

The Challenge of Epilepsy

Epilepsy accounts for about \$15.5 billion in direct costs (medical) and indirect costs (lost or reduced earnings and productivity) each year. Adults with epilepsy report worse mental health, more cognitive impairment, and barriers in social participation. People with epilepsy also experience health and social disparities, such as worse health-related quality of life and low socioeconomic status.

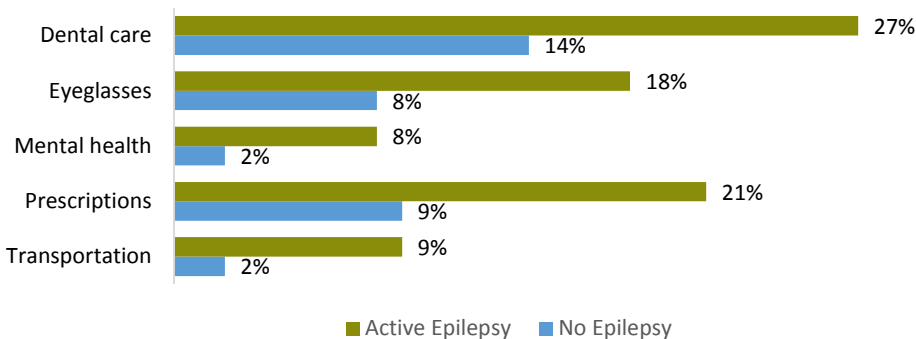
Children younger than age 2 years and adults older than 65 are more likely to have epilepsy because risk factors are more common in these age groups. Delayed recognition of seizures and inadequate treatment increase a person's risk of subsequent seizures, brain damage, injuries, disability, and early death. More than one-third of people with epilepsy continue to have seizures despite treatment. People with epilepsy often have other chronic conditions that need to be managed, such as depression, heart disease, and asthma.

Although epilepsy is widely recognized by the public, it is poorly understood, even among people who know someone with the disorder. Public misunderstanding and stigma can limit life opportunities for people with epilepsy.

CDC's Response

The National Center for Chronic Disease Prevention and Health Promotion (NCCDPHP) works in four key areas or domains: epidemiology and surveillance, environmental approaches, health care system interventions, and community programs linked to clinical services. This comprehensive approach supports healthy choices and behaviors, makes healthier options more available, and helps Americans better manage their health.

Percentage of Adults With and Without Epilepsy Who Have Difficulty Getting Health Care^a



^a Defined as the inability to afford these types of care or get transportation to health care in the past year. Note: "Active Epilepsy" defined as a person with a diagnosis of epilepsy who is currently taking medicine to control the disorder or who has had at least one seizure in the past year, or both. "No Epilepsy" defined as a person with no history of ever being diagnosed with epilepsy or seizure disorder.

Source: [Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013](#). *Epilepsy Behav.* 2015;55:184-188.

"We need strong public health programs to promote health and quality of life for people with epilepsy and to improve public understanding of this condition."

*Phil Gattone
President and CEO,
Epilepsy Foundation*



CDC works with local, state, and national partners to research, test, and share strategies and programs to improve the lives of people with epilepsy. With \$8.5 million in FY 2017 funding, CDC's Epilepsy Program supports these efforts by focusing its activities in three of NCCDPHP's four domains: epidemiology and surveillance, environmental approaches, and community programs linked to clinical services.

Epidemiology and Surveillance

Studying Epilepsy in Communities

CDC supports research to better understand the scope of epilepsy in the United States by collecting data on incidence and prevalence, risk factors, severity, quality of life, and the risk of early death. CDC is funding studies to examine how epilepsy affects different population groups. For example, researchers in New York are analyzing electronic health records from multiple institutions to describe the incidence, prevalence, comorbidities, mortality, and quality of ambulatory care for people with rare forms of epilepsy.

In South Carolina, researchers are using health care system data to examine the relationship between co-occurring disorders and epilepsy outcomes, health care use and cost, and death in people with epilepsy. These data will help guide research, quality improvements, care management, and referrals to advocacy organizations.

Analyzing Data to Guide Interventions and Track Progress

Healthy People 2020 objectives call for increasing the proportion of people with epilepsy and uncontrolled seizures who receive appropriate medical care. CDC's analysis of 2010 and 2013 data from the National Health Interview Survey found that about 39% of adults who experienced seizures in the past year had not seen a neurologist. This finding suggests that many people are not receiving the right kind of care for this complex condition.

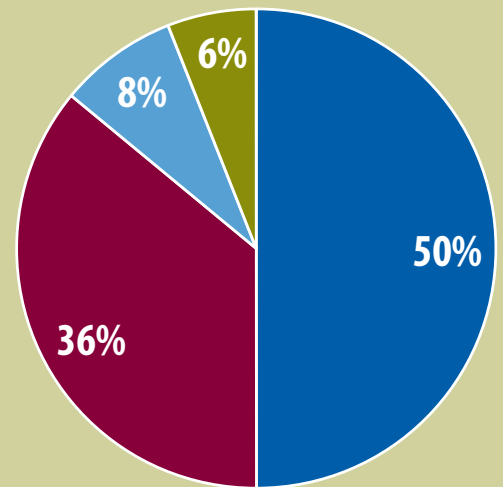
In 2014, CDC and the National Institutes of Health launched the Sudden Death in the Young Registry, which identifies cases of sudden unexpected death in epilepsy (SUDEP) and sudden cardiac deaths in children aged 19 or younger in 10 localities. Information from this registry will help researchers identify risk factors for SUDEP.

CDC's Epilepsy Program is also working with the agency's Center for Global Health to develop a new method to screen for and monitor treatment of cysticercosis infection from pork tapeworms, which is a leading cause of epilepsy and seizures in some developing countries and some immigrant populations in the United States.

Environmental Approaches

People with epilepsy may be stigmatized and isolated because others believe myths about epilepsy, misunderstand the abilities of people with epilepsy, fear seizures, or lack knowledge about seizure

Percentage of Adults with Active Epilepsy Who Saw a Doctor in the Past 12 Months



- Saw general doctor and specialist
- Saw general doctor but not specialist
- Saw specialist but not general doctor
- Did not see general doctor or specialist

Source: National Health Interview Survey, 2010 and 2013 data.



first aid or are uncomfortable providing it. CDC has a longstanding partnership with the Epilepsy Foundation to conduct public education and awareness campaigns to increase understanding about epilepsy and reduce stigma.

CDC also supports the Epilepsy Foundation to develop and conduct training for school nurses, child care and school staff, first responders, adult care facility staff, and law enforcement personnel. For example, the foundation has reached nearly 280,000 students and teachers with its Seizures and You: Take Charge of the Facts program. With CDC support, the foundation also manages a 24/7 Epilepsy & Seizures Helpline in English and Spanish that provides assistance to thousands of people with epilepsy and their families every year.

Community Programs Linked to Clinical Services

Since 2007, CDC has supported the [Managing Epilepsy Well \(MEW\) Network](#), whose members conduct research on epilepsy self-management in partnership with community stakeholders. The MEW Network is part of CDC's Prevention Research Centers Program. Current members are Case Western Reserve University, Dartmouth College, Morehouse School of Medicine, New York University School of Medicine, the University of Arizona, the University of Illinois at Chicago, the University of Minnesota, and the University of Washington.

MEW Network researchers develop and evaluate interventions, provide professional trainings, and share findings and evidence-based programs. For example, WebEase (Epilepsy Awareness, Support, and Education) is a free online program that improves self-management behaviors. Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) reduces depression in people with epilepsy. Researchers are working to adapt both of these programs for Spanish speakers.

Another MEW Network program is PACES (Program for Active Consumer Engagement in Epilepsy Self-Management), which helps people gain confidence in their ability to manage their epilepsy and better manage medication side effects like fatigue. In addition, HOBSCOTCH (Home Based Self-management and COgnitive Training CHanges lives) helps adults with epilepsy and memory problems.

Project UPLIFT and HOBSCOTCH are delivered by telephone, which removes barriers such as lack of transportation or stigma. Health professionals can also earn continuing education credits for becoming trained in these programs.

The MEW Network is also evaluating the effectiveness of an electronic decision-support tool designed to improve patient-provider communication for both English- and Spanish-speaking adults with epilepsy. In addition, new studies are being conducted to develop Internet-based self-management programs for youth with epilepsy and for adults or their caregivers.

Future Directions

CDC will continue to work with its partners to implement IOM's recommendations. In 2017, CDC will work with the Epilepsy Foundation to help more people with epilepsy get appropriate and timely medical care. The goal is to improve social participation (e.g., employment, school attendance), health, and quality of life for people with epilepsy and decrease the public stigma of epilepsy.

The MEW Network will continue to refine and evaluate its programs, identify new ways to deliver them, and work with health care providers and others to expand access to self-management interventions. CDC will use existing surveillance systems to examine health care use and trends, causes of death, and other important epilepsy outcomes.

CDC is guiding the development of demonstration projects that examine existing or new health reform reimbursement options for community programs that serve people with epilepsy.



For more information, contact

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