



Epilepsy Fact Sheet

DEFINITION: Epilepsy is the general term for a variety of neurological conditions characterized by recurrent, 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 half of all cases, the cause is either unknown or presumed to be genetic. Among the remaining half, the following are possible causes:

- **Brain injury**—traumatic brain injury or prenatal/birth injury (e.g. lack of oxygen)
- **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**
- **Infection**—meningitis, encephalitis, and, in some cases, measles, diphtheria, and others
- **Poisoning**—including lead poisoning, alcohol or drug abuse, and environmental toxins

ROLE OF

GENETICS:

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. In addition, some epilepsies are related to new genetic mutations and are not inherited.

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 30 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.

Generalized 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.

Atonic Seizure: sudden loss of muscle tone that may cause a drop of the head or fall to the ground; the person usually regains consciousness promptly with little or no confusion; typically lasts less than 15 seconds; because people with these seizures fall so suddenly, many have to wear helmets.

Tonic Seizure: sudden stiffening of the body, which may cause a fall if standing; most often occurs during sleep; the person usually regains consciousness promptly with little or no confusion; typically lasts less than 20 seconds

Myoclonic Seizure: sudden, involuntary, brief, shock-like bodily jerk caused by contractions of one or more muscles or muscle groups; often occur in clusters

Focal Impaired Awareness Seizure (Complex Partial Seizure): usually starts with blank stare, followed by chewing, walking about, random movements, vocalizations, picking at clothing, or other actions that the individual cannot control (automatisms); 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.

Focal Aware Seizure (Simple Partial Seizure): person is fully aware during the seizure; may involve jerking or other body movements, sensory distortions or hallucinations, changes in thinking or emotions, changes in bodily functions, or other symptoms that are not obvious to the onlooker; referred to as an aura if it precedes another seizure

Focal to Bilateral Tonic-Clonic Seizure (Secondarily Generalized Seizure): seizure that begins in one part of the brain and spreads to both sides of the brain to become a tonic-clonic 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 911].
- 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 60 different types of epilepsy. Recent international reclassification of symptoms, improved brain wave monitoring technology, 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—About 460,000 children in the U.S. have epilepsy. While some will eventually outgrow their epilepsy, many continue to struggle with seizures into adulthood. Epilepsy and its treatment can also impact school performance and social integration. With appropriate supports, however, children with epilepsy can succeed in school and beyond.

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 developing countries is twice that of the United States. 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 do not get the treatment they need 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.**

Epilepsy Foundation of Michigan

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