



Epilepsy Fact Sheet

DEFINITION: Epilepsy is the general term for a variety of seizure disorders characterized by recurring, unprovoked seizures.

SEIZURE: A seizure is a brief disturbance in the electrical activity of the brain that causes temporary changes in movement, awareness, feelings, or behavior. Up to thirty million Americans (one in every ten) have had, or will have, at least one seizure at some time in their lives.

PREVALENCE: Epilepsy is the fourth most common neurological disorder in the United States after Alzheimer's disease, stroke, and migraine. It is greater in prevalence than cerebral palsy, multiple sclerosis and Parkinson's disease combined. Nearly three million people (one percent of the population) in the United States have some form of epilepsy. Nearly four percent of Americans (1 in 26) will develop epilepsy at some point in their lives. The Epilepsy Foundation of Michigan estimates that over 100,000 people in the state have the disorder. In addition, a large number of adults and children have undetected or untreated epilepsy.

Epilepsy is prevalent among other disability groups such as autism (25.5%), cerebral palsy (13%), Down syndrome (13.6%), and intellectual disability (25.5%). For people with both cerebral palsy and intellectual disability, the prevalence of epilepsy is 40%.

INCIDENCE: About 150,000 new cases are diagnosed each year in the United States.

AGE OF ONSET: Anyone can develop epilepsy at any time. Incidence is highest among the very young and the very old.

CAUSES: In about 60% of cases, there is no known cause. Among the remaining 40%, the following causes are most frequent:

- **Traumatic brain injury**—the more severe the injury, the greater the risk of developing epilepsy
- **Disorders of brain development**—congenital abnormalities of the brain, malformations of blood vessels, autism, cerebral palsy, intellectual disability, and others
- **Brain tumor, stroke, and Alzheimer's disease**
- **Poisoning**—including lead poisoning, alcohol or drug abuse, and environmental toxins
- **Infection**—meningitis, encephalitis, and, in some cases, measles, diphtheria, and others

ROLE OF

HEREDITY:

All people inherit varying degrees of susceptibility to seizures. The genetic factor is assumed to be greater in generalized epilepsy, when seizures start early in life, and when no specific cause can be identified. Children of a parent with epilepsy have only about a 6% chance of developing epilepsy, with the risk being greater when the mother has it than when the father does.

TREATMENT:

Modern medical treatment methods can achieve complete or nearly complete control of seizures in about 60 – 70% of cases. In many cases, however, seizures are highly resistant to current therapies.

Medication—The major form of treatment is long-term antiepileptic drug therapy. Over 20 antiepileptic drugs are currently in use. While multiple-drug therapy is sometimes necessary, single-drug therapy is more common.

Surgery—When medication has failed, surgery may be an option. The most common form takes place when the tissue causing seizures is confined to a small area of the brain that can be safely removed without damaging personality or function.

Responsive Neurostimulation—The Responsive Neurostimulation System (RNS System) monitors electrical activity in the brain and delivers stimulation to the seizure focus when the onset of a seizure is detected. The device is implanted in the brain and skull and can sometimes prevent a seizure before it happens.

Vagus Nerve Stimulator—This device, implanted under the skin on the chest wall, periodically stimulates the brain through the vagus nerve and can reduce seizures in some patients.

Ketogenic Diet—This doctor-prescribed, high-fat, low-carbohydrate, reduced-calorie diet may succeed in some childhood cases when standard treatment fails.

SEIZURE TYPES:

There are over 20 different seizure classifications. The following are some of the more common types:

Generalized Tonic Clonic Seizure (formerly called grand mal): sudden fall and period of rigidity followed by muscle jerks, shallow breathing, pale or bluish skin, and possible vomiting or loss of bowel or bladder control; usually lasts a couple of minutes; normal breathing and complexion return promptly; some confusion and/or fatigue may occur, followed by a return of full consciousness.

Absence Seizure (formerly called petit mal): most common in children; looks like a blank stare; lasts for only a few seconds; may be accompanied by rapid blinking or chewing movements; person will be unaware of what happened during seizure, but will quickly return to full consciousness once the seizure has stopped; seizures often occur frequently throughout the day; *atypical absence seizures* begin and end more gradually and may last a bit longer; absence seizures may be mistaken for ADHD, behavior problems, or learning disabilities.

Drop Seizure: includes two distinct types of seizures, tonic and atonic—both which frequently result in falling; in a tonic seizure, there is a sudden or gradual stiffening of the body, which often causes the individual to fall if standing; atonic seizures cause a sudden loss of muscle tone that may cause a drop of the head or fall to the ground; with both types of seizures, if consciousness is lost, the person usually regains it promptly with little

or no confusion; because people with these seizures fall so suddenly, many have to wear helmets.

Myoclonic Seizure: seizure in which the primary symptom is one or more sudden, involuntary, brief, shock-like bodily jerks caused by contractions of one or more muscles or muscle groups; often associated with childhood epilepsy syndromes.

Complex Partial Seizure: usually starts with blank stare, followed by chewing, walking about, random movements, vocalizations, picking at clothing, and other actions that the individual cannot control; person is unresponsive and awareness of surroundings is clouded; usually lasts 1-2 minutes; person will have no memory of what happened during the seizure and may be confused for several minutes after the seizure has stopped; in some cases, complex partial seizures may simply look like prolonged absence seizures; may be mistaken for mental illness, drug use, intoxication, aggression, or behavior problems.

Simple Partial Seizure: person is fully aware during the seizure; may involve jerking or other body movements, sensory distortions or hallucinations, unusual physical or emotional feelings, and other symptoms that are not obvious to the onlooker; may lead to another seizure.

FIRST AID:

For tonic clonic and complex partial seizures, remain calm, and check your watch or a clock once the seizure starts (to time the duration of the seizure). When the seizure ends, ask the person his or her name and location and help to reorient. If disorientation or fatigue persists, allow the person to rest somewhere comfortable.

For complex partial seizures, gently redirect from, block, or remove hazards. Explain what is happening to bystanders. Do not restrain forcefully.

For tonic clonic seizures, lower the person to the floor to prevent falls and injuries. Gently turn the person on one side to keep the airway open. Place a soft object under the person's head (e.g. a sweater or pillow) or cradle the head with your hand. Gently loosen any restrictive clothing and remove glasses. Move any potentially dangerous objects in the immediate area. If possible, cover the person with a blanket to maintain dignity (some people may lose bowel or bladder control during a seizure).

DO NOT...

- place anything in the mouth of someone having a seizure or touch or hold the tongue.
- restrain the person having a seizure.
- administer liquids or foods until the person is fully conscious.
- attempt to give oral medications during the seizure.
- administer oxygen or CPR during the seizure.

CALL 911 IF...

- the seizure lasts for more than 5 minutes.
- the seizure stops and is followed by another seizure without the person fully regaining consciousness.
- this is the person's first seizure or if you don't know whether or not the person has had a seizure before [NOTE: if the person has a medical ID or jewelry that says "epilepsy," there is no need to call].

- the seizure takes place in water.
- the person is injured during the seizure (especially the head).
- the person has diabetes or is pregnant.
- normal breathing or complexion does not return after the seizure has stopped.

FOR PEOPLE IN WHEELCHAIRS... lowering them to the floor is generally unnecessary and may cause additional injury. It is easier to try to maintain them in a sitting position in the wheelchair. Do this by following these steps:

- Stand behind the chair. Gently slip your arms under the person's arms to support the body in a sitting position.
- Support the person's chin in a neutral position to facilitate breathing.
- Remain with the person, monitoring respiratory status until fully recovered.

**MAJOR
PROBLEMS:**

Treatment—Despite available therapies, about one third of all cases show little or no improvement as a result of treatment and have seizures that are considered intractable. New medications with fewer side effects are desperately needed both for cases resistant to treatment and for patients under multiple-drug therapy for whom single-drug therapy is not yet possible.

Diagnosis—There are more than 40 different types of epilepsy. Recent international reclassification of symptoms, along with improved brain wave monitoring technology, new and efficient methods to precisely measure blood drug levels, non-invasive brain imaging, and brain function measurement technologies, now permit the more specific diagnosis and treatment of epilepsy. Convulsive seizures are easily recognized, but there are other less apparent forms of epilepsy marked by non-convulsive seizure types. Early diagnosis and treatment is crucial. Children and adults with undiagnosed or ineffectively treated seizures risk developing a more severe, more difficult-to-treat condition.

Unemployment/Underemployment—Twenty to thirty percent of people with epilepsy who are physically able to work are unemployed. Many of those who are employed have been forced to accept positions far below their ability and educational achievement. For many people, having epilepsy has been less of a problem than overcoming negative attitudes about their intellectual and physical abilities. Changes in the law, like parts of the Americans with Disabilities Act (ADA), and public education efforts offer hope in this area.

Impact on Children—The National Center for Health Statistics reports 422,000 cases of epilepsy in children 18 years of age and under, based on the 1988 National Health Interview Survey. Of these children, 65.5 percent have special needs ("condition caused problems during the past year, such as missing school, staying in bed, or feeling upset most or all of the time"). In addition, children with epilepsy are at special risk of learning difficulties.

Mortality—Epilepsy carries an increased risk of death from a variety of causes. Most seizures are benign, but a prolonged seizure can evolve into status epilepticus, a condition that sometimes leads to brain injury and, occasionally, death. People with epilepsy also have a greater than average risk for suicide, sudden unexpected death, and accidental death, especially drowning.

Transportation—In many cases, people with epilepsy are dependent on friends, family, or public transportation to get where they need to go. The limited availability of such

assistance often acts as a major barrier to employment, health care, socialization, and much more.

Social and Emotional Effects—Depression, isolation, stress, and fear of having seizures are all common consequences of epilepsy. Lack of public understanding and the persistent stigma associated with epilepsy only compound these problems.

Memory and Thinking Difficulties – Epilepsy Foundation of Michigan’s 2008 Needs Assessment Survey showed that memory and thinking problems limited quality of life in 90% of respondents. In fact, memory problems were cited more often and had a greater impact on quality of life than seizures.

A Worldwide

Problem:

The World Health Organization estimates there are 50 million people with epilepsy throughout the world. The annual incidence in third world nations is twice that of the United States (100/100,000 compared to 50/100,000). In many countries, epilepsy remains a stigmatizing condition surrounded with mystical beliefs and social taboos. On a global basis, an astonishing 75% of people with epilepsy receive no treatment for their seizures.

For more information on epilepsy, please contact Epilepsy Foundation of Michigan at 800-377-6226 or visit our website at www.epilepsymichigan.org.

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