



and their families in varying degrees. Social stigma can be understood when epilepsy is viewed in terms of the following commonly held cultural values.

**INDEPENDENCE:** No one is completely independent. However, this quality is highly prized in our culture, and most people like to think of themselves as independent. A person with epilepsy can be made to feel dependent by daily medications, frequent doctor visits, restriction from certain employment opportunities, sometimes being unable to get a driver's license, and perhaps by the need to rely on total strangers for help during a seizure.

**APPEARANCE:** During most seizures the person simply does not look nice. Students are very conscious, as we all are, of accepted standards of beauty or attractiveness. To fall short of these standards, even if only during brief seizures, may be socially painful.

**SELF-CONTROL:** Most of us want to feel and appear in control of ourselves and our situation. During a seizure all semblance of self-control is lost. This can be frightening to the observer as well as to the person with epilepsy.

**HEALTH:** The frequent use of the words "health and happiness" together as if they were synonymous, reflects how highly we prize health. A child with epilepsy is often thought of as having an illness and viewed negatively.

**PERFECTION:** Many times people forget that this quality is not enjoyed by anyone. To the extent that parents, children, or school personnel may view epilepsy as a sign of imperfection, epilepsy becomes a burden.

The impact of these cultural values varies among children with epilepsy and their families. Education about social values helps the family, child, and peers cope with social stigma. Equally important is consistent, unconditional acceptance of the child.

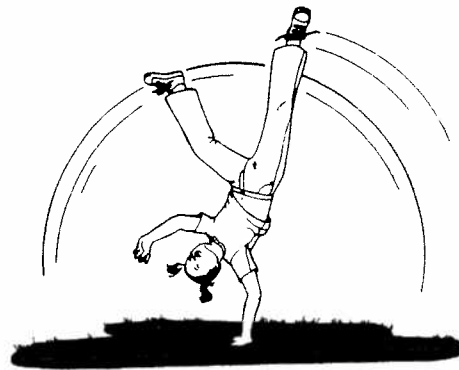
## **SPECIFIC PROBLEM AREAS**

Other problems, sometimes associated with epilepsy, which may affect the child, family and school personnel include overprotection, physical limitations and driving restrictions.

**OVERPROTECTION:** Many parents and school personnel will be overprotective of the child with

epilepsy. While this may be understandable, it is destructive, since the child is not allowed to learn from mistakes and experience and may begin to expect preferential treatment. School personnel need to avoid overprotection, particularly the failure to give the child age-appropriate responsibilities.

**PHYSICAL EXERCISE:** Exercise is important to all children, including those with epilepsy. Each child with epilepsy has his own personal limit, and some may wish to participate in potentially dangerous sports. The benefits of participation should be weighed against the possible psychological problems resulting from unnecessary restriction. There is no "safe" situation and, if a child is to learn, some risks must be taken. If certain activities must be restricted due to poor seizure control, substitute exercise needs to be found. In general, children with epilepsy whose seizures are controlled with medication can participate in the same activities as their classmates.



**WATER SAFETY:** Participation in swimming and other water sports raises special issues. Water is a potentially fatal hazard if a child has an unexpected seizure. However, with careful supervision by a well informed staff (and permission from parents and the physician) safe participation is possible.

**DRIVING:** Students of eligible age should be encouraged to take the classroom part of driver's training even if seizures are presently poorly controlled. Seizure control may be obtained later, and insurance premiums may then be lower. Also, much of driver's training pertains to general and pedestrian safety and is beneficial to non-drivers as well. In all states a person can be licensed, if he or she can show that seizures have been controlled for the period of time required by each state.

## **MEDICAL ASPECTS**

**DEFINITION:** Epilepsy is a name given to the tendency to have recurring seizures. Seizures are temporary states of abnormal brain function. They

are characterized by alteration of consciousness, feeling, behavior, autonomic function (sweating, paleness, redness, etc.), somatic sensation (e.g., tingling hand), or motor activity. By definition, these alterations are always associated with abnormal electrical discharges in the person's brain.

**DETECTION:** It is important for school personnel to be able to recognize epilepsy. The following descriptions of the most common types of seizures will aid in recognition.

**ABSENCE** (petit mal): The seizure is brief and subtle, involving only a 3 to 30 second lapse of consciousness, beginning and ending abruptly, which usually resembles a blank stare. There may be eye-blinking or involuntary facial movements, but the child does not lose posture nor have violent leg or arm movements. Often absence seizures are mistaken for daydreaming. If untreated, a child may have between 50 and 200 lapses a day, and may be missing a significant amount of what happens in the classroom. Absence lapses are relatively easy to diagnose clinically and are almost always quickly brought under control with medication. Some behaviors which may indicate absence lapses include:

- repeated short daydreaming spells
- a seeming inability to hear complete sentences or directions
- repeated blank stares

Absence seizures usually begin in early childhood and may disappear or change in nature by the age of fifteen.

**GENERALIZED TONIC-CLINIC** (grand mal or major motor): This seizure is the most alarming to school personnel and other students. The child will suddenly lose consciousness and fall, if standing, or slump over, if sitting. As the air rushes from the lungs, a scream or other noise may be emitted. The muscles first become rigid or stiff (the tonic stage) and there are jerking movements of the arms and legs (the clonic stage). The child may bite his tongue or lose control of his bladder. Breathing is labored or jerky and at times seems to have stopped completely. The child may have a pale or bluish complexion. The convulsion lasts from 1 to 3 minutes and is usually followed by confusion, muscle fatigue and possible headache.

If the child passes from one seizure to another without regaining consciousness, or if the seizure lasts more than 5 minutes, medical assistance is warranted. Usually, after resting, the student can and should be allowed to continue with normal school activities.

Generalized tonic-clinic seizures may begin at any age, but often first occur before puberty.

**COMPLEX PARTIAL** (psychomotor or temporal lobe): This seizure type varies a great deal in appearance and may be mistaken for emotional disturbance or mental aberration. The seizure generally lasts between 2 and 4 minutes and is often preceded by an aura. The aura is a strange sensation and involves alterations in hearing, smell or sight, or may involve a strong emotional sensation, such as fear or anxiety. Behavior during the seizure varies from person to person, but for any individual the same behavior regularly occurs during each seizure. For this reason the behavior is often referred to as stereotyped behavior. Common to most psychomotor seizures are the following:

- sudden arrest of activity with staring
- blank, dazed facial expression (the person appears to be unaware of his environment)
- a clouding of consciousness (the person cannot accurately interpret his environment)
- repetitive, automatic and purposeless behavior. It is generally these poorly coordinated automatic behaviors that vary from person to person.
- lip-smacking, chewing movements with the mouth, playing with near by objects, incoherent or irrelevant speech.
- The child may walk about and does not lose posture. Although the activity may be conditioned by the immediate environment and appear to be purposeful behavior, the person will have no memory of his behavior. After the seizure, the child may be confused and will need reorientation to the environment. The child should then be encouraged to continue with his normal school activities.

Complex partial seizures can occur at any age.

## FIRST AID

Seizures are not painful and the child has no memory of them. Once the seizure has begun, there is nothing one can do to stop it. It is understandable that the observer may feel frightened, helpless and generally out of control of the situation.

**Absence** (petit mal): There is nothing to do for absence seizures, other than to report them to the school nurse and the parent.

**Generalized tonic-clonic** (grand mal and major motor):

1. Keep calm. Loosen the child's collar and put something soft under the head. You cannot

stop the seizure. Let the seizure run its course. Do not try to restrain the child.

2. Remove hard, sharp or hot objects from the area.
3. DO NOT FORCE ANYTHING BETWEEN THE CHILD'S TEETH.
4. After the seizure, turn the child to one side to allow saliva to drain from the mouth. Do not offer anything to drink until the child is fully awake. Let the child rest if he wishes.
5. If the seizures last beyond 5 minutes, or if the child seems to pass from one seizure to another without regaining consciousness, call for medical assistance and notify the parents. This rarely happens, but it *is* a medical emergency and should be treated immediately.

**Complex partial** (psychomotor or temporal lobe):

1. Do not try to stop or restrain the child.
2. Try to remove harmful objects from the child's pathway or to coax the child away from them.
3. Use a calm, soft voice when talking to the child.

## RESPONSIBILITIES OF SCHOOL PERSONNEL

The manner in which seizures are handled should be consistent between home and school. It is up to school personnel to contact parents for information and to develop a plan for handling in-school seizures. (Refer to information form on page 6.) If the school is prepared, the occurrence of a seizure will not totally disrupt the classroom or cause undue attention.

Other children may react with surprise, fear, or revulsion to a seizure. School personnel can be very instrumental in preventing any lasting negative reaction on the part of other students. If the children are old enough to understand, the nature of epilepsy should be explained. If not, a simple reassurance that it does not hurt and will soon pass will suffice. To the child with the seizure, it is vitally important that continued acceptance be assured through the calm, open behavior of school staff.

**MEDICATION:** The great majority of children with epilepsy maintain seizure control through daily medication. The child may be taking these medications during the school day. Over 50% of all people with epilepsy can have their seizures controlled with medicine; another 20-30% obtain improved



control. When seizures are partially controlled, their characteristic appearance may change. Thus, someone with generalized tonic-clonic seizures may appear to shift to absence attacks. A small number are not helped at all by medication or may become worse.

It is not known how antiepileptic medication controls seizures. There is no "best" drug known to control all types of seizures, nor a "best" daily dosage. Different drugs control different seizures. The response within each individual child varies according to metabolism rate, body weight, and age. The physician attempts to find a level at which the best possible control can be achieved with the lowest amount of medication. Sometimes, more than one medication is needed.

Because children grow and because body weight, age and metabolism change, medication levels must also change. Thus it may be a long time before the right medicine is found, and once found, it will need frequent adjustment as the child grows.

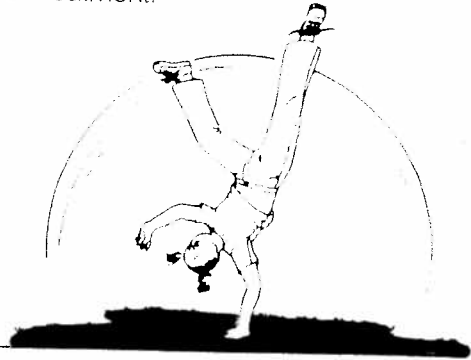
**SIDE EFFECTS:** Most antiepileptic drugs are safe, but as with other medicines, side effects can, and do, result. As medications are changed to allow for changes in growth, metabolism and body weight, temporary side effects can often appear. As the child adjusts to the medication, these effects should lessen, or disappear.

Five medicines are of particular importance to school personnel because of their widespread usage in children with epilepsy: phenobarbital, phenytoin (Dilantin), ethosuximide (Zarontin), valproate (Depakane or Depakote) and carbamazepine (Tegretol). Common side effects from these drugs include drowsiness, lethargy, hyperactivity, loss of muscular coordination, double vision, confusion, slurred speech, nausea, increase in body hair, tremor, anemias, sleep disturbance, loss of appetite, stomach aches and gum swelling. School personnel should keep in mind that, most of the time, these side effects do not occur to an extent which would impair normal school activities. The adjustment of drug levels in children is an ongoing process and school personnel must be alert to possible side effects. Some side effects

may be unavoidable, but others may be reduced with different medication or a change in dose. Therefore, if side effects are noticed, they should be reported to the parents.

First aid for a child known to have seizures should be coordinated with the family. Successful medical management of epilepsy depends on accurate observation and reporting of seizures. Because the physician rarely sees the child's seizures, it is vitally important for school personnel to communicate any observations during a seizure to the family. In recording a seizure observation one should include: date, time of day, duration of seizure

(timed), description of what occurred. (Refer to anecdotal record below). This information will then be available to the physician to use in diagnosis and treatment.



### INFORMATION FORM FOR THE STUDENT WITH EPILEPSY

NAME \_\_\_\_\_ BIRTHDATE \_\_\_\_\_

PARENTS \_\_\_\_\_ SEX \_\_\_\_\_

\_\_\_\_\_ HOME PHONE \_\_\_\_\_

ADDRESS \_\_\_\_\_

PHYSICIAN \_\_\_\_\_ (CITY) \_\_\_\_\_ (STATE) \_\_\_\_\_ (ZIP) \_\_\_\_\_

TYPE OF EPILEPSY \_\_\_\_\_

RECEIVING TREATMENT      YES      NO

TYPE OF MEDICATION \_\_\_\_\_

TIME MEDICATION IS TAKEN \_\_\_\_\_

POSSIBLE SIDE EFFECTS \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

LIKELIHOOD AND FREQUENCY OF SEIZURES DURING SCHOOL HOURS \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

ANY LIMITATIONS SPECIFIED BY PHYSICIAN \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

PARENTS' COMMENTS \_\_\_\_\_

\_\_\_\_\_

\_\_\_\_\_

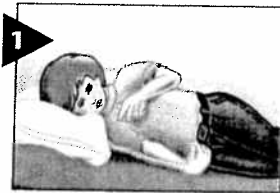
DESIRED 1ST AID PROCEDURES \_\_\_\_\_

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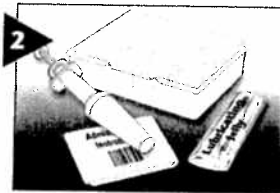
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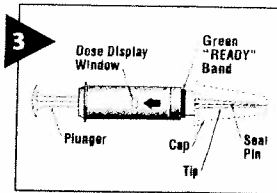
## Administration and Disposal Instructions



**1** Put person on their side where they can't fall.

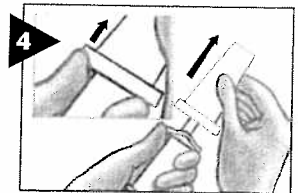


**2** Get medicine.

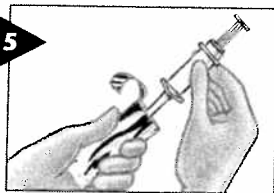


**3** Get syringe.

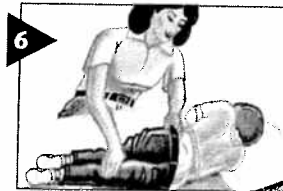
*Note: Seal Pin is attached to the cap.*



**4** Push up with thumb and pull to remove cap from syringe. **Be sure Seal Pin is removed with the cap.**



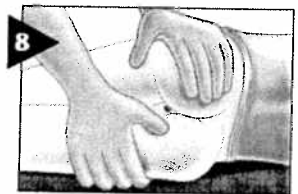
**5** Lubricate rectal tip with lubricating jelly.



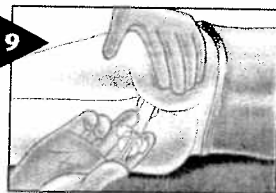
**6** Turn person on side facing you.



**7** Bend upper leg forward to expose rectum.

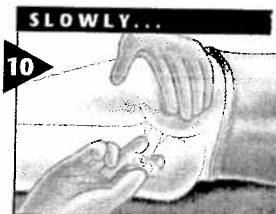


**8** Separate buttocks to expose rectum.

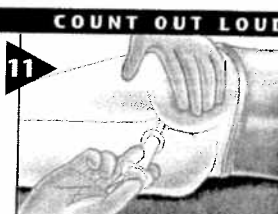


**9** Gently insert syringe tip into rectum.

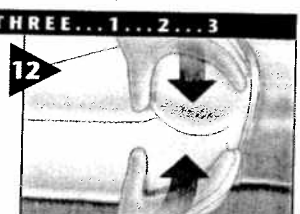
*Note: Rim should be snug against rectal opening.*



**10** Slowly count to 3 while gently pushing plunger in until it stops.



**11** Slowly count to 3 before removing syringe from rectum.



**12** Slowly count to 3 while holding buttocks together to prevent leakage.



**ONCE DIASTAT® IS GIVEN**

Keep person on side facing you, note time given and continue to observe.

### DISPOSAL INSTRUCTIONS FOR DIASTAT ACUDIAL

**14a**

- Pull on plunger until it is completely removed from the syringe body.
- Point tip over sink or toilet.

**14b**

- Replace plunger into syringe body, gently pushing plunger until it stops.
- Flush toilet or rinse sink with water until gel is no longer visible.

SINK OR TOILET

This step is for Diastat® AcuDial™ users only

At the completion of step 14a:

- Discard all used materials in the garbage can.
- Do not reuse.
- Discard in a safe place away from children.

**DISPOSAL FOR DIASTAT 2.5 MG**

At the completion of step 13:

- Discard all used materials in the garbage can.
- Do not reuse.
- Discard in a safe place away from children.



**CALL FOR HELP IF ANY OF THE FOLLOWING OCCUR**



- Seizure(s) continues 15 minutes after giving DIASTAT or per the doctor's instructions.
- Seizure behavior is different from other episodes.
- You are alarmed by the frequency or severity of the seizure(s).
- You are alarmed by the color or breathing of the person.
- The person is having unusual or serious problems.

Local Emergency Number: \_\_\_\_\_

Doctor's Number: \_\_\_\_\_

*Always be sure to call your doctor's 911*

Information for Emergency Squad: Time DIASTAT given: \_\_\_\_\_ Dose: \_\_\_\_\_

**Diastat AcuDial™**  
(diazepam rectal gel)