



Fact Sheet:

Incidence and Prevalence of the Major Causes of Adult-Onset Brain Impairment

Overview

Many of the diseases and disorders that affect the brain are progressive and their incidence and prevalence increase with age. Caring for those with adult-onset brain impairments frequently becomes a 24-hour, 7-day a week role. As the population ages, the need for care and for understanding the impact of these disorders on families becomes even more pressing.

A recent report released by the Federal Interagency Forum on Aging-Related Statistics¹, states that 35.8% of those 85 or older have moderate or severe memory impairment. Persons 85 years and older are the fastest growing segment of the population. By 2020, it is estimated that almost one million persons will be age 85+ in California alone – twice as many as there are today.²

The loss of cognitive and functional abilities affects the individual and his or her family in profound ways. Caring for adults with cognitive impairments is often very stressful and demanding. Caregivers cope with their loved ones' memory loss, behavioral and personality changes, chronic care needs and the high costs of care. Caregiving can span

decades, can impact both the physical and mental health of the caregiver and can result in extreme economic hardship.

The following tables estimate the incidence and prevalence of the major causes of brain impairment in adulthood in the United States in general and in California in particular. The estimates are conservative, excluding rare disorders for which reliable data are not available.

- Table 1 shows an estimated 1.2 million people aged 18 years and older who are diagnosed annually with adult onset brain disease/disorders in the United States (i.e., the *incidence*).
- Table 2 estimates that between 13.3 and 16.1 million individuals age 18 and over are afflicted with common brain disorders and diseases (i.e., the number of people currently living with the impairment, or *prevalence*).
- Table 3 looks at the data in comparison to the overall population of the United States and California. An estimated 13% - 16% of the United States and California households may be dealing with the burden of caring

for a loved one with an adult-onset brain disease/disorder.

Diagnosis/ Cause	People Diagnosed Annually
Alzheimer's Disease	250,000 ²
Amyotrophic Lateral Sclerosis	5,000 ^{3,4}
Brain Tumor	33,039 ⁵
Epilepsy	135,500 ^{6,7}
HIV – Associated Neurocognitive Disorder	1,196 ⁸
Huntington's Disease	N/A
Multiple Sclerosis	10,400 ⁹
Parkinson's Disease	54,927 ¹⁰
Stroke	600,000 ¹¹
Traumatic Brain Injury	80,000 ¹²
TOTAL ESTIMATED INCIDENCE	1,170,062

- More than one million adults in the U.S. are diagnosed annually with a chronic brain disease or disorder. The need for both long-term care and support for family caregivers is dramatic. Many of these conditions, for example Alzheimer's, Stroke and Parkinson's, are associated with increasing age. Given the aging of the United States population, figures will increase proportionately in the coming decades.

DIAGNOSIS/ CAUSE	People Currently Living with Disorder:	
	Low Estimate	High Estimate
Alzheimer's Disease	4,000,000 ¹	4,000,000 ²
Amyotrophic Lateral Sclerosis	20,000 ³	30,000 ⁴
Brain Tumor	N/A	N/A
Epilepsy	1,984,000 ^{5,6}	2,000,000 ⁷
HIV- Associated Neurocognitive Disorder	14,537 ⁸	58,150 ⁹
Huntington's Disease	30,000 ¹⁰	30,000 ¹¹
Multiple Sclerosis	250,000 ^{12,13}	350,000 ¹⁴
Parkinson's Disease	500,000 ¹⁵	1,500,000 ¹⁶
Stroke	4,000,000 ¹⁷	4,400,000 ¹⁸
Traumatic Brain Injury	2,500,000 ¹⁹	3,700,000 ²⁰
TOTAL ESTIMATED INCIDENCE	13,298,537	16,068,150

- Table 2 dramatically illustrates the long-term nature of caregiving for many of these conditions. While it is estimated that one quarter of a million people are diagnosed with Alzheimer's annually in the United States, there are an estimated four million people living with the disease, many of whom require 24-hour care.

	United States	California
Total Population	274,634,000 ¹	34,336,091 ²
Total Population 18+	20,852,000 ³	30,000 ⁴
Total Households	101,041,000 ⁵	12,242,576 ⁶
Total Estimated Adults with Brain Impairment		
a. Low Estimate	13,298,537	1,622,422 ⁷
b. High Estimate	16,068,150	1,960,314 ⁸
Percentage of Adult Population Affected by Brain Impairment		
a. Low Estimate	6.5%	6.5%
b. High Estimate	7.9%	7.9%
Percentage of Households Affected by Brain Impairment		
a. Low Estimate	13.2%	13.3%
b. High Estimate	15.9%	16.0%

- The 16% figure for the number of households affected by brain impairment only begins to elucidate the impact of brain impairment upon family caregivers and the long-term care system. With many individuals requiring 24-hour care, there are often several family members from different households involved in the caregiving process including spouses, adult children, siblings and friends. Often these caregivers are juggling the responsibilities of caregiving, child rearing and employment simultaneously.

Footnotes

Overview:

¹ Federal Interagency Forum on Aging-Related Statistics (2000). *Older Americans 2000: Key Indicators of Well-Being*.

² California Health and Human Services Agency (January, 1999). Report on Long-Term Care Programs and Options for Integration. Sacramento, CA.

Table 1:

¹ Due to differences in reporting and data collection, estimates vary and in some cases the figures are for slightly different populations (e.g. aged 13+ or aged 15+) as noted.

² Alzheimer's Disease Education & Referral Center, Personal Communication, October 10, 2000 based on figures from 1991. Silver Spring, MD.

³ Amyotrophic Lateral Sclerosis Association (1999) *ALS and the ALS Association*, Calabasas Hills, CA

⁴ National Institute of Neurological Disorders and Stroke (2000), *Amyotrophic Lateral Sclerosis*, Bethesda, MD.

⁵ American Brain Tumor Association (2000). *Facts and Statistics*, Des Plaines, IL.

⁶ Epilepsy Foundation (2000). *Cost Study Shows Divide in Treatment Effect*, Landover, MD.

⁷ Persons 15 years of age and older.

⁸ Centers for Disease Control and Prevention (1999), *HIV/AIDS Surveillance Report*, 1997 Vol. 9 Number 2, Atlanta, GA. [Note: Includes ages 13 and above.]

⁹ National Institute of Neurological Disorders and Stroke (2000), *Multiple Sclerosis: Hope Through Research*, Bethesda, MD.

¹⁰ American Parkinson's Disease Association, Personal Communication October 10, 2000. Figure derived from an incidence of 20 cases/100,000 and an estimated population of 274,634,000 from U.S. Census Bureau (1999). *Statistical Abstract of the United States: 1999*. [Note: Projections for the year 2000.]

¹¹ American Heart Association (2000), *2000 Heart and Stroke Statistical Update*, Dallas, TX

¹² Centers for Disease Control and Prevention (2000), *Epidemiology of Traumatic Brain Injury in the United States*, Atlanta, GA [Note: Estimate includes all age groups and only those who have TBI-related disabilities. Estimates are based on provisional data.]

Table 2:

¹ Alzheimer's Disease and Related Disorders Association, Inc. (2000), *General Statistics/Demographics*, Chicago, IL.

² *ibid.*

³ National Institute of Neurological Disorders and Stroke (2000), *Amyotrophic Lateral Sclerosis*, Bethesda, MD.

⁴ Amyotrophic Lateral Sclerosis Association (1999) *ALS and the ALS Association*: Calabasas Hills, CA.

⁵ Epilepsy Foundation (2000), *Cost Study Shows Divide in Treatment Effect*, Landover, MD.

⁶ Persons 15 years of age and older.

⁷ National Institute of Neurological Disorders and Stroke (2000), *Seizures*

and Epilepsy: Hope Through Research, Bethesda, MD.

⁸ Centers for Disease Control and Prevention (1999), *HIV/AIDS Surveillance Report*, 1997 Vol. 9 Number 2, Atlanta, GA. [Note: Includes ages 13 and above. Estimated from 1997 data on percentage of individuals developing AIDS-Indicator conditions multiplied by the estimated of number of adults/adolescents currently living with AIDS. Overall the CDC reports that the incidence of HIV dementia is decreasing.]

⁹ Berghuis, J. P., Uldall, K. K. and Lalonde, B. (1999). *Validity of Two Scales in Identifying HIV-Associated Dementia*, *Journal of Acquired Immune Deficiency Syndromes*, Volume 21, pp. 134-140. [Note: Based on the high end of their estimate of 7–20% of HIV/AIDS patients developing dementia times the CDC estimate of individuals currently living with AIDS.]

¹⁰ National Institute of Neurological Disorders and Stroke (2000), *Huntington's Disease Hope Through Research*, Bethesda, MD.

¹¹ An estimated 150,000 additional persons are at risk of inheriting Huntington's disease from a parent.

¹² National Institute of Neurological Disorders and Stroke (2000), *Multiple Sclerosis: Hope Through Research*, Bethesda, MD.

¹³ The National Multiple Sclerosis Society Information Resource Center and Library (2000), *Multiple Sclerosis Information Sourcebook*, New York, NY.

¹⁴ National Institute of Neurological Disorders and Stroke (2000), *Multiple Sclerosis: Hope Through Research*, Bethesda, MD.

¹⁵ National Institute of Neurological Disorders and Stroke (2000),

Parkinson's Disease Hope Through Research, Bethesda, MD.

¹⁶ National Parkinson Foundation (1998), *What the Patient Should Know*, Miami, FL.

¹⁷ National Stroke Association (1999), *Brain Attack Statistics*, Englewood, CO.

¹⁸ American Heart Association (2000), *2000 Heart and Stroke Statistical Update*, Dallas, TX.

¹⁹ National Institutes of Health (1998) NIH consensus statement on rehabilitation of persons with traumatic brain injury: Bethesda, MD. [Note: Estimate includes all ages.]

²⁰ Thurman, D. J. (1999) Preliminary estimate of prevalence for adults age 18+ living with an acquired brain injury. Personal communication, January 8, 1999. National Center for Injury Prevention and Control Centers for Disease Control, Atlanta, GA.

Table 3:

¹ U.S. Census Bureau (1999). *Statistical Abstract of the United States: 1999*. [Note: Population figures for the U.S. and California are projections for the year 2000.]

² State of California, Department of Finance (May, 2000). *City/County Population and Housing Estimates, 1991-2000, with 1990 Census Counts*. Sacramento, CA.

³ U.S. Census Bureau (1999). *Statistical Abstract of the United States: 1999*. [Note: Population figures for the U.S. and California are projections for the year 2000.]

⁴ State of California, Department of Finance (December, 1998). *Race/Ethnic Population with Age and Sex Detail, 1970-2040*. Sacramento, CA. [Note: Based on projections for the year 2000.]

⁵ U.S. Census Bureau (1999). *Estimates of Housing Units, Households, Households by Age of Householder and Persons per Household: July 1, 1998*.

⁶ State of California, Department of Finance (May, 2000). *City/County Population and Housing Estimates, 1991-2000, with 1990 Census Counts*. Sacramento, CA.

⁷ These estimates are based on the percentage of population age 18+ years residing in CA.

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⁹ Assumes one brain impaired individual per household.

Resources

Southern Caregiver Resource Center
3675 Ruffin Road, Suite 230
San Diego, CA 92123
(858) 268-4432; (800) 827-1008 (in CA)
Fax: (858) 268-7816
E-mail: scrc@caregivercenter.org
Web site: www.caregivercenter.org

The Southern Caregiver Resource Center offers services to family caregivers of adults with chronic and disabling health conditions, and is for residents of San Diego and Imperial counties. Services include information and referral, counseling, family consultation and case management, legal and financial consultation, respite care, education and training, and support groups.

Family Caregiver Alliance

235 Montgomery Street, Suite 950
San Francisco, CA 94104
(415) 434-3388 (800) | 445-8106
Web site: www.caregiver.org
E-mail: info@caregiver.org

Family Caregiver Alliance (FCA) seeks to improve the quality of life for caregivers through education, services, research and advocacy. Through its National Center on Caregiving, FCA offers information on current social, public policy and caregiving issues and provides assistance in the development of public and private programs for caregivers.