

Epilepsy

How CDC Improves the Lives of People With Epilepsy

Epilepsy, also known as seizure disorder, is a common brain condition that causes repeated seizures. In the United States, about 3 million adults and 470,000 children and teens younger than 18 have epilepsy.

Adults with epilepsy report worse physical and mental health and are more likely to report being unable to afford different types of health care than adults without the disorder. In 2016, health care spending for epilepsy was \$8.6 billion in direct costs.

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

Children and older adults are more likely to have epilepsy because risk factors are more common in these groups. Getting the wrong diagnosis or the wrong treatment can increase a person's risk of later 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.

With \$9.5 million in FY 2020 funding, CDC's [Epilepsy Program](#) works with partners to research, test, and share strategies and programs to improve the lives of people with epilepsy.

Measuring How Many People Have Epilepsy

CDC uses data from the National Health Interview Survey (NHIS) and other surveys to study new cases of epilepsy, how many people are living with epilepsy, risk factors, severity, quality of life, and the risk of early death. These data help researchers better understand the scope of epilepsy in the United States.

In the United States:



56% OF ADULTS

taking medicine for epilepsy still have seizures.



32% OF ADULTS

with epilepsy are unable to work.



53% OF ADULTS

with uncontrolled seizures live in households earning less than \$25,000 a year.





CDC's analysis of 2017 NHIS data found that about one-third of adults with epilepsy had not seen a neurologist or epilepsy specialist in the past year.

In 2014, CDC and the National Institutes of Health launched the Sudden Death in the Young Case Registry, which identifies cases of sudden unexpected death in epilepsy (SUDEP), sudden unexpected infant death, and sudden cardiac death in children aged 19 or younger. Currently, this work is taking place in 13 states or jurisdictions. The registry will help researchers identify SUDEP risk factors so scientists can better understand how to prevent it.

Studying Interventions to Find Out What Works Best

Since 2007, CDC has supported the [Managing Epilepsy Well \(MEW\) Network](#), whose members study epilepsy self-management with community partners. MEW Network researchers develop and evaluate interventions, provide professional trainings, and share findings and promising programs. The following are MEW programs:

- [HOBSCOTCH](#) (HOMe-Based Self-management and COgnitive Training CHanges lives) helps adults with epilepsy and memory problems.
- [MINDSET](#) (Self-Management Epilepsy Decision Support for Adult People with Epilepsy and Their Providers) is a tablet-based program rated positively by doctors and patients for improving discussion about self-management.
- [PACES](#) (Program for Active Consumer Engagement in Self-management in epilepsy) helps people gain confidence in their ability to manage their epilepsy and reduce medication side effects.
- [Project UPLIFT](#) (Using Practice and Learning to Increase Favorable Thoughts) reduces depression in people with epilepsy.
- [SMART](#) (Self-management for people with epilepsy and a history of negative health events) reduces seizure frequency and improves mood.

Funding the Epilepsy Foundation to Share Information

People with epilepsy may encounter stigma and feel isolated because others continue to believe myths about epilepsy, misunderstand the abilities of people with epilepsy, or fear seizures. Some people lack knowledge about seizure 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, law enforcement personnel, and health providers. The Epilepsy Foundation also provides a 24/7 Epilepsy & Seizures Helpline in English and Spanish that connects people to resources in their own communities.