



Epilepsy: Just the Facts

About Epilepsy

- Epilepsy is a medical condition that produces seizures affecting a variety of mental and physical functions. It's also called a *seizure disorder*. When a person has two or more seizures, they are considered to have epilepsy.
- Epilepsy is among the least understood of major chronic medical conditions, even though one in three adults knows someone with the disorder.¹
- Approximately 1 in 26 people will develop epilepsy at some point in their lives.²
- Epilepsy is not a single entity, but a family of more than 40 syndromes.³
- Epilepsy affects over 2.2 million people in the U.S.⁴ and 65 million worldwide.⁵

Prevalence

- Epilepsy is the fourth most common neurological disorder in the United States after Alzheimer's disease and stroke.⁶ Its prevalence is greater than that of cerebral palsy, multiple sclerosis and Parkinson's disease combined.⁷
- This year another 200,000 people in the U.S. will be diagnosed with epilepsy.⁸
- Some 40 percent of people with epilepsy are severely affected and continue to have seizures despite treatment.⁹

Cost

- Epilepsy imposes an annual economic burden of \$17.6 billion¹⁰ on the nation in associated health care costs and losses in employment, wages and productivity.
- Epilepsy and its treatment may impact someone's quality of life with side effects such as pain, depression, anxiety, reduced vitality and insufficient sleep or rest—similar to arthritis, heart problems, diabetes and cancer.¹¹

Age of Onset

- Epilepsy strikes most often among the very young and the very old, although anyone can develop it at any age. In the U.S., it currently affects more than 326,000 children under the age of fifteen, more than 90,000 of whom have severe seizures that cannot be adequately treated.¹²
- The number of cases in the elderly is beginning to soar as the baby boom generation approaches retirement age. Currently more than 570,000 adults age 65 and above in the U.S. have the condition.¹³

Mortality

- The mortality rate among people with epilepsy is two to three times higher—and the risk of sudden death is 24 times greater—than that of the general population.¹⁴
- The risk of death increases for people with epilepsy, with an estimated 10 years of life lost for people whose epilepsy has a known cause and 2 years lost for people with epilepsy from an unknown cause.¹⁵
- This year an estimated 25,000 to 50,000 will die of seizures and related causes, including status epilepticus (non-stop seizures), sudden unexpected death in epilepsy (SUDEP), drowning and other accidents.¹⁶

Stigma

- The leading non-medical problem confronting people with epilepsy is discrimination in education, employment and social acceptance.¹⁷

- Some people with epilepsy do not even know they have it because they've been told they have a seizure disorder instead. This euphemism arose because of the stigma associated with epilepsy, a stigma that the Epilepsy Foundation and others have fought to dispel.¹⁸

Diagnosis and Treatment

- On average, it is 14 years between the onset of epilepsy and surgical intervention for seizures uncontrollable by medication. American physicians may be unaware of the safety and efficacy of epilepsy surgery, making it among the most underused of proven, effective therapeutic interventions in the field of medicine.¹⁹
- Lack of knowledge about proper seizure first aid exposes affected individuals to injury from unnecessary restraint and from objects needlessly forced into their mouths.²⁰

Co-Morbidity

- Epilepsy is prevalent among those with other disabilities, such as autism (25.4 percent), cerebral palsy (13 percent), Down syndrome (13.6 percent), and mental retardation (25.5 percent)—while 40 percent of adults who have both cerebral palsy and mental retardation also have epilepsy.²¹
- The association between epilepsy and depression is especially strong. More than one of every three persons with epilepsy are also affected by the mood disorder, and people with a history of depression are 3 to 7 times more likely to develop epilepsy than the average person.²²

¹ Kobau R, Price P. Knowledge of epilepsy and familiarity with this disorder in the U.S. population: Results from the 2002 HealthStyles survey. *Epilepsia*. 2003;44(11):1449–1454.

² M.J. England et al. / *Epilepsy & Behavior* 25 (2012) 266–276. Web site, <http://iom.edu/~media/Files/Report%20Files/2012/Epilepsy/epilepsyEBarticleFinal.pdf>

³ National Institute of Neurological Disorders and Stroke. Web site, <http://www.ninds.nih.gov/>

⁴ Projection based on Begley CE, et al. The cost of epilepsy in the United States: An estimate from population-based clinical and survey data. *Epilepsia*. 2000;41(3):342–351 and U.S. Census Bureau 2010 population estimate of 308,000,000.

⁵ Annual Report 2003: Global Campaign Against Epilepsy, p. 2. Published by World Health Organization, International Bureau for Epilepsy and International League Against Epilepsy.

⁶ Hauser A. Epidemiology of seizures and epilepsy in the elderly. In: Rowan A, Ramsay R, eds. *Seizures and epilepsy in the elderly*. Boston: Butterworth-Heinemann, 1997:7–18.

⁷ National Academies, Institute of Medicine, *Epilepsy Across the Spectrum: Promoting Health and Understanding*, 2012. Accessed at: <http://www.iom.edu/~/media/Files/Reports/2012/Epilepsy-Across-the-Spectrum.aspx> Cerebral palsy (764,000), multiple sclerosis (350,000–500,000), Parkinson's disease (1.5 million) equal 2,614,000–2,764,000.

⁸ See note 4 above.

⁹ The prevalence of intractable epilepsy ranges from less than 25 percent to over 44 percent dependant on the source. (A figure of 44 percent is cited in the Epilepsy Foundation's National Cost of Epilepsy Study.) The range is narrowed in this fact sheet to simplify the conflicting reports.

¹⁰ Begley, op.cit. Reported cost of \$12.5 billion for prevalent cases in 1995 is converted here to 2009 dollar value using Bureau of Labor Statistics automated online constant dollars conversion calculator.

¹¹ From Centers for Disease Control and Prevention. Health-related quality of life among persons with epilepsy. *JAMA*, 2001;285(7):878.

¹² See note 4 above.

¹³ See note 4 above.

¹⁴ Ficker, DM. Sudden unexplained death and injury in epilepsy. *Epilepsia*. 2000;41(Suppl 2):S7–S12.

¹⁵ Institute of Medicine, “Highlights from Epilepsy Across the Spectrum: Promoting Health and Understanding.” National Academies, Institute of Medicine, *Highlights from Epilepsy Across the Spectrum: Promoting Health and Understanding A Focus on Mortality and Sudden Unexpected Death in Epilepsy, 2012*. Accessed at:

<http://www.iom.edu/~media/Files/Report%20Files/2012/Epilepsy/IOM%20Report%20Highlights%20for%20PAME%20Conference.pdf>

¹⁶ Data from DeLorenzo, et al, Virginia Medical College (22,000–42,000 annual deaths from status epilepticus) to which an assumed increase from SUDEP, accidents, and other direct causes are added. Note that it is expressed in terms of “deaths due to seizures” rather than “deaths due to epilepsy,” as half of status cases occur in people with no prior history of seizures or epilepsy.

¹⁷ Morrell MD, Pedley, TA. “The scarlet E”: Epilepsy is still a burden. *Neurology*. 2000;54:1882–83. The major portion of advocacy activity conducted by the Epilepsy Foundation and its local affiliates focuses on discriminatory issues and practices.

¹⁸ Epilepsy Foundation, Professional Advisory Board.

¹⁹ Engel, JR Jr. A greater role for surgical treatment of epilepsy: Why and when? *Epilepsy Currents*. 2003;3(2):37–40.

²⁰ Repeated surveys by the Epilepsy Foundation, the previously cited CDC report, and numerous other surveys have documented the low level of public knowledge about seizures and epilepsy, including persistent misconceptions about seizure first aid.

²¹ McDermott S, Moran R. Prevalence of epilepsy in adults with mental retardation and related disabilities in primary care. *American Journal of Mental Retardation*. 2005;10(1):48–56.

²² Kanner AM. Depression and epilepsy: A new perspective on two closely related disorders. *Epilepsy Currents*. 2006;6(5):141–46.