

CHAPTER ONE

What Do Attorneys and Advocates Need to Know About Seizures and Epilepsy in Order to Provide Effective Advocacy?¹

1.1 Q: What is a seizure?²

A: A seizure is an event in the brain which is characterized by excessive electrical discharges. Seizures may cause a myriad of clinical changes. A few of the possibilities may include unusual mental disturbances such as hallucinations, abnormal movements, such as rhythmic jerking of limbs or the body, or loss of consciousness. In addition to abnormalities during the seizure itself (the ictal period), individuals may have abnormal mental experiences immediately before or after the seizure (perictal/postictal periods), or even in between seizures (the interictal period).

1.2 Q: What is epilepsy?

A: Epilepsy, also referred to as a seizure disorder, is generally defined by a tendency for recurrent seizures, unprovoked by any known cause such as hypoglycemia. There are a variety of causes for epilepsy, including head trauma, cerebrovascular disease, encephalitis, bacterial meningitis and neurological deficits at birth such as cerebral palsy and mental retardation.

1.3 Q: How common is epilepsy?

A: Epilepsy is one of the most common serious neurological conditions, affecting between four and ten school-aged children per every thousand. Overall, approximately three million persons have this condition in the U.S. alone

1.4 Q: How is epilepsy classified?

A: Epilepsy should be considered a general clinical term describing many different conditions, rather than a specific diagnosis. Epilepsy has been classified in multiple ways, each of value for different purposes. One form of classification is by the clinical description of the seizure type (see Question 1.5). This is useful for describing what happens to the person during the seizure, for educating care providers, aides, and teachers on what to expect and for planning necessary services, accommodations, or modifications

¹Most of the material in this chapter is drawn from “Managing Students with Seizures, A Quick Reference Guide for School Nurses,” First Edition, published by the Epilepsy Foundation in 2006.

² The author acknowledges Dr. Russell Margolis, professor of psychiatry and neurology at Johns Hopkins School of Medicine for the information contained in answers 1.1, 1.2, and 1.4.

in the school or child care setting. A second way of classifying seizures is by etiology or cause: epilepsy can be idiopathic, which means it is of unknown cause, though often it is familial; or it can be considered symptomatic, caused by a brain injury such as trauma or stroke. Epilepsy can also be part of a more complex syndrome in which the brain and possibly other organs are affected. If this is the case, seizures may be only one of many issues that will need to be addressed in the education or child care setting. A third classification scheme is based on how well seizures are controlled by medicines.

1.5 Q: Are there different types of seizures?

A: Yes. There are a number of different types of seizures, but they fall into two major groups -- partial seizures and generalized seizures.

1.6 Q: What are partial seizures? (*Managing Students with Seizures*, pp. 15-16)

A: Partial seizures are seizures in which the electrical short-circuit of the neurons are limited to a specific area of the brain. Partial seizures are divided into two categories: simple partial seizures, in which the person experiencing the seizure does not lose consciousness, and complex partial seizures, in which the person having the seizure loses consciousness or has impaired consciousness.

Simple partial seizures result from “abnormal neuronal activity in specific limited areas of the brain that affect movement, sensation or emotion.” *Managing Students with Seizures* at 16. During a simple partial seizure, a person remains aware of what is going on, but may be limited in how he or she can react. He or she may not be able to speak, or may experience tingling or nausea, visual distortions, or other symptoms that may serve as a warning of a more severe seizure to come.³

Complex partial seizures begin in one area of the brain but usually spread to other portions of the brain including the opposite side and involve a change in consciousness. The person who has the seizure usually will not remember what happened during the seizure. While having the seizure, the person may engage in automatic behaviors such as lip smacking, chewing or swallowing, fidgeting, or other repetitious, stereotypic behaviors. In some cases, complex partial seizures may cause a person to engage in more significant behaviors such as undressing, screaming, running, and flailing. (If a person experiencing is touched or restrained, he or she may become combative.) These behaviors are much less common but create obvious difficulties for the people who experience them. *Managing Students with Seizures* at 16.

³ As with the visual and other neurological disturbances that may precede a migraine headache for some people, these pre-seizure events or symptoms are called an “aura.”

1.7 Q: What are generalized seizures? (*Managing Students with Seizures*, pp. 17-18)

A: Generalized seizures are seizures that affect both sides of the brain and produce loss of consciousness for either a brief or longer period of time. There are several types of generalized seizures: absence seizures, atonic or drop seizures, and tonic, clonic, myoclonic, and tonic-clonic seizures.

Absence seizures (sometimes called “petit mal” seizures) are usually just a few seconds long. They happen suddenly and the person will stop whatever he or she was doing, then resume it as soon as the seizure is over. The person may have many absence seizures or clusters of seizures during the course of a day. More common in children than in adults, absence seizures are frequently so brief that they escape detection.

Atonic or drop seizures produce a sudden loss of muscle tone. The person’s head will drop, or the person may fall to the ground. These seizures occur with no warning and can result in injury. Anti-epileptic drugs usually have limited effectiveness in controlling atonic seizures.

Tonic seizures are seizures in which the person’s leg, arm, or body muscles stiffen. His or her arms or legs may extend. The person usually remains conscious.

During clonic seizures, a person’s arms and legs jerk rhythmically. Clonic seizures by themselves are not common.

Myoclonic seizures are seizures in which the person experiences quick, brief muscle contractions that usually occur on both sides of the body at the same time. They look like quick muscle jerks.

Tonic-clonic seizures (sometimes called “grand mal” seizures) are the most common type of seizure. They begin with a tonic phase, in which the arms and legs stiffen, and then continue with a clonic phase, in which the limbs and face jerk. During the tonic portion of a seizure, a person may have an initial vocalization followed by their breathing slowing or stopping; during the clonic portion, breathing usually returns, but may be irregular, noisy or seem labored. The person may be incontinent and may bite his or tongue or the inside of his or her mouth during the seizure.

1.8 Q: Are there particular epilepsy syndromes or conditions?

A: Yes. There are many, many syndromes associated with epilepsy. Classifying epilepsy by seizure type alone leaves out other important information about the patient and the episodes themselves. Classifying into syndromes takes a number of characteristics into account, including the type of seizure; typical EEG recordings; clinical features such as behavior during the seizure; the expected course of the disorder; precipitating features; expected response to treatment; and genetic factors.

Epilepsy syndromes include, but are not limited to, frontal lobe epilepsy, temporal lobe epilepsy, childhood absence epilepsy, Landau-Kleffner syndrome, Benign Rolandic Epilepsy, Lennox-Gastaut syndrome, Rasmussen's syndrome, and Juvenile Myoclonic Epilepsy.⁴

The temporal lobes are the parts of the brain just above the ears. People with temporal lobe epilepsy most commonly have complex partial seizures with automatic behaviors. Many people with temporal lobe epilepsy also have simple partial seizures in which they may experience nausea or vomiting, or feelings that are difficult to describe (auras). Other auras may include smells, tastes, or hallucinations of voices, music, or visual phenomena.

People with frontal lobe epilepsy have partial seizures that may cause muscle weakness, thrashing movements during sleep, or posturing with head jerking to one side and one arm lifting into a frozen position. Frontal lobe complex partial seizures are usually less than one minute in length and often occur during the night, causing a disruption in sleep, which in turn can make the person sleepy during the day and cause behavior problems and poor performance in school. Frontal lobe seizures can involve screaming, bicycling movements and other socially difficult behaviors. (*Managing Students with Seizures*, p. 20). In many cases these seizures tend to cluster.

Childhood absence epilepsy is also known as petit mal epilepsy and causes frequent absence seizures. It manifests itself between ages three and ten and about 40% of children with the condition will outgrow it or go into remission by the time they reach their teens.

Landau-Kleffner syndrome is rare. It manifests itself between ages three and seven and causes seizures and regression in speech. Children with this syndrome have simple partial and tonic-clonic seizures.

Benign Rolandic Epilepsy accounts for more than one third of the cases of epilepsy that begin in middle childhood between ages three and thirteen. Seizures occur primarily at night and are of the simple partial type, causing drooling and an inability to speak, although this may be followed by a convulsion of the body. These seizures tend to occur most often as the child is getting drowsy or attempting to go to sleep. Children are otherwise normal, and 95% of children with this condition outgrow it by age 15.

Lennox-Gastaut syndrome causes mixed types of seizures and is difficult to treat. Seizures begin between the ages of one and eight. Children with Lennox-Gastaut syndrome often have developmental delay and may have mental retardation.

Rasmussen's syndrome, also known as Rasmussen's encephalitis, is a rare disorder in which one half of the brain is affected and produces seizures on the opposite side of the

⁴ Unless otherwise noted, all information in this answer was obtained from <http://www.epilepsyfoundation.org/about/types/syndromes/index.cfm> downloaded April 18, 2007

body. Among the treatments that have been tried is surgery to remove the affected half of the brain.

Juvenile myoclonic epilepsy, also known as Janz's syndrome, generally begins in adolescence with a generalized seizure. Seizures are not likely to be outgrown.

1.9 Q: Can seizures be triggered by anything in particular?

A: For some people, sensitivity to flickering or strobe lights is a trigger for seizures. Lack of sleep, stress, and failure to take seizure medications can also trigger seizures. In some cases, the trigger can be very specific and somewhat unusual. For many people, there are no known triggers for their seizures.

1.10 Q: What is the appropriate intervention for a child who has a seizure at school or in a child care setting?

A: If a child has epilepsy, it is essential that he or she have a health plan that describes the care he or she will need at school or while at child care. The plan should address administration of any routine or emergency medications, how to handle seizures if they occur, and whether emergency personnel need to be contacted and, if so, under what circumstances. If the child receives special education, the health plan should be incorporated into his or her individualized education program. The rest of this manual will address these issues in detail.

In general, it is important for teachers and staff to remain calm and reassuring, both to the student and to other students or children. Staff need to speak calmly, and to observe and time the seizure and what is happening. They should protect the student's privacy to the extent possible and ensure that the student is safe, either lying down or away from potentially harmful objects. The student should not be restrained. Nothing should be placed in the student's mouth. If the student has a seizure action plan, it must be followed. If necessary, emergency medical staff must be contacted, and/or Diastat Acudial or as-needed ("prn") medication needs to be administered if a student's health plan so requires for a lengthy seizure or cluster of seizures. The purpose of Diastat Acudial or other medication or of emergency medical intervention is to avoid the onset of status epilepticus or to minimize its risks if it occurs.

1.11 Q: What is status epilepticus?

A: Status epilepticus is a period of prolonged seizure activity, either because of one seizure that does not end or because of a series of seizures that continue without the person returning to baseline. Current medical definitions consider 10 minutes as the amount of time after which uninterrupted seizure activity would be considered status epilepticus. It is possible that brain damage or death can result from status seizures. 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.

1.12 Q: What are the practical implications of this information for attorneys and advocates working with children with epilepsy and their families?

A: In order to provide effective advocacy, attorneys and advocates need to have a full understanding about epilepsy, and the child's seizures and his or her medications and any side effects. Also, the advocate or attorney will need to communicate effectively with school or child care center nurses or other staff about any accommodations, services, or supports the child may need. Some children have well-controlled epilepsy and may never have a seizure in school or the child care setting; others may have occasional seizures. And some children -- those attorneys and advocates are most likely to represent -- may have frequent seizures and need special education, health services, or other accommodations at school or in child care.

1.13 Q: How may epilepsy affect a student?

A: Epilepsy can affect a student in a number of ways, depending on the type of seizures he or she experiences and other factors. It is important for all staff who work with students who have epilepsy to understand the effect of the student's particular seizures on his or her educational performance. For example, if a student has absence seizures, he or she may have many seizures in a day, but they may not be immediately obvious. However, they will interrupt the student's ability to concentrate and his or her learning or educational performance may be affected. If absence seizures are not identified, a teacher may think the student is not paying attention and may penalize him or her for poor performance in class or on tests. Tonic-clonic seizures may leave a student lethargic or sleepy, or with a headache. It may take several minutes or several hours to recover fully. Students with drop seizures are at risk of injury, as are students with other types of seizures, depending on their location and situation at the time of a seizure.

The student's mental state before, during, and after a seizure may be affected, and can have an impact on his or her educational performance, as can the medicines he or she takes to control seizures. Medicines may have an impact on the student's mental and physical state.

Students with epilepsy that is not well-controlled are likely to be more significantly affected educationally. They may have significant side effects from the medications they take, as well as effects from the many seizures they experience. Additionally, they may be limited in the sports or physical education activities they can participate in at school, and may experience social isolation or teasing. They may also be absent or late to school more frequently, depending on when seizures occur and how long it takes to recover from the seizures. In addition to the immediate effects of the seizures themselves, students with epilepsy may also experience anxiety about having seizures or because they know that school staff are afraid of their seizures.

1.14 Q: How is epilepsy treated?

A: Epilepsy is generally treated with medications. Other treatments include the ketogenic diet, the vagus nerve stimulator and surgery.

1.15 Q: What are the standard antiepileptic drugs (AEDs)?

A: Common AEDs include the following:

Ativan (lorezepam)	Lamictal (lamotrigine)
Carbatrol (extended release carbamazepine)	Lyrica (pregabalin)
Depakene (valproic acid)	Mysoline (primidone)
Depakote (divalproex acid)	Neurontin (gabapentin)
Diastat Acudial (diazepam rectal gel)	Tegretol (carbamazepine)
Dilantin (phenytoin)	Phenobarbital (phenobarbital)
Felbatol (felbamate)	Topamax (topiramate)
Gabitril (tiagabine)	Trileptal (oxcarbazepine)
Keppra (levetiracetam)	Zarontin (ethosuximide)
Klonopin (clonazepam)	Zonegran (zonisamide)
	Versed (midazolam)

Each of these drugs is generally most effective for particular types of seizures. For example, Zonegran is most effective for partial seizures and generalized tonic-clonic seizures, but Zarontin is most effective for absence seizures. Diastat AcuDial (diazepam gel), which is rectal valium, is intended to break a prolonged seizure or a cluster of seizures; it is not intended for daily use.

Ativan (lorezepam) and Versed (midazolam) are benzodiazepines well known to control seizures when used in an emergency room or hospital setting. Pre-hospital use of these agents for seizure clusters or to break a prolonged seizure prior to the development of status epilepticus is a concept many doctors favor. These medications have undergone some testing where the drug is placed or sprayed inside the cheek or under the tongue in a person who is seizing. However, since they have not completed the clinical trials required to attain FDA approval for treatment of seizures, they are not widely available for this purpose and their use has been limited to physicians who feel comfortable in providing this option.

1.16 Q: What are the side effects of the AEDs?

A: The side effects of the AEDs are not all the same, but many of the AEDs have similar side effects such as sedation or sleepiness, loss of appetite, and dizziness. A side effect of some AEDs may be either weight gain or loss. Some AEDs cause dry mouth, while others cause hypersalivation. More significantly, some AEDs can cause kidney stones, behavior changes, liver failure, or other serious complications.

1.17 Q: What is the ketogenic diet?⁵

A: The ketogenic diet is a high-fat diet that imitates starvation by keeping the body in ketosis—that is, in a state in which the body is burning fat for energy instead of carbohydrates. It is not clear why this is an effective seizure treatment, but for a number of children, it has proven quite effective, either by itself, or in combination with medication. The diet is extremely rigid, as food and liquid must be measured, the ratio of fats to carbohydrates and proteins must be carefully controlled, and often, even the tiniest deviation from the diet, such as carbohydrates in toothpaste, an over-the-counter cough medicine, or suntan lotion, can throw a child out of ketosis and cause seizures. Currently, variants of the diet, including the Atkins diet, are also being used as treatments for epilepsy.

1.18 Q: Does the ketogenic diet have side effects or drawbacks?

A: Yes. Side effects can include dehydration, constipation, and complications from kidney stones or gall stones. Additionally, people on the diet need vitamin supplements because the diet lacks certain vitamins. For children and adolescents on the diet who are cognitively aware of the limitations of the diet, the small portions of food and the restricted foods can be a big issue. The strict requirements of the diet can impose a burden on families. However, a great deal of information and support for families is available from Johns Hopkins Hospital, online family support networks, the Epilepsy Foundation, and other sources.

1.19 Q: What is the vagus nerve stimulator (VNS)?

A: The VNS is similar to a pacemaker, but it stimulates the vagus nerve in the neck, instead of the heart. It is a device that delivers “preprogrammed electrical impulses to the vagus nerve on an ongoing basis.” *Managing Students with Seizures* at 33. The VNS is usually implanted in the upper left chest or under the arm; it stimulates the vagus nerve, which then sends electrical impulses to the parts of the brain that affect seizures. *Id.* If a person has a seizure aura or begins to have a seizure, the VNS can be swiped with a magnet to send additional electrical current to abort or minimize the seizure. Depending on the child’s ability, he or she, a school nurse, or other trained personnel (such as a child care worker) can swipe the stimulator with the magnet if a child with a VNS has a seizure in school or in a child care setting.

1.20 Q: Does the VNS have side effects or drawbacks?

A: Reported side effects include hoarseness, tingling in the neck when the VNS is

⁵ Much of the information in the answers to questions 1.15 and 1.16 are drawn from “Ketogenic Diet,” downloaded from <http://www.epilepsyfoundation.org/answerplace/Medical/treatment/diet/ketowhatitdo.cfm> on April 14, 2007.

activated, insomnia, and difficulty swallowing. The magnet must be kept away from anything that is sensitive to magnetic fields such as computers, credit cards, and videotapes.