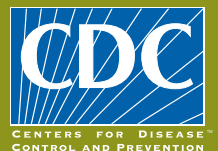




TARGETING EPILEPSY
 IMPROVING THE LIVES
 OF PEOPLE WITH ONE
 OF THE NATION'S MOST
 COMMON NEUROLOGICAL
 CONDITIONS

AT A GLANCE
 2009

NATIONAL CENTER FOR CHRONIC DISEASE PREVENTION AND HEALTH PROMOTION
 IMPROVING HEALTH AND QUALITY OF LIFE FOR ALL PEOPLE





Epilepsy: Widely Recognized, Poorly Understood

What Is Epilepsy?

Epilepsy is a chronic neurological condition characterized by recurrent seizures. A seizure happens when abnormal electrical activity in the brain causes an involuntary change in body movement or function, sensation, awareness, or behavior. Seizures can vary from a momentary disruption of the senses, to short periods of unconsciousness or staring spells, to convulsions. Some people have only one type of seizure. Others have more than one type. The term *epilepsy* can be used interchangeably with the term *seizure disorder*. Epilepsy is a chronic condition and cannot be transmitted from person to person.

What Causes Epilepsy?

Epilepsy can be caused by many different conditions that affect a person's brain. Examples of these conditions include stroke, head trauma, complications during childbirth, infections (such as meningitis, encephalitis, cysticercosis, or brain abscess), and certain genetic disorders. Often, no definite cause can be found.

Why Is Epilepsy a Public Health Problem?

Epilepsy affects an estimated 2.5 million people in the United States and each year accounts for \$15.5 billion in direct costs (medical) and indirect costs (lost or reduced earnings and productivity). More than one-third of people with epilepsy continue to have seizures despite treatment. Each year, about 200,000 new cases of epilepsy are diagnosed in the United States. Children younger than 2 years of age and adults older than 65 are most likely to be affected. In addition, people of low socioeconomic status, those who live in urban areas, and members of some minority populations are at increased risk for epilepsy.

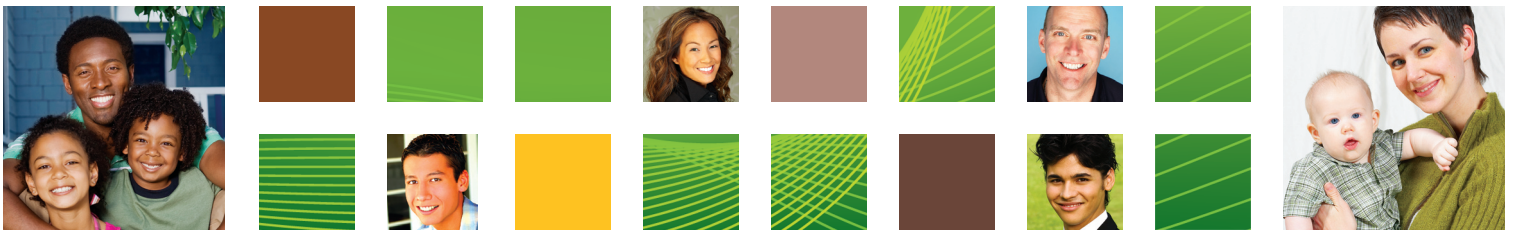
Delayed recognition of seizures and inadequate treatment, which may result from lack of specialty care, greatly increases a person's risk for subsequent seizures, brain damage, disability, and death from injuries incurred during a seizure. Epilepsy is a widely recognized health condition, but one that is poorly understood by the public, even among people who know someone with the disorder. Lack of knowledge about the causes of epilepsy has been associated with negative attitudes, beliefs, and stigma. Lack of understanding about epilepsy is a leading cause of discrimination in the workplace and in schools.

What Can Be Done to Improve the Lives of People With Epilepsy?

In 2003, the second National Conference on Public Health and Epilepsy, *Living Well With Epilepsy II*, brought together experts in the field, as well as people with epilepsy and their families. Participants discussed the need for early recognition, diagnosis, and treatment of epilepsy; advances in epidemiology and surveillance; better self-management; and improved quality of life.

Conference participants also called for

- Better access to specialty care and comprehensive systems of care, as well as improved early detection and treatment of seizures.
- Established criteria to determine quality of care in epilepsy.
- Better understanding of the diagnosis and treatment of the consequences of epilepsy, especially in the areas of mental health and cognition.
- Systems and models of care that foster empowerment and independence for people with epilepsy and support their efforts toward improved seizure control and a good quality of life.
- Methods and systems to monitor trends related to critical issues, such as disease burden, mortality risks, and incidence and prevalence in diverse populations.
- Research and communication approaches to combat the stigma associated with epilepsy, which will improve community awareness and the quality of life and care of people with epilepsy.
- Public education to improve people's ability to recognize seizures and give first aid.



CDC's National Leadership

During the past 14 years, CDC's Epilepsy Program has steadily increased its ability to effectively address public health issues related to epilepsy. The program works to protect the health of people living with epilepsy, improve the quality of life of people living with this condition, and decrease the stigma associated with the disorder. To achieve these goals, the program has established national and local partnerships to increase public awareness and deliver targeted educational messages. The Epilepsy Program supports activities in several key areas, including communication and education, research, and self-management.

Communication and Education

CDC has a long-standing partnership with the national Epilepsy Foundation to conduct multifaceted public education and awareness campaigns. These campaigns are designed to increase awareness about and acceptance of people with epilepsy and to counteract the social stigma associated with this disorder through education and community programs.

Past campaigns have focused on underserved population groups, including African Americans, women, and young people. The 2007–2008 campaign expanded its focus on African American and Hispanic communities. Campaign activities included

- Providing Epilepsy Foundation affiliates with tools and resources (grants, outreach strategies) to reach local African American communities.
- Developing a new Spanish Web site and a culturally based training curriculum for community health workers.

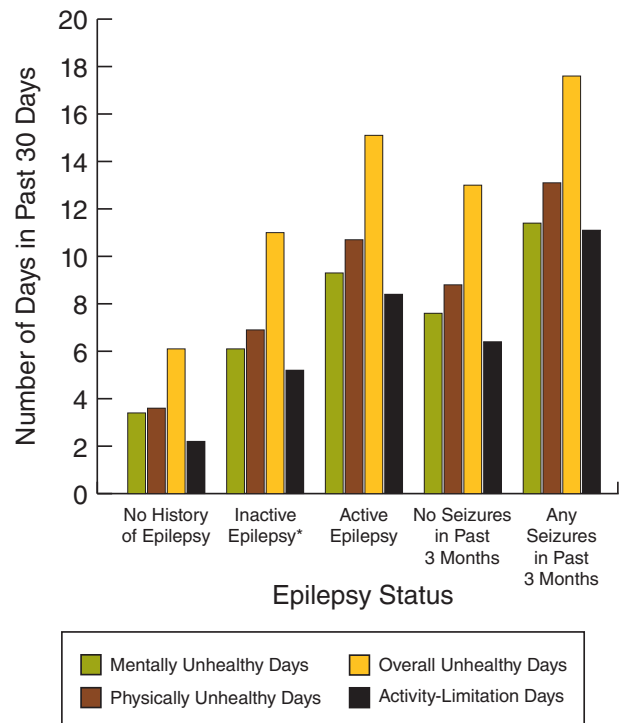
In 2000, CDC developed the tool kit “No Label Required” for teenagers with epilepsy to help them make informed decisions about issues of greatest concern in their lives. Building on the success of this tool kit, CDC worked with the Epilepsy Foundation to develop and test an award-winning tool kit for parents, “You Are Not Alone: Toolkit for Parents of Teens with Epilepsy.” Tool kit components are designed to empower and support parents while encouraging their teenagers toward self-management and are available at <http://www.cdc.gov/epilepsy>. Both tool kits have been distributed in traditional and nontraditional ways, including at summer camps and schools, on Web sites, as part of educational campaigns, and through Epilepsy Foundation affiliates.

Epidemiological and Prevention Research

CDC is supporting epidemiological studies to define the incidence and prevalence of epilepsy in different racial and ethnic populations in the United States. These studies also are being used to identify (1) risk factors and the severity of epilepsy in minority communities, (2) health disparities and contributing factors among people with epilepsy, and (3) process and outcome measures that may be used to define optimum care for epilepsy.

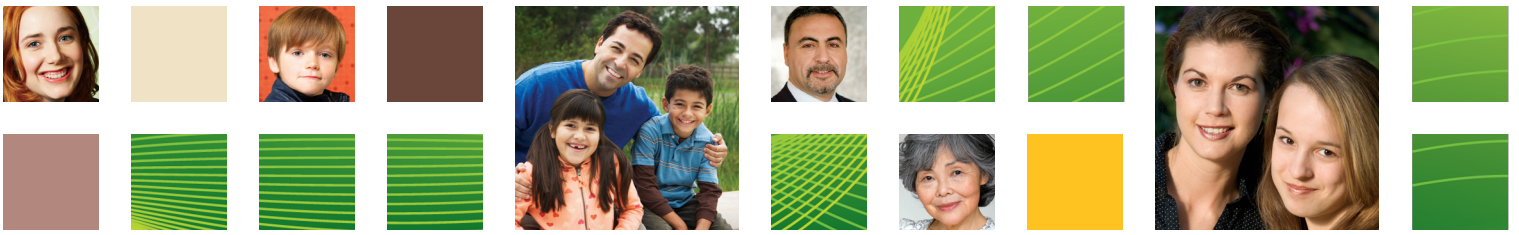
Since 1998, some state health departments have used Behavioral Risk Factor Surveillance System (BRFSS) surveys to estimate self-reported epilepsy prevalence and study relationships between associated behavioral risk factors, chronic disease comorbidity, and health-related quality of life. Nineteen states

Health-Related Quality of Life Among Adults With Active Epilepsy and Recent Seizures



*Respondents diagnosed with a seizure disorder or epilepsy but who had not had a seizure in the past 3 months and were not taking medication for epilepsy.

Source: *MMWR* 2008;57(SS-6).



CDC's National Leadership (continued)

have collected data on the prevalence of epilepsy in adults reporting a history of epilepsy, and of those, 13 states have collected more detailed information about current treatment for epilepsy, symptoms of epilepsy, access to care, and impairments in health-related quality of life (see charts on pages 3 and 4).

CDC is supporting population-based studies of epilepsy incidence and prevalence and assessing the relationships between demographic variables, socioeconomic status, health care use, cost, and outcomes in different population groups in the District of Columbia and in several states. Research is also being conducted to estimate epilepsy prevalence and treatment patterns in older adults using Medicare claims data.

Self-Management and Mental Health

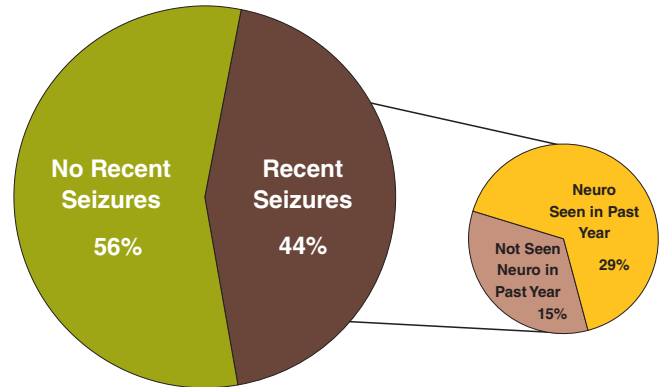
Improving the ability of people with epilepsy to better manage the disorder is a priority for CDC's Epilepsy Program. In 2008, a computer-based, theory-driven epilepsy self-management program developed for adults with epilepsy was found to be an effective management tool. Research is underway to evaluate home-based interventions for treating depression in people with epilepsy. Research is also continuing in collaboration with the Substance Abuse and Mental Health Services Administration to examine the issue of stigma.

Future Directions

CDC will continue to collaborate with the Epilepsy Foundation to expand education and awareness programs that target different groups, including racial and ethnic minorities, students and staff of middle schools and high schools, parents of teenagers with epilepsy, the unemployed and underemployed, older adults, and police and emergency responders. In addition, strategies will be developed and implemented to address the needs of veterans who have endured traumatic brain injuries resulting in epilepsy.

CDC's Epilepsy Program will continue to use state surveillance data to expand its study of the prevalence of self-reported epilepsy in selected state populations. The program also will

One-Third of People with Epilepsy AND Recent Seizures Have Not Seen a Neurologist in Past Year



Source: MMWR 2008;57(SS-6).

continue intramural and extramural research activities to better understand the epidemiology of epilepsy.

Some of this research will focus on higher-risk subpopulations, specifically older adults and children. The incidence of epilepsy and seizures and their co-occurrence with other conditions in nursing home residents will be studied, as well as the prevalence of developmental and other disabilities among children with epilepsy in rural populations. In addition, analysis of epilepsy-related data from the 2003 and 2005 California Health Interview Survey will be expanded to

- Obtain population-based estimates of the prevalence of epilepsy and burden of impaired quality of life in persons with epilepsy by race, ethnicity, and seizure frequency.
- Gather epilepsy-related data in racial and ethnic populations.
- Identify levels of psychological distress, health disparities, and unmet mental health needs in adults with epilepsy.

**For more information, please contact the Centers for Disease Control and Prevention
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