



Targeting Epilepsy

One of the Nation's Most Common Disabling Neurological Conditions 2008



“America has the capacity to prevent or mitigate many of the adverse consequences of epilepsy, but ambitious efforts and persistence are needed. The time to act is now.”

*Eric R. Hargis
President and CEO of the Epilepsy Foundation
Past chairperson of the National Health Council*

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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 just one type of seizure. Others have more than one type. The term “epilepsy” can be used interchangeably with the term “seizure disorder.” Epilepsy is not contagious and cannot be transmitted from person to person.

What Causes Epilepsy?

Epilepsy can occur as a result of 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 2.7 million people in the United States and costs about \$15.5 billion in medical costs and lost or reduced earnings and productivity each year. 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 age 2 years and adults older than 65 years 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 greatly increase 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, 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?

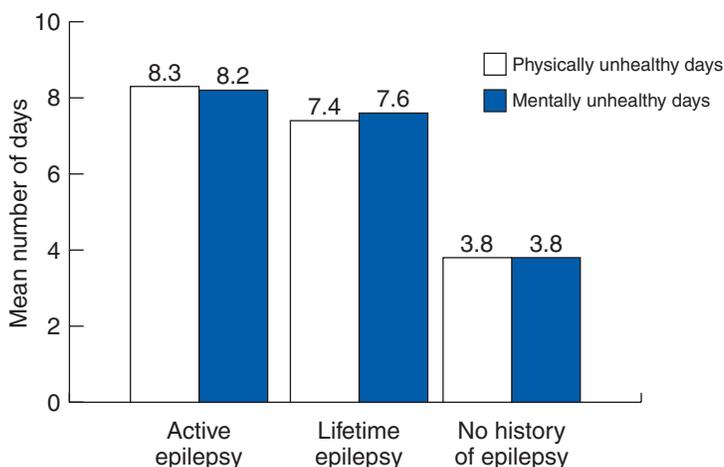
The second National Conference on Public Health and Epilepsy, titled Living Well With Epilepsy II, brought together experts in the field, as well as

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 that will 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.

Number of Physically or Mentally Unhealthy Days Reported by California Adults, by Epilepsy Status*



* During the previous 30 days.

Source: 2003 California Health Interview Survey (n = 41,494).

CDC's National Leadership

CDC is committed to ensuring that all people, especially those at greater risk for health disparities, will achieve their optimal lifespan with the best possible quality of health in every stage of life. With agency-wide health protection goals that support healthy people in healthy places across all life stages, CDC is setting the agenda to enable people to enjoy a healthy life by delaying death and the onset of illness and disability by accelerating improvements in public health.

Over the past 13 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 their quality of life, and decrease the stigma associated with this 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 worked with the national Epilepsy Foundation for several years 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.

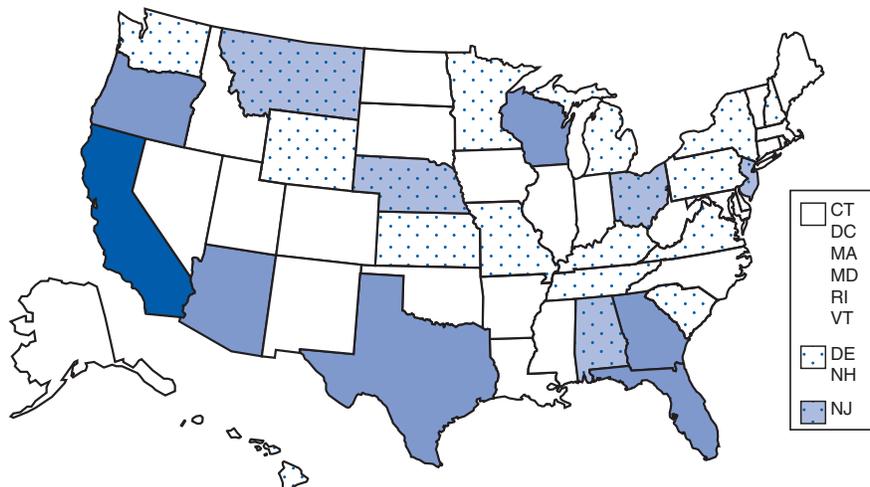
Past campaigns have focused on underserved population groups, including African Americans, women, and young people. The 2006–2007 campaign addressed the needs of Hispanic and African American communities. Campaign activities included the following:

- Providing basic information about epilepsy to the Hispanic community through national and local partnerships.
- Providing Epilepsy Foundation affiliates with tools and resources to reach local African American and Hispanic communities.
- Creating a needs assessment and evaluation system to measure the effectiveness of campaign components.

Messages were aired on 210 Spanish-language radio stations, and articles were sent to 97 Spanish-language newspapers, reaching as many as 25 million people. Epilepsy information also was widely distributed at national conferences targeting the Hispanic community and through publications targeting African Americans.

In addition, CDC developed a tool kit called *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, in collaboration with the Epilepsy Foundation, developed and tested an award-winning tool kit for parents called *You Are Not*

States Collecting Epilepsy Prevalence Data



- No data being collected.*
- ◻ Data collected on 2005 BRFSS.†
- ◻ Data collected on 2006 BRFSS.
- ◻ Data collected on 2003 and 2005 California Health Interview Survey.

* Includes U.S. territories.

† Behavioral Risk Factor Surveillance System.

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. The tool kit includes a letter to parents, a brochure, a resource guide, an audio-cassette, stationery, and a videotape with a user's guide. All materials are available on the Internet 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 supports epidemiological studies to define the incidence and prevalence of epilepsy in different U.S. racial and ethnic populations. These studies 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.

Nineteen state health departments have used Behavioral Risk Factor Surveillance System (BRFSS) surveys to collect data on self-reported epilepsy prevalence and associated behavioral risk factors, chronic disease comorbidity, and health-related quality of life (see map, page 3). In addition, CDC is conducting research on the prevalence of self-reported epilepsy in California using the California Health Interview Survey (see chart, page 2).

CDC also 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 Texas, New York City, South Carolina, rural Kansas, and the District of Columbia, and along the underserved Arizona-Mexico border.

Self-Management and Mental Health

Improving the ability of people with epilepsy to better manage the disorder is a priority for CDC. In 2007, researchers worked to develop and test a computer-based, theory-driven epilepsy self-management program for adults, including veterans with epilepsy. They also were working to develop and test home-based interventions for treating depression in people with epilepsy and to examine the stigma associated with epilepsy and mental illness in collaboration with the Substance Abuse and Mental Health Services Administration.

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, and police and emergency responders. CDC also will refine its focus on older adults with epilepsy by developing and implementing educational programs that target the public and health care providers. New program initiatives will seek to identify 1) issues, priorities, and strategies necessary to address sudden unexplained death in epilepsy and 2) ways to support young people with epilepsy as they move into the workforce.

In addition, CDC will continue to analyze epilepsy data from BRFSS surveys and to work with state health departments and the Epilepsy Foundation to add questions about epilepsy and seizures to future surveys. A new initiative will examine associations between epilepsy and psychological distress in adults participating in the California Health Interview Survey.

CDC also will continue to collaborate on research projects with the Association of American Medical Colleges and the Association of Schools of Public Health to increase knowledge in the following areas:

- The epidemiology of epilepsy, specifically the incidence and prevalence, risk factors, and severity of this disorder among minority populations in the United States.
- The prevalence of epilepsy, patterns of care, and health outcomes among older Americans.
- Health disparities and factors that contribute to health disparities among people with epilepsy.

CDC's Epilepsy Program will continue to work with the Prevention Research Centers (PRC) to fund a coordinating center and a collaborating center to create a network of PRCs for epilepsy self-management intervention research. The Managing Epilepsy Well (MEW) network will develop and implement a coordinated, applied research agenda; conduct research activities that promote self-management and quality of life; and identify and collaborate with state and local public and mental health agencies, as well as with other social services agencies, to implement activities.

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