



## 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 a person 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 million people in the U.S (1% of U.S. adults and 0.6% of children are estimated to have active epilepsy).<sup>2</sup> and 65 million people worldwide.<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. will be diagnosed with epilepsy.<sup>6</sup>
- About 30% percent of people with epilepsy have seizures that do not respond to medication or their medications are not working well enough.<sup>7</sup>

### Cost

- Epilepsy imposes an annual economic burden of \$19.26 billion on the nation in associated health care costs and losses in employment, wages and productivity.<sup>8</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>9</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>10</sup>
- Currently more than 460,000 children age 0 to 17 years are living with epilepsy in the United States.<sup>11</sup>
- The yearly incidence of epilepsy among elderly people between the ages of 65 and 69 is 90 per 100,000, but it rises to more than 150 per 100,000 for those over 80.<sup>12</sup>
- The number of cases in the elderly is beginning to soar as baby boomers enter retirement age. Currently, more than 570,000 adults age 65 and above in the U.S. have the condition.<sup>13</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.
- The yearly incidence of SUDEP in the U.S. is 1.22 out of 1,000 people with epilepsy. Approximately 2,750 people with epilepsy died of SUDEP in 2013 in the U.S.
- There is an increased risk of premature death for people with epilepsy. People with epilepsy due to a known cause live 10 years less than average and even those without a known cause live 2 years less than average. The risk of dying early for people with epilepsy is greater for people with poorly controlled 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>14</sup> People with epilepsy may also fear the perception that epilepsy has a stigma even when this isn't manifest.
- Some people with epilepsy 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>15</sup>

## Diagnosis and Treatment

- One in every three people who have epilepsy have seizures that do not respond to medication.<sup>16</sup>
- Epilepsy is typically treated by medication first. If medications do not control seizures, other treatments may be tried, including, surgery, vagus nerve stimulation, responsive neurostimulation, 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.

## 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>17</sup>
- Other common co-morbidities 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> Kobau, R., Yuo, Y., Zack, M., Helmers, S., & Thurman, D. Centers for Disease Control and Prevention, MMWR. (2012). *Morbidity and mortality weekly report* (61). Retrieved from U.S. Government Printing Office website: [http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6145a2.htm?s\\_cid=mm6145a2\\_e](http://www.cdc.gov/mmwr/preview/mmwrhtml/mm6145a2.htm?s_cid=mm6145a2_e)

<sup>3</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>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 February 14, 2014. Web site, [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> Begley, op.cit. Reported cost of \$12.5 billion for prevalent cases in 1995 is converted here to 2014 dollar value using Bureau of Labor Statistics automated online constant dollars conversion calculator.

<sup>9</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>10</sup> Introduction." *Epilepsy Across the Spectrum: Promoting Health and Understanding*. Washington, DC: The National Academies Press, 2012. Page 26.

<sup>11</sup> Centers for Disease Control and Prevention. *Epilepsy Fast Facts*. Last updated January 16, 2013. [http://www.cdc.gov/epilepsy/basics/fast\\_facts.htm](http://www.cdc.gov/epilepsy/basics/fast_facts.htm)

<sup>12</sup> Wallace, H., Shorvon, S., & Tallis, R. (1998). The annual incidence of epilepsy (recurrent unprovoked seizures) rises from 90 per 100 000 in people between the ages of 65 and 69 to more than 150 per 100 000 for those over 80. *Lancet*, 352(9145), 1970-3. Retrieved from <http://www.ncbi.nlm.nih.gov/pubmed/9872246/>

<sup>13</sup> Annual Report 2003: Global Campaign Against Epilepsy, p. 2. Published by World Health Organization, International Bureau for Epilepsy and International League Against Epilepsy.

<sup>14</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>15</sup> Epilepsy Foundation, Professional Advisory Board.

<sup>16</sup> Health Care: Quality, Access, and Value." *Epilepsy Across the Spectrum: Promoting Health and Understanding*. Washington, DC: The National Academies Press, 2012. Page 166.

<sup>17</sup> Kanner AM. Depression and epilepsy: A new perspective on two closely related disorders. *Epilepsy Currents*. 2006;6(5):141-46.