

# EPILEPSY: JUST THE FACTS

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## Epilepsy

- Epilepsy is a neurological disorder defined by recurring seizures that are not provoked by another reversible medical problem. A person is diagnosed with epilepsy if an individual has:
  - At least one unprovoked seizure with a risk of more (or recurring) seizures
  - A form of reflex seizures, which means that seizures may be triggered or provoked by specific situations or stimuli, or
  - Been diagnosed with a specific epilepsy syndrome.
- Epilepsy is among the least understood of major chronic medical conditions, even though one in three adults knows someone with the disorder.<sup>1</sup>
- Epilepsy is made up of many different types of seizures or syndromes, affects people throughout the lifespan, and can have many different causes and associated conditions.

## Prevalence

- Epilepsy affects at least 3.4 million people in the U.S. and 65 million people worldwide.<sup>2</sup>
- 1.2% of U.S. adults and children are estimated to have active epilepsy.<sup>3</sup>
- It is estimated that 1 in 26 people will develop epilepsy at some point in their life.
- Epilepsy is the fourth most common neurological disorder in the United States after migraine, stroke, and Alzheimer's disease.<sup>4</sup> Its prevalence is greater than that of cerebral palsy, multiple sclerosis and Parkinson's disease combined.<sup>5</sup>
- Each year, approximately 150,000 people in the U.S. are diagnosed with epilepsy.<sup>6</sup>

## Cost

- Epilepsy imposes an annual economic burden of \$15.5 billion on the nation in associated health care costs and losses in employment, wages, and productivity.<sup>7</sup>
- Epilepsy and its treatment may impact someone's quality of life with side effects such as pain from seizure-related injuries, depression, anxiety, sleep disorders or insufficient sleep or rest, or injuries—similar to arthritis, heart problems, diabetes and cancer.<sup>8</sup> These quality of life factors result in higher costs associated with epilepsy that are difficult to quantify.

## Age of Onset

- Epilepsy strikes most often among the very young and the very old, although anyone can develop it at any age.<sup>9</sup> Veterans are at higher risk of developing epilepsy than the public because they are more likely to have traumatic brain injuries (TBI) and post-traumatic stress disorder (PTSD).<sup>10</sup>
- About 3 million adults aged 18 years or older have active epilepsy and currently more than 470,000 children ages 0 to 17 years are living with epilepsy in the United States.<sup>11</sup>
- Nearly 1 million of those adults living with active epilepsy are aged 55 or older. Epilepsy is also more likely to develop in older adults.<sup>12</sup>

## Mortality

- The mortality rate among people who have epilepsy is 1.6 to 3 times higher than that of the general population.
- The most common cause of death is SUDEP, or sudden unexpected death in epilepsy.
- Each year, about 1 in 1,000 adults and 1 in 4,500 children with epilepsy die from SUDEP. This is the leading cause of death in people with uncontrolled seizures. More people die from SUDEP each year than from sudden infant death syndrome (SIDS) and accidental exposure to fires, flames and smoke combined
- There is an increased risk of premature death for people with epilepsy. The risk of dying early for people with epilepsy is greater for those with uncontrolled seizures.

## Stigma

- A major issue of concern is stigma; stigma manifests itself in the form of discrimination against people who have epilepsy as it relates to their education, employment, and even social acceptance.<sup>13</sup> People with epilepsy may also fear the perception that epilepsy has a stigma.

- Some people do not even know they have epilepsy 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.<sup>14</sup>

## Diagnosis and Treatment

- Epilepsy is typically treated by medication first. If medications do not control seizures, other treatments may be tried, including, surgery, vagus nerve stimulation, responsive neurostimulator, and dietary therapies.
- New approaches to medications, surgeries, devices, and other therapies are being explored to try and close the treatment gap for people with poorly controlled epilepsy.
- As much as 30% to 40% of people with epilepsy have seizures that do not respond to medication or their medications are not working well enough.<sup>15</sup>

## Co-Morbidity

- The association between epilepsy and depression is especially strong. More than one of every three persons with epilepsy are also affected by a mood disorder, with rates as high as 1 in 2 for people with poorly controlled seizures. People with a history of depression also are 3 to 7 times more likely to develop epilepsy than the average person.<sup>16</sup>
- Other common comorbidities include migraine headaches and anxiety in adults and behavioral problems in children, such as attention deficit disorder and learning disorders.
- Some co-morbidities caused by the same condition affecting the brain that is the cause of the epilepsy include cognitive impairment, hemiparesis, cerebral palsy, focal neurological deficits from stroke, and similar focal neurological conditions.

<sup>1</sup> 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. [http://www.ninds.nih.gov/disorders/epilepsy/detail\\_epilepsy.htm#254753109](http://www.ninds.nih.gov/disorders/epilepsy/detail_epilepsy.htm#254753109)

<sup>2</sup> Ngugi, A., Bottomley, C., Kleinschmidt, I., Sander, J., & Newton, C. (2010). Estimation of the burden of active and life-time epilepsy: A meta-analytic approach. *Epilepsia*, 51(5), 883-890. doi: 10.1111/j.1528-1167.2009.02481.

<sup>3</sup> Zack MM, Kobau R. National and State Estimates of the Numbers of Adults and Children with Active Epilepsy — United States, 2015. *MMWR Morb Mortal Wkly Rep* 2017;66:821–825. DOI: <http://dx.doi.org/10.15585/mmwr.mm6631a1>. Retrieved from CDC <https://www.cdc.gov/mmwr/volumes/66/wr/mm6631a1.htm>

<sup>4</sup> Introduction." *Epilepsy Across the Spectrum: Promoting Health and Understanding*. Washington, DC: The National Academies Press, 2012 Page 24.

<sup>5</sup> Cerebral palsy (207,000), multiple sclerosis (266,000), plus Parkinson's disease (349,000)" 1 Introduction." *Epilepsy Across the Spectrum: Promoting Health and Understanding*. Washington, DC: The National Academies Press, 2012. Page 25.

<sup>6</sup> Epidemiology and Prevention." *Epilepsy Across the Spectrum: Promoting Health and Understanding*. Washington, DC: The National Academies Press, 2012 .Page 111.

<sup>7</sup> National Institute of Neurological Disorders and Stroke. Last updated December 6, 2017. Website [http://www.ninds.nih.gov/disorders/epilepsy/detail\\_epilepsy.htm#254883109](http://www.ninds.nih.gov/disorders/epilepsy/detail_epilepsy.htm#254883109)

<sup>8</sup> David E. Friedman, Shahidul Islam, Alan B. Ettinger, Health-related quality of life among people with epilepsy with mild seizure-related head injuries, *Epilepsy & Behavior*, Volume 27, Issue 3, June 2013, Pages 492-496, ISSN 1525-5050, <http://dx.doi.org/10.1016/j.yebeh.2013.02.009>.(<http://www.sciencedirect.com/science/article/pii/S1525505013000590>)

<sup>9</sup> Introduction ." *Epilepsy Across the Spectrum: Promoting Health and Understanding* . Washington, DC: The National Academies Press, 2012 Page 26.

<sup>10</sup>Centers for Disease Control and Prevention. Epilepsy in Veterans. Last updated November 9, 2017 <https://www.cdc.gov/features/epilepsy-in-veterans/index.html>

<sup>11</sup> Centers for Disease Control and Prevention. *Epilepsy Fast Facts*. Last updated April 23, 2018 [http://www.cdc.gov/epilepsy/basics/fast\\_facts.htm](http://www.cdc.gov/epilepsy/basics/fast_facts.htm)

<sup>12</sup> Centers for Disease Control and Prevention. *Epilepsy and Seizures in Older Adults*. Last updated May 15, 2018 <https://www.cdc.gov/features/epilepsy-older-adults/index.html>

<sup>13</sup> Paula T. Fernandes, Dee A. Snape, Roy G. Beran, Ann Jacoby, Epilepsy stigma: What do we know and where next?, *Epilepsy & Behavior*, Volume 22, Issue 1, September 2011, Pages 55-62, ISSN 1525-5050, <http://dx.doi.org/10.1016/j.yebeh.2011.02.014>. (<http://www.sciencedirect.com/science/article/pii/S1525505011000709>)

<sup>14</sup> Epilepsy Foundation, Professional Advisory Board.

<sup>15</sup> National Institute of Neurological Disorders and Stroke. Last updated December 6, 2017. Website [http://www.ninds.nih.gov/disorders/epilepsy/detail\\_epilepsy.htm#254883109](http://www.ninds.nih.gov/disorders/epilepsy/detail_epilepsy.htm#254883109)

<sup>16</sup> Kanner AM. Depression and epilepsy: A new perspective on two closely related disorders. *Epilepsy Currents*. 2006;6(5):141-46.