Seizure Information**

<table>
<thead>
<tr>
<th>Seizure Type</th>
<th>Length</th>
<th>Frequency</th>
<th>Description</th>
</tr>
</thead>
</table>

**Seizure triggers or warning signs:**

**Student’s response after a seizure:**

## Basic First Aid: Care & Comfort

Please describe basic first aid procedures:

Does student need to leave the classroom after a seizure?  
☐ Yes  ☐ No

If YES, describe process for returning student to classroom:

## Basic Seizure First Aid

- Stay calm & track time
- Keep child safe
- Do not restrain
- Do not put anything in mouth
- Stay with child until fully conscious
- Record seizure in log

For tonic-clonic seizure:
- Protect head
- Keep airway open/watch breathing
- Turn child on side

## Emergency Response

A “seizure emergency” for this student is defined as:

**Seizure Emergency Protocol**

(Write all that apply and clarify below)

☐ Contact school nurse at ________
☐ Call 911 for transport to ________
☐ Notify parent or emergency contact
☐ Administer emergency medications as indicated below
☐ Notify doctor
☐ Other ________

## Treatment Protocol During School Hours (include daily and emergency medications)

|-------------|------------|---------------------------|------------------------------------------|

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

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

Describe any special considerations or precautions:

Physician Signature ___________________________ Date ____________

Parent/Guardian Signature ______________________ Date ____________
Appendix B:
SEIZURE RECOGNITION AND FIRST-AID CHART
First Aid for Seizures
(Complex partial, psychomotor, temporal lobe)

1. Recognize common symptoms

BLANK STARING  CHEWING  FUMBLING  WANDERING  SHAKING  CONFUSED SPEECH

2. Follow first-aid steps

TIME THE SEIZURE  DON'T GRAB OR HOLD  EXPLAIN TO OTHERS  BLOCK HAZARDS

SPEAK CALMLY

People who've had this type of seizure should be fully conscious and aware before being left on their own. Make sure they know the date, where they are, and where they're going next. Confusion may last longer than the seizure itself and may be hazardous. If full awareness does not return, call for medical assistance.
Primeros auxilios para convulsiones
(Crisis parciales complejas, psicomotrices, de lóbulo temporal)

1. Reconocer los síntomas comunes

- Mirada perdida
- Masticación
- Movimientos torpes
- Caminar sin rumbo
- Temblores
- Habla confusa

2. Seguir los pasos de primeros auxilios

- Medir la duración de la convulsión
- Hacer un registro
- No sujetar ni agarrar
- Explicar a otros
- Bloquear los peligros
- Hablar con calma
- Lláma a la EMS

Antes de que se les pueda dejar solas, las personas que han tenido este tipo de convulsión deben estar completamente conscientes y haber recobrado el conocimiento. Asegúrese de que sepan la fecha, dónde están y adónde se dirigen. La confusión puede ser peligrosa porque a veces dura más que la convulsión propiamente. Si la persona no recobra el conocimiento por completo, solicite asistencia médica.
First Aid for Seizures
(Convulsive, generalized tonic-clonic, grand mal)

DON'T PUT ANYTHING IN MOUTH
LOOK FOR MEDICAL ALERT IDENTIFICATION

CUSHION HEAD, REMOVE GLASSES
LOosen TIGHT CLOTHING
TURN ON SIDE

TIME THE SEIZURE WITH A WATCH
AS SEIZURE ENDS, OFFER HELP
DON'T HOLD DOWN

Most seizures in people with epilepsy are not medical emergencies. They end after a minute or two without harm and usually do not require a trip to the emergency room.

But sometimes there are good reasons to call for emergency help. A seizure in someone who does not have epilepsy could be a sign of a serious illness.

Other reasons to call an ambulance include:
- A seizure that lasts more than 5 minutes
- No “epilepsy” or “seizure disorder” identification
- Slow recovery, a second seizure, or difficulty breathing afterwards
- Pregnancy or other medical diagnosis
- Any signs of injury or sickness

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Primeros auxilios para convulsiones
(Convulsiones tonicoclónicas generalizadas)

NO COLOCAR NADA EN LA BOCA
LOCALIZAR LA IDENTIFICACIÓN DE ALERTA MÉDICA

MEDIR LA DURACIÓN DE LA CONVULSIÓN CON UN RELOJ

EN CUANTO TERMINE LA CONVULSIÓN, OFRECER AYUDA

NO INMOVILIZAR A LA PERSONA

PROTEGER LA CABEZA, QUITAR LOS ANTEOJOS

AFLOJAR LA ROPA APRETADA

COLOCAR A LA PERSONA DE COSTADO

La mayoría de las convulsiones que acontecen a las personas con epilepsia no constituyen emergencias médicas. Generalmente duran sólo uno o dos minutos sin causar daños y no suelen requerir una visita a la sala de emergencias.

Sin embargo, a veces existen buenas razones para solicitar ayuda de emergencia. En personas que no tienen epilepsia, una convulsión podría ser señal de enfermedad grave.

Otras razones para llamar a una ambulancia:
- La convulsión dura más de 5 minutos
- No se localiza una identificación que asiente: epilepsia o trastorno convulsivo
- Recuperación lenta, una segunda convulsión o dificultad para respirar después de la crisis
- Embarazo u otro diagnóstico médico
- Cualquier señal de lesión o enfermedad

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Appendix C: ANTIEPILEPTIC MEDICATIONS CHART
### Medicines for Epilepsy

This chart is designed to help people with epilepsy (seizure disorders) become more familiar with the medications they are taking. It is not designed for use by health or other professionals to identify drugs. Other drugs not listed here may also be prescribed to prevent seizures.

The pictures are of brand name drugs as of the printing date. However, drugs may change in appearance from time to time. Generic versions of these drugs (labeled in italics, under the brand name) will look different from the brand name drugs.

The list of side effects is not complete because of space limitations. For a complete list, consult your doctor, nurse,

<table>
<thead>
<tr>
<th>Form (of brand name product)</th>
<th>Brand Name (generic name - images not shown)</th>
<th>Average Adult Daily Dose</th>
<th>Some Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td></td>
<td><strong>ATIVAN</strong> (lorazepam)</td>
<td>1 mg – 10 mg</td>
<td>Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes</td>
</tr>
<tr>
<td></td>
<td><strong>CARBATROL</strong> (extended release carbamazepine)</td>
<td>600 mg – 1200 mg</td>
<td>Dizziness, drowsiness, blurred or double vision, nausea, skin rash, abnormal blood counts (Rare)</td>
</tr>
<tr>
<td></td>
<td><strong>DEPAMINE</strong> (valproate)</td>
<td>1750 mg – 3000 mg</td>
<td>Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor</td>
</tr>
<tr>
<td></td>
<td><strong>DEPAMINE</strong> (extended release valproate)</td>
<td>1750 mg – 3000 mg</td>
<td>Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor</td>
</tr>
<tr>
<td></td>
<td><strong>DEPAMINE</strong> (extended release divalproex sodium)</td>
<td>2000 mg – 3500 mg</td>
<td>Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor</td>
</tr>
<tr>
<td></td>
<td><strong>DIAMON SEQUENCES</strong> (extended-release acetazolamide)</td>
<td>250 mg – 1000 mg</td>
<td>Appetite loss, frequent urination, drowsiness, confusion, numbness of extremities, kidney stones</td>
</tr>
<tr>
<td></td>
<td><strong>DIAMON</strong> (phenytoin)</td>
<td>200 mg – 400 mg</td>
<td>Dizziness, insomnia, motor twitches, nausea, rash, gum overgrowth, hair loss, thickening of features</td>
</tr>
<tr>
<td></td>
<td><strong>FELBATOL</strong> (felbamate)</td>
<td>1200 mg – 3400 mg</td>
<td>Anorexia, vomiting, insomnia, nausea, headache, liver and blood toxicity</td>
</tr>
<tr>
<td></td>
<td><strong>GARIROL</strong> (tiagabine)</td>
<td>32 mg – 56 mg</td>
<td>Tremor, dizziness, nervousness, difficulty concentrating, sleepiness, weakness</td>
</tr>
<tr>
<td></td>
<td><strong>KEPRA</strong> (levetiracetam)</td>
<td>1000 mg – 3000 mg</td>
<td>Sleepiness, fatigue, poor coordination, loss of strength, dizziness</td>
</tr>
<tr>
<td></td>
<td><strong>KOOPA XR</strong> (extended release levetiracetam)</td>
<td>1000 mg – 3000 mg</td>
<td>Sleepiness, fatigue, poor coordination, loss of strength, dizziness</td>
</tr>
<tr>
<td></td>
<td><strong>KLONOPIN</strong> (clonazepam)</td>
<td>1.5 mg – 20 mg</td>
<td>Dizziness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes</td>
</tr>
<tr>
<td></td>
<td><strong>LAMICTAL</strong> (lamotrigine)</td>
<td>100 mg – 500 mg</td>
<td>Dizziness, headache, blurred vision, clumsiness, sleepiness, nausea, skin rash</td>
</tr>
<tr>
<td>Brand Name</td>
<td>Dose Range</td>
<td>Side Effects</td>
<td></td>
</tr>
<tr>
<td>------------</td>
<td>------------</td>
<td>-------------</td>
<td></td>
</tr>
<tr>
<td>LYRICA® (pregabalin)</td>
<td>150 mg - 600 mg</td>
<td>Dizziness, blurred vision, weight gain, sleepiness, difficulty concentrating, swelling of hands and feet, dry mouth</td>
<td></td>
</tr>
<tr>
<td>MYOSOLINE® (promazine)</td>
<td>250 mg - 1000 mg</td>
<td>Drowsiness, dizziness, appetite loss, fatigue, drowsiness, hyperirritability, insomnia, depression, hypokinesia (children)</td>
<td></td>
</tr>
<tr>
<td>NEURONTIN® (gabapentin)</td>
<td>900 mg - 3600 mg</td>
<td>Sleepiness, dizziness, clumsiness, fatigue, twitching</td>
<td></td>
</tr>
<tr>
<td>PHENOBARBITAL (phenobarbital)</td>
<td>100 mg</td>
<td>Drowsiness, irritability, hyperactivity (children), behavioral problems, difficulty concentrating, depression</td>
<td></td>
</tr>
<tr>
<td>PHENYTOIN® (extended phenytoin sodium)</td>
<td>200 mg - 400 mg</td>
<td>Dizziness, insomnia, motor twitches, nausea, rash, gum overgrowth, hair loss, thinning of features</td>
<td></td>
</tr>
<tr>
<td>TEGRETOL® (carbamazepine)</td>
<td>600 mg - 1200 mg</td>
<td>Dizziness, drowsiness, blurred or double vision, nausea, skin rashes, abnormal blood counts (rare)</td>
<td></td>
</tr>
<tr>
<td>TEGRETOL XR® (extended release carbamazepine)</td>
<td>600 mg - 1200 mg</td>
<td>Dizziness, drowsiness, blurred or double vision, nausea, skin rashes, abnormal blood counts (rare)</td>
<td></td>
</tr>
<tr>
<td>TOPAMAX® (topiramate)</td>
<td>200 mg - 400 mg</td>
<td>Confusion, sleepiness, dizziness, clumsiness, difficulty thinking or talking, tingling sensation of the skin, nausea, decreased appetite</td>
<td></td>
</tr>
<tr>
<td>TRAXENE® (clonazepam)</td>
<td>15 mg - 45 mg</td>
<td>Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes</td>
<td></td>
</tr>
<tr>
<td>TRILEPTAL® (tromethamine)</td>
<td>600 mg - 2400 mg</td>
<td>Difficulty concentrating, sleepiness, fatigue, dizziness, double vision, nausea, unsteadiness, rash</td>
<td></td>
</tr>
<tr>
<td>ZABONIN® (zonisamide)</td>
<td>500 mg - 1500 mg</td>
<td>Appetite loss, nausea, drowsiness, headache, dizziness, fatigue, rash, abnormal blood counts (rare)</td>
<td></td>
</tr>
<tr>
<td>ZONEGRAN® (zonisamide)</td>
<td>100 mg - 600 mg</td>
<td>Sleepiness, dizziness, loss of appetite, headache, nausea, irritability, difficulty concentrating, unsteadiness, fever, kidney stones, rash, should not be used in individuals allergic to sulfa drugs</td>
<td></td>
</tr>
</tbody>
</table>

The following medicine is not prescribed for daily, long-term use, but to stop episodes of prolonged or cluster seizures.

<table>
<thead>
<tr>
<th>Brand Name</th>
<th>Dose Range</th>
<th>Side Effects</th>
</tr>
</thead>
<tbody>
<tr>
<td>DIABETIC ACUPLICITM (diabetes rectal gel)</td>
<td>Average Single Dose 0.2 mg - 0.5 mg/kg</td>
<td>Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes</td>
</tr>
</tbody>
</table>

* Sometimes prescribed for epilepsy, but not FDA approved for that use.
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