

Planning Ahead Can Save the Life of a Child with Epilepsy

By Laura Apel and Jan Carter Hollingsworth

A primer article on the necessity for a seizure emergency plan and for added awareness and education about the administration of emergency antiepileptic medication within the school environment



What the Epilepsy Statistics Show

Three million Americans have epilepsy, a chronic neurological condition characterized by recurrent epileptic seizures unprovoked by any known cause. Those at risk for epilepsy include individuals with mental retardation, cerebral palsy, autism, stroke, major head trauma, central nervous system (CNS) hemorrhage, CNS infection, dementia, and brain tumor. Of this group, 300,000 have a first convulsion each year, and 120,000 are under 18 years of age. With 10 percent of Americans likely to have a seizure within their lifetime and 200,000 new cases of epilepsy diagnosed each year, it is a condition that requires a great deal of attention and support. Jack Pellock, MD, who is Professor and Chair of the Division of Child Neurology with Virginia Commonwealth University in Richmond, VA, also notes that for some individuals epilepsy can prove fatal:

Managing Stigma in School

By Robert J. Mittan, PhD

EDITOR'S NOTE : READERS WILL NOTICE THAT IN THIS PIECE, DR. MITTAN USES SOME VERNACULAR TERMS, SUCH AS "BUTT" AND "HEINIE." THIS CHOICE OF WORDS WAS DELIBERATE AND IS IN NO WAY MEANT TO BE CRUDE, INSENSITIVE, OR OFFENSIVE. RATHER, DR. MITTAN CHOSE TO GIVE PARENTS A MODEL OF KID-FRIENDLY LANGUAGE THEY MIGHT USE IN GIVING AN EXPLANATION TO YOUNGER SCHOOL AGE CHILDREN ABOUT A POTENTIALLY DELICATE SUBJECT MATTER—THE USE AND DELIVERY METHOD OF CERTAIN ANTIEPILEPTIC MEDICATIONS.

The importance of having an emergency plan for your student with epilepsy cannot be overemphasized. In the case of seizures, stigma management is really fear management. People who have never seen a seizure before become frightened when suddenly confronted with one. It is a natural reaction that does not imply the person is prejudiced – just unprepared. Our society puts great emphasis on being in control of one's behavior and actions. Seizures violate this social value big time. And seizures often do so without advanced warning or explanation. Teachers and students witnessing such a dramatic event are left to their own, often uninformed ideas, to explain what they are seeing. Fear inspires stigma when explanations of seizures are in short supply.

Ignorance creates fear. Fear inspires stigma. Having a complete plan for the management of your child's seizures in the classroom short circuits this natural progression of unwanted events. When teachers and students are familiar with what seizures are, what your child's seizures look like, and most important what to do when a seizure occurs, it removes the ignorance, which removes the fear, which then removes the most common cause of stigma in the classroom.

There is an all-too-common misconception that the best way to manage stigma is to keep epilepsy a secret. Some social research finds this approach seldom works. Despite one's best efforts at hiding, people around the person with epilepsy usually know. What would that mean for your child in school? Hiding something from others must mean what is deliberately hidden is a bad thing, or why hide it? This teaches others that epilepsy is a bad thing. Hiding teaches epilepsy is a stigma! Should your student have an unexpected seizure in the midst of such secrecy, witnesses are taught twice that epilepsy is a stigma: fear causes stigma and exposing the "terrible secret" confirms epilepsy must be stigmatizing.

To reduce stigma in the classroom, *disclosure* is key. Disclosure is necessary to work out a plan for handling seizures in the classroom. Disclosure has to take place in advance, otherwise it is of little use – the stigmatizing damage will already have been done. What should a parent disclose? Just about everything to the teacher, school nurse,

“Approximately 42,000 deaths are caused by epilepsy annually.”

With 326,000 school children through age 14 diagnosed with epilepsy, seizure preparedness and expanded awareness and education on what to do when a child has a seizure while at school is an extremely important and complex issue being faced by parents of children with this disability. When a seizure occurs at school patients and families should have an emergency

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plan, and schools need to have a seizure emergency treatment protocol in place as well.

administration, and especially classmates.

What needs to be disclosed? First, remember stigma management in the classroom is fear management. A seizure will be much less frightening to witnesses if they know exactly what to expect. Teachers and classmates need a complete, step-by-step description of what your child does during his or her seizure – every little detail. This changes the natural reaction of surprise to an unexpected seizure into one of prediction, “What the...? Oh, Johnny is having a seizure! His Mom said his head will turn to the left, and his left arm will get stiff...(recognition). Then she said he would get stiff all over and fall down (prediction) – we’d better help him down (action). Then he should start shaking like he was having convulsions (prediction). We need to turn him on his side then (action).” Recognition, prediction, and appropriate action replace fear – and stigma.

Note in this example not only was the seizure described, but the proper first aid was described as well. There is nothing worse than feeling helpless and not knowing what to do in a medical emergency. On the other hand, there is nothing more empowering and self-satisfying than knowing exactly how to help someone during a seizure – especially to kids. People feel great about themselves after helping someone else. Disclosing epilepsy and its first aid is a way of enabling classmates to feel great about themselves for helping someone in need. If your child is at risk of going into one seizure after another (serial seizures) or unusually prolonged seizures, you can explain that special medications may be a necessary part of first aid.

When medication is necessary, you can explain that during a seizure it is often dangerous to give medication by mouth. The only other practical way to deliver medication quickly is through the butt. The delicate tissues inside the heinie are exceptionally good at absorbing medication, so even if this route sounds gross, it is a very intelligent way to safely provide a person with emergency medication. Since many people would consider exposing their hind end embarrassing, it is best to give the person privacy for the procedure. This procedure needs to be explained to the teacher and classmates. If classmates are suddenly ushered out of the classroom without explanation, what would have been understood as a matter of privacy becomes some sort of serious medical emergency born out of what seems like sudden, dramatic actions taken by school staff without explanation. Again, the notion that what cannot be discussed must be bad. The event *without* a prior explanation is certain to stir fear and stigma. The event *with* prior explanation only results in the idea that the student (appropriately) does not want to show his or her bare heinie to the world – resulting in a big difference in the level of fear and stigma.

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The Importance of a Seizure Emergency Plan

Even patients with well-controlled seizures have breakthrough seizures, and seizures can happen anywhere and at any time. Of the 67 percent of schools that call emergency medical services (EMS) annually for a student, 16 percent of these calls will be for seizures. One of nine schools can expect to have a seizure emergency at their school annually. Because this is such a prevalent issue, the benefits of an emergency treatment plan must be stressed. As Kathryn A. O’Hara, RN, an Epilepsy Nurse Clinician and Nurse Manager in child neurology explains, “Anyone, even those people well-controlled, are at risk for a seizure so a plan should be in place as to what to do if a seizure occurs. The plan should include a description of the person’s seizure, how long it lasts, and what the postictal period (the time frame following a seizure) is like. It’s important to know the difference of what is typical for a patient and what is not.” A well executed plan reduces morbidity and mortality, empowers school personnel to respond to a seizure emergency, potentially prevents emergency department visits, helps reduce negative social consequences, minimizes classroom disruption, and reduces school liability risks.

The goal of having the proper plan in place is to stop seizures quickly, remain safe in the school setting while experiencing a seizure, recover satisfactorily after the seizure, and return to the classroom as soon as possible. According to Orrin Devinsky, MD, who is Professor of Neurology, Neurosurgery, and Psychiatry at NYU School of Medicine and directs the NYU Comprehensive Epilepsy Center and the Saint Barnabas Institute of Neurology and Neurosurgery, “All children with active epilepsy should have an emergency plan in

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the school environment to make sure that the right first aid measures are employed and that potentially dangerous interventions are avoided. Teachers, school nurses, and others should be aware of the child's seizure type and their typical duration. They should be familiar with first aid, including when to call for help or administer rescue medication." A solid plan begins with the basics: the student's name, the parent and physician's contact information, the type and duration of the seizure that might be expected from the particular student, and the current medications and dosages that the student uses as well as whether or not that medication is available at school. All activity involved with the seizure should then be carefully documented.

Antiepileptic Medication and the School Environment

Essential to this plan is the knowledge that seizures need to be treated quickly, within 5-10 minutes of onset. Pellock notes, "The mortality rate associated with seizures lasting 30 minutes or longer may be as high as 19 percent." For many, timely treatment is often in the form of a seizure rescue medication that is prescribed by the child's physician. Local emergency medical services (EMS) treatment can take more than 30 minutes in some areas. The ideal seizure rescue medication is one that is easily administered to convulsing patients, does not cause serious adverse effects, has rapid onset of action, and is easily used by non-medically trained personnel. If the seizure lasts more than five minutes or the student goes from one seizure to another, the rescue medication should be given, and the student should be observed until the seizure stops. If the seizure does not stop within 10 minutes of administering the medication, EMS should be called. Also, if the student has fallen or if a head or neck injury is suspected, EMS should be called immediately.

Because seizures (especially for children who have a history of prolonged seizure events) need to be treated as soon as possible, having the effective medication available

is crucial. As Devinsky explains, "Prolonged clonic seizures, can injure the brain. seizures, especially the more serious tonic- Therefore, although the goal is to prevent

The Basics of Epilepsy and Seizures

Orrin Devinsky, MD, who is Professor of Neurology, Neurosurgery, and Psychiatry at NYU School of Medicine and directs the NYU Comprehensive Epilepsy Center and the Saint Barnabas Institute of Neurology and Neurosurgery, has done extensive research and published widely in the area of epilepsy. Dr. Devinsky answers some basic questions about epilepsy below.

WHAT IS THE DIFFERENCE BETWEEN THE TERM *EPILEPSY* AND THE TERM *SEIZURE*?

A *seizure* is a brief, excessive discharge of brain electrical activity that changes how a person feels, senses, thinks, or behaves. *Epilepsy* is a disorder in which a person has two or more seizures without a clear cause, such as alcohol withdrawal. In other words, epilepsy is a condition of recurrent and unprovoked seizures. The seizures may result from a hereditary tendency or a brain injury. The cause is often unknown, particularly in otherwise healthy people without apparent risk factors.

WHAT ARE THE DIFFERENT KINDS OF SEIZURES AND HOW DO THEY PRESENT?

Epileptic seizures can be broadly divided into two groups: (1) **primary generalized** and (2) **partial**. Primary generalized seizures begin with a widespread, excessive electrical discharge simultaneously involving both sides of the brain. In contrast, partial seizures begin with an abnormal electrical discharge restricted to one, or several, discrete area(s). Distinguishing primary generalized seizures from partial seizures is critical because the diagnostic tests and the drugs used to treat these disorders differ. A description of what happened before, during, and after the seizure, as well as recordings of electrical activity generated by the brain (brain waves), helps to determine the type of seizure.

PRIMARY GENERALIZED SEIZURES

- Absence seizures
- Myoclonic seizures
- Atonic seizures
- Clonic seizures
- Tonic seizures
- Tonic-clonic seizures

PARTIAL SEIZURES (SEIZURES ORIGINATING IN SPECIFIC PARTS OF THE BRAIN)

- Simple partial seizures (consciousness not impaired)
- With motor symptoms (jerking, stiffening)
- With somatosensory (touch) or specialized sensory (smell, hearing, taste, sight) symptoms
- With autonomic symptoms (heart rate change, internal sensations)
- With psychic symptoms (déjà vu, dreamy state)
- Complex partial seizures (consciousness impaired, automatisms usually present)
- Partial seizures secondarily generalized to tonic-clonic seizures

Training School Personnel

An integral part of any seizure emergency plan is the training and education of school personnel. School personnel should be taught to:

- Recognize seizure activity
- Understand causes, triggers, and presentations specific to any given student
- Differentiate between what is typical seizure activity and what is atypical, potentially more serious, activity specific for an individual student
- Administer first aid for seizures
- Know when to call for caregiver(s) responsible for managing seizure emergency
- Know appropriate postictal care
- Know when to call EMS

Learning How to Properly, Safely, and Easily Administer Diazepam Rectal Gel

For many, the thought of administering diazepam rectal gel (brand name Diastat) may be daunting. However, information is power, and the following Web site offers a step-by-step video presentation as well as written and illustrated instructions on administration of this potentially lifesaving medication. To access these instructions, visit <http://www.diastat.com/2-Administer/#>.

P.hysiology
E.ducation
A.dvocacy
R.esearch
L.egal/Legislative/Legacy
S.upport Systems

Take Home Messages and EP P.E.A.R.L.S.

Many of EP's articles have a scientific and/or technical slant, involving subjects like medical conditions, therapy modalities, legal issues, etc. Below are a few PEARLS that can be gleaned from this article. Think of it as the nuts and bolts of the more detailed aspects of this subject.

- For students with seizures, having an emergency plan in place that includes what to do if a seizure occurs at school is crucial and can save a student's life.
- A seizure emergency plan is a unified, cooperative effort among the patient, the patient's parents/caregivers, the patient's physician(s), and trained school personnel, including individuals like the school nurse, teachers, and school administrators whereby the seizure activity is managed with the goal of minimizing adverse effects, both physical and social.
- Knowing your specific school district's stance/rules on the administration of potentially lifesaving antiepileptic medication in the school setting is a paramount consideration when putting together a seizure emergency plan. Federal law is written to allow for all students to receive the medications they need when they need them while at school. Sometimes staunch advocacy on the part of a parent encountering a less than cooperative school district is necessary. Know your child's rights!
- An effective antiepileptic medication called diazepam, which is offered as a one dose, rectally administered application is often a safe and potentially lifesaving option for many children with seizure activity. Rectal administration has proven to be a safe and extremely fast-acting method of medication delivery for diazepam with few side effects for the patient. Additionally the drug delivery system was specifically designed to be easy to administer by non-medical caregivers.

seizures from happening, a secondary goal is to reduce both the duration and intensity of seizures. Antiepileptic medications help to both prevent seizures and reduce seizure duration and intensity. Rescue medications such as rectal diazepam (Diastat) can help to stop seizure clusters or prolonged seizures." The one dose rectal form of diazepam seems to be the drug of choice because absorption through the tissues in the rectum happens very quickly. It is best to have the drug with the student, if possible, rather than in the school nurse's station, in the school office, etc. since the effectiveness of the diazepam is dependent on the quickest administration. Ensuring that the medication is available when it is needed is an issue that many parents face when discussing the emergency plan for their child with their school.

Medication administration is a related health service under the IDEA. These services are provided by a "qualified school nurse or other qualified person" and are designed to enable a student with a disability to receive a free appropriate public education as described in his or her IEP. Therefore, it is a school's responsibility to administer antiepileptic medication and emergency antiepileptic medication at school. The level to which a school is able to react to a student's seizure varies though. As O'Hara explains, "this really depends on what area in the country you live. Many school districts require training in regards to seizures and first aid, but many do not. The school nurse can provide training or the school can contact their local EFA and ask for training, and many Epilepsy Centers offer training seminars. If everyone knows what to do for someone having a seizure there is less likelihood of panic, and the student is at less risk for injury." Because some states and schools state that only a nurse can administer emergency antiepileptic medication and a nurse is not always available to do so, it is important that parents learn their child's rights when it comes to this issue.

The Epilepsy Foundation's position on this topic is: "because medicines, including rectally administered diazepam, can be administered by non-medical personnel who have received proper instruction, lack of access to a

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doctor or full-time nurse is not an acceptable reason to refuse to administer the medication onsite or to deny a child or student access to the program.” They urge providers of child care and educational services to work with the child, his or her parents, and the child’s treating physician to learn how and when to administer the appropriate treatment. If a school district says that only a nurse can administer the medication but there is no nurse available, the Epilepsy Foundation recommends that the parent determine if the school district’s position is based on the state’s nurse practice act, its education code, or its own rules. According to the Foundation’s manual, *Legal Rights of Children with Epilepsy in School and Child Care*, “Sometimes, a state law may permit delegation, but the nurse for the school or the district’s health department does not wish to delegate. If the nurse practice act requires administration of the medication by a nurse, the district must obtain a nurse if there is no nurse at the student’s school or nearby school. Possible options for the school district include contracting with a private nursing agency, hiring a nurse or looking to the local health department.”

O’Hara feels that the school nurse has an integral role in the plan and that “it is their job to make sure school personnel are adequately trained to recognize seizures and provide first

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aid for seizures training. School personnel should include aids, cafeteria workers, and bus drivers. They need to make sure a seizure plan is in place and that the school personnel know what to do. If rescue medication is prescribed, they need to know when to use it and make sure school personnel are properly trained to administer the rescue medication.”

Maintaining a Student’s Privacy and Preserving Dignity

Privacy is also a big issue when considering the overall emergency plan. School personnel should be sure to take simple steps like moving other students out of the general area where the seizing student is being treated. As O’Hara explains, “We should always take in to consideration privacy issues, but there are many ways to provide privacy. Very cheaply the school can have small drapes/covers to provide privacy. They can buy Mylar covers that are about one inch by four inch in size. The student can have one of these in their backpacks as well. The use of screens and/or

a blanket provide privacy as well.” These actions are especially compassionate for the student who will have medication administered as a way of maintaining the student’s dignity and privacy. (For more information on this issue of reducing stigma for the child with epilepsy, see the sidebar on page 42 entitled, “Managing Stigma in School.”)

The bottom line is that seizures need to be treated quickly, and often calling 911 and waiting for EMS to arrive do not get the patient the help they need soon enough. School districts are required to provide staff to administer emergency antiepileptic medication to students with epilepsy. The standard out-of-hospital medication for treatment of prolonged or cluster seizures is diazepam (Diatat). Because this medication was specifically developed to be administered by people without medical training, such as parents, teachers, and other caregivers, there is no excuse for not ensuring that students at school immediately receive the treatment they need. •