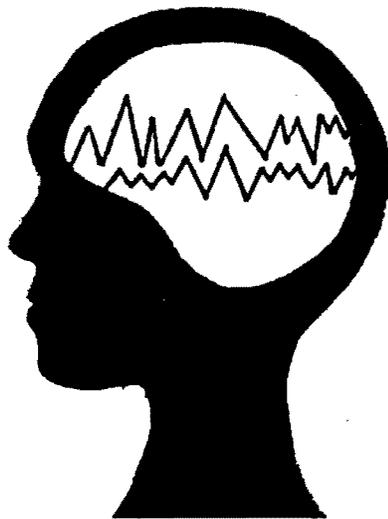


ANSWERS TO
YOUR QUESTIONS
ABOUT

EPILEPSY



THE EPILEPSY CENTER
UNIVERSITY OF NORTH CAROLINA
CHAPEL HILL



KEEPING YOU WELL AND WELL-INFORMED

INTRODUCTION

Whether you have just been told you have epilepsy, or if you have had it for many years, we feel it is important that you have information about your condition.

This pamphlet will answer these questions:

- What is epilepsy?
- What is a seizure?
- What causes epilepsy?
- How does my doctor know I have epilepsy?
- Are there different kinds of seizures?
- What types of treatment are available for seizures?
- What should I do when someone has a seizure?
- How do I lead a normal life?

This pamphlet will not answer all your questions. Please feel free to ask us any other questions you have. In order for you to get the best care for your epilepsy, it is your responsibility to know as much as possible about your condition.

This pamphlet is not intended to provide medical advice. Please discuss all questions you have about the treatment of your epilepsy with your doctor.

THE BRAIN

Our brains work to control every thought, feeling, movement and action of our bodies and minds. It is kind of like a big computer. Our nerves bring messages from all parts of the body to the brain. The brain itself has billions of neurons or nerve cells. The brain organizes all the information and sends out messages back to the body. It does many hundreds of jobs all at the same time. We usually don't even stop to think about the actions our brain controls. For example, it allows us to walk and talk, read and write, think and plan. It lets us know when we are hungry or cold, happy or sad.

WHAT IS A SEIZURE?

Sometimes some of the nerve cells in the brain do not work right. The messages get scrambled up. There is a sudden discharge of abnormal electrical activity. It is like a short circuit. That is when a seizure happens. When a seizure happens, the person behaves or feels in a way that is not normal. Once the seizure is over, the nerve cells return to normal and the person eventually returns to his or her usual level of functioning. All epileptic seizures start in the brain.

Seizures are a symptom or physical sign that the brain is not working properly. Seizures might be a sign that someone has epilepsy. Not everyone who has a seizure has epilepsy. About 1 out of 10 people will have a seizure at some time in their lives. Acute illness, high fevers, strokes, brain tumors, head injuries, lack of oxygen, infections, street drugs and other poisons might cause a person to have a seizure. If the person gets well and stops having seizures, they probably do not have epilepsy. It is only when seizures recur unexpectedly and come back over a period of time that the diagnosis of epilepsy is made.

WHAT IS EPILEPSY?

Epilepsy is the neurological condition related to recurrent unprovoked seizures. This means it affects the nerve cells (neurons) in the brain. It is one of the most common neurological conditions, affecting about 1 out of every 150-200 people all over the world. It is found in males and females of every age and ethnic group.

WHAT CAUSES SEIZURES?

For about 50% of people with epilepsy, their doctors will never find a cause for their seizures. We know that sometimes seizures can run in families and have a genetic link. If the parents have a gene for epilepsy

their children can inherit the chance for developing seizures, just like the child of someone with diabetes inherits the chance for developing diabetes. This does not mean that every child born to a woman with epilepsy will develop seizures. The risk is slightly higher (about 3 in 100) than if the mother does not have epilepsy (2 in 1000).

For the other approximately 50% of people we can find a cause. These include:

- severe head injuries
- strokes
- brain infections
- birth injuries which damage the brain
- lack of oxygen which damages the brain
- abnormalities in the way the brain was formed
- prolonged high fevers in children
- over exposure to poisons like lead paint
- exposure to street drugs—cocaine, crack or alcohol

There is always a physical reason why someone has seizures. Epilepsy is not caused by seeing something that frightens you. However, stress can make you more likely to have recurrent seizures if you already have a seizure disorder. Many years ago some people thought that seizures were a curse from God or that the person with seizures was possessed by the devil. This is not true.

HOW DOES MY DOCTOR KNOW I HAVE EPILEPSY?

People are usually seen by a neurologist if their doctor thinks they may have a seizure disorder. A neurologist is a doctor specially trained to understand conditions that affect the brain and nervous system. The neurologist will review your medical history, perform a physical examination and may order some tests.

HISTORY

The neurologist will probably start by getting your medical history. This includes the following information:

- your birth history - Were there any problems when your mother was pregnant with you, or delivered you?
- your developmental history - Did you have any problems while growing up? Did you walk, talk and do other things at the same age as your brothers or sisters? Did you have problems learning?

- history of any severe head injuries, brain infection, high fevers
- history of other neurological or emotional problems in your family
- history of any other medical or surgical problems
- exposure to any poisons like lead paint
- your use of alcohol or street drugs
- family history of seizures or other medical or emotional problems

EYE WITNESS DESCRIPTION

Next, the neurologist will want to get a complete description of the behavior which may be a seizure. What you do immediately before, during and after these events will help the doctor decide whether or not they may be seizures. It is very helpful to bring along a written description of what you do before, during and after your seizures. We have a pamphlet which will help you write this. It is also very important that you bring someone with you to your doctor's appointment who has actually seen you have a seizure so the doctor can ask him or her questions. You probably will not remember what happens during your seizures, so this person's information is very important.

OTHER TESTS

Your doctor may order some tests including:

- **MRI scan:** This is a special type of Xray which shows the brain's structure. It may show if there is an abnormality in the brain which could be the cause of your seizures.
- **EEG:** This test shows your brain waves. It only lasts about an hour and it shows electrical brain waves. If you have a seizure during the test, it may show a brain wave pattern which tells your doctor what kind of seizure you are having. Between seizures your brain wave patterns may be normal. Many people with seizures can have normal EEGs.
- **Sleep deprived EEG:** If the routine EEG was normal you may have a sleep deprived EEG. Going without sleep stresses the brain and makes it more likely that a seizure will happen. You will probably be asked to go to bed much later than normal or to get up very early (for example 2 or 3 AM) and then stay awake until the EEG test.
- **Blood tests:** There are other conditions which can cause seizures. An example of this is uncontrolled diabetes. Your doctor might do some other tests to make sure there is not another physical cause for your seizures.
- **Sleep studies:** Some people have events in their sleep that can look like seizures. If you only have your events in sleep, sleep studies may be ordered to decide if they are seizures or something else.

If these tests do not give your doctor enough information there are two other tests that may be done:

- **An Ambulatory EEG:** With this test EEG electrodes are placed on your head and you go home with a small, portable recording device. It looks somewhat like a Holter monitor that people wear for EKG testing. You wear this for 1-2 days and then come back in to the hospital to have it removed. This gives us a longer EEG to look at.
- **Video-EEG monitoring:** If we still can't get an answer for you, your doctor might have you come into the hospital for what is called Video-EEG monitoring. For this test you are admitted to the hospital for a few days. EEG electrodes are placed on your head and you are continuously video taped until you have several of your seizures. This testing also helps your doctor decide what type of seizures you have. Medical treatment is chosen based on your seizure type.

ARE THERE DIFFERENT KINDS OF SEIZURES?

There are two basic types of seizures, generalized and partial. In a generalized seizure, the abnormal electrical discharge is found in the whole brain. There are several different types of generalized seizures. Partial seizures begin in one part of the brain but they can spread to involve the whole brain. There are three groups of partial seizures. The EEG may show us which type of seizure you have. Over the past ten to fifteen years we have found out much more information about seizures. There is now an international classification for seizures. This means that, wherever you would go in the world, doctors and nurses will use the same names (in their language) for describing your seizures. The names that you might have heard for seizures have changed. We will use the new names for this pamphlet.

Here is a list of the old and new names for seizures:

GENERALIZED SEIZURES

OLD	NEW
petit mal	absence
Grand Mal	tonic-clonic
minor motor	myoclonic
drop attacks, akinetic	atonic

PARTIAL SEIZURES

OLD	NEW
auras, focal motor, focal sensory Jacksonian	simple partial
psychomotor seizures temporal lobe seizures	complex partial
Grand Mal (with a warning or start as a partial seizure)	complex partial with secondary generalization

GENERALIZED SEIZURES:

- **Tonic-clonic:** A tonic-clonic seizure is what people usually think of when you say the word "seizure". The first sign of the seizure might be a cry or shout. This happens when the muscles in the chest contract and push the air out of the lungs through partially closed vocal cords. Then the person blacks out (falls out) and suddenly stiffens and falls. Their eyes may roll back up into their head. This is the tonic part of the seizure. They then begin to have generalized shaking or convulsions of the whole body. They may briefly stop breathing and turn blue. This happens because the muscles in the chest are contracted. The person might drool or look like they are foaming around the mouth. Because the person does not swallow during the seizure, saliva pools in his or her mouth and the air being pushed out of the lungs causes the saliva to look frothy. Sometimes they make grunting noises or have heavy breathing. Some people wet themselves or lose control of their bowels. They might bite their

tongues or the insides of their cheeks causing the saliva to become blood tinged. The stiff or tonic part lasts a few seconds. The shaking or clonic part lasts about a minute. After the jerking stops, the person usually goes limp and may start taking large, gasping breaths. Once the seizure is over, the person usually responds quickly but they may be very tired. They may report muscle soreness and headache and need to sleep for a period of time. For the person seeing someone have a tonic-clonic seizure it seems to last for a very long time, but most seizures last under 5 minutes. Tonic-clonic seizures of the generalized type can start at any age and usually respond well to treatment.

- **Absence:** True absence seizures are most common in children. With an absence seizure, the person suddenly stops what he or she was doing. They might stare and fail to respond to what is happening around them. Some people blink their eyes or smack their lips or experience small jerking movements or tremors. The seizure lasts only a few seconds and then the person returns to what he or she was doing before the seizure started. The person will not be confused but will not remember what happened during the seizure. Children can have many hundreds of these seizures in a day. Absence seizures are often diagnosed when the child starts school. Families may get reports from the teacher that the child is “day dreaming” or not paying attention in class. Many children outgrow absence seizures. Response to treatment is usually very good. There is a good chance that the child will eventually be able to come off medical treatment once they near adulthood. There is a genetic link for this type of seizure. In other words, it sometimes runs in families.
- **Atonic:** With an atonic seizure, the person suddenly goes limp and will usually fall if standing up. Witnesses to the seizure often describe the person as a “rag doll” during the seizure. There is a smaller version of this seizure in which the person may just nod his or her head forward or bend at the waist suddenly. Atonic seizures are brief. They usually indicate that the person has some type of other neurological problem. Atonic seizures are difficult to control and can happen at any age but are more common in children. Some people with this type of seizure wear a protective helmet to protect themselves from getting a head injury.

- **Tonic:** In a tonic seizure the person suddenly stiffens, blacks out and falls, "like a tree". These seizures are also usually brief. For many people, they come out of the seizure just as they hit the ground. Injuries are common with this type of seizure because it happens without warning and the person falls suddenly. Many people who have this type of seizure wear protective helmets to prevent head injury. Like the atonic seizures, tonic seizures are associated with other neurological problems. They also can be difficult to control.
- **Myoclonic:** These are brief, sudden, muscle spasms or jerks. Myoclonic seizures can be mild or severe. The person might have just one or two or a long series. The person usually does not black out with this type of seizure but remains aware of what is happening around him or her. These seizures are more common just after waking or when falling off to sleep. They also tend to occur when the person tries to do something, like pick up a glass or eat. Myoclonic seizure can be hard to control and can be associated with more serious neurological conditions. Myoclonic seizures can also be seen as part of a genetically linked type of epilepsy which can be controlled with medication.

PARTIAL SEIZURES

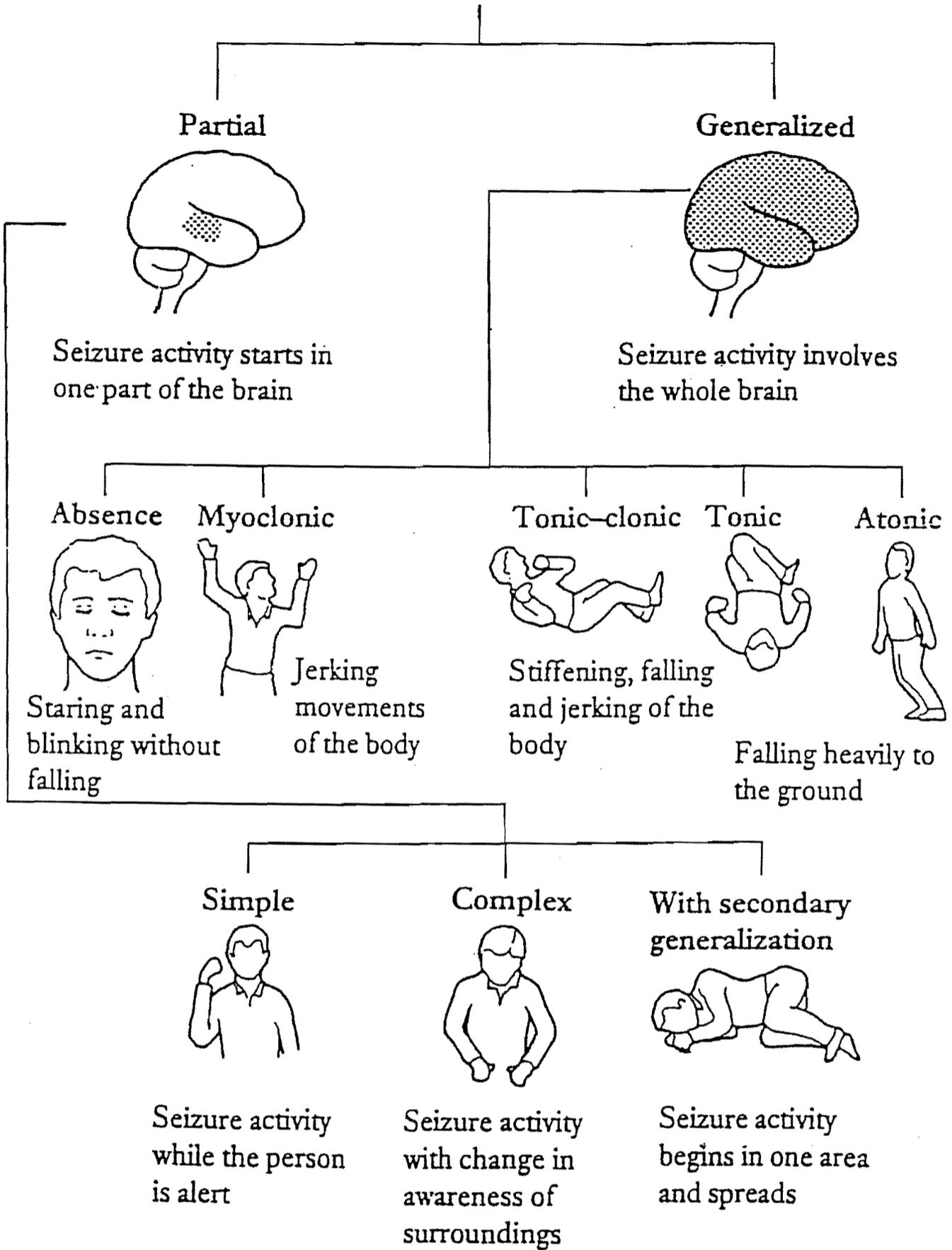
- **Simple Partial:** These seizures start in one part of the brain. What the person does or feels depends on where in the brain the seizure starts. Different parts of the brain control different activities and sensations. Simple partial seizures are similar to the aura or warning a person gets before a seizure. They do not black out (fall out) with this type of seizure. An arm or leg might move or the person might get a funny feeling like butterflies in his or her stomach or suddenly feel afraid. Simple partial seizures are usually very short. They can happen at any age.
- **Complex Partial:** If a simple partial seizure spreads to a larger area of the brain it can become a complex partial seizure. With a complex partial seizure the person will usually black out (fall out). They may have lip smacking or chewing. They may wander around and pick at things. They usually do not respond if spoken to and may mumble or

talk in a way that does not make sense. These seizures last about a minute or two. The person is usually confused after the seizure and it may take a while for them to return to normal. They usually do not remember what happened during the seizure. Complex partial seizures can start at any age.

- **Secondarily Generalized Tonic-Clonic:** A complex partial seizure which starts in one part of the brain can spread to include the whole brain. The person usually gets an “aura” or warning before going into the seizure. The partial part of this seizure may be very short, lasting only a second or two. Once this type of seizure spreads to the whole brain, it looks exactly like a “Grand Mal” or tonic-clonic seizure. This type of seizure can happen at any age. It can happen in people with partial seizures who miss doses of their seizure medicines or when they are switching from one drug to another.

**THE DRAWINGS ON THE NEXT PAGE WILL HELP DESCRIBE
THE DIFFERENT SEIZURE TYPES**

SEIZURE



WHAT TYPES OF TREATMENTS ARE AVAILABLE FOR SEIZURES?

MEDICATION

The most common form of treatment for seizures is medication, also called antiepileptic drugs. What medication you take depends on your type of seizures and your age. Some medicines work better for specific seizure types. So, if you know someone else who has seizures, he or she may take a different medicine than you do.

It may take some time and trial before you and your doctor find the drug or drugs that work best for you. You have a very important role to play in your seizure management. You need to take your medicines exactly as the doctor has prescribed them. Missing doses can cause you to have more seizures. If you are troubled with side effects of your drugs, you need to talk with your doctor. Sometimes just a small change in the dose or time of day you take your drugs can take care of these problems. If you have trouble remembering when to take your medicines, using a multi-dose pill box, a watch alarm or a calendar might help.

Please read our pamphlet about medications. It will help you understand how to take medicines safely and effectively.

SURGERY

Another form of treatment for people with very severe epilepsy is surgery. There are several different types of operations that can be done for seizures. The type of surgery offered is based on the type of seizures the person has. If you have been taking your medicines as prescribed and are still having seizures, you might want to talk to your doctor to see if surgery might be an option for you. Epilepsy surgery is normally done at large Epilepsy Centers in the United States.

KETOGENIC DIET

Some children and young adults have been put on a special diet, called a ketogenic diet. In some cases this has helped the person's seizure control. You might see magazine or newspaper articles or TV programs about this diet. This diet must be prescribed by a doctor and the family needs to work closely with a dietitian in order for this to be successful. It can be very dangerous to be on this diet without medical supervision.

COMMON ANTIEPILEPTIC DRUGS

Trade Name <i>generic name</i>	Seizure Type	Common Side Effects
Dilantin <i>phenytoin</i>	generalized tonic-clonic, partial	dizziness, drowsiness, double vision, enlargement of gums, acne, excessive hair growth
Tegretol <i>carbamazepine</i>	partial, secondarily generalized tonic-clonic, tonic-clonic, tonic	blurred and double vision, sedation, dizziness, ataxia
Depakote <i>sodium valproate</i> <i>divalproex sodium</i>	absence, myoclonic, generalized tonic-clonic, complex partial	sedation, dizziness, tremor, amenorrhea
Phenobarbital	partial and secondarily generalized tonic, clonic, all generalized types	sedation, ataxia, irritability in children, depression, cognitive impairment
Mysoline <i>primidone</i>	same as phenobarbital	same as phenobarbital but slightly less
Neurontin <i>gabapentin</i>	partial and secondarily generalized tonic-clonic	double vision, dizziness, tremor, sedation
Lamictal <i>lamotrigine</i>	partial, secondarily generalized tonic-clonic tonic-clonic, tonic, atypical absence	drowsiness, dizziness, double vision
Felbatol <i>felbamate</i>	partial and secondarily generalized tonic-clonic, atonic and atypical absences	headache, loss of appetite, insomnia, sedation, dizziness, ataxia
Zarontin <i>ethosuximide</i>	absence	nausea, hiccoughs, sedation, headache
Klonopin <i>clonazepam</i>	myoclonic, absence, atonic	sedation, cognitive impairment, irritability, behavioral changes
Diamox <i>acetazolamide</i>	partial, secondarily generalized tonic-clonic, tonic-clonic, absence, myoclonic, catamenial	tingling in arms and legs, nausea, sedation
**Topamax topiramate(may be available in 1997)	partial and generalized	sedation, possible kidney stones
**Sabril vigabatrin(may be available in 1997)	partial and secondarily generalized	sedation, dizziness, headache, tremor
**tiagabine (still being tested)	partial	sedation, dizziness, nausea, headache
Cerebyx <i>fosphenytoin</i>	for <u>emergency use</u> IM and IV form of Dilantin	same as Dilantin
Valium <i>diazepam</i>	for <u>emergency use</u> in status epilepticus	sedation, ataxia
Ativan <i>lorazepam</i>	for <u>emergency use</u> in status epilepticus	same as Valium

** Indicates new drugs still awaiting approval from the Food and Drug Administration as of late 1996.

OTHER TREATMENT

Drug Studies

Many large medical centers or hospitals have a special Epilepsy Center or Clinic. These centers usually have access to medicines not yet available to the general public. They do research to see how well these drugs work before they are released by the Food and Drug Administration for sale. You might be eligible for one of these drug studies if your seizures are very difficult to control. Your doctor can find out about this for you.

Vagal Nerve Stimulator

There is also a mechanical device called a Vagal Nerve Stimulator. This is placed in the chest by an operation. It looks like a heart pacemaker and works in a similar way. The person can trigger the device at the beginning of the seizure. Right now the Vagal Nerve Stimulator is in the research stage. Most epilepsy centers which are studying this device have research studies which are full at present. However, in the future, there will probably be more chances for people with the right type of seizure to have access to this device.

Stress Management

Stress does not cause seizures in people who do not have epilepsy. However, some people with epilepsy find that their seizures are worse during periods of stress. There are a number of ways to learn how to control stress including: biofeedback, relaxation exercises, guided imagery and meditation. At the UNC Epilepsy Center, the Nurse Clinician can instruct you in a variety of relaxation techniques. Counseling with a psychologist can also be helpful. Your doctor can set up a referral for this type of care. Joining a support group can put you in touch with other people with epilepsy who share your experiences. To find out about support groups in your area call the Epilepsy Foundation of America at 1-800-EFA-1000.

Good Health Practices

Maintaining good health is a key to helping your epilepsy. In some individuals regular exercise and good sleep can decrease the occurrence of seizures. Exercise for 30-45 minutes three times a week (especially in the morning) can help control seizures and improve your sleep. We also have some basic sleep rules to help you get quality sleep. If sleep is a problem, speak with us for more details.

The foods you eat can also help you reduce the risk of recurrent seizures. A good balanced diet with adequate calories and vitamins is essential. Fad diets and quick weight loss programs can increase your risk for recurrent seizures. Overall, the better care you give your body, the better chance your body has of overcoming the seizures.

A note about food . . . some people feel that sugar, certain foods, or food additives increase their seizures. Please discuss this concern with your doctor.

WHAT SHOULD I DO WHEN SOMEONE HAS A SEIZURE?

Seeing someone have a seizure can be a frightening experience. This is especially true if the person is a family member or friend. No matter what type of seizure the person has the best thing you can do is to **keep calm**, **protect** the person from injury and **reassure** him or her. There are certain suggestions for different seizure types.

TONIC-CLONIC (GRAND MAL)

- If the person has a warning it is best to get him or her to a safe place, for example sitting down in a chair or on the floor.
- Once the seizure starts, try to turn him or her to one side.
- If he or she is jerking too hard, try to turn the head to one side.
- If you can't turn the person while the clonic (jerking) part of the seizure is going on, do this as soon as the seizure is over.
- Loosen any tight clothing around the neck.
- **NEVER PUT ANYTHING IN HIS OR HER MOUTH.**
- Don't put water on his or her face.
- Don't give the person anything to drink
- Move anything, like a chair or table, out of the way.
- If you can, put a soft object—a pillow, cushion, sweater, your hands, etc.—under the person's head.
- Stay with the person until he or she is fully recovered.
- If the seizure lasts more than 5 minutes, call 911 and get medical help.
- If the person does not fully recover from one seizure before going into another, call 911 and get medical help.
- If the person is a stranger, look for a Medic Alert necklace or bracelet and call 911.

- Don't try to restrain or hold down the person after the seizure is over. If they need to get up and walk around let them do it but stay with them. Don't try to stop their movement unless they are in a dangerous situation— like walking out into traffic.

TONIC AND ATONIC

- These seizures happen suddenly without warning.
- People often fall with this type of seizure.
- If the person has frequent seizures he or she may need to wear a protective helmet to prevent head injuries.
- Some families pad sharp ends on furniture, and put carpets in the whole house.
- Some families find living in a one story home safer than one with stairs.

MYOCLONIC

- People are usually alert during this type of seizure.
- If there is a time of day when these are more frequent the person should avoid hot liquids (coffee, tea, hot chocolate), avoid cooking and not use sharp utensils like knives during this time.

ABSENCE

- There is a very low risk for injury.
- The person does need reassurance that you will stay with them until they recover, especially if they are having frequent seizures.
- At school, a “buddy” (classmate) can help a child keep their place in class room assignments and reading lessons.

SIMPLE PARTIAL

- There is no need for intervention.
- Reassure the person and stay with him or her until recovered.

COMPLEX PARTIAL

- Do not restrain the person
- If they are walking around and may injure themselves, gently steer them away from harm.
- Remove dangerous objects— such as sharp knives or forks, pens and pencils or hot drinks gently from their hands.
- Reassure the person during the seizure.
- Stay with the person until fully recovered.

COMPLEX PARTIAL WITH SECONDARY GENERALIZATION

- Do the same thing you would do for a tonic-clonic (Grand Mal) seizure.

The other thing you can do to help for any seizure type is to be a good observer. The information you can provide about a person's seizure is very helpful to the doctor.

HOW DO I LEAD A NORMAL LIFE?

Living with seizures can be difficult, especially if your seizures are hard to control. Here are a few suggestions.

- Remember that even though they are troublesome, seizures are only one part of your life.
- Work to control your seizures, do not let them control you.
- Develop interests, try hobbies, join clubs, become active in your church.
- Join a support group. You can find out about support groups in your area by calling the Epilepsy Foundation of America at 1-800-EFA-1000.
- Develop a positive attitude. Remind yourself of all the things you can do. Don't dwell on your restrictions.
- If you are a parent of a child with epilepsy try to allow your child to be as active as possible. He or she should have the same discipline, chores and love and attention which brothers and sisters receive.
- Remember you are not an epileptic. You are a person who happens to have epilepsy.
- Remember that there are many people who do not understand epilepsy. Try to be patient with them. There is a lot you can teach them. If they see you being active and enjoying life they will learn that people with epilepsy are just like everyone else.

OTHER HINTS: (especially if you live alone)

- Take showers rather than baths. Even a small amount of water in a tub is a drowning risk if you were to have a seizure and black out.
- Turn down the thermostat on your hot water heater to avoid scald burns.
- Use rubber gloves when washing dishes. This helps avoid scald burns or cuts from broken glassware or knives if you have a seizure.
- Use a microwave for cooking instead of an electric or gas range.
- Wear a Medic Alert bracelet or necklace to let people know you have a seizure disorder.
- Always wear a helmet if bicycling or roller blading.
- Never swim alone.
- Avoid climbing on high ladders.
- Always wear your seat belt when riding in a car.
- If you have frequent seizures, carry a written description of your seizures, the medicines you take and your doctor's name and phone number with you at all times.

CONCLUSION

As we said at the beginning of this pamphlet, we have not been able to answer all the questions you might have about your seizure disorder. We've added a few blank pages so you can write down any questions you have. Please bring your notebook with you to every clinic visit. Write down your questions and we will try to answer them. You can also call the Epilepsy Nurse Clinician at 919-~~966-0205~~ 843-1839

