

At A Glance 2015

Targeting Epilepsy

One of the Nation's Most Common Neurological Conditions



Epilepsy is a condition that is not well understood and often not well addressed, despite being widely recognized. In 2012, the Institute of Medicine (IOM) released [*Epilepsy Across the Spectrum: Promoting Health and Understanding*](#), a report that calls for more public health action on epilepsy. The report makes recommendations for enhancing or expanding surveillance and prevention, access to care, partnerships, and professional, patient, and public education.

The Centers for Disease Control and Prevention (CDC) uses the IOM's recommendations to guide research, program activities, and services in collaboration with partners, including nonprofit organizations, academic researchers, and communities. Through these efforts, CDC seeks to improve health and quality of life and decrease stigma for people with epilepsy.

Public Health Problem

The Nature of Epilepsy

Epilepsy, also known as seizure disorder, 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, while others have more than one type. Epilepsy is referred to as a spectrum disorder because seizure types, frequency, and other symptoms can vary.

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

The Challenge of Epilepsy

Epilepsy accounts for \$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, barriers in social participation, and worse health-related quality of life than adults without epilepsy. About 1 out of every 26 people will develop epilepsy at some

Fast Facts

- ◆ About 1% of US adults aged 18 or older and 0.6% of children aged 17 or younger have active epilepsy. About 2.9 million adults and children had active epilepsy in 2013.
- ◆ Epilepsy can shorten a person's life and severely reduce overall well-being and full participation in daily activities.
- ◆ CDC works with the Epilepsy Foundation to develop and share public education programs and campaigns and to provide services for people with epilepsy and their families.



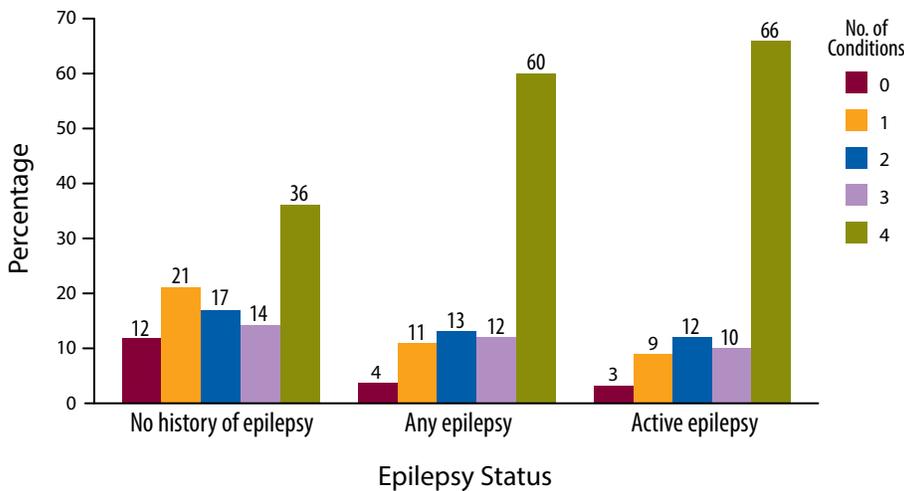
National Center for Chronic Disease Prevention and Health Promotion
Division of Population Health



point in their lives. Children younger than 2 and adults older than 65 are particularly vulnerable because risk factors for epilepsy 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.

Percentage of Adults with Select Conditions, by Number of Conditions and Epilepsy Status



Notes: Conditions include self-reported cardiovascular, neurological, metabolic, respiratory, dermatological, inflammatory, musculoskeletal, malignant, ulcerative, and hepatic conditions and overweight/obesity. See source for epilepsy definitions.
 Source: [Comorbidity in Adults with Epilepsy — United States, 2010](#). *MMWR*. 2013;62(43):849-853.

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.

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 nearly \$8 million in FY 2015 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.

“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*



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 several studies to examine how epilepsy affects different population groups. For example, researchers in New York are looking at the degree to which co-occurring mental illness and low income contribute to death in people with 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. They have found that children with epilepsy are more likely to die than children without epilepsy, and they have identified the leading causes of these early deaths.

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 data from the National Health Interview Survey found that about 50% of adults with active epilepsy had seen a neurologist or epilepsy specialist in the past 12 months. This finding suggests that many people are not receiving the right kind of care for this complex condition.

Analysis of the 2010 data also found that adults with epilepsy, especially those with active epilepsy, were more likely than those without epilepsy to report four or more co-occurring medical conditions. They were also less likely to report no other conditions. (A person with active epilepsy is someone with a diagnosis of epilepsy who is currently taking medicine to control their disorder or who has had at least one seizure in the past year, or both.)

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 nine localities. Information from this registry will help researchers identify and prevent risk factors for SUDEP.

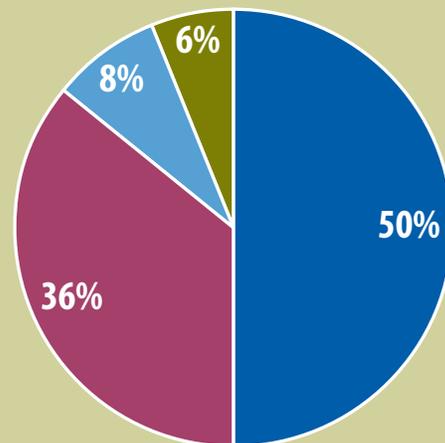
CDC's Epilepsy Program is also working with the agency's Center for Global Health to develop a new method to screen for and monitor treatment of cysticercosis infection from pork tapeworms, which is a leading cause of epilepsy and seizures in some developing countries and some immigrant populations in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

Environmental Approaches

Improving Public Awareness and Social Participation

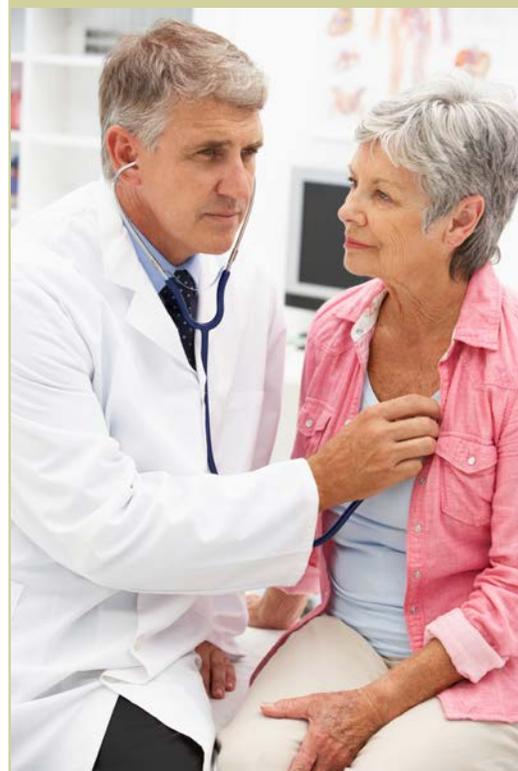
People with epilepsy may be stigmatized and isolated because others believe myths about epilepsy, misunderstand the abilities of people with epilepsy, fear seizures, or lack knowledge about seizure first aid or are not comfortable providing it. CDC has a longstanding partnership with the Epilepsy Foundation to conduct public education and awareness campaigns to increase understanding about this condition and to reduce stigma. Past

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.



campaigns have focused on specific population groups, such as African Americans, Hispanics, Asians, women, and young people.

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 more than 260,000 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 information and referrals to thousands of people with epilepsy and their families every year.

In addition, CDC is funding research at Case Western Reserve University to develop and test new communication strategies to combat epilepsy stigma in youth and young adults.

Community Programs Linked to Clinical Services

Supporting the Managing Epilepsy Well Network

Since 2007, CDC has supported the [Managing Epilepsy Well \(MEW\) Network](#), whose members promote epilepsy self-management by conducting research in partnership with community stakeholders. The MEW Network is part of CDC's Prevention Research Centers Program. It currently includes 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. Legacy members include Emory University, the University of Texas Health Sciences Center at Houston, and the University of Michigan.

MEW Network researchers develop and evaluate interventions, provide professional trainings, and share findings and evidence-based programs. An example of these programs is WebEase (Epilepsy Awareness, Support, and Education), a free online program that has been shown to improve self-management behaviors. Other programs include Project UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) and PEARLS (Program to Encourage Active, Rewarding Lives), which address the high rates of depression in people with epilepsy.

Because Project UPLIFT and PEARLS can be delivered by telephone, Internet, or in a person's home, they help eliminate barriers to care, 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 currently evaluating the effectiveness of an electronic decision-support tool designed to improve patient-provider communication about epilepsy self-management for both English- and Spanish-speaking adults with epilepsy. Researchers are also evaluating telephone-based programs designed to reach adults with epilepsy who live in rural areas or those with memory impairment. In addition, new studies are being conducted to develop a self-management program for young people with epilepsy and for adults who have refractory epilepsy or other co-occurring problems.

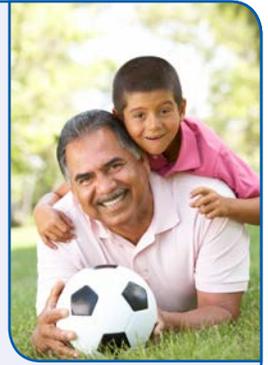
Future Directions

CDC will continue to work with its partners to implement the IOM's

recommendations. Working with the Epilepsy Foundation, CDC will expand programs that focus on racial and ethnic minority groups, students and school staff, parents, people who are unemployed, older adults, law enforcement personnel, and first responders.

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 and support for the network's self-management interventions. CDC will use existing surveillance systems to examine health care use and trends, causes of death, and other outcomes important in epilepsy.

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



For more information, contact

Centers for Disease Control and Prevention
National Center for Chronic Disease Prevention
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[Epilepsy Program](#)

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