

Spinal Cord Disability Fact Sheet

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- Approximately 700,000 Americans have disabilities of the spinal cord. These disabilities include traumatic spinal cord injury, multiple sclerosis, spina bifida, poliomyelitis, amyotrophic lateral sclerosis (Lou Gehrig's disease), and syringomyelia, among others. United Spinal Association's membership is open to all these individuals, regardless of their ages.

Spinal Cord Injury

- Every 41 minutes a person in the United States sustains a spinal cord injury; there are about 11,000 new cases of spinal cord injury reported in the United States each year.
- The total number of people with spinal cord injuries in the United States is estimated to be 222,000 to 285,000.
- In the first year after a spinal cord injury, when medical intervention is most intense, costs range from \$209,000 to \$710,000. Every year thereafter, spinal cord injured people will incur annual costs of between \$14,000 and \$127,000. For an individual suffering a severe spinal injury at 25 years of age, total lifetime costs will cost between \$624,000 and \$2.8 million dollars. In 1996, the total annual cost of SCI in the United States was estimated to be \$9.73 billion, including approximately \$2.6 billion in lost productivity.

Multiple Sclerosis

- There are at least 400,000 individuals living with multiple sclerosis (MS) in our nation today. Over 10,000 new cases are diagnosed every year. MS is a progressive disease that attacks the protective myelin sheath surrounding nerve cells in the central nervous system, blocking the transmission of motor signals to the limbs. For reasons that have yet to be fully understood, MS strikes women at approximately two to three times the rate that it strikes men.
- Based on a 1994 Duke University study, the average annual direct and indirect cost of MS is estimated at \$57,500 per person due to lost wages, increased medical care and other expenses. With an estimated 400,000 people in the U.S. living with MS, this amounts to a direct and indirect cost to the nation of \$23 billion every year.

Spina Bifida

- An estimated 70,000 people in the United States are currently living with spina bifida, the most common, permanently disabling birth defect. Spina bifida is a neural tube defect that happens in the first months of pregnancy when the spinal column doesn't close completely. The average total lifetime cost to society for each infant born with spina bifida is approximately \$532,000 per child. This estimate is only an average and for many children the total cost may be well above \$1 million. Estimated total annual medical care and surgical costs for persons with spina bifida in the United States exceed \$200 million.

Amyotrophic Lateral Sclerosis--Lou Gehrig's Disease

- More people die every year of ALS than of Huntington's disease or multiple sclerosis and it occurs two-thirds as frequently as multiple sclerosis. Approximately 5,600 people in the U.S. are diagnosed with ALS each year. The incidence of ALS (two per 100,000 people) is five times higher than Huntington's disease and about equal to multiple sclerosis. It is estimated that as many as 30,000 Americans may have the disease at any given time.
- The life expectancy of an ALS patient averages about two to five years from the time of diagnosis. ALS occurs throughout the world with no racial, ethnic or socioeconomic boundaries. ALS can strike anyone, and it is projected that of the U.S. population living today, in excess of 300,000 Americans will die from ALS unless a cure or prevention is found.

- In the later stages, ALS requires nursing management of a patient who is alert but functionally quadriplegic with intact sensory function, bedridden, and aware that he or she is going to die. The financial cost to families of persons with ALS is exceedingly high. In the advanced stages care can cost up to \$200,000 a year. Entire savings of relatives of patients with ALS are quickly depleted because of the extraordinary cost involved in their care.

Secondary Conditions

- Beyond the prevalence and economic cost, individuals living with paralysis have significantly increased overall health concerns and are susceptible to a number of serious secondary conditions such as pressure ulcers and respiratory infections. It was complications from a pressure ulcer led to the death of Christopher Reeve in 2005.

Employment and Insurance

- The 2000 Census showed that people with disabilities are far less likely to be employed, and the rates are even higher for African Americans and Hispanics with disabilities. A substantially higher percentage of people with disabilities are poor compared to the non-disabled. Recent statistics show that 10 years after injury, only 32% of people with paraplegia are employed and only 24% of people with quadriplegia are working. This means that roughly 70% of people with spinal cord disabilities are unemployed.
- Many insurance plans have dramatically reduced coverage for hospital and rehabilitation stays, giving an individual with spinal cord disability less time to learn coping strategies for returning to life in the community. This frequently leads to increased secondary complications, less community interaction, and a greater sense of isolation.

Sources: *National Spinal Cord Injury Statistical Center, University of Alabama at Birmingham; Spina Bifida Association; National MS Society; Christopher Reeve Paralysis Foundation; Russell Research—Status of Persons with Spinal Cord Injury/Disease: Highlights; The ALS Association.*

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