



PRC

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

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



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.



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US Department of Health and Human Services
Centers for Disease Control and Prevention
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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.





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 2013.¹ 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.² 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 from learning skills and techniques that help them better manage their disorder and its effects on daily life. Adopting and reinforcing self-management behaviors requires an active partnership between a person with epilepsy and the person's health care provider.

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.



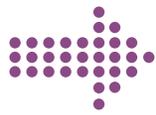
Emphasis on Mental Health

Although epilepsy and mental illness are separate conditions, people who have epilepsy often have depression, anxiety, worry, negative feelings about life, and difficulties with memory and concentration. For some people, the conditions affecting the brain that cause epilepsy can also cause mental illness. People with epilepsy sometimes encounter negative and stigmatizing attitudes from the public that harm their self-esteem and limit their life opportunities.

In addition, loss of independence, including loss of driving privileges for some or lack of access to public transportation for others, further affects quality of life. People with epilepsy might have problems negotiating workplace accommodations, challenging their ability to work full-time.

For these reasons, the MEW Network has made the mental health needs of people with epilepsy a priority.





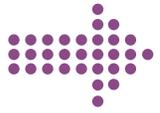
The MEW Network's Community of Practice

The MEW Network forms a community of practice in which all participants work to improve the effective management of epilepsy. Working together, members deepen the community's knowledge and expertise. In addition, the network's collaborating centers are partners in defining the structure of the network and setting its research agenda and priorities.

Members also identify and track meaningful outcomes, such as products, collaboration, and network expansion, to gauge the network's progress and success. In addition to these outcomes, the network also affects the field of public health by doing the following:

- Measuring progress and promoting standards of research in the field of epilepsy self-management.
- Supporting and promoting key national initiatives.
- Improving analytic and reporting capabilities.
- Supporting professional training opportunities.
- Sharing information about MEW Network programs with professionals and the public.





The MEW Network Centers and Members

The MEW Network is made up of a coordinating Prevention Research Center (PRC), collaborating PRCs, associate members, at-large members, and participating partners. Together, these members expand capacity, expertise, and resources to support self-management efforts and to increase use of MEW Network programs and tools.

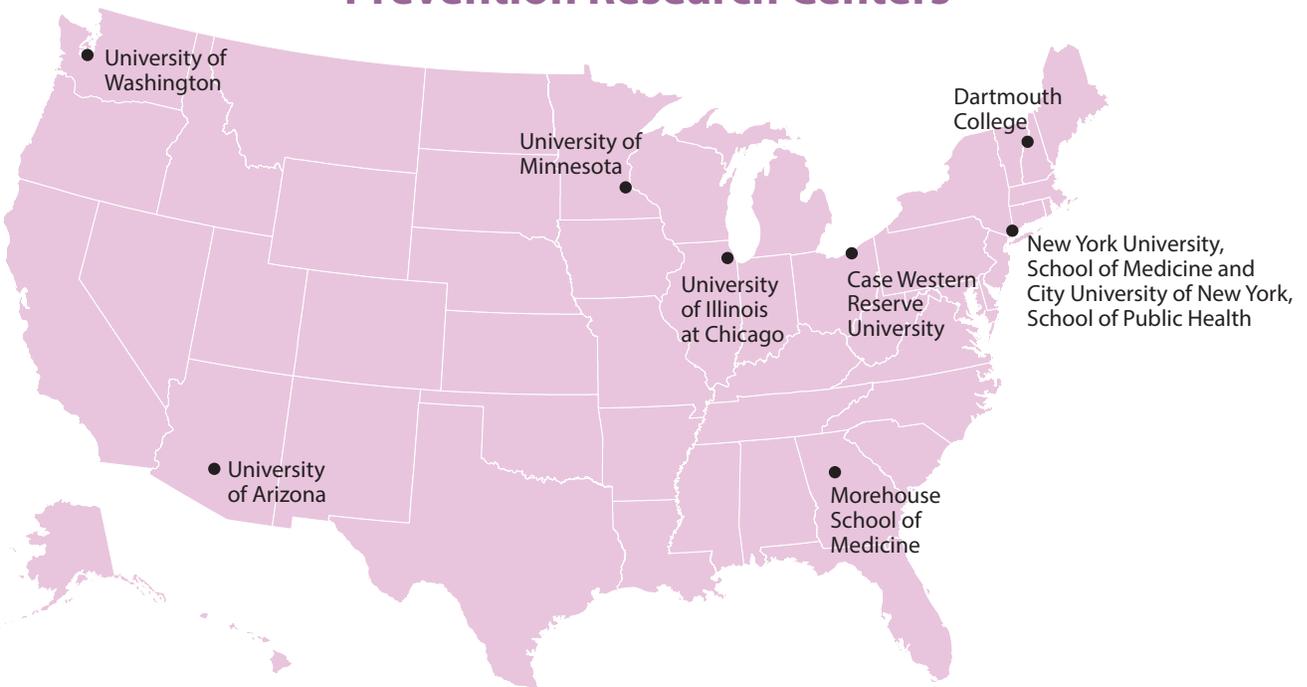
The coordinating center's primary goal is to provide leadership and coordination of efforts across the MEW Network. The coordinating center is also engaged in program development. Dartmouth College in Lebanon, New Hampshire, is the coordinating PRC.

The collaborating PRCs are currently funded and responsible for a variety of tasks, including development and implementation

of actions within the network. The following are collaborating PRCs:

- ▶ Case Western Reserve University PRC (Cleveland, Ohio)
- ▶ University of Washington PRC (Seattle, Washington)
- ▶ University of Arizona PRC (Tucson, Arizona)
- ▶ Morehouse School of Medicine PRC (Atlanta, Georgia)
- ▶ New York University PRC (New York City, New York)
- ▶ University of Illinois at Chicago PRC (Chicago, Illinois)
- ▶ University of Minnesota PRC (Minneapolis, Minnesota)

Managing Epilepsy Well (MEW) Network Prevention Research Centers





Associate members are previously funded network sites that remain active in network-specific research or in distributing network programs or tools.

- Emory University (Atlanta, Georgia)
- University of Texas Health Sciences Center (Houston, Texas)

At-large members are organizations or groups that are nominated to represent partners or agencies not funded under the Network Special Interest Project cooperative agreement. The following foundation is an at-large member: National Epilepsy Foundation.

Participating partners are institutions, organizations, or agencies that have a vested interest in MEW Network activities, but are not affiliated with a PRC. The following organization is a participating partner: American Epilepsy Society.



MEW Network Workgroups

The MEW Network forms a community of practice, which provides a forum for colleagues in and outside of the network to participate in and lead network workgroups. MEW Network workgroups accelerate a project by advancing a particular epilepsy self-management topic. Workgroups include the following:

Self-Management in Pediatric Epilepsy

The Self-Management in Pediatric Epilepsy Workgroup has identified the main topics of epilepsy management in pediatric epilepsy and the challenges of transitioning from family-centered to independent epilepsy management. Members have conducted a comprehensive literature review, are currently summarizing current programs that are available for pediatric epilepsy, and are developing research questions that examine self-management among young people with epilepsy and their families.

Self-Management Measurement Tool

The MEW Network identified the need for a standard way to measure improvements in self-management outcomes. The Self-Management Measurement Tool Workgroup defined epilepsy self-management, identified the components of epilepsy self-management, developed a measurement tool, and validated the tool.

Dissemination and Sustainability

The Dissemination and Sustainability Workgroup leads efforts to share information about network products with the public with an aim to increase their use. Accomplishments include coordinating a series of public webinars on epilepsy self-management and developing a social networking strategy, which includes recording podcasts and using Twitter to share information about MEW Network programs (@MEWNetwork).



Members of the Self-Management Measurement Tool Workgroup conducted a series of studies to assess the reliability and validity of the Epilepsy Self-Management Tool. This tool is available on the MEW Network website at <http://managingepilepsywell.org/research/instruments.html>.

Integrated Database

The Integrated Database Workgroup is developing an integrated database among the eight network PRCs to create a common resource to capture, store, share, and query data. The database will help members use resources efficiently and enhance collaborative efforts among centers. The integrated database will also store information about non-network programs that show other successful ways to help care for people with epilepsy.

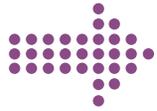
e-Tools and Technology

The e-Tools and Technology Workgroup examined the use and effectiveness of electronic tools (e-Tools) and technology for delivering epilepsy self-management. The use of technology increases access to self-management programs among people with limited mobility or people in rural areas. Accomplishments include the preparation and publication of an article describing the use of e-Tools for chronic disease and epilepsy self-management.

Epilepsy and Stigma

The Epilepsy and Stigma Workgroup finalized a chapter about epilepsy and stigma that is included in the book *The Interictal State in Epilepsy: Co-morbidities and Quality of Life*. The chapter, titled Implications for Understanding and Combating Stigma, provides an overview of the stigma of epilepsy, including its causes, mediating factors, and manifestations. See the Selected Research Findings section of this booklet for a full reference.





Epilepsy Self-Management Programs

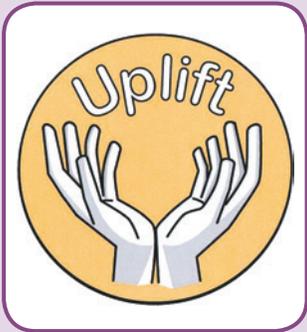
Research Findings

The MEW Network members share research findings to produce effective programs and resources. For example, researchers from the Dartmouth College PRC participated in the University of Washington PRC's PEARLS training and adapted its problem-solving section to be included in the HOBSCOTCH program. The network shares its findings in scientific and professional literature, on its website, and at professional conferences and events. During 2007-2015, the MEW Network produced more than 50 scientific journal articles, 4 book chapters, and 65 scientific presentations and posters. The MEW Network also shares its work through the MEW website.

“One thing I’m taking away from the program is the knowledge that I’m in control of myself, and that I’m able to make myself feel good when I get into a stressful or upsetting situation, especially when it is a result of my epilepsy.”

—UPLIFT Participant

Evidence-Based Programs



UPLIFT (Using Practice and Learning to Increase Favorable Thoughts) is an 8-week program delivered through the Internet or by phone to groups of adults who have both epilepsy and depression. Participants learn how to identify and modify their thoughts and how to become aware of and nonreactive to negative thoughts. An effectiveness study³ found that participants' symptoms of depression decreased, and their knowledge and skills increased after completing the program. With funding from the National Institutes of Health, Project UPLIFT was adapted into a depression prevention intervention. The modified program proved to be effective⁴ in preventing major depressive disorder among people with epilepsy who have mild depression symptoms through an evaluation at multiple sites across the MEW Network.

MEW Network researchers are adapting and testing Project UPLIFT among African Americans in Georgia and among Spanish-speaking adults with epilepsy in New York. A version for caregivers is also in development. In addition to helping people in the epilepsy community, Project UPLIFT is also being tested as a way to help pregnant women in rural areas and people with cystic fibrosis.

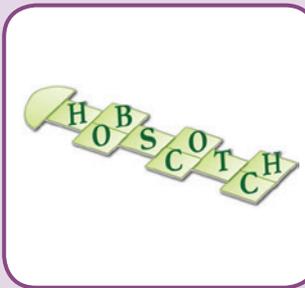
Learn more at <http://managingepilepsywell.org/programs/uplift.html>.



PEARLS (Program to Encourage Active, Rewarding Lives) is an effective home-based depression treatment program for adults with epilepsy and depression.⁵ The program is delivered by a trained counselor in the participant's home and consists of eight sessions. Through these one-on-one visits, the participant learns how to address issues that contribute to depression, such as being socially alone and not being independent. Research by the University of Washington has shown that adults with epilepsy who participated in the PEARLS program were less depressed and had fewer suicidal thoughts for 12 to 18 months compared with program participants who received usual care.⁶

The PEARLS training is available online and offers professional certification credits.

Learn more at www.pearlsprogram.org/.



HOBSCOTCH (Home-Based Self-Management and Cognitive Training Changes Lives) is a program led by Dartmouth College that is designed to address memory and attention problems among people with epilepsy through a combination of in-person visits and phone calls that provide coaching. About half of people who experience seizures report more difficulties with memory than people without seizures.⁷ An evaluation of this program found that it improved participants' quality of life and some aspects of memory function, specifically attention.⁸

Learn more at <http://managingepilepsywell.org/programs/hobscotch.html>.



WebEase (Epilepsy Awareness, Support, and Education) is a web-based self-management program for adults with epilepsy. By using WebEase, users can learn, adjust, or reinforce self-management skills related to medication taking, stress, and sleep management. Results from a 2011 study showed that participation in and completion of the WebEase program significantly improved self-efficacy and medication adherence and showed trends for improvement in other self-management behaviors.⁹ Researchers are working to translate WebEase into Spanish.

Learn more at www.webease.org/.



PACES for Epilepsy (Program for Active Consumer Engagement in Self-Management) is an epilepsy self-management program that is tailored for individuals' specific self-management needs, such as stress, mood and memory, and information processing concerns. The 8-week program for urban-dwelling adults includes in-person sessions with a trained professional and a peer who has epilepsy. A 2015 study found that after 6 months, adults with epilepsy showed improvements in their understanding of their condition and their ability to manage

medication side effects, such as fatigue.¹⁰ Researchers are adapting PACES for use with rural-dwelling adults.

Learn more at <http://managingepilepsywell.org/programs/paces.html>.

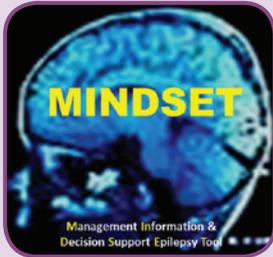


TIME (Targeted Self-Management for Epilepsy and Mental Illness) is a program for adults who have both epilepsy and a serious mental illness, such as severe depression, bipolar disorder, or schizophrenia.

The TIME program, adapted from an effective self-management program for people with diabetes and a serious mental illness,¹¹ consists of 12 weekly group sessions that include education, behavioral modeling, and group support. Groups are co-led by a nurse educator and a peer educator, which is a key feature of the TIME program. During these sessions, the group addresses the challenges that a person is likely to experience when they have both epilepsy and a serious mental illness. Educational topics include personalized goal-setting, medication adherence, and dealing with the double stigma of having both epilepsy and a serious mental illness. A 2016 study found that after 4 months, TIME was effective in reducing depressive symptoms in participants compared with control subjects.¹²

Learn more at <http://managingepilepsywell.org/research/past/TIME.html>.

Promising Programs



MINDSET (Management Information and Decision Support Epilepsy Tool)

is a clinic-based computer program designed to enhance epilepsy self-management communication between patients and their health care professionals.¹³ On the basis of the patient's symptoms, behavior, thoughts, and attitudes, the program will give the patient and the health care professional information about the patient's self-management needs. It also gives recommendations on important discussion points for the clinic visit, patient management goals, and suggestions for a patient self-management

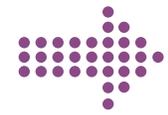
action plan after the clinic visit. Further studies of effectiveness and a Spanish version are underway in Arizona and Texas.

Learn more at http://managingepilepsywell.org/research/arizona_mindset.html.

New Programs

The MEW Network has new programs that include a focus on minorities, underserved populations, and youth:

- ▶ The network is testing use of video conferencing through tablets to improve self-management skills and quality of life. It is also testing a web-based group format approach designed to reach people at high risk of negative health events, such as seizures, hospitalizations, accidents or traumatic injuries, or self-harm attempts.
- ▶ An online intervention incorporating elements of healthy youth development among teens with epilepsy is also being developed.



Conclusion

Since its inception in 2007, the MEW Network has advanced epilepsy self-management research and program implementation. However, the combined and persistent efforts of multiple partners will be needed to make evidence-based epilepsy self-management programs widely available to people with epilepsy. Ultimately, disseminating epilepsy self-management programs among communities will require the support of public health, health care, social services, payers, and other community partners.





Selected Research Findings

MEW Network members distribute research findings so that effective programs and resources are available to people with epilepsy. Information is shared in a variety of formats for a variety of audiences. For example, the network shares its findings in the scientific peer-reviewed and professional literature, on its website, and at professional conferences and events.

The following are publication highlights from the network. For more, visit CDC's Epilepsy website at www.cdc.gov/epilepsy/publications/articles/chronological.htm.

- ▶ Begley CE, Shegog R, Iyagba B, et al. Socioeconomic status and self-management in epilepsy: comparison of diverse clinical populations in Houston, Texas. *Epilepsy Behav.* 2010;19(3):232-238.
- ▶ Begley C, Shegog R, Harding A, Goldsmith C, Hope O, Newmark M. Longitudinal feasibility of MINDSET: a clinic decision aid for epilepsy self-management. *Epilepsy Behav.* 2015;44C:143-150. doi:10.1016/j.yebeh.2014.12.031.
- ▶ Caller TA, Ferguson RJ, Roth RM, et al. A cognitive behavioral intervention (HOBSCOTCH) improves quality of life and attention in epilepsy. *Epilepsy Behav.* 2016;57(Pt A):111-117. doi:10.1016/j.yebeh.2016.01.024.
- ▶ Chaytor N, Ciechanowski P, Miller JW, et al. Long-term outcomes from the PEARLS randomized trial for the treatment of depression in patients with epilepsy. *Epilepsy Behav.* 2011;20(3):545-549.
- ▶ Clark NM, Stoll S, Sweetman M, Youatt EJ, Derry R, Gorelick A. Fostering epilepsy self-management: the perspectives of professionals. *Epilepsy Behav.* 2010;19(3):255-263.
- ▶ Dilorio C, Bamps Y, Walker ER, Escoffery C. Results of a research study evaluating WebEase, an online epilepsy self-management program. *Epilepsy Behav.* 2011;22(3):469-474.
- ▶ Dilorio C, Bamps Y, Edwards AL, et al. The Prevention Research Centers' Managing Epilepsy Well Network. *Epilepsy Behav.* 2010;19(3):218-224.
- ▶ Escoffery C, Bamps YA, LaFrance W, et al. Factor analyses of an Adult Epilepsy Self-Management Measurement Instrument (AESMMI). *Epilepsy Behav.* 2015;50:184-189.
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- ▶ Kobau R, Price P, Hawkins NA. News from the CDC: translating epilepsy self-management research to practice. *Transl Behav Med.* 2012;2(2):124-125.
- ▶ Sahoo S, Zhang GQ, Bamps Y, et al. Managing information well: towards an ontology-driven informatics platform for data sharing and secondary use in epilepsy self-management research centers. *Health Informatics J.* 2016;22(3):548-561. doi:10.1177/1460458215572924.
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In May 2012, MEW Network members conducted the first in a series of webinars dedicated to the topic of epilepsy self-management. The intent of the series was to provide an overview on how self-management differs from patient education programs and to highlight MEW resources.

These webinars are intended for a wide range of community epilepsy stakeholders and are publicly available on the MEW website at <http://managingepilepsywell.org>. Also available on the website are podcast interviews with researchers from each of the network centers highlighting various programs and studies.



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Building Healthier Communities Together

For the most up-to-date information about what the MEW Network is doing to promote epilepsy self-management, visit CDC's Epilepsy Program website at www.cdc.gov/epilepsy and the MEW Network's website at <http://managingepilepsywell.org>

For information about the Prevention Research Centers, see the program's website at www.cdc.gov/prc or contact the Centers for Disease Control and Prevention National Center for Chronic Disease Prevention and Health Promotion

4770 Buford Highway NE, Mail Stop F-78

Atlanta, GA, 30341-3717

1-800-CDC-INFO (232-4636)

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