



# MANAGING SEIZURES

## INFORMATION FOR CAREGIVERS

## ABOUT THE EPILEPSY FOUNDATION

The Epilepsy Foundation is the national voluntary agency solely dedicated to the welfare of the more than three 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 services, education, advocacy and research. In addition to programs conducted at the national level, people with epilepsy are also served by local Epilepsy Foundation affiliates across the country.

If you have any questions about epilepsy and seizure disorders, living with epilepsy, or helping a friend or family member who has epilepsy, please visit us on the Web at [www.EpilepsyFoundation.org](http://www.EpilepsyFoundation.org) or call

800-332-1000. Our Web site has information about the disorder, offers opportunities to network with others touched by epilepsy through our eCommunities forums and Web events. You can also subscribe to our bi-monthly magazine *EpilepsyUSA*. Each issue contains exciting developments for people affected by seizure disorders—new treatments and medicines, ground-breaking research, safety tips, personal stories, advice for parents and much, much more—all delivered right to your door.



## MANAGING SEIZURES

Epilepsy (also called a seizure disorder) is a medical condition that affects many people. It is a disorder of the brain.

When electrical signals in the brain misfire, they can cause seizures. Seizures may change a person's awareness, or movements, or sensations.

Nearly three million Americans of all ages live with epilepsy. About a million of them still have seizures, even though they take medicine to prevent them.

When people have seizures, they rely on family or other caregivers to look after them during the seizure, and to do the right things.

## PLANNING AHEAD

This pamphlet is for caregivers who are looking after a child or an adult who has seizures. It's designed to help you plan ahead so that when a seizure happens you'll know what to do and when to do it.

The first step in planning how to handle seizures is to talk with the doctor and get his advice. He or she knows your child (or family member's) seizure history. He is the best person to help you plan the best response.

## ABOUT SEIZURES

There are several kinds of seizures and they all look different. The kind of seizure that requires first aid makes a person fall, get stiff, and then shake for a short time.

Breathing may be faint, and even stop briefly. Then the shaking and jerking slows down and stops after a minute or two. Breathing starts again and slowly gets back to normal.

These seizures may be called different names—convulsive seizures, grand mal seizures, or the one the doctors use - generalized tonic clonic seizures.

You don't have to do much when seizures only last a short time and there are no other injuries or health problems. Just follow the standard first aid steps.

## STANDARD FIRST AID

### **Here's what you do:**

- Keep the person from getting hurt while the shaking or jerking continues
- Put something flat and soft under her head; loosen anything tight around her neck
- Turn her on one side to prevent choking
- Keep track of the time
- As the jerking slows down, make sure she is breathing normally

- Talk calmly and help her to get back to normal again.

### **Here's what you don't do:**

- Don't put anything in her mouth
- Don't restrain
- Don't try to give medicine or anything to drink until she's fully awake and aware

If you help care for someone who has a vagus nerve stimulation (VNS) implant, ask the doctor if there's any special action you should take if that person has a seizure. The doctor may suggest that you use a special magnet to try to stop the seizure. He or she will show you how to do that.

### **SHOULD YOU ALWAYS CALL 911?**

Yes, if the doctor says you should. Also call if:

- The seizure goes on longer than five minutes, or
- Another seizure starts right after the first one ends, or
- The person has trouble breathing, seems hurt or in pain, or
- Isn't getting back to normal the way he usually does

You needn't call 911 if:

- The seizure ends after a couple of minutes, and
- The person wakes up and starts breathing normally again, and
- Is fully awake and aware after a short rest

### **PROLONGED OR CLUSTER SEIZURES**

Some children and adults have convulsive seizures that go on for a long time. Some have seizures that happen in groups, or clusters.

Seizures which produce body jerking, staring spells, or a state of confusion can also occur in clusters and fail to stop in the usual way.

Ask your doctor how you should plan to manage this type of seizure. There are treatments that may help you handle them at home and avoid a trip to the hospital.

The treatments include use of the VNS magnet or a rectal applicator containing epilepsy medicine to stop the seizure. You would need special training from your health care team in how to give these treatments.

### **WHEN IT'S AN EMERGENCY**

Seizures that go on for a long time and cannot be stopped by any in-home therapy sometimes become nonstop seizures. A seizure that won't stop after several minutes is called status epilepticus. A seizure that won't stop is a medical emergency that needs treatment at the hospital to bring the seizure under control.

If your child or adult family member has experienced episodes of nonstop seizures that required hospital treatment, you will want to have a plan of action ready in case they occur again.

## YOUR PLAN OF ACTION

Your plan could include some or all of the following:

- Ask the doctor if there is anything you can do to stop a seizure from developing into status.
- If you've been trained in how to use in-home therapy to stop a seizure, make sure that a responsible caregiver is also trained.
- Ask how long you should wait before calling an ambulance if the seizures do not stop.
- Be aware of where the nearest hospital is, how long it takes to get there.
- If you live a long way from the hospital, you may plan to call earlier than you would if it were closer.
- If several hospitals are nearby, ask the doctor in advance which one to call.
- Ask the doctor if she will arrange for "standing orders" to be kept in the emergency room so a non-stop seizure can be managed as your doctor directs.
- Ask for a copy for yourself if you and your child travel out of town.
- Leave detailed written instructions with babysitters or adult caregivers.

Fortunately, most seizures, even when prolonged, will end without injury. The important thing is to work with your doctor and have a plan to follow if they occur.

## MEDICINES FOR EPILEPSY

The chart on the overleaf 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. The list includes drugs that are sometimes prescribed for epilepsy, but not FDA-approved for that use. 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 (listed in italics, under the brand name) will look different from the brand name drugs. Drugs shown below are not actual size.

The list of side effects is not complete because of space limitations. For a complete list, consult your doctor, nurse, or pharmacist. More detailed sources of information on side effects include the drug's prescribing information sheet, or the Physician's Desk Reference.

# Medicines for Epilepsy

FORM (of brand name product)	BRAND NAME (generic name)	AVERAGE ADULT DAILY DOSE	SOME SIDE EFFECTS
 0.5 mg      1 mg      2 mg	<b>*ATIVAN®</b> (lorazepam)	1 mg–10 mg	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
 200 mg      400 mg	<b>BANZEL™</b> (rufinamide)	3200 mg	Drowsiness, vomiting, headache, fatigue, loss of appetite and dizziness.
 100 mg      200 mg      300 mg	<b>CARBATROL®</b> (extended release carbamazepine)	600 mg–1200 mg	Dizziness, drowsiness, blurred or double vision, nausea, skin rashes, abnormal blood counts (rare)
 250 mg	<b>DEPAKENE®</b> (valproate)	1750 mg–3000 mg	Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor
 Sprinkles 125 mg      125 mg      250 mg      500 mg	<b>DEPAKOTE®</b> (divalproex sodium)	1750 mg–3000 mg	Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor
 250 mg      500 mg	<b>DEPAKOTE® ER</b> (extended release divalproex sodium)	2000 mg–3500 mg	Upset stomach, altered bleeding time, liver toxicity, hair loss, weight gain, tremor
 Generic available in 125 mg and 250 mg tablets	<b>DIAMOX® SEQUELS®</b> (extended-release acetazolamide)	250 mg–1000 mg	Appetite loss, frequent urination, drowsiness, confusion, numbness of extremities, kidney stones

Actual doses for a person with epilepsy may be higher or lower than the doses listed.

## SOME SIDE EFFECTS

Not all individuals experience side effects. This partial list names some side effects individuals may experience.



**DILANTIN®**  
*(phenytoin)*

200 mg–400 mg

Clumsiness, insomnia, motor twitching, nausea, rash, gum overgrowth, hairiness, thickening of features



**FELBATOL®**  
*(felbamate)*

1200 mg–3600 mg

Anorexia, vomiting, insomnia, nausea, headache, liver and blood toxicity



**GABITRIL®**  
*(tiagabine)*

36 mg–56 mg

Tremor, dizziness, nervousness, difficulty concentrating, sleepiness, weakness



**KEPPRA®**  
*(levetiracetam)*

1000 mg–3000 mg

Sleepiness, fatigue, poor coordination, loss of strength, dizziness



**KEPPRA XR™**  
*(extended release levetiracetam)*

1000 mg–3000 mg

Sleepiness, fatigue, poor coordination, loss of strength, dizziness



Also available as wafers in blister packs

**KLONOPIN®**  
*(clonazepam)*

1.5 mg–20 mg

Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes



**LAMICTAL®**  
*(lamotrigine)*

100 mg–500 mg

Dizziness, headache, blurred vision, clumsiness, sleepiness, nausea, skin rash



**LYRICA®**  
*(pregabalin)*

150 mg–600 mg

Dizziness, blurred vision, weight gain, sleepiness, difficulty concentrating, swelling of hands and feet, dry mouth



50 mg

225 mg

**MYSOLINE®**  
*(primidone)*

250 mg–1000 mg

Clumsiness, dizziness, appetite loss, fatigue, drowsiness, hyperirritability, insomnia, depression, hyperactivity (children)

**NEURONTIN®**  
*(gabapentin)*

900 mg–3600 mg

Sleepiness, dizziness, clumsiness, fatigue, twitching

**PHENOBARBITAL**  
*(phenobarbital)*

15 mg–100 mg

Drowsiness, irritability, hyperactivity (children), behavioral problems, difficulty concentrating, depression

**PHENYTEK®**  
*(extended phenytoin sodium)*

200 mg–400 mg

Clumsiness, insomnia, motor twitching, nausea, rash, gum overgrowth, hairiness, thickening of features

**TEGRETOL®**  
*(carbamazepine)*

600 mg–1200 mg

Dizziness, drowsiness, blurred or double vision, nausea, skin rashes, abnormal blood counts (rare)

**TEGRETOL XR®**  
*(extended release carbamazepine)*

600 mg–1200 mg

Dizziness, drowsiness, blurred or double vision, nausea, skin rashes, abnormal blood counts (rare)

**TOPAMAX®**  
*(topiramate)*

200 mg–400 mg

Confusion, sleepiness, dizziness, clumsiness, difficulty thinking or talking, tingling sensation of the skin, nausea, decreased appetite

	<b>TRANXENE®</b> ( <i>clorazepate</i> )	15 mg–45 mg	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes
	<b>TRILEPTAL®</b> ( <i>oxcarbazepine</i> )	600 mg–2400 mg	Difficulty concentrating, sleepiness, fatigue, dizziness, double vision, nausea, unsteadiness, rash
	<b>VIMPAT®</b> ( <i>lacosamide</i> )	200 mg–400 mg	Dizziness, headache, nausea, vomiting, double vision, blurred vision, walking difficulty, drowsiness, diarrhea, falls, unintentional rapid eye movement, tremor
	<b>ZARONTIN®</b> ( <i>ethosuximide</i> )	500 mg–1500 mg	Appetite loss, nausea, drowsiness, headache, dizziness, fatigue, rash, abnormal blood counts (rare)
	<b>ZONEGRAN®</b> ( <i>zonisamide</i> )	100 mg–600 mg	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)
	<i>The following medicine is not prescribed for daily, long-term use, but to stop episodes of prolonged or cluster seizures.</i>		
	<b>DIASTAT® ACUDIAL™</b> ( <i>diazepam rectal gel</i> )	Average Single Dose 0.2 mg. – 0.5 mg./kg.	Drowsiness, sleepiness, fatigue, poor coordination, unsteadiness, behavior changes

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

# Seizure Recognition and First Aid

SEIZURE TYPE	WHAT IT LOOKS LIKE	WHAT IT IS NOT	WHAT TO DO
<b>Generalized Tonic Clonic</b>  (Also called Grand Mal)	Sudden cry, fall, rigidity, followed by muscle jerks, shallow breathing or temporarily suspended breathing, bluish skin, possible loss of bladder or bowel control, usually lasts a couple of minutes. Normal breathing then starts again. There may be some confusion and/or fatigue, followed by return to full consciousness.	Heart attack. Stroke.	Look for medical identification. Protect from nearby hazards. Loosen ties or shirt collars. Protect head from injury.  Turn on side to keep airway clear unless injury exists. Reassure as consciousness returns.  If single seizure lasted less than 5 minutes, ask if hospital evaluation wanted.  If multiple seizures, or if one seizure lasts longer than 5 minutes, call an ambulance. If person is pregnant, injured, or diabetic, call for aid at once.
<b>Absence</b>  (Also called Petit Mal)	A blank stare, beginning and ending abruptly, lasting only a few seconds, most common in children. May be accompanied by rapid blinking, some chewing movements of the mouth. Child or adult is unaware of what's going on during the seizure, but quickly returns to full awareness once it has stopped. May result in learning difficulties if not recognized and treated.	Daydreaming. Lack of attention. Deliberate ignoring of adult instructions.	No first aid necessary, but if this is the first observation of the seizure(s), medical evaluation should be recommended.
<b>Simple Partial</b>	<p>Jerking may begin in one area of body, arm, leg, or face. Can't be stopped, but patient stays awake and aware. Jerking may proceed from one area of the body to another, and sometimes spreads to become a convulsive seizure.</p> <p>Partial sensory seizures may not be obvious to an onlooker. Patient experiences a distorted environment. May see or hear things that aren't there, may feel unexplained fear, sadness, anger, or joy. May have nausea, experience odd smells, and have a generally "funny" feeling in the stomach.</p>	Acting out, bizarre behavior. Hysteria. Mental illness. Psychosomatic illness. Parapsychological or mystical experience.	<p>No first aid necessary unless seizure becomes convulsive, then first aid as above</p> <p>No immediate action needed other than reassurance and emotional support.</p> <p>Medical evaluation should be recommended.</p>

## Complex Partial

(Also called Psychomotor or Temporal Lobe)

Usually starts with blank stare, followed by chewing, followed by random activity. Person appears unaware of surroundings, may seem dazed and mumble. Unresponsive. Actions clumsy, not directed. May pick at clothing, pick up objects, try to take clothes off. May run, appear afraid. May struggle or flail at restraint. Once pattern established, same set of actions usually occur with each seizure. Lasts a few minutes, but post-seizure confusion can last substantially longer. No memory of what happened during seizure period.

Drunkenness.  
Intoxication on drugs.  
Mental illness.  
Disorderly conduct.

Speak calmly and reassuringly to patient and others.  
Guide gently away from obvious hazards.  
Stay with person until completely aware of environment.  
Offer to help getting home.

## Atonic Seizures

(Also called Drop Attacks)

A child or adult suddenly collapses and falls. After 10 seconds to a minute he recovers, regains consciousness, and can stand and walk again.

Clumsiness.  
Normal childhood "stage."  
In a child, lack of good walking skills.  
In an adult, drunkenness, acute illness.

No first aid needed (unless he hurt himself as he fell), but the child should be given a thorough medical evaluation.

## Myoclonic Seizures

Sudden brief, massive muscle jerks that may involve the whole body or parts of the body. May cause person to spill what they were holding or fall off a chair.

Clumsiness.  
Poor coordination.

No first aid needed, but should be given a thorough medical evaluation.

## Infantile Spasms

These are clusters of quick, sudden movements that start between three months and two years. If a child is sitting up, the head will fall forward, and the arms will flex forward. If lying down, the knees will be drawn up, with arms and head flexed forward as if the baby is reaching for support.

Normal movements of the baby.  
Colic.

No first aid, but doctor should be consulted.



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*Epilepsy Foundations throughout the country have additional materials  
and offer a variety of programs to help people understand this common disorder.*

*For further information about epilepsy and the name of the Epilepsy Foundation nearest you,  
log on to [www.epilepsyfoundation.org](http://www.epilepsyfoundation.org) or call 800-332-1000.*

This pamphlet is intended to provide basic information about epilepsy to the general public. It is not intended to, nor does it, constitute medical advice. Readers are warned against changing medical schedules or life activities based on the information it contains without first consulting a physician.