Patient Handouts

Epilepsy

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What is epilepsy?

Epilepsy is a brain disorder in which clusters of nerve cells, or neurons, in the brain sometimes signal abnormally. Neurons normally generate electrochemical impulses that act on other neurons, glands, and muscles to produce human thoughts, feelings, and actions. In epilepsy, the normal pattern of neuronal activity becomes disturbed, causing strange sensations, emotions, and behavior, or sometimes *convulsions*, muscle spasms, and loss of consciousness. During a seizure, neurons may fire as many as 500 times a second, much faster than the normal rate of about 80 times a second. In some people, this happens only occasionally; for others, it may happen up to hundreds of times a day.

More than 2 million people in the United States—about 1 in 100—have experienced an unprovoked seizure or been diagnosed with epilepsy. For about 80 percent of those diagnosed with epilepsy, seizures can be controlled with modern medicines and surgical techniques. However, about 20 percent of people with epilepsy will continue to experience seizures even with the best available treatment. Doctors call this situation *intractable epilepsy*. Having a seizure does not necessarily mean that a person has epilepsy. Only when a person has had two or more seizures is he or she considered to have epilepsy.

Epilepsy is not contagious and is not caused by mental illness or mental retardation. Some people with mental retardation may experience seizures, but seizures do not necessarily mean the person has or will develop mental impairment. Many people with epilepsy have normal or above-average intelligence. Famous people who are known or rumored to have had epilepsy include the Russian writer Dostoyevsky, the philosopher Socrates, the military general Napoleon, and the inventor of dynamite, Alfred Nobel, who established the Nobel prize. Several Olympic medalists and other athletes also have had epilepsy. Seizures sometimes do cause brain damage, particularly if they are severe. However, most seizures do not seem to have a detrimental effect on the brain. Any changes that do occur are usually subtle, and it is often unclear whether these changes are caused by the seizures themselves or by the underlying problem that caused the seizures.

While epilepsy cannot currently be cured, for some people it does eventually go away. One study found that children with *idiopathic epilepsy*, or epilepsy with an unknown cause, had a 68 to 92 percent chance of becoming seizure-free by 20 years after their diagnosis. The odds of becoming seizure-free are not as good for adults, or for children with severe epilepsy syndromes, but it is nonetheless possible that seizures may decrease or even stop over time. This is more likely if the epilepsy has been well-controlled by medication or if the person has had epilepsy surgery.

What causes epilepsy?

Epilepsy is a disorder with many possible causes. Anything that disturbs the normal pattern of neuron activity—from illness to brain damage to abnormal brain development—can lead to seizures.

Epilepsy may develop because of an abnormality in brain wiring, an imbalance of nerve signaling chemicals called neurotransmitters, or some combination of these factors. Researchers believe that some people with epilepsy have an abnormally high level of *excitatory neurotransmitters* that increase neuronal activity, while others have an abnormally low level of *inhibitory neurotransmitters* that decrease neuronal activity in the brain. Either situation can result in too much neuronal activity and cause epilepsy. One of the most-studied neurotransmitters that plays a role in epilepsy is GABA, or gamma-aminobutyric acid, which is an inhibitory neurotransmitter. Research on GABA has led to drugs that alter the amount of this neurotransmitter in the brain or change how the brain responds to it. Researchers also are studying excitatory neurotransmitters such as *glutamate*.

In some cases, the brain's attempts to repair itself after a head injury, stroke, or other problem may inadvertently generate abnormal nerve connections that lead to epilepsy. Abnormalities in brain wiring that occur during brain development also may disturb neuronal activity and lead to epilepsy.

Research has shown that the cell membrane that surrounds each neuron plays an important role in epilepsy. Cell membranes are crucial for neurons to generate electrical impulses. For this reason, researchers are studying details of the membrane structure, how molecules move in and out of membranes, and how the cell nourishes and repairs the membrane. A disruption in any of these processes may lead to epilepsy. Studies in animals have shown that, because the brain continually adapts to changes in stimuli, a small change in neuronal activity, if repeated, may eventually lead to full-blown epilepsy. Researchers are investigating whether this phenomenon, called *kindling*, may also occur in humans.

In some cases, epilepsy may result from changes in non-neuronal brain cells called glia. These cells regulate concentrations of chemicals in the brain that can affect neuronal signaling.

About half of all seizures have no known cause. However, in other cases, the seizures are clearly linked to infection, trauma, or other identifiable problems.

Genetic factors. Research suggests that genetic abnormalities may be some of the most important factors contributing to epilepsy. Some types of epilepsy have been traced to an abnormality in a specific gene. Many other types of epilepsy tend to run in families, which suggests that genes influence epilepsy. Some researchers estimate that more than 500 genes could play a role in this disorder. However, it is increasingly clear that, for many forms of epilepsy, genetic abnormalities play only a partial role, perhaps by increasing a person's susceptibility to seizures that are triggered by an environmental factor.

Several types of epilepsy have now been linked to defective genes for *ion channels*, the "gates" that control the flow of ions in and out of cells and regulate neuron signaling. Another gene, which is missing in people with *progressive myoclonus epilepsy*, codes for a protein called cystatin B. This protein regulates enzymes that break down other proteins. Another gene, which is altered in a severe form of epilepsy called *LaFora disease*, has been linked to a gene that helps to break down carbohydrates.

While abnormal genes sometimes cause epilepsy, they also may influence the disorder in subtler ways. For example, one study showed that many people with epilepsy have an abnormally active version of a gene that increases resistance to drugs. This may help explain why anticonvulsant drugs do not work for some people. Genes also may control other aspects of the body's response to medications and each person's susceptibility to seizures, or *seizure threshold*. Abnormalities in the genes that control neuronal migration—a critical step in brain development— can lead to areas of misplaced or abnormally formed neurons, or *dysplasia*, in the brain that can cause epilepsy. In some cases, genes may contribute to development of epilepsy even in people with no family history of the disorder. These people may have a newly developed abnormality, or *mutation*, in an epilepsy-related gene.

Other disorders. In many cases, epilepsy develops as a result of brain damage from other disorders. For example, brain tumors, alcoholism, and Alzheimer's disease frequently lead to epilepsy because they alter the normal workings of the brain. Strokes, heart attacks, and other conditions that deprive the brain of oxygen also can cause epilepsy in some cases. About 32 percent of all newly developed epilepsy in elderly people appears to be due to cerebrovascular disease, which reduces the supply of oxygen to brain cells. Meningitis, AIDS, viral encephalitis, and other infectious diseases can lead to epilepsy, as can hydrocephalus—a condition in which excess fluid builds up in the brain. Epilepsy also can result from intolerance to wheat gluten (known as *celiac* disease), or from a parasitic infection of the brain called neurocysticercosis. Seizures may stop once these disorders are treated successfully. However, the odds of becoming seizure-free after the primary disorder is treated are uncertain and vary depending on the type of disorder, the brain region that is affected, and how much brain damage occurred prior to treatment.

Epilepsy is associated with a variety of developmental and metabolic disorders, including cerebral palsy, neurofibromatosis, pyruvate deficiency, tuberous sclerosis, Landau-Kleffner syndrome, and autism.

Epilepsy is just one of a set of symptoms commonly found in people with these disorders.

Head injury. In some cases, head injury can lead to seizures or epilepsy. Safety measures such as wearing seat belts in cars and using helmets when riding a motorcycle or playing competitive sports can protect people from epilepsy and other problems that result from head injury.

Prenatal injury and developmental problems. The developing brain is susceptible to many kinds of injury. Maternal infections, poor nutrition, and oxygen deficiencies are just some of the conditions that may take a toll on the brain of a developing baby. These conditions may lead to cerebral palsy, which often is associated with epilepsy, or they may cause epilepsy that is unrelated to any other disorders. About 20 percent of seizures in children are due to cerebral palsy or other neurological abnormalities. Abnormalities in genes that control development also may contribute to epilepsy. Advanced brain imaging has revealed that some cases of epilepsy that occur with no obvious cause may be associated with areas of dysplasia in the brain that probably develop before birth.

Poisoning. Seizures can result from exposure to lead, carbon monoxide, and many other poisons. They also can result from exposure to street drugs and from overdoses of antidepressants and other medications.

Seizures are often triggered by factors such as lack of sleep, alcohol consumption, stress, or hormonal changes associated with the menstrual cycle. These *seizure triggers* do not cause epilepsy but can provoke first seizures or cause breakthrough seizures in people who otherwise experience good seizure control with their medication. Sleep deprivation in particular is a universal and powerful trigger of seizures. For this reason, people with epilepsy should make sure to get enough sleep and should try to stay on a regular sleep schedule as much as possible. For some people, light flashing at a certain speed or the flicker of a computer monitor can trigger a seizure; this problem is called *photosensitive epilepsy*. Smoking cigarettes also can trigger seizures. The nicotine in cigarettes acts on receptors for the excitatory neurotransmitter acetylcholine in the brain, which increases neuronal firing. Seizures are not triggered by sexual activity except in very rare instances.

What are the different kinds of seizures?

Doctors have described more than 30 different types of seizures. Seizures are divided into two major categories—*focal seizures* and *generalized seizures*. However, there are many different types of seizures in each of these categories.

Focal seizures. Focal seizures, also called partial seizures, occur in just one part of the brain. About 60 percent of people with epilepsy have focal seizures. These seizures are frequently described by the area of the brain in which they originate. For example, someone might be diagnosed with partial frontal lobe seizures.

In a *simple focal seizure*, the person will remain conscious but may experience unusual feelings or sensations that can take many forms. The person may experience sudden and unexplainable feelings of joy, anger, sadness, or nausea. He or she also may hear, smell, taste, see, or feel things that are not real.

In a *complex focal seizure*, the person has a change in or loss of consciousness. His or her consciousness may be altered, producing a dreamlike experience. People having a complex partial seizure may display strange, repetitious behaviors such as blinks, twitches, mouth movements, or even walking in a circle. These repetitious movements are called *automatisms*. They also may fling objects across the room or strike out at walls or furniture as though they are angry or afraid. These seizures usually last just a few seconds.

Some people with focal seizures, especially complex focal seizures, may experience *auras*—unusual sensations that warn of an impending seizure. These auras are actually simple partial seizures in which the person maintains consciousness. The symptoms an individual person has, and the progression of those

symptoms, tends to be *stereotyped*, or similar every time.

The symptoms of focal seizures can easily be confused with other disorders. For instance, the dreamlike perceptions associated with a complex partial seizure may be misdiagnosed as migraine headaches, which also can cause a dreamlike state. The strange behavior and sensations caused by partial seizures also can be mistaken for symptoms of narcolepsy, fainting, or even mental illness. It may take many tests and careful monitoring by a knowledgeable physician to tell the difference between epilepsy and other disorders.

Generalized seizures. Generalized seizures are a result of abnormal neuronal activity in many parts of the brain. These seizures may cause loss of consciousness, falls, or massive muscle spasms.

There are many kinds of generalized seizures. In *absence seizures*, the person may appear to be staring into space and/or have jerking or twitching muscles. These seizures are sometimes referred to as *petit mal seizures*, which is an older term. *Tonic seizures* cause stiffening of muscles of the body, generally those in the back, legs, and arms. *Clonic seizures* cause repeated jerking movements of muscles on both sides of the body. *Myoclonic seizures* cause jerks or twitches of the upper body, arms, or legs. *Atonic seizures* cause a loss of normal muscle tone. The affected person will fall down or may nod his or her head involuntarily. *Tonic-clonic seizures* cause a mixture of symptoms, including stiffening of the body and repeated jerks of the arms and/or legs as well as loss of consciousness. Tonic-clonic seizures are sometimes referred to by an older term: *grand mal seizures*.

Not all seizures can be easily defined as either partial or generalized. Some people have seizures that begin as partial seizures but then spread to the entire brain. Other people may have both types of seizures but with no clear pattern.

Society's lack of understanding about the many different types of seizures is one of the biggest problems for people with epilepsy. People who witness a non-convulsive seizure often find it difficult to understand that behavior which looks deliberate is not under the person's control. In some cases, this has led to the affected person being arrested or admitted to a psychiatric hospital. To combat these problems, people everywhere need to understand the many different types of seizures and how they may appear.

What are the different kinds of epilepsy?

Just as there are many different kinds of seizures, there are many different kinds of epilepsy. Doctors have identified hundreds of different *epilepsy syndromes*—disorders characterized by a specific set of symptoms that include epilepsy. Some of these syndromes appear to be hereditary. For other syndromes, the cause is unknown. Epilepsy syndromes are frequently described by their symptoms or by where in the brain they originate. People should discuss the implications of their type of epilepsy with their doctors to understand the full range of symptoms, the possible treatments, and the prognosis.

People with **absence epilepsy** have repeated absence seizures that cause momentary lapses of consciousness. These seizures almost always begin in childhood or adolescence, and they tend to run in families, suggesting that they may be at least partially due to a defective gene or genes. Some people with absence seizures have purposeless movements during their seizures, such as a jerking arm or rapidly blinking eyes. Others have no noticeable symptoms except for brief times when they are "out of it." Immediately after a seizure, the person can resume whatever he or she was doing. However, these seizures may occur so frequently that the person cannot concentrate in school or other situations. Childhood absence epilepsy usually stops when the child reaches puberty. Absence seizures usually have no lasting effect on intelligence or other brain functions.

Temporal lobe epilepsy. Temporal lobe epilepsy, or TLE, is the most common epilepsy syndrome with partial seizures. These seizures are often associated with auras. TLE often begins in childhood. Research has shown that repeated temporal lobe seizures can cause a brain structure called the *hippocampus* to shrink over time. The hippocampus is important for memory and learning. While it may take years of

temporal lobe seizures for measurable hippocampal damage to occur, this finding underlines the need to treat TLE early and as effectively as possible.

Neocortical epilepsy is characterized by seizures that originate from the brain's cortex, or outer layer. The seizures can be either focal or generalized. They may include strange sensations, visual hallucinations, emotional changes, muscle spasms, convulsions, and a variety of other symptoms, depending on where in the brain the seizures originate.

There are many other types of epilepsy, each with its own characteristic set of symptoms. Many of these, including **Lennox-Gastaut syndrome** and **Rasmussen's encephalitis**, begin in childhood. Children with Lennox-Gastaut syndrome have severe epilepsy with several different types of seizures, including atonic seizures, which cause sudden falls and are also called *drop attacks*. This severe form of epilepsy can be very difficult to treat effectively. Rasmussen's encephalitis is a progressive type of epilepsy in which half of the brain shows continual inflammation. It sometimes is treated with a radical surgical procedure called hemispherectomy (see the section on Surgery). Some childhood epilepsy syndromes, such as childhood absence epilepsy, tend to go into remission or stop entirely during adolescence, whereas other syndromes such as **juvenile myoclonic epilepsy** and Lennox-Gastaut syndrome are usually present for life once they develop. Seizure syndromes do not always appear in childhood, however.

Epilepsy syndromes that are easily treated, do not seem to impair cognitive functions or development, and usually stop spontaneously are often described as benign. Benign epilepsy syndromes include **benign infantile encephalopathy** and **benign neonatal convulsions**. Other syndromes, such as early **myoclonic encephalopathy**, include neurological and developmental problems. However, these problems may be caused by underlying neurodegenerative processes rather than by the seizures. Epilepsy syndromes in which the seizures and/or the person's cognitive abilities get worse over time are called **progressive epilepsy**.

Benign rolandic epilepsy, now formally known as **benign childhood epilepsy with centrotemporal spikes**, is a seizure syndrome that is so named because it usually stops before age 16, and the seizure discharge is localized on EEG studies to a limited area of the brain around the Rolandic (or central) sulcus. The seizures begin between ages 3 and 13, are infrequent, and usually occur during sleep, especially the early morning hours, so anti-epileptic drugs are often not prescribed. The seizures usually consist of muscular twitching confined to one side of the face or body or tingling of one side of the tongue or mouth and may be accompanied by gurgling noises. Some children may have daytime seizures, which may be one sided or bilateral and behavioral or learning problems, in which case anti-epileptic drugs may be prescribed. *[This paragraph was added by MedLink Corporation.]*

Several types of epilepsy begin in infancy. The most common type of infantile epilepsy is **infantile spasms**, clusters of seizures that usually begin before the age of 6 months. During these seizures the infant may bend and cry out. Anticonvulsant drugs often do not work for infantile spasms, but the seizures can be treated with *ACTH* (adrenocorticotropic hormone) or *prednisone*.

When are seizures not epilepsy?

While any seizure is cause for concern, having a seizure does not by itself mean a person has epilepsy. First seizures, febrile seizures, nonepileptic events, and eclampsia are examples of seizures that may not be associated with epilepsy.

First seizures. Many people have a single seizure at some point in their lives. Often these seizures occur in reaction to anesthesia or a strong drug, but they also may be unprovoked, meaning that they occur without any obvious triggering factor. Unless the person has suffered brain damage or there is a family history of epilepsy or other neurological abnormalities, these single seizures usually are not followed by additional seizures. One recent study that followed patients for an average of 8 years found that only 33 percent of people have a second seizure within 4 years after an initial seizure. People who did not have a second seizure within that time remained seizure-free for the rest of the study. For people who did have a

second seizure, the risk of a third seizure was about 73 percent on average by the end of 4 years.

When someone has experienced a first seizure, the doctor will usually order an *electroencephalogram, or EEG*, to determine what type of seizure the person may have had and if there are any detectable abnormalities in the person's brain waves. The doctor also may order brain scans to identify abnormalities that may be visible in the brain. These tests may help the doctor decide whether or not to treat the person with antiepileptic drugs. In some cases, drug treatment after the first seizure may help prevent future seizures and epilepsy. However, the drugs also can cause detrimental side effects, so doctors prescribe them only when they feel the benefits outweigh the risks. Evidence suggests that it may be beneficial to begin anticonvulsant medication once a person has had a second seizure, as the chance of future seizures increases significantly after this occurs.

Febrile seizures. Sometimes a child will have a seizure during the course of an illness with a high fever. These seizures are called *febrile seizures* (febrile is derived from the Latin word for "fever") and can be very alarming to the parents and other caregivers. In the past, doctors usually prescribed a course of anticonvulsant drugs following a febrile seizure in the hope of preventing epilepsy. However, most children who have a febrile seizure do not develop epilepsy, and long-term use of anticonvulsant drugs in children may damage the developing brain or cause other detrimental side effects. Experts at a 1980 consensus conference coordinated by the National Institutes of Health concluded that preventive treatment after a febrile seizure is generally not warranted unless certain other conditions are present: a family history of epilepsy, signs of nervous system impairment prior to the seizure, or a relatively prolonged or complicated seizure. The risk of subsequent non-febrile seizures is only 2 to 3 percent unless one of these factors is present.

Researchers have now identified several different genes that influence the risk of febrile seizures in certain families. Studying these genes may lead to new understanding of how febrile seizures occur and perhaps point to ways of preventing them.

Nonepileptic events. Sometimes people appear to have seizures, even though their brains show no seizure activity. This type of phenomenon has various names, including nonepileptic events and pseudoseizures. Both of these terms essentially mean something that looks like a seizure but isn't one. Nonepileptic events that are psychological in origin may be referred to as psychogenic seizures. Psychogenic seizures may indicate dependence, a need for attention, avoidance of stressful situations, or specific psychiatric conditions. Some people with epilepsy have psychogenic seizures in addition to their epileptic seizures. Other people who have psychogenic seizures do not have epilepsy at all. Psychogenic seizures cannot be treated in the same way as epileptic seizures. Instead, they are often treated by mental health specialists.

Other nonepileptic events may be caused by narcolepsy, Tourette syndrome, cardiac arrhythmia, and other medical conditions with symptoms that resemble seizures. Because symptoms of these disorders can look very much like epileptic seizures, they are often mistaken for epilepsy. Distinguishing between true epileptic seizures and nonepileptic events can be very difficult and requires a thorough medical assessment, careful monitoring, and knowledgeable health professionals. Improvements in brain scanning and monitoring technology may improve diagnosis of nonepileptic events in the future.

Eclampsia. Eclampsia is a life-threatening condition that can develop in pregnant women. Its symptoms include sudden elevations of blood pressure and seizures. Pregnant women who develop unexpected seizures should be rushed to a hospital immediately. Eclampsia can be treated in a hospital setting and usually does not result in additional seizures or epilepsy once the pregnancy is over.

How is epilepsy diagnosed?

Doctors have developed a number of different tests to determine whether a person has epilepsy and, if so, what kind of seizures the person has. In some cases, people may have symptoms that look very much like a seizure but in fact are nonepileptic events caused by other disorders. Even doctors may not be able to tell the difference between these disorders and epilepsy without close observation and intensive testing.

EEG monitoring. An EEG records brain waves detected by electrodes placed on the scalp. This is the most common diagnostic test for epilepsy and can detect abnormalities in the brain's electrical activity. People with epilepsy frequently have changes in their normal pattern of brain waves, even when they are not experiencing a seizure. While this type of test can be very useful in diagnosing epilepsy, it is not foolproof. Some people continue to show normal brain wave patterns even after they have experienced a seizure. In other cases, the unusual brain waves are generated deep in the brain where the EEG is unable to detect them. Many people who do not have epilepsy also show some unusual brain activity on an EEG. Whenever possible, an EEG should be performed within 24 hours of a patient's first seizure. Ideally, EEGs should be performed while the patient is sleeping as well as when he or she is awake, because brain activity during sleep is often quite different than at other times.

Video monitoring is often used in conjunction with EEG to determine the nature of a person's seizures. It also can be used in some cases to rule out other disorders such as cardiac arrhythmia or narcolepsy that may look like epilepsy.

Brain scans. One of the most important ways of diagnosing epilepsy is through the use of brain scans. The most commonly used brain scans include *CT (computed tomography)*, *PET (positron emission tomography)* and *MRI (magnetic resonance imaging)*. CT and MRI scans reveal the structure of the brain, which can be useful for identifying brain tumors, cysts, and other structural abnormalities. PET and an adapted kind of MRI called *functional MRI (fMRI)* can be used to monitor the brain's activity and detect abnormalities in how it works. *SPECT (single photon emission computed tomography)* is a relatively new kind of brain scan that is sometimes used to locate seizure foci in the brain.

In some cases, doctors may use an experimental type of brain scan called a *magnetoencephalogram*, or *MEG*. MEG detects the magnetic signals generated by neurons to allow doctors to monitor brain activity at different points in the brain over time, revealing different brain functions. While MEG is similar in concept to EEG, it does not require electrodes and it can detect signals from deeper in the brain than an EEG. Doctors also are experimenting with brain scans called *magnetic resonance spectroscopy (MRS)* that can detect abnormalities in the brain's biochemical processes, and with near-infrared spectroscopy, a technique that can detect oxygen levels in brain tissue.

Medical history. Taking a detailed medical history, including symptoms and duration of the seizures, is still one of the best methods available to determine if a person has epilepsy and what kind of seizures he or she has. The doctor will ask questions about the seizures and any past illnesses or other symptoms a person may have had. Since people who have suffered a seizure often do not remember what happened, caregivers' accounts of the seizure are vital to this evaluation.

Blood tests. Doctors often take blood samples for testing, particularly when they are examining a child. These blood samples are often screened for metabolic or genetic disorders that may be associated with the seizures. They also may be used to check for underlying problems such as infections, lead poisoning, anemia, and diabetes that may be causing or triggering the seizures.

Developmental, neurological, and behavioral tests. Doctors often use tests devised to measure motor abilities, behavior, and intellectual capacity as a way to determine how the epilepsy is affecting that person. These tests also can provide clues about what kind of epilepsy the person has.

Can epilepsy be prevented?

Many cases of epilepsy can be prevented by wearing seatbelts and bicycle helmets, putting children in car seats, and other measures that prevent head injury and other trauma. Prescribing medication after first or second seizures or febrile seizures also may help prevent epilepsy in some cases. Good prenatal care, including treatment of high blood pressure and infections during pregnancy, can prevent brain damage in the developing baby that may lead to epilepsy and other neurological problems later. Treating cardiovascular disease, high blood pressure, infections, and other disorders that can affect the brain during adulthood and aging also may prevent many cases of epilepsy. Finally, identifying the genes for many

neurological disorders can provide opportunities for genetic screening and prenatal diagnosis that may ultimately prevent many cases of epilepsy.

How can epilepsy be treated?

Accurate diagnosis of the type of epilepsy a person has is crucial for finding an effective treatment. There are many different ways to treat epilepsy. Currently available treatments can control seizures at least some of the time in about 80 percent of people with epilepsy. However, another 20 percent — about 600,000 people with epilepsy in the United States — have intractable seizures, and another 400,000 feel they get inadequate relief from available treatments. These statistics make it clear that improved treatments are desperately needed.

Doctors who treat epilepsy come from many different fields of medicine. They include neurologists, pediatricians, pediatric neurologists, internists, and family physicians, as well as neurosurgeons and doctors called epileptologists who specialize in treating epilepsy. People who need specialized or intensive care for epilepsy may be treated at large medical centers and neurology clinics at hospitals, or by neurologists in private practice. Many epilepsy treatment centers are associated with university hospitals that perform research in addition to providing medical care.

Once epilepsy is diagnosed, it is important to begin treatment as soon as possible. Research suggests that medication and other treatments may be less successful in treating epilepsy once seizures and their consequences become established.

Medications. By far the most common approach to treating epilepsy is to prescribe antiepileptic drugs. The first effective antiepileptic drugs were bromides, introduced by an English physician named Sir Charles Locock in 1857. He noticed that bromides had a sedative effect and seemed to reduce seizures in some patients. More than 20 different antiepileptic drugs are now on the market, all with different benefits and side effects. The choice of which drug to prescribe, and at what dosage, depends on many different factors, including the type of seizures a person has, the person's lifestyle and age, how frequently the seizures occur, and, for a woman, the likelihood that she will become pregnant. People with epilepsy should follow their doctor's advice and share any concerns they may have regarding their medication.

Doctors seeing a patient with newly developed epilepsy often prescribe carbamazepine, valproate, lamotrigine, oxcarbazepine, or phenytoin first, unless the epilepsy is a type that is known to require a different kind of treatment. For absence seizures, ethosuximide is often the primary treatment. Other commonly prescribed drugs include clonazepam, phenobarbital, and primidone. Some relatively new epilepsy drugs include tiagabine, gabapentin, topiramate, levetiracetam, and felbamate. Other drugs are used in combination with one of the standard drugs or for intractable seizures that do not respond to other medications. A few drugs, such as fosphenytoin, are approved for use only in hospital settings to treat specific problems such as status epilepticus (see section, "Are There Special Risks Associated With Epilepsy?"). For people with stereotyped recurrent severe seizures that can be easily recognized by the person's family, the drug diazepam is now available as a gel that can be administered rectally by a family member. This method of drug delivery may be able to stop prolonged or repeated seizures before they develop into status epilepticus.

For most people with epilepsy, seizures can be controlled with just one drug at the optimal dosage. Combining medications usually amplifies side effects such as fatigue and decreased appetite, so doctors usually prescribe monotherapy, or the use of just one drug, whenever possible. Combinations of drugs are sometimes prescribed if monotherapy fails to effectively control a patient's seizures.

The number of times a person needs to take medication each day is usually determined by the drug's half-life, or the time it takes for half the drug dose to be metabolized or broken down into other substances in the body. Some drugs, such as phenytoin and phenobarbital, only need to be taken once a day, while others such as valproate must be taken two or three times a day.

Most side effects of antiepileptic drugs are relatively minor, such as fatigue, dizziness, or weight gain. However, severe and life-threatening side effects such as allergic reactions can occur. Epilepsy medication also may predispose people to developing depression or psychoses. People with epilepsy should consult a doctor immediately if they develop any kind of rash while on medication, or if they find themselves depressed or otherwise unable to think in a rational manner. Other danger signs that should be discussed with a doctor immediately are extreme fatigue, staggering or other movement problems, and slurring of words. People with epilepsy should be aware that their epilepsy medication can interact with many other drugs in potentially harmful ways. For this reason, people with epilepsy should always tell doctors who treat them which medications they are taking. Women also should know that some antiepileptic drugs can interfere with the effectiveness of oral contraceptives, and they should discuss this possibility with their doctors.

Since people can become more sensitive to medications as they age, they may need to have their blood levels of medication checked occasionally to see if the dose needs to be adjusted. The effects of a particular medication also sometimes wear off over time, leading to an increase in seizures if the dose is not adjusted. People should know that some citrus fruit, in particular grapefruit juice, may interfere with breakdown of many drugs. This can cause too much of the drug to build up in their bodies, often worsening the side effects.

People taking epilepsy medication should be sure to check with their doctor and/or seek a second medical opinion if their medication does not appear to be working or if it causes unexpected side effects.

Tailoring the dosage of antiepileptic drugs. When a person starts a new epilepsy drug, it is important to tailor the dosage to achieve the best results. People's bodies react to medications in very different and sometimes unpredictable ways, so it may take some time to find the right drug at the right dose to provide optimal control of seizures while minimizing side effects. A drug that has no effect or very bad side effects at one dose may work very well at another dose. Doctors will usually prescribe a low dose of the new drug initially and monitor blood levels of the drug to determine when the best possible dose has been reached.

Generic versions are available for many antiepileptic drugs. The chemicals in generic drugs are exactly the same as in the brand-name drugs, but they may be absorbed or processed differently in the body because of the way they are prepared. Therefore, patients should always check with their doctors before switching to a generic version of their medication.

Discontinuing medication. Some doctors will advise people with epilepsy to discontinue their antiepileptic drugs after 2 years have passed without a seizure. Others feel it is better to wait for 4 to 5 years. Discontinuing medication should **always** be done with a doctor's advice and supervision. It is very important to continue taking epilepsy medication for as long as the doctor prescribes it. People also should ask the doctor or pharmacist ahead of time what they should do if they miss a dose. Discontinuing medication without a doctor's advice is one of the major reasons people who have been seizure-free begin having new seizures. Seizures that result from suddenly stopping medication can be very serious and can lead to status epilepticus. Furthermore, there is some evidence that uncontrolled seizures trigger changes in neurons that can make it more difficult to treat the seizures in the future.

The chance that a person will eventually be able to discontinue medication varies depending on the person's age and his or her type of epilepsy. More than half of children who go into remission with medication can eventually stop their medication without having new seizures. One study showed that 68 percent of adults who had been seizure-free for 2 years before stopping medication were able to do so without having more seizures and 75 percent could successfully discontinue medication if they had been seizure-free for 3 years. However, the odds of successfully stopping medication are not as good for people with a family history of epilepsy, those who need multiple medications, those with partial seizures, and those who continue to have abnormal EEG results while on medication.

Surgery. When seizures cannot be adequately controlled by medications, doctors may recommend that the person be evaluated for surgery. Most surgery for epilepsy is performed by teams of doctors at medical centers. To decide if a person may benefit from surgery, doctors consider the type or types of seizures he or she has. They also take into account the brain region involved and how important that region is for everyday behavior. Surgeons usually avoid operating in areas of the brain that are necessary for speech, language, hearing, or other important abilities. Doctors may perform tests such as a Wada test (administration of the drug amobarbitol into the carotid artery) to find areas of the brain that control speech and memory. They often monitor the patient intensively prior to surgery in order to pinpoint the exact location in the brain where seizures begin. They also may use implanted electrodes to record brain activity from the surface of the brain. This yields better information than an external EEG.

A 1990 National Institutes of Health consensus conference on surgery for epilepsy concluded that there are three broad categories of epilepsy that can be treated successfully with surgery. These include focal seizures, seizures that begin as focal seizures before spreading to the rest of the brain, and unilateral multifocal epilepsy with infantile hemiplegia (such as Rasmussen's encephalitis). Doctors generally recommend surgery only after patients have tried two or three different medications without success, or if there is an identifiable brain lesion--a damaged or dysfunctional area--believed to cause the seizures.

A study published in 2000 compared surgery to an additional year of treatment with antiepileptic drugs in people with longstanding temporal lobe epilepsy. The results showed that 64 percent of patients receiving surgery became seizure-free, compared to 8 percent of those who continued with medication only. Because of this study and other evidence, the American Academy of Neurology (AAN) now recommends surgery for TLE when antiepileptic drugs are not effective. However, the study and the AAN guidelines do not provide guidance on how long seizures should occur, how severe they should be, or how many drugs should be tried before surgery is considered. A nationwide study is now underway to determine how soon surgery for TLE should be performed.

If a person is considered a good candidate for surgery and has seizures that cannot be controlled with available medication, experts generally agree that surgery should be performed as early as possible. It can be difficult for a person who has had years of seizures to fully re-adapt to a seizure-free life if the surgery is successful. The person may never have had an opportunity to develop independence and he or she may have had difficulties with school and work that could have been avoided with earlier treatment. Surgery should always be performed with support from rehabilitation specialists and counselors who can help the person deal with the many psychological, social, and employment issues he or she may face.

While surgery can significantly reduce or even halt seizures for some people, it is important to remember that any kind of surgery carries some amount of risk (usually small). Surgery for epilepsy does not always successfully reduce seizures and it can result in cognitive or personality changes, even in people who are excellent candidates for surgery. Patients should ask their surgeon about his or her experience, success rates, and complication rates with the procedure they are considering.

Even when surgery completely ends a person’s seizures, it is important to continue taking seizure medication for some time to give the brain time to re-adapt. Doctors generally recommend medication for 2 years after a successful operation to avoid new seizures.

Surgery to treat underlying conditions. In cases where seizures are caused by a brain tumor, hydrocephalus, or other conditions that can be treated with surgery, doctors may operate to treat these underlying conditions. In many cases, once the underlying condition is successfully treated, a person’s seizures will disappear as well.

Surgery to remove a seizure focus. The most common type of surgery for epilepsy is removal of a *seizure focus*, or small area of the brain where seizures originate. This type of surgery, which doctors may refer to as a *lobectomy* or *lesionectomy*, is appropriate only for partial seizures that originate in just one area of the brain. In general, people have a better chance of becoming seizure-free after surgery if they have a small, well-defined seizure focus. Lobectomies have a 55-70 percent success rate when the type of

epilepsy and the seizure focus is well-defined. The most common type of lobectomy is a *temporal lobe resection*, which is performed for people with temporal lobe epilepsy. Temporal lobe resection leads to a significant reduction or complete cessation of seizures about 70 - 90 percent of the time.

Multiple subpial transection. When seizures originate in part of the brain that cannot be removed, surgeons may perform a procedure called a *multiple subpial transection*. In this type of operation, which was first described in 1989, surgeons make a series of cuts that are designed to prevent seizures from spreading into other parts of the brain while leaving the person's normal abilities intact. About 70 percent of patients who undergo a multiple subpial transection have satisfactory improvement in seizure control.

Corpus callosotomy. Corpus callosotomy, Corpus callosotomy, or severing the network of neural connections between the right and left halves, or *hemispheres*, of the brain, is done primarily in children with severe seizures that start in one half of the brain and spread to the other side. Corpus callosotomy can end drop attacks and other generalized seizures. However, the procedure does not stop seizures in the side of the brain where they originate, and these partial seizures may even increase after surgery.

Hemispherectomy and hemispherotomy. These procedures remove half of the brain's cortex, or outer layer. They are used predominantly in children who have seizures that do not respond to medication because of damage that involves only half the brain, as occurs with conditions such as Rasmussen's encephalitis, Sturge-Weber syndrome, and hemimegencephaly. While this type of surgery is very radical and is performed only as a last resort, children often recover very well from the procedure, and their seizures usually cease altogether. With intense rehabilitation, they often recover nearly normal abilities. Since the chance of a full recovery is best in young children, hemispherectomy should be performed as early in a child's life as possible. It is rarely performed in children older than 13.

Devices. The vagus nervestimulator was approved by the U.S. Food and Drug Administration (FDA) in 1997 for use in people with seizures that are not well-controlled by medication. The vagus nerve stimulator is a battery-powered device that is surgically implanted under the skin of the chest, much like a pacemaker, and is attached to the vagus nerve in the lower neck. This device delivers short bursts of electrical energy to the brain via the vagus nerve. On average, this stimulation reduces seizures by about 20-40 percent. Patients usually cannot stop taking epilepsy medication because of the stimulator, but they often experience fewer seizures and they may be able to reduce the dose of their medication. Side effects of the vagus nerve stimulator are generally mild, but may include ear pain, a sore throat, or nausea. Adjusting the amount of stimulation can usually eliminate these side effects. The batteries in the vagus nerve stimulator need to be replaced about once every 5 years; this requires a minor operation that can usually be performed as an outpatient procedure.

Several new devices may become available for epilepsy in the future. Researchers are studying whether *transcranial magnetic stimulation*, a procedure which uses a strong magnet held outside the head to influence brain activity, may reduce seizures. They also hope to develop implantable devices that can deliver drugs to specific parts of the brain.

Diet. Studies have shown that, in some cases, children may experience fewer seizures if they maintain a strict diet rich in fats and low in carbohydrates. This unusual diet, called the *ketogenic diet*, causes the body to break down fats instead of carbohydrates to survive. This condition is called ketosis. One study of 150 children whose seizures were poorly controlled by medication found that about one-fourth of the children had a 90 percent or better decrease in seizures with the ketogenic diet, and another half of the group had a 50 percent or better decrease in their seizures. Moreover, some children can discontinue the ketogenic diet after several years and remain seizure-free. The ketogenic diet is not easy to maintain, as it requires strict adherence to an unusual and limited range of foods. Possible side effects include retarded growth due to nutritional deficiency and a buildup of uric acid in the blood, which can lead to kidney stones. People who try the ketogenic diet should seek the guidance of a dietician to ensure that it does not lead to serious nutritional deficiency.

Researchers are not sure how ketosis inhibits seizures. One study showed that a byproduct of ketosis called beta-hydroxybutyrate (BHB) inhibits seizures in animals. If BHB also works in humans, researchers may eventually be able to develop drugs that mimic the seizure-inhibiting effects of the ketogenic diet.

Other treatment strategies. Researchers are studying whether biofeedback—a strategy in which individuals learn to control their own brain waves—may be useful in controlling seizures. However, this type of therapy is controversial and most studies have shown discouraging results. Taking large doses of vitamins generally does not help a person's seizures and may even be harmful in some cases. But a good diet and some vitamin supplements, particularly folic acid, may help reduce some birth defects and medication-related nutritional deficiencies. Use of non-vitamin supplements such as melatonin is controversial and can be risky. One study showed that melatonin may reduce seizures in some children, while another found that the risk of seizures increased measurably with melatonin. Most non-vitamin supplements such as those found in health food stores are not regulated by the FDA, so their true effects and their interactions with other drugs are largely unknown.

How does epilepsy affect daily life?

Most people with epilepsy lead outwardly normal lives. Approximately 80 percent can be significantly helped by modern therapies, and some may go months or years between seizures. However, epilepsy can and does affect daily life for people with epilepsy, their families, and their friends. People with severe seizures that resist treatment have, on average, a shorter life expectancy and an increased risk of cognitive impairment, particularly if the seizures developed in early childhood. These impairments may be related to the underlying conditions that cause epilepsy or to epilepsy treatment rather than the epilepsy itself.

Behavior and emotions. It is not uncommon for people with epilepsy, especially children, to develop behavioral and emotional problems. Sometimes these problems are caused by embarrassment or frustration associated with epilepsy. Other problems may result from bullying, teasing, or avoidance in school and other social settings. In children, these problems can be minimized if parents encourage a positive outlook and independence, do not reward negative behavior with unusual amounts of attention, and try to stay attuned to their child’s needs and feelings. Families must learn to accept and live with the seizures without blaming or resenting the affected person. Counseling services can help families cope with epilepsy in a positive manner. Epilepsy support groups also can help by providing a way for people with epilepsy and their family members to share their experiences, frustrations, and tips for coping with the disorder.

People with epilepsy have an increased risk of poor self-esteem, depression, and suicide. These problems may be a reaction to a lack of understanding or discomfort about epilepsy that may result in cruelty or avoidance by other people. Many people with epilepsy also live with an ever-present fear that they will have another seizure.

Driving and recreation. For many people with epilepsy, the risk of seizures restricts their independence, in particular the ability to drive. Most states and the District of Columbia will not issue a driver’s license to someone with epilepsy unless the person can document that they have gone a specific amount of time without a seizure (the waiting period varies from a few months to several years). Some states make exceptions for this policy when seizures don’t impair consciousness, occur only during sleep, or have long auras or other warning signs that allow the person to avoid driving when a seizure is likely to occur. Studies show that the risk of having a seizure-related accident decreases as the length of time since the last seizure increases. One study found that the risk of having a seizure-related motor vehicle accident is 93 percent less in people who wait at least 1 year after their last seizure before driving, compared to people who wait for shorter intervals.

The risk of seizures also restricts people’s recreational choices. For instance, people with epilepsy should not participate in sports such as skydiving or motor racing where a moment’s inattention could lead to injury. Other activities, such as swimming and sailing, should be done only with precautions and/or supervision. However, jogging, football, and many other sports are reasonably safe for a person with epilepsy. Studies to date have not shown any increase in seizures due to sports, although these studies

have not focused on any activity in particular. There is some evidence that regular exercise may even improve seizure control in some people. Sports are often such a positive factor in life that it is best for the person to participate, although the person with epilepsy and the coach or other leader should take appropriate safety precautions. It is important to take steps to avoid potential sports-related problems such as dehydration, overexertion, and hypoglycemia, as these problems can increase the risk of seizures.

Education and employment. By law, people with epilepsy or other handicaps in the United States cannot be denied employment or access to any educational, recreational, or other activity because of their seizures. However, one survey showed that only about 56 percent of people with epilepsy finish high school and about 15 percent finish college — rates much lower than those for the general population. The same survey found that about 25 percent of working-age people with epilepsy are unemployed. These numbers indicate that significant barriers still exist for people with epilepsy in school and work. Restrictions on driving limit the employment opportunities for many people with epilepsy, and many find it difficult to face the misunderstandings and social pressures they encounter in public situations. Antiepileptic drugs also may cause side effects that interfere with concentration and memory. Children with epilepsy may need extra time to complete schoolwork, and they sometimes may need to have instructions or other information repeated for them. Teachers should be told what to do if a child in their classroom has a seizure, and parents should work with the school system to find reasonable ways to accommodate any special needs their child may have.

Pregnancy and motherhood. Women with epilepsy are often concerned about whether they can become pregnant and have a healthy child. This is usually possible. While some seizure medications and some types of epilepsy may reduce a person's interest in sexual activity, most people with epilepsy can become pregnant. Moreover, women with epilepsy have a 90 percent or better chance of having a normal, healthy baby, and the risk of birth defects is only about 4-6 percent. The risk that children of parents with epilepsy will develop epilepsy themselves is only about 5 percent unless the parent has a clearly hereditary form of the disorder. Parents who are worried that their epilepsy may be hereditary may wish to consult a genetic counselor to determine what the risk might be. Amniocentesis and high-level ultrasound can be performed during pregnancy to ensure that the baby is developing normally, and a procedure called a maternal serum alpha-fetoprotein test can be used for prenatal diagnosis of many conditions if a problem is suspected.

There are several precautions women can take before and during pregnancy to reduce the risks associated with pregnancy and delivery. Women who are thinking about becoming pregnant should talk with their doctors to learn any special risks associated with their epilepsy and the medications they may be taking. Some seizure medications, particularly valproate, trimethadione, and phenytoin, are known to increase the risk of having a child with birth defects such as cleft palate, heart problems, or finger and toe defects. For this reason, a woman's doctor may advise switching to other medications during pregnancy. Whenever possible, a woman should allow her doctor enough time to properly change medications, including phasing in the new medications and checking to determine when blood levels are stabilized, before she tries to become pregnant. Women should also begin prenatal vitamin supplements - especially with folic acid, which may reduce the risk of some birth defects — well before pregnancy. Women who discover that they are pregnant but have not already spoken with their doctor about ways to reduce the risks should do so as soon as possible. However, they should continue taking seizure medication as prescribed until that time to avoid preventable seizures. Seizures during pregnancy can harm the developing baby or lead to miscarriage, particularly if the seizures are severe. Nevertheless, many women who have seizures during pregnancy have normal, healthy babies.

Women with epilepsy sometimes experience a change in their seizure frequency during pregnancy, even if they do not change medications. About 25 to 40 percent of women have an increase in their seizure frequency while they are pregnant, while other women may have fewer seizures during pregnancy. The frequency of seizures during pregnancy may be influenced by a variety of factors, including the woman's increased blood volume during pregnancy, which can dilute the effect of medication. Women should have their blood levels of seizure medications monitored closely during and after pregnancy, and the medication dosage should be adjusted accordingly.

Pregnant women with epilepsy should take prenatal vitamins and get plenty of sleep to avoid seizures caused by sleep deprivation. They also should take vitamin K supplements after 34 weeks of pregnancy to reduce the risk of a blood-clotting disorder in infants called neonatal coagulopathy that can result from fetal exposure to epilepsy medications. Finally, they should get good prenatal care, avoid tobacco, caffeine, alcohol, and illegal drugs, and try to avoid stress.

Labor and delivery usually proceed normally for women with epilepsy, although there is a slightly increased risk of hemorrhage, eclampsia, premature labor, and cesarean section. Doctors can administer antiepileptic drugs intravenously and monitor blood levels of anticonvulsant medication during labor to reduce the risk that the labor will trigger a seizure. Babies sometimes have symptoms of withdrawal from the mother's seizure medication after they are born, but these problems wear off in a few weeks or months and usually do not cause serious or long-term effects. A mother's blood levels of anticonvulsant medication should be checked frequently after delivery as medication often needs to be decreased.

Epilepsy medications need not influence a woman's decision about breast-feeding her baby. Only minor amounts of epilepsy medications are secreted in breast milk; usually not enough to harm the baby and much less than the baby was exposed to in the womb. On rare occasions, the baby may become excessively drowsy or feed poorly, and these problems should be closely monitored. However, experts believe the benefits of breast-feeding outweigh the risks except in rare circumstances.

To increase doctors' understanding of how different epilepsy medications affect pregnancy and the chances of having a healthy baby, Massachusetts General Hospital has begun a nationwide registry for women who take antiepileptic drugs while pregnant. Women who enroll in this program are given educational materials on pre-conception planning and perinatal care and are asked to provide information about the health of their children (this information is kept confidential). Women and physicians can contact this registry by calling 1-888-233-2334 or 617-726-7739 (fax: 617-724-8307).

Women with epilepsy should be aware that some epilepsy medications can interfere with the effectiveness of oral contraceptives. Women who wish to use oral contraceptives to prevent pregnancy should discuss this with their doctors, who may be able to prescribe a different kind of antiepileptic medication or suggest other ways of avoiding an unplanned pregnancy.

Are there special risks associated with epilepsy?

Although most people with epilepsy lead full, active lives, they are at special risk for two life-threatening conditions: status epilepticus and sudden unexplained death (SUDEP).

Status epilepticus. Status epilepticus is a potentially life-threatening condition in which a person either has prolonged seizures or does not fully regain consciousness between seizures. Although there is no strict definition for the time at which a seizure turns into status epilepticus, most people agree that any seizure lasting longer than 5 minutes should, for practical purposes, be treated as though it was status epilepticus. There is some evidence that 5 minutes is sufficient to damage neurons and that seizures are unlikely to end on their own by that time.

Status epilepticus affects about 195,000 people each year in the United States and results in about 42,000 deaths. While people with epilepsy are at an increased risk for status epilepticus, about 60 percent of people who develop this condition have no previous seizure history. These cases often result from tumors, trauma, or other problems that affect the brain and may themselves be life-threatening.

While most seizures do not require emergency medical treatment, someone with a prolonged seizure lasting more than 5 minutes may be in status epilepticus and should be taken to an emergency room immediately. It is important to treat a person with status epilepticus as soon as possible.

The mortality rate of status epilepticus can be fairly high (about 20 percent), especially if treatment is not initiated quickly. One study showed that 80 percent of people in status epilepticus who received medication within 30 minutes of seizure onset eventually stopped having seizures, whereas only 40 percent recovered

if 2 hours had passed before they received medication. Doctors in a hospital setting can treat status epilepticus with several different drugs and can undertake emergency life-saving measures, such as administering oxygen, if necessary. With optimal neurological care, adherence to a medication regimen, and a good prognosis (no no known underlying uncontrolled brain or other organic disease) an individual in good health—even someone who has been diagnosed with epilepsy—can survive with minimal or no brain damage, and can decrease their risk of death, and even avoid these seizures in the future.

Status epilepticus can be divided into two categories: convulsive (in which outward signs of a seizure are observed) and nonconvulsive (which has o outward signs and is diagnosed by an abnormal EEG). Nonconvulsive status epilepticus may appear as a sustained episode of confusion or agitation in someone who does not ordinarily have that kind of mental impairment. While this type of episode may not seem as severe as convulsive status epilepticus, it should still be treated as an emergency.

Sudden unexplained death. For reasons that are poorly understood, people with epilepsy have an increased risk of dying suddenly for no discernible reason. This condition, called sudden *unexplained death*, can occur in people without epilepsy, but epilepsy increases the risk about two-fold. Researchers are still unsure why sudden unexplained death occurs. One study suggested that use of more than two anticonvulsant drugs may be a risk factor. However, it is not clear whether the use of multiple drugs causes the sudden death, or whether people who use multiple anticonvulsants have a greater risk of death because they have more severe types of epilepsy.

What research is being done on epilepsy?

Scientists are studying the underlying causes of the epilepsies in children, adults and the elderly, as well as following brain trauma, stroke, and brain tumors.

Ongoing research is focused on developing new model systems that can be used to more quickly screen potential new treatments for the epilepsies. Scientists continue to study how neurotransmitters interact with brain cells to control nerve firing and how non-neuronal cells in the brain contribute to seizures. New genetic information may allow doctors to prevent the epilepsies or to predict which treatments will be most beneficial to an individual with specific type(s) of the epilepsies. Researchers are continually improving MRI and other brain scans to assist in the diagnosis of the epilepsies and the ability to identify the source (focus) of the seizures in the brain.

Researchers funded by the National Institutes of Health have developed a flexible brain implant that could one day be used to treat seizures. In animal studies, the researchers used the device—a type of electrode array that conforms to the brain's surface—to take an unprecedented look at the brain activity underlying seizures. This research will help determine which individuals are candidates to undergo brain surgery as a treatment for epilepsy.

One new research initiative is focused on the identification of genes that may influence or cause the epilepsies. For more information, see http://www.epgp.org.

Researchers are studying the cause(s) and risk factors that lead to sudden and unexpected death in individuals with epilepsy. Other scientists are investigating novel, innovative approaches to studying the epilepsies. Two new areas of research in the epilepsies include prevention of seizures (anti-epileptogenesis) and the role of inflammation in epilepsy. Researchers are exploring the causes of epilepsy in individuals with specific genetic disorders (Dravet Syndrome, Tuberous Sclerosis Complex, Rett Syndrome), as well as after traumatic brain injury, stroke, or a brain tumor in order to understand the underlying mechanisms that lead to seizures. This research will provide the opportunity to develop new therapies designed to prevent epilepsy from developing in those individuals who are at high risk.

Although little is known about the role of inflammation in the epilepsies, researchers are examining whether activation of the innate immune system and associated inflammatory reactions in the brain may mediate some of the molecular and structural changes occurring during and after seizure activity. Whether the

immune response that takes place in the brain is beneficial or toxic is still an open and intriguing question that is being addressed.

What to do if you see someone having a seizure

If you see someone having a seizure with convulsions and/or loss of consciousness, here's how you can help:

• Roll the person on his or her side to prevent choking on any fluids or vomit.
• Cushion the person's head.
• Loosen any tight clothing around the neck.
• Keep the person's airway open. If necessary, grip the person's jaw gently and tilt his or her head back.
• Do NOT restrict the person from moving unless he or she is in danger.
• Do NOT put anything into the person's mouth, not even medicine or liquid. These can cause choking or damage to the person's jaw, tongue, or teeth. Contrary to widespread belief, people cannot swallow their tongues during a seizure or any other time.
• Remove any sharp or solid objects that the person might hit during the seizure.
• Note how long the seizure lasts and what symptoms occurred so you can tell a doctor or emergency personnel if necessary.
• Stay with the person until the seizure ends.

Call 911 if:

• The person is pregnant or has diabetes.
• The seizure happened in water.
• The seizure lasts longer than 5 minutes.
• The person does not begin breathing again or does not return to consciousness after the seizure stops.
• Another seizure starts before the person regains consciousness.
• The person injures himself or herself during the seizure.
• This is a first seizure or you think it might be. If in doubt, check to see if the person has a medical identification card or jewelry stating that they have epilepsy or a seizure disorder.

After the seizure ends, the person will probably be groggy and tired. He or she also may have a headache and be confused or embarrassed. Be patient with the person and try to help him or her find a place to rest if he or she is tired or doesn't feel well. If necessary, offer to call a taxi, a friend, or a relative to help the person get home safely.

If you see someone having a non-convulsive seizure, remember that the person's behavior is not intentional. The person may wander aimlessly or make alarming or unusual gestures. You can help by following these guidelines:

• Remove any dangerous objects from the area around the person or in his or her path.
• Don't try to stop the person from wandering unless he or she is in danger.
• Don't shake the person or shout.
• Stay with the person until he or she is completely alert.

Conclusion

Many people with epilepsy lead productive and outwardly normal lives. Many medical and research advances in the past two decades have led to a better understanding of epilepsy and seizures than ever before. Advanced brain scans and other techniques allow greater accuracy in diagnosing epilepsy and determining when a patient may be helped by surgery. More than 20 different medications and a variety of surgical techniques are now available and provide good control of seizures for most people with epilepsy. Other treatment options include the ketogenic diet and the first implantable device, the vagus nerve stimulator. Research on the underlying causes of epilepsy, including identification of genes for some forms of epilepsy and febrile seizures, has led to a greatly improved understanding of epilepsy that may lead to more effective treatments or even new ways of preventing epilepsy in the future.

Information resources

BRAIN
P.O. Box 5801
Bethesda, Maryland 20824
800-352-9424
www.ninds.nih.gov

Charlie Foundation to Help Cure Pediatric Epilepsy
515 Ocean Avenue, Suite 602N
Santa Monica, California 90402
(310) 395-6751
www.charliefoundation.org

Citizens United for Research in Epilepsy (CURE)
223W. Erie, Suite 2 SW
Chicago, IL 60654
312-255-1801, 800-765-7118
www.CUREepilepsy.org

Epilepsy Foundation
8301 Professional Place
Landover, Maryland 20785
301-459-3700, 800-332-1000
www.epilepsyfoundation.org

People Against Childhood Epilepsy (PACE)
7 East 85th Street, Suite A3
New York, New York 10028
(212) 665-PACE (7223)
www.paceusa.org

Antiepileptic Drug Pregnancy Registry
Massachusetts General Hospital
121 Innerbelt Road, Room 220
Somerville, Massachusetts 02143
888-233-2334
www.aedpregnancyregistry.org

Epilepsy Therapy Project
P.O. Box 742
10 N Pendelton Street
Middleburg, VA 20118
www.epilepsy.com/
540-687-8077

This information was developed by the National Institute of Neurologic Disorders and Stroke.

National Institute of Neurologic Disorders and Stroke. Seizures and Epilepsy: Hope Through Research. Available at: http://www.ninds.nih.gov/disorders/epilepsy/detail_epilepsy.htm. Last accessed January 10, 2014.

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