



## Introduction

Epilepsy is a disorder of the central nervous system resulting in unprovoked seizures that happen more than once. A seizure is a brief disruption of electrical activity in the brain that affects other brain functions. Epilepsy is not a mental illness, a sign of mental retardation, nor is it contagious. Having uncontrolled epilepsy can alter a person's life, however, since it is impossible to know when the next seizure will happen. This can cause problems at school, holding a job, or getting a driver's license. Persons with epilepsy may also face discrimination from others who sometimes do not understand what is happening during a seizure.

More than half the time, the cause of epilepsy is unknown. When the cause can be determined, it is most often due to head injury, infection or a tumor in the brain, a stroke, degenerative diseases such as Alzheimer's disease, substance abuse, or heredity.

Epilepsy is the third most common neurological disorder in the United States after Alzheimer's disease and stroke.<sup>1</sup> It costs the nation about \$12.5 billion in direct and indirect costs annually.<sup>2</sup>

Epilepsy affects children and adults, men and women, and persons of all races, religions, ethnic backgrounds, and social classes. Individuals in certain populations are at higher risk. Most people learn they have epilepsy when they are young children or after age 65, but epilepsy can occur at any age. By age 20, one percent of the population has been diagnosed with epilepsy, climbing to three percent among those aged 80 years and older. By the age of 80, ten percent of people are likely to have experienced a seizure in their lifetime.<sup>3</sup> As the baby boom generation approaches retirement age, New York will probably see more cases of epilepsy, because risk factors for epilepsy such as Alzheimer's disease and stroke are more common in older adults.<sup>4</sup> The risk of premature death in persons with epilepsy is two to three times higher than for the general population.<sup>5</sup>

This report provides the first population based estimates of the prevalence of epilepsy in adults who live in New York and data on how it affects them. It includes recommended public health actions to address epilepsy and reduce its impact.

## EPILEPSY AMONG ADULTS IN NEW YORK STATE

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## Data Collection

The Behavioral Risk Factor Surveillance System (BRFSS) is a statewide random-digit-dialing telephone survey of the non-institutionalized adult population aged 18 years and older. The BRFSS began in New York State in 1983 and has been conducted annually since 1985 using methods and procedures established by the Centers for Disease Control and Prevention (CDC). It provides state-specific information on behaviors and risk factors for chronic diseases, infectious diseases, and other health conditions for New York State adults. The BRFSS is also useful to estimate the prevalence of self-reported, physician-diagnosed diseases and conditions.

Information about epilepsy was collected for the first time in 2005 using the BRFSS. A set of five questions developed by the CDC's Epilepsy Program was included in the questionnaire, which was administered to 3,571 New York adults over the course of the year. The first question asked respondents if they had ever been told by a doctor that they have a seizure disorder or epilepsy. The responses to this question provided an estimate of the lifetime prevalence, or history, of epilepsy in a representative sample of adults. Those who answered "yes" to this question (n=53 [see Technical Note below]) were then asked additional questions about treatment and seizure frequency, the impact of epilepsy on their normal activities, and whether they had seen a neurologist or epilepsy specialist about their condition. Among those with a history of epilepsy, people currently taking medication for seizure control or who have had one or more seizures in the last three months were classified as having active epilepsy.

This report summarizes information obtained from these five questions and also includes results from other questions asked during the telephone interview to better understand the profile of persons with epilepsy and to make comparisons with those not having epilepsy or seizure disorders.

[Technical Note: Guidelines for drawing inferences from BRFSS data include a minimum of 50 respondents and confidence intervals with a half-width of 10 or less. BRFSS reporting of weighted results based on a small number of respondents can mislead the reader into believing that a given finding is more precise than it actually is. Consequently, users should pay particular attention to the size of the subgroup and the confidence interval in this report.]

## Lifetime Prevalence of Epilepsy

The lifetime prevalence, or history, of epilepsy was 1.3% (n=53; 95% CI: 0.9%-1.7%). There were some variations in lifetime prevalence by gender (females, 1.4%; males, 1.3%), age group (18-44 yr, 1.3%; ≥ 45 yr, 1.2%), and household income (<\$20,000, 2.5%; \$20,000-\$49,999, 1.2%; ≥ \$50,000, 1.0%), but none of these differences was statistically significant.

Comparing the respondents who reported a lifetime prevalence of epilepsy to those without epilepsy indicated that, among working-age adults who were 18-64 years old, 41.0% (n=17; 95% CI: 23.9%-58.0%) of those with a lifetime history of epilepsy reported either being out of work or unable to work, compared to 11.8% (n=321; 95% CI: 10.2%-13.3%) of those without epilepsy, a statistically significant difference. Also, those with epilepsy were nearly twice as likely as those without epilepsy to report an annual household income of less than \$20,000 (29.3% [n=16; 95% CI: 15.0%-43.6%] vs. 15.1% [n=564; 95% CI: 13.6%-16.6%]), although the difference was not statistically significant.

## Medication Use

All respondents with a history of epilepsy were asked if they are currently taking any medicine to control their seizure disorder or epilepsy. Two-thirds (66.2% [n=32; 95% CI: 51.9%-80.5%]) of the eligible respondents reported they were taking such medication. There were no statistically significant differences in reported medication use by gender or age group.

## Seizure History

The effective management of epilepsy aims to reduce the number of seizures with minimal treatment side effects. Extensive research demonstrates that uncontrolled seizures are associated with worse sociodemographic and health outcomes (e.g., unemployment, lower income, psychosocial comorbidity, and poor quality of life). For about 80% of those diagnosed with epilepsy, seizures can be controlled with medicines and surgery.<sup>6</sup> Among the remaining 20% who continue to experience seizures, the reasons may relate to inappropriate treatment, patient non-compliance, poor tolerance of anti-epilepsy medications, and coexisting chronic conditions or sleep disturbances that may increase seizure risk.

Respondents were asked how many seizures they had in the past three months. More than one-third (34.8% [n=18; 95% CI: 19.8%-49.8%]) of respondents with epilepsy reported having at least one seizure in this time period. There were no significant gender differences in recent seizure history. The majority of respondents (96.4% [n=17; 95% CI: 89.2%-100.0%]) who reported having a recent seizure were on epilepsy medication.

## Specialty Care

Many people see health care providers who are unfamiliar with the complexities of epilepsy and would often benefit from seeing an epilepsy specialist. Additionally, those who have epilepsy may not see epilepsy specialists because of lack of health care coverage, a shortage of specialists in their geographic area, or a failure to understand the benefits of seeing a health professional with specialty training in epilepsy.<sup>7</sup> Only about half (52.7% [n=25; 95% CI: 37.1%-68.3%]) of the respondents

with a lifetime history of epilepsy reported that they had seen a neurologist or epilepsy specialist in the past year for their epilepsy or seizure disorder.

## Active Epilepsy

The prevalence of active epilepsy was 0.9% (n=33; 95% CI: 0.5%-1.2%). The small sample size of people with active epilepsy did not permit further analysis. The respondents identified as having active epilepsy represented 67.5% (n=33; 95% CI: 53.3%-71.7%) of those with a lifetime prevalence of epilepsy. About half (51.6% [n=18; 95% CI: 32.0%-71.2%]) of those with active epilepsy reported having had a seizure during the previous three months, and 72.7% (n=23; 95% CI: 55.3%-90.1%) reported having seen a neurologist or epilepsy specialist in the past year. The majority of respondents (96.4% [n=17; 95% CI: 89.2%-100.0%]) who reported having a recent seizure were on epilepsy medication.

## Impact on Health and Quality of Life

A person's self-rated health and ability to carry out daily activities are often affected by epilepsy. This may be due to physical and psychosocial difficulties, the prospect of having a seizure, side effects of anticonvulsant therapy, lifestyle restrictions, and perceived stigmatization. For chronic diseases like epilepsy, health-related quality of life (HRQOL) is an important measure of the disease burden placed on affected individuals. The responses to four BRFSS questions are used to construct the HRQOL measures (general self-rated health and the number of days during the 30 days preceding the survey when physical health was not good, mental health was not good, or usual activities were limited).

### • Self-Rated Health

Self-rated health consisted of the response to the single item, "Would you say your health in general is excellent, very good, good, fair, or poor?" It is among the most frequently assessed health status measures and has been found to be an excellent predictor of future health.<sup>8</sup> Respondents with a lifetime history of epilepsy were significantly more likely to rate their health as fair or poor than those without epilepsy (42.0% [n=19; 95% CI: 26.0%-58.0%] vs. 15.5% [n=587; 95% CI: 14.1%-17.0%]). The contrast was even more striking when comparing those with active epilepsy who rated their health as fair or poor to those without epilepsy (51.7% [n=13; 95% CI: 32.0%-71.5%] vs. 15.5% [n=587; 95% CI: 14.1%-17.0%]).

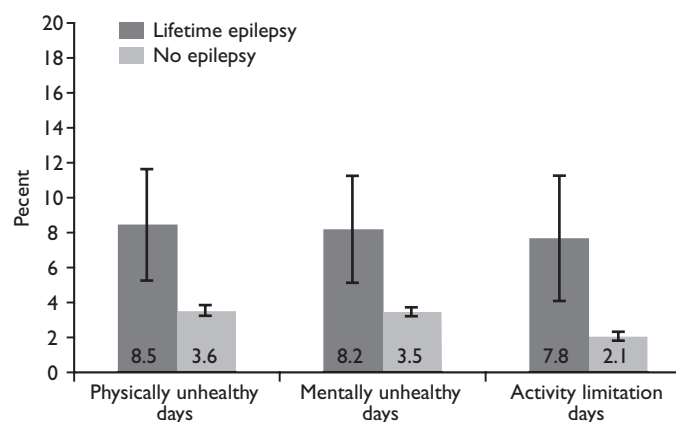
### • Unhealthy Days

Unhealthy days are the number of days during the previous 30 days when respondents felt their physical or mental health was not good. For those with epilepsy, this provides a measure of the personal impact of epilepsy that can be compared with the effect of other diseases and conditions.

To obtain this estimate, all BRFSS respondents were asked two questions about their recent physical or mental health: "Now think about your physical health, which includes physical illness and injury, for how many days during the past 30 days was your physical health not good?" and "Now thinking about your mental health, which includes stress, depression, and problems with emotions, for how many days during the past 30 days was your mental health not good?" A third question was asked to determine recent activity limitation due to poor health: "During the past 30 days, for about how many days did poor physical or mental health keep you from doing your usual activities, such as self-care, work, or recreation?"

As shown in Figure 1, compared to respondents who did not have epilepsy, those with a history of epilepsy reported, on average, more days that were either physically unhealthy (8.5 days [n=52; 95% CI: 5.3-11.7] vs. 3.6 days [n=3,427; 95% CI: 3.3-3.9]) or mentally unhealthy (8.2 days [n=53; 95% CI: 5.2-11.3] vs. 3.5 days [n=3,434; 95% CI: 3.1-3.8]). Persons with epilepsy also reported that their activities had been limited an average of 7.8 days (n=52; 95% CI: 4.2-11.5) during the previous 30 days, compared to just 2.1 days (n=3,473; 95% CI: 1.2-2.4) among those without epilepsy. All of these differences were statistically significant.

Figure 1  
Mean number of unhealthy days during past 30 days among New York adults, by epilepsy status: 2005 BRFSS



Note: Error bars represent 95% confidence intervals.

Table 1

**Mean number of unhealthy and activity limitation days among New York adults reporting a history of epilepsy: 2005 BRFSS**

	Physically unhealthy days		Mentally unhealthy days		Activity limitation days	
	Mean # days*	95% CI†	Mean # days	95% CI	Mean # days	95% CI
Taking medicine (n=32)	10.3	6.2-14.5	9.2	5.3-13.1	10.0	4.8-15.1
Not taking medicine (n=21)	5.0	1.3-8.7	6.3	1.6-10.9	3.8	1.0-6.6
Had seizure during preceding 3 months (n=18)	12.5	5.9-19.2	13.2	7.5-18.8	14.3	7.4-21.3
No seizures during preceding 3 months (n=34)	6.5	3.7-9.4	5.6	2.5-8.8	4.2	1.4-6.9
No longer has epilepsy (n=1)	---‡	---	---‡	---	---‡	---

\* Mean number of days during preceding 30 days.

† CI, confidence interval.

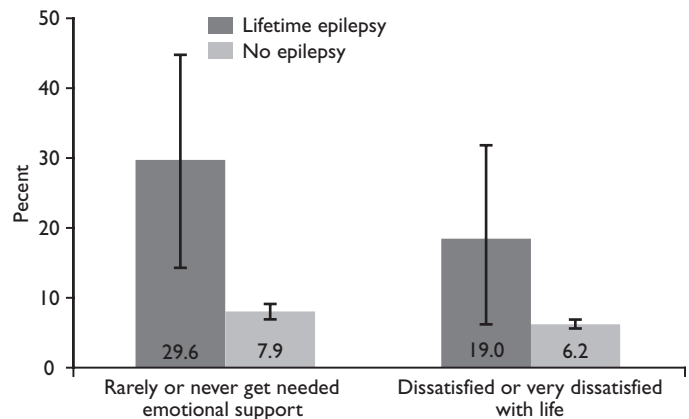
‡ Data excluded because of small sample size.

As summarized in Table 1, people who were taking medicine to control their epilepsy reported a greater number of physically and mentally unhealthy days than did those who were not taking medicine. Similarly, respondents who had a recent seizure reported more unhealthy days than did those who had no recent seizure. A similar pattern was observed regarding the number of days respondents reported being unable to carry out their usual activities.

**• Emotional Support and Life Satisfaction**

Respondents were asked two questions to assess emotional support and life satisfaction: “How often do you get the social and emotional support you need?” (always, usually, sometimes, rarely, never), and “In general, how satisfied are you with your life?” (very satisfied, satisfied, dissatisfied, very dissatisfied). As shown in Figure 2, respondents with epilepsy were significantly more likely than those without epilepsy to report rarely or never getting the social and emotional support they need (29.6% [n=13; 95% CI: 14.1%-45.0%] vs. 7.9% [n=276; 95% CI: 6.8%-9.0%]). Moreover, 19.0% (n=11; 95% CI: 6.6%-31.4%) of persons with epilepsy reported that they were dissatisfied or very dissatisfied with life, compared with just 6.2% (n=206; 95% CI: 5.1%-7.3%) of people without epilepsy, although this difference was not statistically significant. Nevertheless, the patterns suggest that persons with epilepsy are less likely to receive needed emotional support or be satisfied with their life.

**Figure 2**  
**Insufficient emotional support and dissatisfaction with life among New York adults, by epilepsy status: 2005 BRFSS**

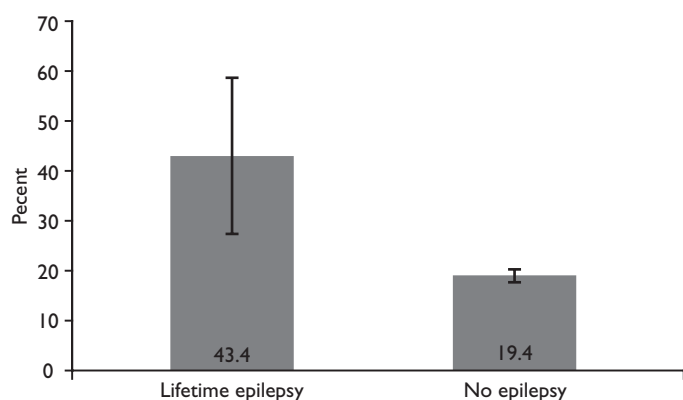


Note: Error bars represent 95% confidence intervals.

## Disability

The disability status of respondents was determined by the answers to two questions: “Are you limited in any way in any activities because of physical, mental, or emotional problems?” and “Do you now have any health problem that requires you to use special equipment, such as a cane, a wheelchair, a special bed, or a special telephone?” Respondent were considered as having a disability if they answered “yes” to either of these questions. Persons with epilepsy were more than twice as likely as those without epilepsy to report having a disability (43.4% [n=24; 95% CI: 27.8%-59.0%] vs. 19.4% [n=778; 95% CI: 17.9%-21.0%]), a difference that was statistically significant (Figure 3).

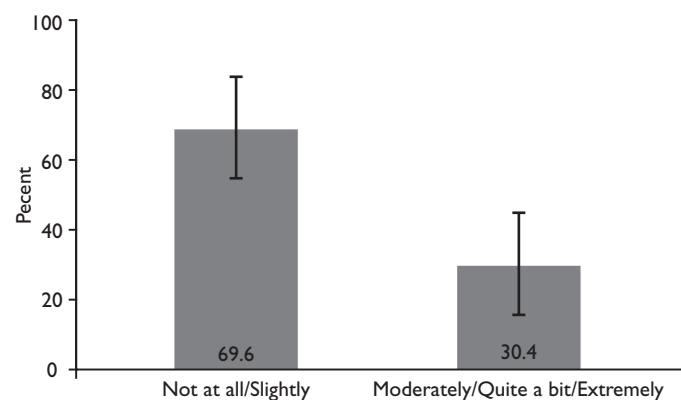
**Figure 3**  
**Prevalence of disability among New York adults, by epilepsy status: 2005 BRFSS**



Note: Error bars represent 95% confidence intervals.

Persons with epilepsy were asked, “During the past month, to what extent has epilepsy or its treatment interfered with your normal activities like working, school, or socializing with family or friends?” (not at all, slightly, moderately, quite a bit, extremely). As shown in Figure 4, more than two-thirds (69.6% [n=38; 95% CI: 54.8%-84.3%]) of respondents said “not at all” or “slightly,” although nearly a third (30.4% [n=14; 95% CI: 15.7%-45.2%]) of respondents indicated that epilepsy interfered with normal activities either moderately, quite a bit, or extremely.

**Figure 4**  
**Extent to which epilepsy has interfered with normal activities during the past month among New York adults, by epilepsy status: 2005 BRFSS**

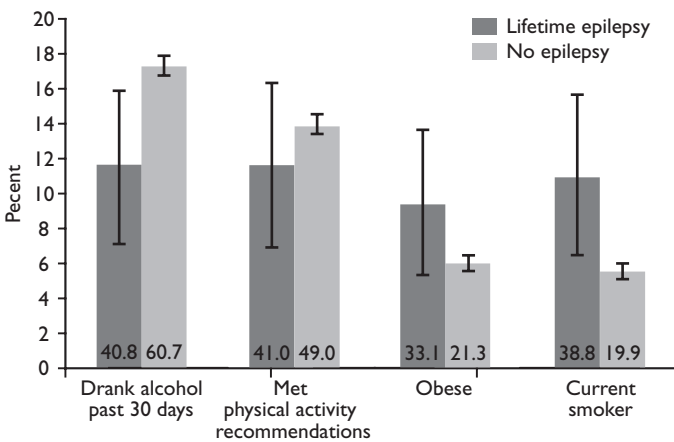


Note: Error bars represent 95% confidence intervals.

## Healthy Behaviors

A major focus of the BRFSS is to learn about health-related behaviors linked to leading causes of preventable morbidity and mortality. Respondents were asked about their physical activity level, whether they currently smoked cigarettes and if they consumed any alcoholic beverages in the past 30 days. They were classified as physically active at the recommended level if they reported adequate physical activity of moderate intensity ( $\geq 30$  minutes per day,  $\geq 5$  days per week) or of vigorous intensity ( $\geq 20$  minutes per day,  $\geq 3$  days per week). In addition, self-reported height and weight values were obtained to determine a body mass index or BMI (calculated as weight in kilograms divided by the square of height in meters). A person with a BMI that was at least 30 was classified as obese. Results from these questions are displayed in Figure 5.

**Figure 5**  
**Health risk behaviors among New York adults, by epilepsy status: 2005 BRFSS**



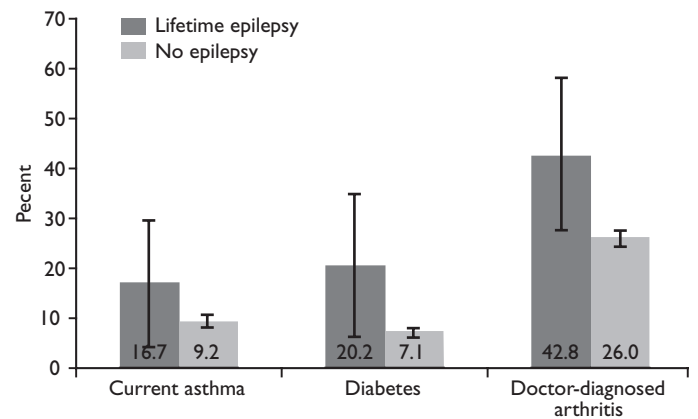
Note: Error bars represent 95% confidence intervals.

Persons with epilepsy were less likely than those without epilepsy to report having had a least one drink of any alcoholic beverage during the preceding 30 days (40.8% [n=23; 95% CI: 25.5%-56.0%] vs. 60.7% [n=2,105; 95% CI: 58.7%-62.6%]) and more likely to report being a current smoker (38.8% [n=17; 95% CI: 22.7%-54.8%] vs. 19.9% [n=658; 95% CI: 18.2%-21.7%]). Both differences were statistically significant. Persons with epilepsy were less likely to have engaged in recommended levels of physical activity and more likely to be obese; however, these differences were not statistically significant.

## Co-existing Chronic Conditions

The BRFSS questionnaire asked about other chronic conditions that might affect the respondents. As shown in Figure 6, persons with epilepsy were more likely than those without epilepsy to report having arthritis, asthma, or diabetes. However, this difference was statistically significant only for self-reported arthritis.

**Figure 6**  
**Prevalence of current asthma, diabetes, and doctor-diagnosed arthritis among New York adults, by epilepsy status: 2005 BRFSS**



Note: Error bars represent 95% confidence intervals.



## Discussion

Using these data, it is estimated that approximately 184,000 adults living in New York have been told they have had a seizure disorder or epilepsy at some point in their life. Two-thirds of the respondents with a history of epilepsy were considered to have active epilepsy, i.e., either on medication or having had a recent seizure, meaning that an estimated 125,000 adults have active epilepsy. People with epilepsy were more likely to be out of work or unable to work, be dissatisfied with life, and to say that they rarely or never get the emotional support they need. Social attitudes towards epilepsy may cause as much or more distress to the individuals and their families and friends than the disease itself. People with epilepsy may struggle to overcome low self-esteem and the stigma that is attached to having epilepsy. The stigma is due, in part, to a lack of understanding by people they see every day – family members, schoolmates, and colleagues.<sup>9</sup> A strong correlation between epilepsy and depression has been demonstrated in a variety of studies. A meta-analysis of 29 studies showed that suicide in patients with epilepsy is more frequent than in the general population.<sup>10</sup>

People with epilepsy were twice as likely as those without epilepsy to report having a disability. Epilepsy is considered one of the nation's most common disabling neurological conditions. Previous surveys have confirmed a greater degree of activity limitation<sup>11,12</sup> and higher rates of disability<sup>11</sup> among adults with epilepsy compared to those without epilepsy. People with a history of epilepsy and seizures, and those whose epilepsy is active are among groups that Congress specifically mentioned when it passed the American with Disabilities Act (ADA) in 1990.

The impact of epilepsy on people's lives can also be seen in terms of lower self-rated health, more days that were defined as physically or mentally unhealthy, or more days when usual activities are limited compared to people who do not have a history of epilepsy. For each of these measures, respondents with a lifetime history of epilepsy fared worse than others. Although New Yorkers were not asked about other commonly-used

quality of life measures such as days of pain, depression, anxiety, sleeplessness, or overall vitality, the association of these measures with epilepsy has been reported elsewhere.<sup>11</sup> Results from other studies based on statewide BRFSS data confirm that, compared to those without epilepsy, people with a history of epilepsy report a lower health-related quality of life.<sup>11,12</sup>

People with a history of epilepsy were significantly more likely to smoke cigarettes, and the data suggest that they may tend to weigh more and be less active. Among chronic conditions assessed, people with epilepsy were more likely to report having arthritis, asthma, or diabetes than those without epilepsy, although the small sample size of people with epilepsy limits the generalizability of these data. Nevertheless, a general pattern of poorer health among people with epilepsy emerges from these results, which is consistent with published studies that document higher rates of chronic illness in people with epilepsy.<sup>13</sup> On a positive note, adults with epilepsy were less likely to report having had a least one drink of any alcoholic beverage during the last month. This may be due to heightened awareness of the increased seizure risk from alcohol consumption and its potential interactions with epilepsy medications.

More information about epilepsy can be obtained at the following websites:

New York State Department of Health:  
<http://www.health.state.ny.us/diseases/conditions/epilepsy/>

Epilepsy Foundation:  
<http://www.epilepsyfoundation.org/>

Centers for Disease Control and Prevention:  
<http://www.cdc.gov/Epilepsy/>

National Institute of Neurological Disorders and Stroke:  
<http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm>

Nationally Association of Chronic Disease Directors  
[http://www.chronicdisease.org/files/public/epilepsy\\_report.pdf](http://www.chronicdisease.org/files/public/epilepsy_report.pdf)

## Endnotes

- <sup>1</sup> 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.
- <sup>2</sup> Begley CE, Famulari M, Annegers JF, Lairson DR, Reynolds TF, Coan S, Dubinsky S, Newmark ME, Leibson C, So EL, Rocca WA. The cost of epilepsy in the United States: an estimate from population-based clinical and survey data. *Epilepsia*. 2000 Mar;41(3):342-351.
- <sup>3</sup> Hauser WA, Annegers JF, Rocca WA. Descriptive epidemiology of epilepsy: contributions of population based studies from Rochester, Minnesota. *Mayo Clinic Proceedings* 1996; 71: 576-586.
- <sup>4</sup> 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* 41(3):342-351, 2000 and U.S. Census Bureau 2005 population estimate of 295,200,000.
- <sup>5</sup> Cockerell OC. The mortality of epilepsy. *Curr Opin Neurol*. 1996 Apr;9(2):93-96.
- <sup>6</sup> National Institutes of Neurological Disorders and Stroke (<http://www.ninds.nih.gov/disorders/epilepsy/epilepsy.htm>)
- <sup>7</sup> Montouris GD. How will primary care physicians, specialists, and managed care treat epilepsy in the new millennium? *Neurology*. 2000;55(11 Suppl 3):S42-44.
- <sup>8</sup> Idler EL, Benyamini Y. Self-rated health and mortality: A review of twenty-seven community studies. *Journal of Health and Social Behavior* 1997; 38:21-37.
- <sup>9</sup> Centers for Disease Control and Prevention (<http://www.cdc.gov/Epilepsy/>)
- <sup>10</sup> Pompili M, Girardi P, Ruberto A, Tatarelli R. Suicide in the epilepsies: a meta-analytic investigation of 29 cohorts. *Epilepsy and Behavior*. 2005 Sep;7(2):305-310.
- <sup>11</sup> Centers for Disease Control and Prevention. Prevalence of epilepsy and health-related quality of life and disability among adults with epilepsy: South Carolina, 2003 and 2004. *Morbidity and Mortality Weekly Report* 2005; 54:1080-1082.
- <sup>12</sup> Centers for Disease Control and Prevention. Health-related quality of life among persons with epilepsy: Texas, 1998. *Morbidity and Mortality Weekly Report* 2001; 50:24-26, 35.
- <sup>13</sup> Gaitatzis A, Carroll K, Majeed A, Sander JW. The epidemiology of the comorbidity of epilepsy in the general population. *Epilepsia* 2004;45:1613-1622.