## **Prevention Research Centers**



The Managing Epilepsy Well Network and Selected Self-Management Programs Putting Collective Wisdom to Work for People with Epilepsy

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This booklet describes the structure and mission of the Centers for Disease Control and Prevention's (CDC's) Managing Epilepsy Well (MEW) Network and presents selected network accomplishments. The MEW Network is a thematic network of CDC's Prevention Research Centers (PRC) Program and is funded by CDC's Epilepsy Program.



#### **Suggested Citation**

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# **About the Managing Epilepsy Well Network**

Since 2007, CDC's Managing Epilepsy Well (MEW) Network has provided national leadership in developing, testing, and distributing innovative self-management programs, tools, and trainings for epilepsy professionals. These efforts help people with epilepsy better manage their disorder and enhance their quality of life. National and local organizations, federal agencies, health care organizations, and people who have epilepsy all participate in the network, which includes a wide range of clinical, public health, social service, and personal expertise.

This expertise has led the network to develop effective programs that people who have epilepsy can use in their homes, at their doctor's offices, or in other community settings. Some of these epilepsy self-management programs are available by phone, online, and on other electronic devices, eliminating barriers to care, such as lack of access to transportation, functional limitations, and stigma.



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# **Epilepsy and Epilepsy Self-Management**

Epilepsy is one of the most common neurological disorders, affecting about 2.9 million people in the United States in 2013.<sup>1</sup> Epilepsy is a general term for conditions with recurring seizures.

Because seizures range in severity, type, and effect and can occur alongside other conditions, epilepsy is also referred to as a spectrum disorder. All seizures involve abnormal electrical activity in the brain that causes an involuntary change in body movement or function, sensation, awareness, or behavior. Usually, a seizure lasts from a few seconds to a few minutes. Epilepsy has many causes, including brain injury, central nervous system infection, stroke, and family tendency. But in most cases, the cause is unknown.

Although there are medications to help prevent seizures, they are not always completely successful—about one-third of people with epilepsy who are receiving care still experience seizures.<sup>2</sup> Uncontrolled seizures can increase risk of injury, anxiety, depression, brain damage, and in rare cases, death. Uncontrolled seizures can also interfere with normal day-to-day activities, such as working, going to school, and socializing with friends and family. For some people with epilepsy, treatment can be complex, and treatment side effects (e.g., memory problems) can add to the challenges of living with epilepsy.

As with any chronic condition, many people with epilepsy can benefit f om learning skills and techniques that help them better manage their disorder and its effects on daily life. Adopting and reinforcing selfmanagement behaviors requires an active partnership between a person with epilepsy and the person's health care provider.

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# Epilepsy self-management encompasses three broad areas:

- Treatment management, such as medication schedules, keeping clinic appointments, and communicating with health care professionals.
- Seizure management, such as recognizing and avoiding seizure triggers whenever possible and keeping track of seizures.
- Lifestyle management, such as getting adequate sleep, reducing stress, and maintaining social support networks.

The MEW Network addresses the gap in evidence-based programs for epilepsy self-management by developing effective programs and tools to help people with epilepsy manage their condition.

## Did you know?

- Health care professionals have described more than 40 different types of seizures.
- Many cases of epilepsy can be prevented by taking measures to prevent head injury and other trauma.
- Proper prenatal care can also prevent some cases of epilepsy.
- First aid for seizures involves responding in ways that can keep the person safe until the seizure stops by itself. Learn about first aid for seizures at www.cdc.gov/epilepsy/ basics/first-aid.htm.

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