

THE COMMUNITY HEALTH WORKER'S TRAINING
CURRICULUM FOR EPILEPSY SELF-MANAGEMENT



October 6, 2017

Prepared for:
Centers for Disease Control and Prevention
NCCDPHP, DPH, AEWB Branch
4770 Buford Hwy, NE
MS-K78
Atlanta, Georgia 30341
(770)488-6087

Prepared by:
Westat
An Employee-Owned Research Corporation®
1600 Research Boulevard
Rockville, Maryland 20850-3129
(301) 251-1500

About The Community Health Worker's Training Curriculum for Epilepsy Self-Management

In the United States, community health workers (CHWs) help us meet our national *Healthy People 2020* goals by conducting community-level activities and interventions that promote health. As defined by the Community Health Workers Section of the American Public Health Association:

“CHWs are frontline public health workers who are trusted members of and/or have an unusually close understanding of the community served. This trusting relationship enables CHWs to serve as a liaison, link, or intermediary between health/social services and the community to facilitate access to services and improve the quality and cultural competence of service delivery. CHWs also build individual and community capacity by increasing health knowledge and self-sufficiency through a range of activities such as outreach, community education, informal counseling, social support, and advocacy.”¹

CHWs can help overcome barriers to controlling chronic disease. As community health educators and role models, CHWs promote, encourage, and support positive, healthful self-management behaviors among their peers. As community advocates, CHWs help people get the services, resources, and follow-up care they need. CHWs serve as patient and community advocates; as “coaches” for disease management; and as patient “navigators,” guiding patients through the health care system. CHWs also strengthen their community’s understanding and acceptance of medical care. The recognition of their successes has led to recommendations that CHWs be included as members of health care teams to help eliminate racial, ethnic, and socioeconomic disparities in health care. In addition, CHWs can educate health care providers and administrators about the community’s health needs and the cultural relevancy of interventions by helping these providers and the managers of health care systems build their cultural competence and strengthen their communication skills.²

About 3 million adults in the U.S. have epilepsy.³ People with epilepsy face a variety of mental, physical, and social challenges. For example, they are at higher risk for developing other chronic conditions such as heart disease, asthma, or depression. They continue to face the stigmatized attitudes of the general public about the disorder and associated discrimination and marginalization that can result.⁴ They are more likely to be unemployed, live at below

¹ American Public Health Association. Community Health Workers. <http://www.apha.org/apha-communities/member-sections/community-health-workers>. Accessed August 29, 2017.

² Centers for Disease Control and Prevention. A Community Health Worker Training Resource for Preventing Heart Disease and Stroke. https://www.cdc.gov/dhdsp/programs/spha/chw_training/pdfs/chw_training.pdf. Published 2015. Accessed August 29, 2017.

³ Zack MM, Kobau R. National and State Estimates of the Numbers of Adults and Children with Active Epilepsy — United States, 2015. *MMWR*. 2017;66:821–825. DOI: <http://dx.doi.org/10.15585/mmwr.mm6631a1>.

⁴ Cui W, Kobau R, Zack MM, Buelow JM, Austin JK. Recent changes in attitudes of US adults toward people with epilepsy — Results from the 2005 SummerStyles and 2013 FallStyles surveys. *Epilepsy Behav*. 2015;52:108-18.

average income levels, and report more impaired quality of life and dissatisfaction with life.^{5,6} Evidence supports use of nontraditional health providers such as CHWs, navigators, advisors, health educators/coaches, and/or peer educators for assistance in the delivery of coordinated medical and social services, self-management, and in reducing disparities.⁷ The 2012 Institute of Medicine's Report on Epilepsy noted that nontraditional health providers such as CHWs offer untapped opportunities for improving outcomes in epilepsy.²

Overview of the CHW's Training Curriculum for Epilepsy Self-Management

The *Community Health Worker's Training Curriculum for Epilepsy Self-Management* contains information and activities on epilepsy and its comorbidities. This information is presented in a format suited for direct training of CHWs. In addition, the appendices include a wealth of resources for epilepsy self-management. The training curriculum is unique because it covers self-management related issues for epilepsy and its comorbidities in plain language.

This curriculum was developed with input from a panel of experts including physicians, epileptologists, public health epilepsy researchers, and leaders in the field of community health workers. Content for the curriculum was obtained mainly from the Epilepsy Foundation website (epilepsy.com) and from the Centers for Disease Control and Prevention (CDC) Epilepsy Program (www.cdc.gov/epilepsy) and formatted similarly to the CDC publication "A Community Health Worker Training Resource for Preventing Heart Disease and Stroke."⁶

A reference in the training curriculum to a specific website, commercial product, process, service, or company does not constitute its endorsement or recommendation by the U.S. government or by the CDC.

We thank you for your interest in this new curriculum, and we welcome feedback on your experiences in putting it to use.

⁵ Institute of Medicine (US) Committee on the Public Health Dimensions of the Epilepsies; England MJ, Liverman CT, Schultz AM, et al., editors. *Epilepsy Across the Spectrum: Promoting Health and Understanding*. Washington DC: National Academies Press (US); 2012. <https://www.ncbi.nlm.nih.gov/books/NBK91506/> doi: 10.17226/13379. Accessed August 29, 2017.

⁶ Kobau R, Cui W, Kadima N, Zack MM, et al. Tracking psychosocial health in adults with epilepsy—estimates from the 2010 National Health Interview Survey. *Epilepsy Behav.* 2014;41:66-73.

⁷ Centers for Disease Control and Prevention. Addressing Chronic Disease through Community Health Workers. https://www.cdc.gov/dhds/docs/chw_brief.pdf. Published April 2015. Accessed August 29, 2017.

Trainer's Guide Section:

How to Use this Training Curriculum

What It Is

The *Community Health Worker's Training Curriculum for Epilepsy Self-Management* contains information on epilepsy, epilepsy treatment, and challenges faced by adults living with epilepsy and serves two purposes:

1. A training manual for educating community health workers (CHWs) on epilepsy for use by various instructors, health educators, nurses, and other health care professionals at health departments, community clinics, community colleges, and other organizations and agencies. Having experienced CHWs as part of the training team can be most helpful to the learning process.
2. A reference and resource for CHWs working directly with community members.

Please keep in mind that the training curriculum is **not intended as a train-the-trainer manual** for CHWs to train people in the community. The rich, detailed information is intended to provide guidance to trainers and to be used as a resource to **complement** other community health worker trainings. Trainers should adapt the content to fit an interactive, dynamic, and engaging training session. **The CHW's training curriculum is recommended for CHWs who already have some experience in their profession and/or who have received basic CHW training, which addresses core skills and competencies required to perform effectively in that role.** Also important to emphasize is that the self-management curriculum focuses on issues pertinent to adults with epilepsy.⁸

Training

Trainers working with CHWs can teach the chapters in the curriculum from beginning to end, or they can teach individual lessons as needed.

Each chapter includes background information, talking points, and examples of actionable epilepsy self-management topics and strategies CHWs might address.

The time to complete the training will be about 5 ½ to 6 hours. The average instruction time for each session (each chapter) is approximately 30 minutes. The length of time for each session will be determined mainly by how involved the CHWs are in the discussions.

⁸ While the background information about epilepsy remains generally relevant to pediatric epilepsy, it is not comprehensive in addressing the unique needs of children and adolescents with epilepsy.

Training Objectives

After completing the CHW's training curriculum CHWs should:

- Understand epilepsy, seizures, and how epilepsy is treated.
- Understand challenges associated with living with epilepsy.
- Have increased knowledge about key epilepsy self-management domains to help people control their seizures, prevent injuries, make healthy lifestyle choices, and improve quality of life.
- Be more confident in their ability to provide self-management support to adults with epilepsy in their communities.
- Have more knowledge about and confidence in their ability to provide appropriate seizure first-aid in their communities
- Be knowledgeable about local resources and the types of assistance available to people with epilepsy in order to empower clients to make use of these resources.
- Be able to apply curriculum content and combined CHW experience and training in chronic disease management to help people with epilepsy and/or other comorbidities improve self-management understanding and behaviors

Training Presentation

The sessions are intended to be taught in an informal manner with as much input from, and interaction with, the CHWs as possible using principles of adult and popular education.

Trainers should explain at the beginning of the course that the instruction is informal and that questions and comments are encouraged. Trainers also should remember to stop and ask if anyone has a question.

Overheads and slides are not provided. Trainers **should provide their own visual aids and materials** if they believe that more graphics or hands-on tools are needed to represent this information.

What CHWs Can Do

Throughout the chapters of the curriculum, you will find lists of helpful suggestions about what CHWs can do (with program support) to help adults with epilepsy manage their disorder.

Epilepsy self-management domains can be categorized into three broad areas: treatment management, seizure management, and lifestyle management. Eleven epilepsy self-management domains within these three broad areas were identified by subject matter experts. They are:

- 1. Healthcare communication**
- 2. Treatment management**
- 3. Coping**
- 4. Social support**
- 5. Seizure tracking**
- 6. Wellness**
- 7. Seizure response**
- 8. Safety**
- 9. Medication adherence**
- 10. Stress management**
- 11. Proactivity.^{9, 10}**

CHWs have been assisting clients with similar self-management domains in other chronic diseases for many years by providing culturally competent health education, social support, coaching, capacity building, resource connection, and health system navigation. The success of CHWs in managing chronic health conditions such as diabetes, hypertension, cancer, and others, show promise for managing epilepsy.

We encourage you to take the time to have the CHWs talk about and share these and many other things they do to help community members. The following is a list of general tips and practices that CHWs can use to help community members with epilepsy improve their health and support people in their access to health care.

- Help clients who do not have a doctor to find one.
- Help clients those who cannot afford a doctor to find free health care or places where cost is based on ability to pay (for example, public health departments, federally-qualified health centers, clinics run by churches, other community clinics).
- Help clients with poor seizure control find a neurologist or epileptologist
- Help clients with epilepsy and co-occurring conditions (e.g., depression, heart disease, diabetes) get appropriate care.

⁹ Escoffery C, Bamps Y, LaFrance WC Jr, et al. Development of the Adult Epilepsy Self-Management Measurement Instrument (AESMMI). *Epilepsy Behav.* 2015;50:172– 183.

¹⁰ Escoffery C, Bamps Y, LaFrance WC Jr, et al. Factor Analyses of an Adult Epilepsy Self-Management Measurement Instrument (AESMMI). *Epilepsy Behav.* 2015;50:184-189.

- Assess barriers to self-management
- Assist clients who do not speak English by translating or connecting them with translation services.
- Help clients who do not have transportation or do not know how to use public transportation to get to the clinic.
- Act as a bridge between your client and their health care team (for example, the doctors, nurses, pharmacists).
- Tell the health care team about specific patient needs, successes, and barriers to self-care (for example, cultural beliefs, motivation, disability, safety issues).
- Get families involved in providing epilepsy self-management support.
- Complement clients and their families when doing a good job of self-management.
- Help link clients to transportation, food banks, employment and other community resources.

Table of Contents

Section 1: Overview on Epilepsy

Chapter	Title
Chapter 1	Understanding Epilepsy
Chapter 2	Treating Epilepsy
Chapter 3	Seizure First Aid

Section 2: Living with Epilepsy

Chapter 4	Challenges of Living with Epilepsy
Chapter 5	Mental Health
Chapter 6	Memory and Cognition

Section 3: Managing Epilepsy

Chapter 7	Treatment Management
Chapter 8	Lifestyle Management
Chapter 9	Safety
Chapter 10	Self-Management Resources
Chapter 11	Case Studies

Appendices:

Appendix A	ILAE 2017 Classification of Seizure Types
Appendix B	Dietary Therapies for Epilepsy
Appendix C	First Aid for Seizures
Appendix D	Drivers Licensing and Mandatory Reporting
Appendix E	Americans with Disabilities Act/Accommodations
Appendix F	Tips for Staying Safe
Appendix G	Sample Action Plan
Appendix H	Self-Management Forms, Tools, and Assessments
Appendix I	Patient Assistance Programs

Section 1: Overview

Understanding Epilepsy

1

Objectives

By the end of this session, community health workers (CHWs) will be able to:

- Describe epilepsy.
- Describe challenges associated with having epilepsy.
- Understand what a seizure is.
- Describe the current terms for types of seizures.

Chapter Outline

- A. Facts about epilepsy
- B. Definition of epilepsy
- C. Who gets epilepsy?
- D. Health disparities in epilepsy
- E. Causes of epilepsy
- F. Seizures

Session Time:

30 minutes

Materials:

ILAE 2017 Classification of Seizure Types - Basic Version

ILAE 2017 Classification of Seizure Types - Expanded Version

ASK THE CHWs:

By a show of hands, how many of you have ever known someone with epilepsy?

This question is designed to establish an idea of the experience level in the room and to engage the participants. Unless the group is small, taking comments from only a few participants will help you manage the limited time.

A. Facts about epilepsy

➤ Talking Points

Epilepsy, or seizure disorder, is one of the most common conditions affecting the brain. There are **approximately 3.4 million** people in the United States with active epilepsy (self-reported doctor-diagnosed epilepsy, under treatment or with recent seizures) and almost twice as many have a history of epilepsy.

Epilepsy is a complex disorder that varies in severity. Some people are only mildly affected with infrequent seizures, while others are severely affected with daily uncontrolled seizures and experience other complications. Many people with epilepsy don't know exactly what happens to them when they have a seizure.

People with epilepsy face a variety of mental, physical, and social challenges because of their epilepsy, and they are likely to have other chronic conditions such as heart disease, asthma, or depression, that can complicate epilepsy management. They are more likely to be unemployed, live at lowest income levels, and report more impaired quality of life and dissatisfaction with life domains.

Some people with epilepsy may experience perceived or actual isolation or exclusion in daily activities that results from the public's negative attitudes toward the disorder and fear of providing seizure first aid. People with epilepsy face additional barriers such as driver's license restrictions and lack of access to

Section 1: Overview

Understanding Epilepsy

1

transportation that impedes daily activities such as getting to places such as doctor's appointments, the pharmacy for medication refills, work, or recreation.

Substantial evidence supports the effectiveness of Community Health Workers (CHWs) for preventing and managing a variety of health conditions such as diabetes, hypertension, asthma, and cancer. This effectiveness is achieved by the CHW's ability to address the numerous barriers to management of chronic disease.

B. Definition of epilepsy

➤ Talking Points

What is epilepsy? It is one of the most common causes of seizures, and is also called a seizure disorder. Specifically, epilepsy is a neurological disorder characterized by recurring seizures not otherwise provoked by acute injury, another medical condition (e.g., diabetes) or other health emergency (e.g., overdose).

Some people can learn what triggers their seizures (e.g., flashing lights; some noises; lack of sleep; stress). Sometimes people with epilepsy with certain types of seizures develop their own techniques to stop a seizure from happening. But, recognizing seizure triggers and trying to stop a seizure from happening isn't possible for everyone.

ASK THE CHWs:

Are you aware that there are over 30 different types of seizures?

Are you aware of activities or situations that seem to trigger seizures?

➤ Talking Points

Over time, some people with epilepsy or their families become aware of certain activities that seem to "trigger" their seizures, and avoiding these triggering activities may reduce the frequency of seizures.

Note: The most common reason seizures recur is skipping medication. It is estimated that about half of the people taking medication for epilepsy do not follow medical instructions properly.

Section 1: Overview

Understanding Epilepsy

1

Other possible triggers include:

- Stress/anxiety
- Exertion or fatigue, or dehydration
- Lack of sleep/time to sleep
- Hormonal cycles in women
- Flashing lights of alternating shade/sun
- Alcohol or illicit drug use
- Some over-the-counter medicines
- Electronic games

However, it's important to note, that people can have very personal and unusual triggers (e.g., sounds; brushing teeth) that differ from these common triggers. The important point is to help people with epilepsy identify their seizure triggers, if possible.

C. Who gets epilepsy?

➤ Talking Points

Epilepsy and seizures can develop in any person at any age and of any race/ethnicity. New cases of seizures and epilepsy are more common in young children and older people, because risk factors are more common in these age groups (e.g., complications before/during childbirth; stroke).

Epilepsy affects people of all races/ethnicities. Some studies show slightly higher rates of epilepsy among Hispanics than non-Hispanics; blacks vs. whites; males vs. females. **Substantial data show that adults and children with epilepsy are more likely to live in low-income households at, or below poverty thresholds.**

D. Health disparities in epilepsy

➤ Talking Points

Where and when people get health care for their epilepsy differs by multiple factors, including their household income, where they live, access to transportation, and cultural beliefs and practices.

Differences in care often lead to what is called a 'treatment gap'. It is possible that these treatment gaps are part of the reason for differences in the quality of epilepsy care and outcomes for some groups.

E. Causes of epilepsy

➤ Talking Points

In 70% of cases, no cause can be found but genetic factors may play a role. Known causes include head injuries, stroke, brain tumors, lead poisoning, problems in brain development before birth, or serious infections during pregnancy, such as encephalitis or meningitis.

Among elderly people, epilepsy is most often caused by stroke, cardiovascular disease, brain tumors or Alzheimer's disease. Returning veterans with serious head injuries may develop epilepsy.

F. Seizures

➤ Talking Points

Seizures associated with epilepsy are caused by disturbances in the normal electrical activity of the brain.

Seizures are generally described in two major groups: generalized seizures and focal seizures.

The difference between the types of seizures is in how and where they begin in the brain.

Recently, The International League Against Epilepsy (ILAE) has approved a new way of organizing seizures that reflects recent advances in our understanding of

Section 1: Overview

Understanding Epilepsy

1

the brain and seizures. This new system will make diagnosis and classification of seizures easier and more accurate. Many people may refer to seizure types by the old names.

ASK THE CHWs:

Have you ever heard any terms related to types of seizures? What are some of those terms?

Recently, new names have been given to different types of seizures. These new names or “classifications” of seizures replace older terms that were used in the past. These terms are relatively new, and many neurologists are not yet using them. Appendix A shows how the new terms match to the old terms.

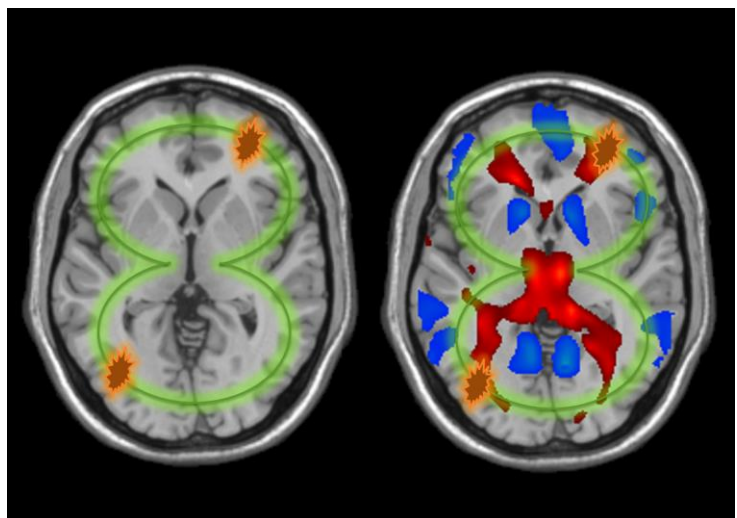
These terms don’t change what occurs during a seizure, but offer a different way of naming seizures. More accurate ways of naming seizures can lead to more appropriate treatment.



TRAINER: SHOW GRAPHIC ILAE 2017 CLASSIFICATION OF SEIZURE TYPES BASIC VERSION.

Seizures are first classified according to where they start in the brain. There are now 3 main categories:

- **Generalized Onset:**
Generalized seizures affect both sides of the brain or large networks of cells on both sides from the beginning of the event. The networks can be on the surface of the brain or involve deeper areas. Generalized seizures don’t need to involve the entire brain, just part of both sides.

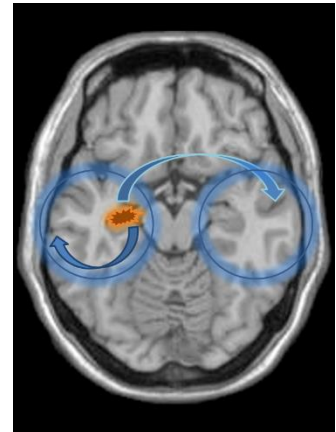


Section 1: Overview

Understanding Epilepsy

1

- **Focal Onset:** The term focal seizure has been used for years, but the lay public and many professionals still use the term partial seizures. In this 2017 Classification, focal seizures will replace partial seizures and refer to those that start in an area or network on one side of the brain. They may start on the surface of the brain or in deeper areas, and can be very localized or spread to larger areas. Sometimes more than one brain area is involved.



- **Unknown Onset:** Seizures may be of unknown onset if the beginning of the seizure is not clear. As more information becomes available over time or through testing, the type of seizure may be changed to a generalized or focal onset seizure.



TRAINER: SHOW GRAPHIC ILAE 2017 CLASSIFICATION OF SEIZURE TYPES EXPANDED VERSION.

Focal onset seizures can further be grouped according to whether a person is aware or not aware during an event.

- **Focal Aware:** During a focal aware seizure, there is no change in a person's awareness, even if they are unable to talk or respond during the event. This replaces the term simple partial seizure.
- **Focal Impaired Awareness:** If awareness is impaired at any time during a focal seizure, it would be called a focal impaired awareness seizure. This replaces the term complex partial seizure.
- **Focal to Bilateral Tonic Clonic:** A focal seizure may start in one part of the brain with the person aware or with impaired awareness. It may then spread to involve both sides of the brain and the person would be unaware during the seizure. Usually other changes occur, for example the seizure may spread to cause body stiffness (tonic) and jerking movements (clonic). The term focal to bilateral tonic clonic will now be used instead of the old term secondary generalized seizure. The term generalized is being used only to describe the onset or beginning of a seizure.

Section 1: Overview

Understanding Epilepsy

1

What happens during a focal seizure can be described as motor or non-motor symptoms.

- **Motor seizures** will have a change in muscle activity of some sort, such as jerking (clonic), stiffness (tonic), loss of muscle tone (atonic), or automatisms (repeated or automatic movements such as arm or mouth movements).
- **Non-motor seizures** can include changes in heart rate, breathing, or color (autonomic); blank stare, stop talking or stop moving (behavioral arrest); confusion, slowed thinking, or problems talking and understanding (cognitive changes); sudden fear, dread, anxiety or even pleasure (emotional); or changes in hearing, vision, taste, or feelings of numbness, tingling, or pain (sensory).

Generalized seizures all affect a person's awareness or consciousness in some way, so the terms 'aware' or 'impaired awareness' are not needed. **Types of generalized seizures are classified by whether they have motor symptoms or non-motor.**

If a seizure's onset is unknown, it can be described by the presence of motor or non-motor symptoms.

- Motor seizures include tonic clonic and epileptic spasms.
- Non-motor includes seizures with behavior arrest.

Some people with epilepsy have only one type of seizure, and many have more than one type. Sometimes, doctors can't diagnose a specific type because no one was around to witness the seizure to describe it for appropriate diagnosis. Many people with epilepsy have a hard time remembering the names of their seizure types.

- Remember that epilepsy is a complex disorder that varies in severity. The most important aspect is to help people learn how to live well with epilepsy.
- Help people to focus on the best way to control seizures.
- Some people with epilepsy can benefit from learning how to cope with the issues that having epilepsy creates.

Section 1: Overview

Treating Epilepsy

2

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Describe the different treatments for epilepsy.
2. Understand the importance of seizure medication.
3. Describe typical side effects of seizure medications.
4. Describe other treatments for epilepsy.
 - a. Special diets
 - b. Devices
 - c. Surgery

Chapter Outline

- A. Overview of medications
- B. Side effects of seizure medications
- C. Drug interactions
- D. Medication summary
- E. Other treatments for Epilepsy

Session Time:

20 minutes

Materials:

None

Section 1: Overview

Treating Epilepsy

2

Now that we understand what epilepsy is, let's talk about how it's treated.

ASK THE CHWs:

What are some treatments for epilepsy?

The four main forms of treatment include medication, surgery, special diets, and medical devices.

A. Overview of medications

➤ Talking Points

One of the most common ways to treat epilepsy is with medicine, sometimes called anti-epileptic drugs (AEDs) or anti-seizure drugs (ASDs). Medicine will successfully control seizures for about 7 out of 10 people with epilepsy.

Therefore two of most important self-management domains for people with epilepsy are treatment and medication adherence (taking medicines the way the doctor tells them to).

It's not uncommon for some people with epilepsy to have to take several different anti-seizure drugs at different times throughout the day. This can be difficult to manage sometimes.

As a CHW, ask your clients....

- if they understand what the medications they are taking are for;
- whether they use any reminders to take their medication as prescribed; whether they have any questions about their medications; and
- encourage them to talk to their doctor if their medication isn't working to prevent their seizures or if they are experiencing bad side effects from their seizure medicines.
- **CHWs should not try and answer their patients' prescription or other medical questions, but direct them to their doctor.**

B. Side effects of seizure medications

➤ Talking Points

People may not want to take their seizure medicines as prescribed because they fear unwanted side effects. Side effects can be addressed by adjusting the dose or how a person takes their medicine.

Some common side effects that may occur when taking seizure medicines include:

- feeling tired,
- stomach upset or discomfort,
- dizziness,
- weight gain, or
- blurred vision.

Other side effects may include cognitive problems - problems with thinking, remembering, paying attention or concentrating, finding the right words, or other symptoms.

Some medicines may also affect a person's energy level, mood, or motivation. Sometimes these problems will go away over time. If someone is having these problems, make sure they discuss it with their doctor.

C. Drug interactions

➤ Talking Points

Seizure medicines can interact with each other and with other medicines. These interactions are common and can be dangerous.

Encourage clients to let their doctor, nurse or pharmacist know about other medications they are taking including all over-the-counter medications, and herbs and dietary supplements.

D. Medication summary

As a CHW, you may be able to help clients who ask for help with improving their medication adherence by:

- Education on **why they are taking the medicine** and **how to take it** (review prescription label).
- Education to **teach reminder strategies** for taking medicines exactly the way a doctor advised, and the critical importance of not skipping a dose or taking too much medicine.
- Fostering **communication skills** to let their health care team know if they have any questions or issues with their medicines.
- Encouraging them to let their health care team know if they are taking over-the-counter medicines (medicine you can get without a prescription).
- Motivational Interviewing to **identify goals** associated with seizure control to encourage medication adherence

E. Other treatments for epilepsy

➤ Talking Points

Besides medicine, there are other ways to help people control their seizures including special diets, therapeutic and seizure alert devices, and surgery. You may be in a doctor's appointment with a patient and they are discussing how to prevent or control seizures. Here's some background information on other epilepsy treatments a neurologist might bring up. Let's briefly review these other treatments.

Special diets

As a CHW, you probably already encourage people to eat a healthy diet, but some people with epilepsy may be following a special diet recommended by their doctor. Certain special diets can help to control seizures, usually in conjunction with seizure medications. There are three dietary therapies that can help people with epilepsy control their seizures: the 1) ketogenic diet, 2) the modified Atkins diet and the 3) Low Glycemic Index treatment (LGIT). However, these dietary therapies are predominately used in children with epilepsy that is not controlled by medication. **These dietary therapies should not be tried unless recommended and monitored by the person's neurologist.** For more information about these special diets, see Appendix B.

Devices

Much research is being done to develop new ways to treat seizures since medicines do not help everyone. Devices are being developed in two main areas: to try and control seizures in those who don't respond to medications and to help detect seizure activity or alert people of possible seizure onset.

Approved Therapeutic Devices are devices that are meant to prevent or control seizures and include Vagus nerve stimulation, and Responsive neurostimulation.

- **Vagus nerve stimulation (VNS)** may also be an option when seizures are hard to control. This procedure involves implanting a small battery (electronic device) in the chest wall, which is connected through electrodes to the vagus nerve in the neck. This device is programmed to deliver small discharges of electrical energy to the brain, through the vagus nerve, which contains motor and sensory fibers that passes through the neck and thorax to the abdomen.
- **Responsive neurostimulation** is a new approach to treating medically uncontrolled focal seizures. The RNS Neurostimulator is placed by a surgeon under the scalp and within the skull. The neurostimulator continuously monitors the brain's activity and is programmed to detect and record the individual's specific patterns that could lead to a seizure. When these patterns are detected, the neurostimulator responds with brief pulses of stimulation intended to disrupt the abnormal brain activity before

Section 1: Overview

Treating Epilepsy

2

a seizure occurs. RNS is only available in highly specialized epilepsy centers under the supervision of epilepsy specialists with advanced training. **An epilepsy center is a department within a hospital accredited by the National Association of Epilepsy Centers (NAEC) that provides routine care to individuals with seizures or epilepsy, and specializes in providing comprehensive diagnostic and treatment services to individuals with uncontrolled seizures.**

Seizure Alerting Devices may help notify others if a seizure happens. There are a few devices available that can detect repeated shaking movements during a seizure. These may work with generalized or focal motor seizures to trigger the device.

- The devices can notify nearby family or caregivers when a seizure occurs through alarms, phone calls or text alerts, depending on the device. A caregiver can then help the person during and after the seizure. For example, they can help reposition the person, making sure they are on their side if they are not conscious. They can also make sure someone doesn't fall asleep on their stomach afterwards. If breathing or other problems occur, they can call for medical help. They may also be able to give rescue medications or call for an ambulance if the seizure lasts too long or the person has repeated seizures.

The seizure alert devices available today are motion detection devices, but research is always being done to develop new devices. There are currently three types of devices available:

- Mattress devices
- Watch devices
- Camera devices

Surgery

Surgery is another alternative for some people whose seizures cannot be controlled by medications, and is an effective alternative to seizure medicines. Many epilepsy experts believe that there are numerous people with seizures that don't fully respond to medication who might benefit from surgery, but are never referred to an epilepsy center for evaluation. The benefits of surgery should be weighed carefully against its risks, however, because there is no guarantee that it will be successful in controlling seizures. A definitive study on the effectiveness of surgery found that:

- After 1 year, 58% of the patients who had undergone surgery had not experienced a focal impaired awareness seizure and 38% had not experienced any seizures, including auras.
- In contrast, only 8% of the patients treated with medication were free of focal impaired awareness seizures, and 3% had no seizures. For the patients treated with surgery who continued to have some seizures, they were less frequent than in the other group, but the severity was similar.
- The quality of life of the patients treated with surgery was judged to be significantly better than for the other patients. Of the patients who had surgery, 55% were working or studying, versus 36% in the other group.

Section 1: Overview

Seizure First Aid

3

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Know what to do if someone has a seizure

Chapter Outline

- A. Understand and be prepared to conduct general first aid for all seizure types

Session Time:

15 minutes

Materials:

Seizure First Aid Guide

A. General first aid for all seizure types

➤ Talking Points

Being prepared and knowing what to do and what not to do if a person has a seizure is an important part of helping people who have epilepsy. The first line of response when a person has a seizure is to provide general *care and comfort* and keep the person *safe*. The information here relates to all types of seizures. What to do in specific situations or for different seizure types is listed in the following pages. Remember that for the majority of seizures, basic seizure first aid is all that may be needed.

Always Stay With the Person Until the Seizure Is Over

- Seizures can be unpredictable and it's hard to tell how long they may last or what will occur during them. Some people can tell you they're going to have a seizure; for others, seizures may start with minor symptoms, but lead to a loss of consciousness or fall. Many seizures may be brief and end in seconds.
- Injury can occur during or after a seizure, requiring help from other people.

Pay Attention to the Length of the Seizure

- Look at your watch and time the seizure – from beginning to the end of the active seizure.
- Time how long it takes for the person to recover and return to their usual activity.
- If the active seizure lasts longer than the person's typical events, call for help.
- If the seizure lasts longer than 5 minutes, or if another seizure starts immediately after one ends, call for help.
- Know when to give 'as needed' or [rescue treatments](#), if prescribed, and when to call for emergency help.

Stay Calm, Most Seizures Only Last a Few Minutes

- A person's response to seizures can affect how other people act. If the first person remains calm, it will help others stay calm too.
- Talk calmly and reassuringly to the person during and after the seizure – it will help as they recover from the seizure.

Prevent Injury by Moving Nearby Objects Out of the Way

- Remove sharp objects.
- If you can't move surrounding objects or a person is wandering or confused, help steer them clear of dangerous situations, for example away from traffic, train or subway platforms, heights, or sharp objects.

Make the Person as Comfortable as Possible

- Help them sit down in a safe place.
- If they are at risk of falling, call for help and gently lay them down on the floor.
- Support the person's head with a jacket, purse, or other soft object to prevent it from hitting the floor.

Keep Onlookers Away

- Once the situation is under control, encourage people to step back and give the person some room. Waking up to a crowd can be embarrassing and confusing for a person after a seizure.
- Ask someone to stay nearby in case further help is needed.

Do Not Forcibly Hold the Person Down

- Trying to stop movements or forcibly holding a person down doesn't stop a seizure. Restraining a person can lead to injuries and make the person more confused, agitated or aggressive. People don't fight on purpose during a seizure. Yet if they are restrained when they are confused, they may respond aggressively.
- If a person tries to walk around, gently guide them away from a potentially dangerous area such as a street and let them walk in a safe, enclosed area if possible.

Do Not Put Anything in the Person's Mouth!

- Jaw and face muscles may tighten during a seizure, causing the person to bite down. If this happens when something is in the mouth, the person may break and swallow the object or break their teeth!
- Don't worry - a person can't swallow their tongue during a seizure.

Section 1: Overview

Seizure First Aid

3

Make Sure Their Breathing is Okay

- If the person is lying down, turn them on their side, with their mouth pointing to the ground. This prevents saliva from blocking their airway and helps the person breathe more easily.
- During a convulsive or tonic-clonic seizure, it may look like the person has stopped breathing. This happens when the chest muscles tighten during the tonic phase of a seizure. As this part of a seizure ends, the muscles will relax and breathing will resume normally.
- Rescue breathing or CPR is generally not needed during these seizure-induced changes in a person's breathing.

Do not Give Water, Pills or Food by Mouth Unless the Person is Fully Alert

- If a person is not fully awake or aware of what is going on, they might not swallow correctly. Food, liquid or pills could go into the lungs instead of the stomach if they try to drink or eat at this time.
- If a person appears to be choking, turn them on their side and call for help. If they are not able to cough and clear their air passages on their own or are having breathing difficulties, call 911 immediately.

Call for Emergency Medical Help

- A seizure lasts 5 minutes or longer.
- One seizure occurs right after another without the person regaining consciousness or coming to between seizures.
- Seizures occur closer together than usual for that person.
- Breathing becomes difficult or the person appears to be choking.
- The seizure occurs in water.
- Injury may have occurred.
- The person asks for medical help
- If the person has another medical condition such as diabetes, or is pregnant.

Section 1: Overview

Seizure First Aid

3

Be Sensitive and Supportive, and Ask Others to Do the Same

- Seizures can be frightening for the person having one, as well as for others. People may feel embarrassed or confused about what happened. Keep this in mind as the person wakes up.
- Reassure the person that they are safe.
- Reorient the person and allow them to continue what they are doing.
- Once they are alert and able to communicate, tell them what happened in very simple terms.

Offer to stay with the person until they are ready to go back to normal activity or call someone to stay with them.



TRAINER: POINT OUT THE SEIZURE FIRST AID GUIDE IN APPENDIX C.

In Appendix C, there is a brief seizure first aid guide produced by the Epilepsy Foundation.

The Epilepsy Foundation of Minnesota has also developed an app that can be downloaded to a smartphone or tablet. It provides assistance with recognizing different types of seizures, knowing what to do, and timing how long the seizure lasts. It can be found at efmn.org/app.

Section 2: Living with Epilepsy

Challenges of Living With Epilepsy

4

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Describe ways epilepsy impacts other aspects of a person's life.

Chapter Outline

- A. Attitudes of others and self-image
- B. Driving limitations
- C. Unhealthy lifestyle and risk for other chronic health conditions
- D. Problems with sleep
- E. Social relationships
- F. Barriers to care
- G. Jobs and unemployment
- H. Legal issues

Session Time:

30 minutes

Materials:

None

Section 2: Living with Epilepsy

Challenges of Living With Epilepsy

4

Now that we've gone over the basics about epilepsy and how it's treated, let's review epilepsy's physical, psychosocial, and economic impact. Epilepsy is often a chronic condition and treatment of seizures is not the only help your clients need. Doctors do not always address the social and economic problems caused by epilepsy because they are focused on treating medical issues. That's where you as a CHW can fill the gap and have an impact.

ASK THE CHWs:

What are the social aspects that you think may have a serious influence on persons with epilepsy?

The physical manifestations of epilepsy, combined with the potential for stigma, affect people with epilepsy in a variety of social situations.

IMPORTANT:

- **The psychosocial impact of epilepsy may be greater than the medical impact, once seizures are successfully controlled.**
- **For people with epilepsy, the negative reactions of others are potentially always present, no matter how well the person with epilepsy is doing or how much he/she has achieved.**

A. Attitudes of others and self-image

➤ Talking Points

An overarching issue affecting people with epilepsy are the attitudes of others and their effects on self-image. Despite efforts to promote public awareness and knowledge about epilepsy, misconceptions and fears among the general public persist.

Stigma comes in many forms. It can be people who still believe cruel and untrue myths about epilepsy that make it seem as if the condition is someone's fault or a punishment. Stigma can cause great unhappiness. Some people with epilepsy may experience discrimination or rejection that can lead to isolation and social problems. Stigma can get in the way of having friends and participating in recreational and social activities. In some communities, there may be additional

Section 2: Living with Epilepsy

Challenges of Living With Epilepsy

4

issues such as language or cultural barriers that can prevent people with epilepsy from receiving good health care. One study found that compared with 2005, many adults still expressed discomfort with being around a person with epilepsy. People with epilepsy are more likely to be unemployed, live at lowest income levels, and report more impaired quality of life and dissatisfaction with life domains leading to poorer self-image.

B. Driving limitations

➤ Talking Points

Another overarching issue that affects myriad other socio-economic issues is the ability to have a driver's license. There are safety risks and legal issues that affect a person with epilepsy's ability to have a legal driver's license. Access to reliable transportation affects many areas of a person's life including access to social support and recreational activities, employment, and access to health care services. Transportation is an even bigger challenge for people living in rural areas without access to public transportation. People with epilepsy who are unable to drive must rely on family, friends, and public transportation to get them to work, doctor visits, and to social activities.

Every state restricts or puts limits on driving for people with seizures, creating a significant barrier to employment, health care and pleasurable recreational activities. Mandatory reporting laws complicate the lives of people with epilepsy further by potentially worsening the relationship with their doctor and/or the patient not receiving proper care because they were afraid to tell their doctor. For more information on driving restrictions and mandatory reporting of seizures for people with epilepsy, refer to Appendix D.

C. Unhealthy lifestyle and risk for other chronic health conditions

➤ Talking Points

Unhealthy lifestyle behaviors associated with poor self-management (i.e., smoking, physical inactivity, poor nutrition, sleep insufficiency) have been shown to be problems among people with epilepsy. These behaviors can increase the

Section 2: Living with Epilepsy

Challenges of Living With Epilepsy

4

risk for heart-disease, diabetes, asthma, and other comorbidities in people with epilepsy. Studies show that adults with epilepsy are more likely to report doctor-diagnosed high blood pressure, stroke, prediabetes, and are more likely to be overweight than those without epilepsy. Adults with epilepsy also report more respiratory problems such as emphysema, chronic bronchitis and asthma than those without epilepsy and were more likely to report myriad other health conditions as well.

D. Problems with sleep

➤ Talking Points

Several studies have confirmed that sleepiness and sleep disorders are common in persons with epilepsy.

- Patients with focal epilepsy have twice the incidence of drowsiness as people who do not have epilepsy, and this greatly worsens quality of life. Much of this may be related to sleep apnea that is frequently undiagnosed.
- Patients taking anticonvulsants or AEDs known to disrupt sleep have increased drowsiness compared to epilepsy patients who are not taking anticonvulsants.
- Other possible reasons for disrupted sleep fall into several categories, including the effects of seizures, insufficient sleep, irregular sleep routine, and coincident sleep disorders.
- Insufficient or irregular sleep can trigger seizures for some people with epilepsy.

E. Social relationships

➤ Talking Points

Dating, sexual activities, marriage and starting a family may be more difficult for a person with epilepsy. Many people have fears about telling potential partners about their epilepsy and keep it a secret. However, having a trusted partner who provides emotional support and sexual intimacy helps people feel better about

Section 2: Living with Epilepsy

Challenges of Living With Epilepsy

4

themselves and reduces anxiety and stress, which leads to better seizure control. However people with epilepsy sometimes have sexual difficulties. These include:

- a low level of sexual desire;
- difficulty becoming sexually aroused;
- intercourse can be painful for some women,
- some men may have difficulty achieving and maintaining an erection.

These problems may be due to the epilepsy itself, the medications used to treat their epilepsy, or reactions of partners and others to their epilepsy. Hormones play an important role in sexual function and some people with epilepsy have alterations in normal hormone levels. Encourage clients to talk to their doctor about trying a different seizure medicine if these issues become a problem. A doctor may refer them to an endocrine specialist to sort out the complex interactions between hormones, seizures, and medications.

Because seizures are unpredictable, people with epilepsy may be reluctant to get out to socialize, and may fear having seizures in public. Additionally, family and friends may sometimes be overprotective or try to restrict social and recreational activities, leading to isolation.

F. Barriers to care

➤ Talking Points

People with epilepsy may also experience barriers to care including transportation issues, costs associated with treating their epilepsy, and lack of knowledge regarding availability of epilepsy specialists in their area.

For example, lack of reliable transportation may play a role in receiving timely health care, including contributing missed appointments and not obtaining medication in a timely manner.

People with epilepsy also incur significant health care costs to treat their epilepsy and any comorbid conditions. Seizure medications can be expensive and injuries sustained during seizures may be costly to treat. Adults with epilepsy are more likely to report an inability to afford prescription medications, mental health, dental, and vision care. People with epilepsy and their family members may need to take extensive leave or unexpected days off work.

Section 2: Living with Epilepsy

Challenges of Living With Epilepsy

4

Adults with epilepsy might face more challenges with accessing and affording specialty care that is required for uncontrolled seizures. While primary care doctors are typically the first type of doctor seen, it is important for a person with epilepsy to consult with a neurologist. For people with seizures that are difficult to diagnose or are not responding to typical treatments, an epilepsy specialist – called an “epileptologist” (a neurologist who specializes in epilepsy) should be consulted. To help people find an epileptologist in their area, the Epilepsy Foundation and American Epilepsy Society have developed a [searchable database](#) of physicians who are epileptologists or specialize in some way in the care or research of people with epilepsy. However, depending on the location there may be very few or even no epilepsy specialists nearby creating challenges to getting the specialized care they need.

G. Jobs and Unemployment

➤ Talking Points

Adults with epilepsy might fear disclosing their epilepsy to an employer or worry about consequences of break-through seizures.

Having a job provides opportunities for social interaction, financial security and often access to health insurance, which is critically important for people with epilepsy. However, about one-half of adults with epilepsy are unemployed or are in unskilled or manual jobs and this trend has persisted despite improvements in treatment and laws protecting employment rights.

Also, lower levels of education seen in people with epilepsy might limit employment opportunities, and driving restrictions limit employment options to positions that do not require a valid driver’s license.

A complex combination of factors may contribute to this trend, including seizure frequency and type, social stigma, low self-esteem, side effects of seizure medications, depression and anxiety, and negative attitudes by employers.

Researchers have found that employers give a variety of different reasons for why they would not want to employ people with epilepsy. Reasons include concerns about the comfort and safety of workers, worries about increased accident rates and subsequent increases in insurance rates, and questions about the need to

Section 2: Living with Epilepsy

Challenges of Living With Epilepsy

4

revise work flows with possible increases in expenses for work-related accommodations, transportation issues, and concern that a seizure might scare customers or clients.

H. Legal Issues

➤ Talking Points

Epilepsy is a condition that has long been misunderstood by the public. People with epilepsy may face unfair treatment in many areas of their lives including with law enforcement, health insurance, housing, child custody and family law, and employment. Luckily, there are many educational initiatives promoting recognition of epilepsy symptoms among police and first responders. Also, The Americans with Disabilities Act (ADA) was enacted to prohibit disability-based discrimination in employment and requires that reasonable accommodations for a known disability unless to do so would impose an undue burden on the employer.

There are many resources available on the Epilepsy Foundation website for assistance with legal issues including criminal defense, family law, housing and employment discrimination, and insurance issues (<http://www.epilepsy.com/get-help/legal-help>). If a client needs assistance with legal problems related to their epilepsy, you can refer them to resources in your area or to the local Epilepsy Foundation affiliate for further help. A brief summary of the impact of the Americans with Disabilities Amendments Act on people with epilepsy can be found in Appendix E.

Section 2: Living with Epilepsy

Mental Health

5

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Understand that certain mental health disorders are more common in people with epilepsy
2. Give guidance to clients on the types of help that are available and where to find them.

Chapter Outline

- A. Depression
- B. Anxiety
- C. Other mental health disorders
 - a. Schizophrenia
 - b. Bipolar disorder

Session Time:

20 minutes

Materials:

None

Section 2: Living with Epilepsy

Mental Health

5

Similar to people with any chronic disease, people with epilepsy are at higher risk for mental health issues such as depression. Depression is the most frequently reported psychiatric disorder by people with epilepsy. **Although the exact relationship between brain abnormalities and anxiety and depression is extremely complex and not very well understood, it is clear that there is a biological or physiological relationship.**

A. Depression

➤ Talking Points

Almost everyone feels unhappy at one time or another in life. Most of the times, it just means one is sad because of something. However, if the sadness or this feeling lasts longer than longer than two weeks and a person has lost interest in things he or she normally enjoys, it may be a sign of major depression.

Depressed people usually feel:

- Powerless
- Hopeless with themselves and their future
- There is nothing they or anyone else can do to improve their lives
 - They have very low self-esteem, a negative view of the world and no hope that things can get better in the future.

Serious or long-lasting depression must be evaluated and treated by a healthcare professional.

ASK THE CHWS:

**In your experience, how do you recognize signs of depression in a person?
What are some signs to look out for to identify possible depression?**

Possible answers:

- Lack of sleep/excessive sleep
- Isolating from others
- Losing interest in personal appearance
- Neglecting personal hygiene
- Excessive crying
- Being angry all the time
- Unable to make decisions
- Feeling worthless

What might you do to help a person with epilepsy cope with depression?

Possible answers:

- Encourage talking to their doctor about therapy or medications
- Refer them to county behavioral health services
- Recommend support groups
- Recommend recreational groups
- Recommend religious groups

IMPORTANT:

- If you believe that a person is in imminent harm, refer that person to emergency care by calling 9-1-1.
- For some people, seizure medication may be a cause of depression. This and other side effects need to be discussed with their doctor.
- When a person with epilepsy is very depressed, they may think about suicide; that is why it is so important to watch for signs in their behavior and in the way they express their feelings.
 - If your client's remarks or behavior indicate they may be contemplating suicide, you may want to ask a question such as, "do you feel like you want to hurt yourself," or "do you feel like you'd be better off dead?"
- If a person is suicidal, follow your organizational protocol. If no protocol is in place, link them to: the Epilepsy Foundation 24/7 Help Line with trained crisis counselors at: (English: 1-800-332-1000, Spanish 1-866-748-8008).
- The National Suicide Prevention Help Line at: 1-800-273-8255

The local Epilepsy Foundation offices can also connect the person with epilepsy and his/her family with resources to reduce depressive symptoms.

B. Anxiety

➤ Talking Points

Anxiety is a common problem for people with epilepsy. Anxiety may occur as a reaction to the diagnosis, as a symptom of the epilepsy or as a side effect of seizure medicines.

The knowledge that a seizure can occur at any time and place without very much warning is a major point of anxiety for many people. Anxiety may follow concerns about when and where to disclose one has epilepsy. **Social support is therefore an important element in the life of a person with epilepsy.**

Several treatment options exist for anxiety in a person with epilepsy.

- Some people do well with counseling. Others need more structured psychotherapy to reduce their experiences of anxiety.
- Behavior therapy, a common form of treatment used for anxiety, is based on teaching specific methods and skills that people can use to reduce anxiety.

In some cases, anti-anxiety medications are used. There is a risk that certain types of anti-anxiety medicines (benzodiazepines such as Xanax, Ativan, Valium) may cause the person become dependent on the medication. This is more likely to happen to people with epilepsy than to others because some medications that are used to lessen anxiety also suppress seizures. The person can become dependent on the medication and have difficulty stopping it. Many doctors prescribe a different class of medications for anxiety (SSRIs such as Paxil, Zoloft, Prozac, Lexapro), but many do prescribe benzodiazepines.

ASK THE CHWS:

In your experience, how do you recognize signs of anxiety in a person with chronic disease? What are some signs to look out for to identify possible anxiety?

Possible answers:

- Feeling nervous, restless, worried
- Trouble thinking
- Sweating
- Lack of sleep/excessive sleep
- Headaches
- Body tension (muscle aches)
- Neglecting personal hygiene
- Being irritable or angry
- Unable to make decisions
- Feeling worthless

What might you do to help a person with epilepsy cope with anxiety?

Possible answers:

- Validate their feelings
- Say encouraging statements
- Suggest getting active (do an enjoyable exercise).
- Recommend doing activities to reduce anxiety (yoga, deep breathing, watching TV, listening to music)
- Limit alcohol and caffeine
- Encourage talking to friends or family members
- Encourage talking to their doctor about therapy or medications.
- Refer them to county behavioral health services

C. Other mental health disorders

➤ Talking Points

Schizophrenia: Epilepsy is a chronic neurological disorder that is diagnosed based on seizure occurrence, but it can also cause many of the symptoms that are typically associated with schizophrenia, another chronic brain disorder.

Many seizures associated with epilepsy, at least at the onset, are focal (partial), which means that abnormal activity begins in one part of the brain. In a focal aware seizure, patients may have unusual feelings or sensations, such as déjà vu, numbness, nausea or a funny feeling in their stomach, or extreme emotions such as elation or fear. Patients can sometimes alert others that they're experiencing this type of seizure. They may have hallucinations involving any of the senses — such as smelling, hearing, or seeing something. Hallucinations are one of the characteristics of schizophrenia. Given the similarities to symptoms of schizophrenia, then, it is not uncommon that the symptoms of focal seizures in particular can be mistaken for this psychotic disorder.

Bipolar Disorder: Bipolar disorder is chronic psychiatric disease with severe changes in mood with a wide spectrum of clinical manifestations.

The incidence of developing bipolar affective disorder and the occurrence of bipolar symptoms is more common in people who have epilepsy than those without epilepsy. Some anticonvulsants are used to treat bipolar disorder because the mood-stabilizing properties of two antiepileptic agents have been demonstrated in patients with bipolar disorder.

ASK THE CHWs:

So, to review, what are some of the issues that make having depression or anxiety more challenging for people with epilepsy?

Possible answers:

- Drug interactions
- Side effects
- Social isolation
- Burden of epilepsy

What are some actions and resources you might recommend to help a person with epilepsy experiencing symptoms of mental illness?

Possible answers:

- Ensure that they talk to their doctor or nurse about their symptoms
- Have them contact their local Epilepsy Foundation office for information on how to join a support group or get care
- Link the person to a county behavioral health provider

As a CHW, you can help a person with epilepsy whom you think might be struggling with emotional problems or symptoms of mental illness by:

- Providing **education** about how common mental illness is in people with epilepsy, and letting them know that it's not simply a by-product of epilepsy.
- Providing education about the importance of seeking mental health care.
- Providing **self-awareness training** by teaching the person how to recognize symptoms of mental illness in themselves

Teaching problem-solving skills to help the person find and get help for mental illness including identifying barriers to seeking care, and discussing ways to resolve them and also talking about concerns they may have about seeking help.

Problem Solving Treatment generally includes these steps:

1. Clarify and define the problem
2. Set realistic goals
3. Generate multiple solutions
4. Evaluate and compare solutions
5. Select a feasible solution
6. Implement the solution
7. Evaluate the outcome

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Understand why people with epilepsy are more likely to experience memory problems.
2. Describe the ways memory problems are treated.

Chapter Outline

- A. How seizures affect memory
- B. Treating memory problems

Session Time:

10 minutes

Materials:

None

Section 3: Managing Epilepsy

Treatment Management

7

People with epilepsy commonly report having problems with their thinking and memory. Here are a few examples of the problems people may report.

- Trouble remembering names or words that they once knew.
- Forgetting appointments or having trouble remembering when to take their medicines.
- Can recall things from the distant past, but can't recall events that happened in the past week.
- Forgetting things more easily as time goes by. Some people say they feel like they've 'missed part of their life'.
- Difficulty paying attention or concentrating.
- Difficulty finding the right words.
- Feel that their thinking is slowed down.

A. How seizures affect memory

➤ Talking Points

Seizures, especially ones that start in the temporal lobe, can cause a major blow to the hippocampus, a part of the brain in the temporal lobe that is responsible for processing memory and emotional responses. If seizures starting here go untreated, the hippocampus starts to harden and shrink. Information may be stored, but in a disorganized way. Luckily, there is one hippocampus on each side of the brain. So if one is affected by seizures, the other can help pick up the slack.

Seizures affect thinking in different ways for everyone. Even if your client has seizures that start near their hippocampus, their memory may not become extremely bad. Many different things need to be considered, such as:

- How long they have had seizures
- How long each seizure lasts
- Personality traits
- The effects of medications

Section 3: Managing Epilepsy

Treatment Management

7

A wide range of medical conditions can also worsen memory. These include:

- cardiovascular disease
- diabetes
- pulmonary (lung) conditions
- sleep disorders, and
- various disorders like lupus, which involve many systems of the body.

Some research has shown that people with epilepsy may be more likely to experience some of these conditions than the general population.

B. Treating memory problems

➤ Talking Points

Medication management:

For people being treated for epilepsy, the most common way to address memory problems is to manage the seizure medication better. Optimal treatment of epilepsy ultimately will enhance memory by reducing seizure frequency and side effects. The doctor may adjust dosages or begin to add or delete various medications. Most often memory will function best when taking the smallest amount of medication that is effective. Some medications also have fewer side effects than others, so sometimes a change to a different medication can help.

Treatment for depression or an anxiety disorder can also have a significant impact on memory. Improving a person's mood by adding an antidepressant medication or psychotherapy to a regimen is more likely to help memory.

Behavioral management:

There are typically two ways to go with behavioral management of a memory disorder. The first is to try to enhance memory functioning by using organization and routine. This might involve keeping frequently misplaced items such as keys and glasses in specific places, such as a hook or shelf near the door. The other approach is to use aids such as notebooks, electronic organizers, and alarms as aids for retaining information and as reminders to do something at a specific time.

Section 3: Managing Epilepsy

Treatment Management

7

Memory rehabilitation:

Some techniques involve the use of association: find some feature of the person or name that you can relate to something else.

Other methods advocate the use of bizarre imagery to get something to stick in your head. For example, to remember that the laundromat is on Maple Lane, you might think of a maple tree sticking out of a washing machine.

If you have clients experiencing memory problems, **encourage them to talk to their doctor**. The doctor can determine the severity, cause, and treatment options. Their doctor might recommend changing their treatment right away - perhaps by lowering the dose of one or more medications or changing other aspects of treatment.

As a CHW you may be able to help clients who report memory difficulties through:

Education to teach basics of memory function, normal memory problems and factors related to seizure-related cognitive problems.

Self-awareness training emphasizing awareness of the multiple influences that affect memory and attention.

Teaching compensatory strategies or skills training to “compensate” for cognitive functions that may be affected.

- Suggest using memory aids (e.g., writing down daily notes in a pad always left on the kitchen counter, making electronic notes or to-do lists in calendar).
- Setting alarms for medicine taking or telling support person to remind person to take medications, using a pill box, etc.

Problem Solving Training to provide the participant with skills to systematically work through memory related difficulties and other problems faced.

Section 3: Managing Epilepsy

Treatment Management

7

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. List ways patients can remember to take medicine.
2. Help patients understand what to do if they have questions about their medicines.
3. Discuss how community health workers can help people overcome barriers to taking their medicines, avoiding seizure triggers, keeping medical appointments, and talking to their doctor.
4. Help people recognize how epilepsy treatment is affecting their life and what they can do to address those issues.

Chapter Outline

- A. Medication management
- B. Seizure management
- C. Clinic management
- D. Epilepsy centers

Session Time:

45 minutes

Materials:

None

Section 3: Managing Epilepsy

Treatment Management

7

Teaching people with epilepsy the skills to self-manage their condition can have a positive impact on their life. Learning self-management skills and resources may help clients:

- Understand how some of the things they do every day can affect their seizure control and overall health
- Talk to their health care team and others more easily
- Keep track of treatments used to manage their seizures.
- Develop an individualized plan for seizure first aid.
- Teach other people how to respond to their seizures appropriately.
- Stay safe.
- Modify their lifestyle and environment to lessen seizure triggers.
- Have a healthy lifestyle.
- Recognize and manage other conditions associated with epilepsy more easily.
- Recognize how epilepsy is affecting their life and what they can do to address these.

Let's go over some ways you as a CHW might be able to help clients learn these important skills.

A. Medication management

➤ Talking Points

We talked earlier about ways to treat epilepsy and prevent seizures. For most people with epilepsy, taking their medication as directed will keep their seizures under control. We also talked about how people may not want to take their seizure medication because of side effects and how sometimes several medications are prescribed which can be confusing for some people.

However, the most important thing you can do for someone with epilepsy is to help them better understand and keep track of the medicine they are taking and understand the importance of sticking to their medication schedule.

Taking medicine isn't always as simple as swallowing a pill. Medicine can only help people if they take it as prescribed. Let's discuss how you, as community health workers, can help people understand why they need to take their medicine, how to get it, and how to take it.

ASK THE CHWs:

What are some reasons why people do not take their medicines as advised by their doctors, and how can community health workers help them overcome these roadblocks? Ask them for suggestions about what they would do to help people get started with their medicines and to keep taking them.

If the following reasons are not mentioned, talk about them.

- People do not know what the medicine is supposed to do.
- They are not sure of how to take their medicines.
- They cannot afford their medicines, so they do not get them.
- To save money, they only take their medicines every other day or they cut their pills in half.
- They are taking so many other medicines that they don't want to take any new ones.
- They don't feel well and think the medicine isn't helping.
- They feel that the medicine is giving them a side effect they don't like.
- They forget to take their medicines.
- They think they can do without their medicines.
- They don't have anyone to help or support them in taking their medicines.
- They have run out of their medicine and haven't submitted their refill on-time.

Section 3: Managing Epilepsy

Treatment Management

7

You can use the strategies below to help clients who are struggling with taking their medication correctly.

- Help clients **make a list** of ALL of their medicines.
- Help clients **understand the instructions** on the pill bottles. They should take the right amount of medicine at the same time every day.
- **Go with clients to see their pharmacist** to get the answers to their questions about their medicine.
- Encourage clients to take their medicine as advised by their doctor.
- Encourage them to **watch for problems** with their medicines and to be active in solving these problems with their doctor or medical team.
- Encourage clients to **call or see their doctors or nurses**, or pharmacists if they have any questions or problems with their medicines. Have them keep track of side effects or missed doses on a calendar or diary.
- Encourage clients to **continue to take their medicines** even if they are feeling better or haven't had any seizures recently. When people stop taking their medicines suddenly, their condition can worsen.
- Encourage clients to **refill prescriptions** in enough time so that they don't run out of medicine. Have them use a calendar or reminder system to make sure they don't run out. Explain and encourage the use of auto-refill options.
- Help clients **apply for free or affordable medicines**. We'll talk more about patient assistance programs later in this training.
- CHWs can be role models by taking their own medicines as advised by their doctor.
- **Help clients organize ways to remember to take their medicines**. One way is to put the pills into a pillbox that is clearly marked with the days of the week and the times of day (such as morning, noon, afternoon, and night). People will build a daily habit of taking their medicine if they use a pillbox, put it in a place they will remember, and take it with them when they leave their home. Some people might need to write down the day and time they took their medication; more than one reminder system may be necessary.
- **Engage clients' family members and friends** to remind them to take their medicine.

Section 3: Managing Epilepsy

Treatment Management

7

The Epilepsy Foundation website has links to forms and tools that you can use with clients to support them in their self-management (see Appendix H for links to specific forms and tools). We'll talk about what those are and how to find them later in this training.

B. Seizure management

➤ Talking Points

Another important aspect of treatment management is managing seizures. Knowing what happens during a seizure and how often they occur are two of the most important seizure details. Keeping track of seizures (when, what happened, and under what circumstances) can help diagnose seizure types, choose appropriate treatments, determine whether a particular medication or treatment is working, identify seizure triggers and determine what lifestyle modification may help.

As a CHW, it is important that you encourage your clients to track their seizures, and seizure triggers. Learning what triggers a seizure by observing patterns recorded on a calendar or in a diary may help people avoid those triggers in the future.

Section 3: Managing Epilepsy

Treatment Management

7

Ask your clients if they track their seizures, and if so, how. If they're not already doing so, coach them to track their seizures and seizure triggers in a diary or calendar.

- Determine what method suits them best (paper vs. electronic calendar) and go over how to use the form or app.
- Teach them to note on their calendar, any changes in their sleep, stress, mood, or other related issues (e.g., menstruation for women; excessive alcohol use; changes in the environment) along with their seizure. This will help them see patterns between their daily activities and seizures.
- Encourage them to ask their doctors about the most important information for them to track, including medication changes, and medication side effects.
- Encourage clients to write down when known triggers occur, or note what happened or how they were feeling just prior to their seizure.
- Stress the importance of writing down the length of the seizure.
- Discuss ways to reduce exposure to triggers or change or modify behavior or lifestyle appropriately.
- Encourage your clients to create a seizure response plan if they don't already have one, and review it at least once a year. It should contain emergency contact information, descriptions of typical seizures, an up-to-date list of medications and doses and other treatments. Talk with your client regarding with whom they'd like to share their seizure response plan to help keep them safe.

Some people find that seizures may occur in a pattern or are more likely to occur in certain situations or under certain conditions. This is important, because avoiding or managing seizure triggers is something that can lessen the chance that a seizure may occur under those circumstances.

Even with medication and careful tracking, sometimes people still experience seizures. Not everyone with epilepsy can recognize seizure triggers. So, it is important that everyone with epilepsy has a seizure response plan. A seizure response plan can help people know what to do in emergency situations.

Section 3: Managing Epilepsy

Treatment Management

7

The Epilepsy Foundation website has links to forms and tools that you can use with clients to support them in their seizure tracking and creating a seizure response plan. We'll talk about what those are and how to find them later in this training.

C. Clinic management

➤ Talking Points

People with epilepsy face many of the same challenges as those with other chronic conditions like heart disease or diabetes. Many of the same techniques you use to help those patients navigate health care systems are also useful for people with epilepsy.

ASK THE CHWs:

What are some things you could do to reduce barriers to keeping up with appointments and making sure your clients get the care they need?

Possible answers:

- Encouraging clients to make and keep appointments and follow-up visits with their doctors.
- Educating clients about the importance of keeping up with recommended blood work and tests recommended by their doctor.
- Empowering clients to share their concerns about their medication, side effects, or feelings with their doctor and to seek referrals to neurologists, psychiatrists, counselors, and other specialists when needed.
- Encouraging clients to share their seizure and seizure triggers diary or calendar with their doctor.
- Helping clients who do not have transportation or do not know how to use public transportation or ride sharing services to get to the clinic.
- Acting as a bridge between your client and their health care team (for example, the doctors, nurses, pharmacists).
- Telling the health care team about specific patient needs, successes, and barriers to self-care (for example, cultural beliefs, motivation, disability, safety issues).

Section 3: Managing Epilepsy

Treatment Management

7

Another important aspect of epilepsy self-management is effective communication with the health care team.

A good patient-doctor relationship is more of a partnership. One way for a person with epilepsy to get high-quality health care is to stay informed about epilepsy and epilepsy treatment options and take an active role in all of the decisions made about their care.

Because doctors only allow about 10-15 minutes per visit, it is important to help prepare your client for their appointment.

ASK THE CHWs:

What are some ways that could help someone with epilepsy get the most out of their appointments?

Possible answers:

- Write down the questions they'd like to ask the doctor
- Bring their seizure tracking and seizure trigger tracking diary or calendar and share it with the doctor
- Bring a list of all of their medications and doses
- Write down symptoms or problems.
- Bring a notebook and take notes about what the doctor says, or bring a friend or relative or the CHW to take notes.
- Ask for a summary of the visit document from the provider.

D. Epilepsy centers

➤ **Talking Points**

Sometimes people struggle to manage their epilepsy and continue to have seizures or other comorbidities, despite being in the care of a neurologist. For these people, a referral to an epilepsy center may help them get the care they need. Epilepsy centers, accredited by the National Association of Epilepsy Centers (NAEC), provide a comprehensive team approach to the diagnosis and treatment of epilepsy. A patient-oriented team will typically include epileptologists, neurosurgeons, neuropsychologists, nurse specialists, EEG technologists, social workers, and others with training and experience in epilepsy care. NAEC defines

Section 3: Managing Epilepsy

Treatment Management

7

four levels of epilepsy care and accredits centers that provide level 3 and 4 care. **NAEC defines four levels of epilepsy care and accredits epilepsy centers that provide level 3 and 4 care:**

- Level 1 epilepsy care typically occurs at an emergency room or a primary care physician's office with an epilepsy evaluation.
- Level 2 epilepsy care involves a consultation with a general neurologist. This consultation may occur at a specialized epilepsy center.
- Levels 3 and 4 care takes place at specialized epilepsy centers.

A **level 3 center** provides the basic range of medical, neuropsychological, and psychosocial services needed to treat patients with refractory epilepsy. Level 3 epilepsy centers provide basic diagnostic evaluations, as well as basic medical, neuropsychological, and psychosocial services, and some provide evaluation for surgery and perform less complex surgical procedures.

A **level 4 center** provides the more complex forms of intensive monitoring, as well as more extensive medical, neuropsychological, and psychosocial treatment. Level 4 centers also offer a complete evaluation for epilepsy surgery.

If seizures have not been brought under control after three months of care by a primary care provider (family physician, pediatrician), further treatment by a neurologist, or an epilepsy center if locally available, is appropriate.

If already in the care of a neurologist and seizures have not been brought under control after 12 months, encourage clients to request a referral to a specialized epilepsy center with an epileptologist.

You can help clients find a level 3 or level 4 epilepsy center by encouraging them to search the database on NAEC website, <https://www.naec-epilepsy.org/about-epilepsy-centers/find-an-epilepsy-center> to find the closest one.

Section 3: Managing Epilepsy

Lifestyle Management

8

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Understand the importance of healthy lifestyle choices in the self-management of epilepsy and common co-occurring conditions
2. Work with communities and community members to maintain a healthy lifestyle by encouraging healthy eating, physical activity, tobacco control, and stress reduction at the individual, family, and community level.
3. Help people take greater control over their health and to self-manage their chronic conditions.

Chapter Outline

- A. Emotional health
- B. Healthy eating/Weight management
- C. Fitness and exercise
- D. Alcohol and recreational drugs
- E. Smoking cessation
- F. Sleep
- G. Stress management
- H. Employment
- I. Driving and transportation
- J. Lifestyle management summary

Session Time:

60 minutes

Materials:

None

Section 3: Managing Epilepsy

Lifestyle Management

8

Addressing epilepsy's effect on daily living is important so that people with epilepsy are able to live a full and productive life. These issues are so important that the Epilepsy Foundation has created the Wellness Institute to recognize the importance of a holistic approach to health. The Wellness Wheel illustrates the aspects of daily life that the Wellness Institute is working to address.



- Emotional health and art therapy
- Diet and nutrition
- Physical activity
- Sleep
- Independent living
- Stress management
- Social relationships
- Education and employment

Helping people with aspects of daily life may seem very familiar to you as a CHW! These topics are important for everyone, but let's go over why managing daily life is so important for a person with epilepsy and think about things you could do to help a person with epilepsy with self-management.

A. Emotional Health

➤ Talking Points

We talked earlier about depression, anxiety, bipolar disorder and schizophrenia and how a person with epilepsy may be at greater risk for these issues. A person's emotional health can greatly impact a person's daily activities and quality of life. **The most important thing anyone can do for a depressed person is to help him or her get a diagnosis and treatment.**

Section 3: Managing Epilepsy

Lifestyle Management

8

CHWs can help by:

- Encouraging clients to tell their doctor about their feelings.
- Telling clients about community mental health centers, family services, social agencies, or places of worship that can help.
- Asking them to track their feelings and symptoms in a calendar just like a seizure calendar, so that they can share the information with their doctor. Some symptoms may be related to epilepsy or epilepsy medications, so having this information will be helpful to determine next steps and appropriate treatment.
- Encouraging the person to stay with treatment until he or she feels better (it may take several weeks), or to talk to his or her doctor about a different treatment.
- Helping them to make the appointment and/or going with them to the doctor.
- Checking on whether or not the depressed person is taking medication
- Encouraging the depressed person to follow the doctor's advice about the use of alcohol while on medicine.
- Offering emotional support.
 - **Don't ignore remarks about suicide.** Report them to the depressed person's doctor and family.
 - Invite the person for walks, outings, to the movies, and other activities that they used to enjoy.

B. Healthy eating/Weight management

➤ Talking Points

As you know, eating healthy and maintaining a healthy weight are important for everyone. Poor dietary choices are linked to increased risk for a range of health conditions, including heart disease, diabetes, cancer, that commonly co-occur in people with epilepsy. We talked earlier about special diets to help control seizures in those for whom medication is not working, but eating healthy for a person with epilepsy doesn't mean they have to be on a special diet. Some foods may aggravate seizures, going long periods of time without eating or "not eating well" can lead to poor seizure control. Encourage your clients to aim for a healthy weight by making appropriate changes in their diet.

Section 3: Managing Epilepsy

Lifestyle Management

8

Here are some suggested strategies to share with clients who would like to lose weight or eat a more healthy diet:

- Educate them about what adults should eat through resources like Myplate (<https://www.choosemyplate.gov/>).
- Suggest water as a beverage and that they get a water bottle.
- Provide a list of drinks with too much sugar (e.g., sodas, lemonades, teas, etc.).
- Recommend limiting the number of foods with sugars (e.g., desserts, etc.).
- Read food labels for calories and other information about what is in the product.
- Keep track of what they eat to make improvements in the foods they eat (<https://www.supertracker.usda.gov/foodtracker.aspx>).

C. Fitness and exercise

➤ Talking Points

Being active and exercising, in recreational activities or sports can improve mental, emotional and physical health. As a CHW, you probably spend a lot of time educating clients about the benefits of physical activity. Exercising can help people think more clearly, boost energy, improve mood and prevent other chronic illnesses. It is recommended that adults be active for 150 minutes per week. That could mean exercising for 30 minutes, 5 times a week. It's important for everyone and should be encouraged for most people with epilepsy.

Sometimes people don't exercise or play sports for fear that it could worsen seizures or lead to injuries. However, exercise is rarely a trigger for seizures. Encourage clients to talk over their exercise plans with their doctor to make sure their chosen activity will not be a trigger for their seizures, and that their doctor or nurse is in agreement with your client's exercise plans. We'll go over some tips for staying safe while exercising later in this training.

Section 3: Managing Epilepsy

Lifestyle Management

8

When talking with clients who are interested in being more active:

- Have them think about fun and safe ways that they can be active.
- Ask them to think about what equipment may help them stay active.
- Encourage walking as a routine exercise and suggest a pedometer or activity tracker.

D. Alcohol and recreational drugs

➤ Talking Points

Another way to encourage a healthy lifestyle in your clients is to advise them to cut back on alcohol. For people with epilepsy, drinking alcohol can have serious consequences. Here are some facts about alcohol and epilepsy.

- In small amounts, alcohol does not cause seizures. A drink or two now and then does not increase seizure activity.
- Small amounts of alcohol doesn't change the amounts of seizure medicines in the blood or change findings on EEG studies.
- Risk for seizures may be higher after having three or more alcoholic beverages, and binge drinking and alcohol withdrawal can lead to status epilepticus (a single seizure lasting more than 5 minutes, or two or more seizures without the person regaining consciousness)-- a life-threatening and potentially fatal outcome.
- Seizure medicines can lower alcohol tolerance, so the immediate effects of alcohol consumption are greater.

Recreational drugs can be dangerous for anyone, but carry a wide variety of risks for people with epilepsy. Using recreational drugs may directly affect the brain and seizures or interact with seizure medications. However their effects on the brain and seizures vary.

For example, cocaine can cause very dangerous seizures within seconds and may be associated with heart attacks, disrupting the heart's normal rhythm (cardiac arrhythmia) and death. Other recreational drugs such as amphetamines or other stimulants and heroin or other opioids do not directly affect the likelihood of seizures in people with epilepsy. However, abuse may cause people to forget their seizure medicine, triggering seizures, and very high doses of amphetamines can cause generalized or unknown onset tonic-clonic seizures, heart attacks, and

Section 3: Managing Epilepsy

Lifestyle Management

8

death. Also, taking large amounts of narcotics can cause serious lack of oxygen to the brain, which can lead to seizures.

E. Smoking cessation

➤ Talking Points

A recent CDC study showed that about 20% of adults with active epilepsy, and almost 22% of adults with a history of epilepsy, currently smoke cigarettes. About 19% of adults without epilepsy currently smoke. These new data show that people with active epilepsy are as likely to smoke cigarettes as people without epilepsy.

About 48% of current smokers with active epilepsy tried to quit in the last year, and 75% wanted to quit. However, less than half (about 47%) of current smokers with active epilepsy reported that a health professional advised them to quit smoking in the past year.

Everyone who smokes is at risk for serious health effects such as stroke, coronary heart disease, many kinds of cancer, asthma, chronic obstructive pulmonary disease (COPD), and tooth loss. By sharing information about the benefits of not smoking, you can encourage people in your community to quit smoking and prevent further damage to their health.

Section 3: Managing Epilepsy

Lifestyle Management

8

As a CHW, you can:

- **ASK** about tobacco use: “Do you currently smoke or use other forms of tobacco?”
- **ASSESS** readiness to quit: “Are you interested in quitting tobacco?”
- **ASSIST** the patient in quitting: IF READY TO QUIT: Provide brief counseling and medication (if appropriate). Refer patients to other support resources that can complement your care (e.g., quitlines, Smokefree.gov, SmokefreeTXT, BeTobaccoFree.gov, group counseling). For tips on how to offer brief counseling, see: www.ahrq.gov/path/tobacco.htm.
- IF NOT READY TO QUIT: Strongly encourage patients to consider quitting by using personalized motivational messages. Let them know you are there to help them when they are ready
- **ARRANGE** for follow up: Follow up regularly with patients who are trying to quit.

For additional free support with quitting smoking, clients can be referred to 1-800-QUIT-NOW, a phone-based service with educational materials, coaches, a quit plan, and referrals to local resources to help people quit tobacco use.

ASK THE CHWs:

As community health workers, what are some techniques you might use to encourage someone to stop smoking?

F. Sleep

➤ Talking Points

Getting a good night's sleep plays a key role in the overall well-being and health of all people. It helps us think more clearly, react more quickly, and generally perform better. When people do not get enough sleep, it can lead to being tired (fatigue). But, it's particularly important for people with epilepsy.

A lack of sleep or poor quality of sleep can increase frequency of seizures. Here are a few reasons why:

- The sleep-wake cycle is associated with prominent changes in brain electrical activity, so seizures and the sleep-wake cycle are often clearly related.
- There are hormonal changes during sleep that could possibly be related to seizures.
- The effects of seizures and seizure medicines may affect sleep quality.

IMPORTANT: If a client reports having seizures during the night or has problems falling asleep, wakes often during the night, or reports being excessively sleepy encourage them to talk to their doctor about adjustments to medication. Not sleeping well at night can worsen seizure control for many people. If medication adjustments aren't helping you may recommend they talk to their doctor about having a consultation with a sleep specialist.

ASK THE CHWs:

What are some tips you can give to your clients to help them get better sleep?

Possible answers:

- Set a specific time to go to bed and wake up.
- Sleep in a dark, quiet environment.
- Keep the temperature comfortable.
- Only use the bedroom for sleeping. No reading, TV, radio, texting, etc.
- Avoid napping during the day.
- Avoid caffeine, alcohol and tobacco
- Keep a consistent bedtime routine

G. Stress management

➤ Talking Points

People with epilepsy who are able to manage their stress report feeling that it has an impact on their seizures. Different things cause stress for different people, and the way stress affects people can change.

The relationship between stress and seizures is not known, but

- Stress creates certain hormones related to the nervous system that can impact the brain.
- Stress can cause sleeping problems, triggering seizures, and
- Chronic stress can lead to anxiety or depression. Sleep problems are symptoms of these mood problems. Being anxious and depressed can also worsen stress, causing a vicious cycle with more seizures and mood problems.

Encourage clients to talk to their doctor, nurse, or counselor about their stress.

ASK the CHWs:

What are some activities that could help to reduce stress?

Possible answers:

- Writing down stressors in a diary.
- Avoiding stressful situations, if possible.
- Getting enough sleep and taking seizure medications on time.
- Finding ways to avoid people and situations that cause anger and anxiety.
- Limiting long naps during the day to prevent sleep problems at night.
- Keeping to a daily routine.
- Exercising safely, each day
- Meditate for 5 to 10 minutes each day
- Connect with others
- Talk to others about your stressors.
- Setting priorities for what is important in life and letting the rest go.
- Making sure the epilepsy team knows that stress is affecting your seizures.
- Seeking counseling or psychotherapy.

H. Employment

➤ Talking Points

Getting a job and maintaining employment may be more difficult for someone with epilepsy, but not impossible.

There are certain things people with epilepsy can do to increase their chances of getting and keeping a job.

- People with uncontrolled seizures should avoid occupations that would require driving as part of the job, or that would involve hazardous situations.
- Some people with epilepsy might consider jobs that allow working at home.
- People with epilepsy can talk with their employer about job accommodations (see Appendix E for resources to discuss job accommodations with employers).

Remind your clients that they don't have to disclose their epilepsy during an interview. Under the Americans with Disabilities Act, people with epilepsy and

Section 3: Managing Epilepsy

Lifestyle Management

8

other disabilities are protected from disclosing their condition during a job interview.

For people who have good seizure control, job possibilities are not limited. Once hired, when discussing epilepsy with an employer, people with epilepsy should be able to explain how much or how little impact having epilepsy has on their ability to perform their job well.

If a client needs help finding a job, there are resources available in the community to help them. For example:

- Local Epilepsy Foundation affiliates offer programs that help people with epilepsy to find jobs. Some have relationships with employers to hire people with epilepsy specifically, so it's worth looking into.
- A local One-Stop Career Center
- A Vocational Rehabilitation Services office

The Americans with Disabilities Act (ADA) prohibits discrimination on the basis of an individual's disability in employment, by state and local governments and their instrumentalities, by public accommodations, in public and private transportation and in communications. The ADA grants all individuals with disabilities uniform protections regardless of which state they live in. We'll talk in more detail about the ADA and job accommodations later in this training.

I. Driving and transportation

➤ Talking Points

As previously mentioned access to reliable transportation affects many areas of a person's life and can be particularly challenging for people living in rural areas.

However, there are options available to people with epilepsy living in both urban and more rural areas. In urban areas, a good option for many people with epilepsy is to use public transportation such as subways, buses, trains, or taxis. Also, many cities and towns have "paratransit" services for people who are not able to use the typical public transportation or when buses or trains are not available. Ride-sharing services might also meet transportation needs, though people who live in more rural areas may have greater difficulties finding paratransit and ride-sharing services.

Section 3: Managing Epilepsy

Lifestyle Management

8

ASK THE CHWs:

How can you help a person with epilepsy problem-solve their transportation needs? What are other resources you can encourage your clients to use?

Possible answers:

- Ask family or friends for rides - offering to pay for gas or help them in other ways may help this arrangement work better for everyone.
- Schedule a routine day and time a family member, friend, or cab can take you places to get groceries, pet food, and other necessary items. Having a routine schedule can help avoid having to ask people over and over again for rides.
- Call 2-1-1 where available. They often have vans that can take people to appointments or stores for errands.
- Contact the local Epilepsy Foundation affiliate, local churches, the Red Cross, or other nonprofit groups in the area. Many have lists of resources or offer volunteers to help people with transportation.

J. Lifestyle management summary

As a CHW you are equipped with the knowledge and tools to help clients with epilepsy lead a better life. Your client might express concerns about different lifestyle areas such as those below. If so,

- Watch for signs of depression and anxiety and encourage your clients to share their feelings with their doctor.
- Get families involved in making healthy choices about eating—both at home and away from home.
- Educate clients about the importance of limiting alcohol intake to no more than one (for women) or two (for men) drinks a day. One drink is 1 oz. of hard liquor, 4 oz. of wine, or 12 oz. of beer.
- Educate clients about the dangers of recreational drug use.
- Encourage people to talk to their doctors about safe physical activity, and encourage them to be more active by at least taking daily walks (with any necessary safety precautions in place). See Appendix F for exercise safety tips.
- Work with community leaders to find safe places for people to walk and encourage the use of other physical activity resources in the community and at work sites. CHWs can start and lead walking groups.
- Educate clients about the importance of getting good sleep and share tips for how to do that.
- Help people find ways to manage and reduce stress.
- Provide education on the health benefits of quitting smoking, and help people who want to quit smoking to quit.
- Connect clients with employment, transportation and legal resources in the community, if needed.

Section 3: Managing Epilepsy

Safety

9

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Recognize risky activities and/or unsafe conditions in the home or work.
2. Coach their client on changes that can be made to their environment or lifestyle to stay safe.
3. Help a client with disclosure issues related to creating a seizure action plan with family, friends, or employers.

Chapter Outline

- A. Safety at home
- B. Safety at work
- C. Safety while exercising
- D. Disclosure and being safe

Session Time:

20 minutes

Materials:

Tips for Staying Safe

Seizure Action Plan

Section 3: Managing Epilepsy

Safety

9

People with epilepsy and their families often express fears about injury. People who have seizures should take extra precautions because while many injuries are minor, serious injuries are also possible.

Things to consider include:

- Seizure risk (how controlled are their seizures)
- Timing of seizures
 - People who have seizures only at night may not need the same precautions as someone whose seizures happen during the day.
- Risk of injury to self and others
 - Risks may vary according to type and frequency of seizures or length of recovery period.
- Dangers and benefits of preferred activities
- Available protective gear or adaptive aids to reduce risk

A. Safety at home

➤ Talking points

The home is the most common place for seizure-related accidents. Every day activities such as bathing and cooking place the person with seizures at risk for injury. Making simple changes in household activities or environment may create a safer home. Having a seizure during sleep can occasionally present other dangers. Being in control of seizures by taking seizure medications as prescribed is the best way to lessen the risk of seizures or injuries.

ASK THE CHWs:

What do you think are possible dangers around the home that should be considered for people with uncontrolled seizures?

Refer to safety tips in Appendix F for this discussion.

ASK THE CHWs:

What are some ways you could empower a client to make their home safer?

Section 3: Managing Epilepsy

Safety

9

B. Safety at work

➤ Talking points

Some work environments pose many possible hazards for people with epilepsy, while others may not be suitable for someone with seizures. When looking at safety in the workplace, consider:

- **The type of job** – Some jobs may pose greater risks or not be right for a person with seizures. Does it involve driving, working around dangerous machinery, flying?
- **Risks in the environment**- Does the work require climbing? Is the area safe if a person were to have a seizure?
- **Work hours** – Some work schedules may increase the likelihood of someone having a seizure, such as frequently changing shifts or night hours resulting in sleep deprivation.
- **Availability of seizure first aid** – Are people available to help if the person needs it or does he work alone? Do people know how to provide appropriate help?
- **Employer and employee attitudes and behaviors** – What are the attitudes and reactions of people in the workplace? Are they supportive and understanding?

The important thing is whether your client is able to do the job as described. Employers are also required to make reasonable accommodations for a disability.

As a CHW you can help clients plan to be safe at work.

- Consider the types of seizures they experience.
- Identify occurrence patterns or triggers
- Identify any dependable warning signs (auras, nausea, etc.)
- Have them consult with the Job Accommodation Network to determine appropriate accommodations within the job's contextual demands.

C. Safety while exercising

➤ Talking points

The need for a person to limit or modify athletic activities depends on the severity of a person's seizures. However, most people with epilepsy can safely exercise in a gym, use exercise equipment, and do other types of exercise, even contact sports such as football, soccer, basketball or hockey.

Using some simple safety precautions, people with epilepsy can be safe and still stay active for their health. This may include:

- Exercising with a friend.
- Having a buddy or friend around when swimming.
- Wearing safety gear.

D. Disclosure and being safe

➤ Talking points

Clients may be concerned about telling friends, family, or people at work about their epilepsy. However, it is important to be prepared in case a seizure happens while at work, while exercising, or socializing. A plan of action is a tool that can be used to prepare for, or respond to, emergency situations that arise when a person has a seizure. It can help them know what to do and who to contact for that client in the event that seizures occur.

Section 3: Managing Epilepsy

Safety

9

ASK THE CHWs:

What are some elements that could be included in a plan of action in the event of a seizure at work?

Possible answers:

- Emergency contact information
- Visual or audible warning signs of an impending seizure
- How/when to provide on-site medical assistance
- How/when to call 9-1-1
- How to provide environmental support
- Who to designate as emergency responders
- Who to go to for help
- How to educate friends, family or co-workers about epilepsy



TRAINER: SHOW EXAMPLE ACTION PLAN IN APPENDIX G.

In Appendix G you'll find a sample action plan form that you can share with your clients.

Section 3: Managing Epilepsy

Self-Management Resources

10

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Identify the self-management domains that a client needs help with.
2. Find forms, apps, and other resources via the Epilepsy Foundation, CDC Epilepsy Program website, or the CDC Managing Epilepsy Well Network website.
3. Be knowledgeable about the types of assistance available to people with epilepsy and be able to share that information with clients and empower them to make use of these resources.

Chapter Outline

- A. Self-management tools
- B. Managing Epilepsy Well (MEW) Network Programs
- C. Social support and support groups
- D. Epilepsy Foundation resources
- E. Patient assistance programs
- F. Additional resources

Session Time:

30 minutes

Materials:

<http://www.epilepsy.com/get-help/managing-your-epilepsy>

Patient Assistance Program Contact Sheet

Section 3: Managing Epilepsy

Self-Management Resources

10

Self-management is what people can do to take care of themselves on a daily basis. By practicing self-management, your clients can manage their epilepsy and have an active and full life. Self-management programs help participants learn more about their condition and teach them proven skills to improve their ability to manage their health.

ASK THE CHWs:

As a CHW how might you help your clients...

- **Follow their medication schedule?**
- **Reduce their stress or depressive symptoms?**
- **Help better communicate with health care providers?**

Educate clients about the importance of:

- Taking medication as prescribed.
- Talking with their healthcare provider when they have questions.
- Recognizing and avoiding seizure triggers (such as stress), when possible.
- Keeping a record of their seizures and looking for patterns, so they can talk about them with their doctor.
- Getting enough sleep.
- Exercising safely.
- Lowering stress.
- Keeping in touch with friends, family, and other people that can help them

Section 3: Managing Epilepsy

Self-Management Resources

10

A. Self-management tools

➤ Talking Points

Recording seizures is important for clients to know more about their seizure patterns and to have this information to share with their doctors. Taking time to track important things related to their epilepsy can help with their care.

As you support clients in their self-management, there are many resources available that can be shared with clients and used in client education. A number of forms are available for download on the Epilepsy Foundation website at: <http://www.epilepsy.com/get-help/managing-your-epilepsy>. You may have other resources that you use with other clients that may be helpful as well. Links to these forms are included in Appendix H.



TRAINER: SELECT A FEW KEY FORMS AND GO OVER THEIR CONTENT AND HOW AND WHEN TO USE THEM. SHOW WHERE THEY ARE LOCATED ON THE INTERNET AND IN APPENDIX H.

Medication and Communication Tools include:

- A medication schedule, a medication records form, lifestyle tips, doctor visit notes, questions for the healthcare team, and a to-do list.

Seizure information forms include:

- Forms to help describe seizures, seizure calendars and instructions, seizure trigger tracking diaries, as well as a sample action plan and first aid.

All of these are paper forms, but nowadays people often prefer to keep track of things electronically on a computer, phone or other electronic device. So, there are electronic diaries available on the internet or through an app as well.

Information about these tools can be found on the [epilepsy.com](http://www.epilepsy.com) website.

Seizure diaries can be used for different purposes. Encourage clients to talk with their doctor to find out what information is most important for them to track such as medication changes and dates, when other medicines are taken and how they felt afterwards, presence of seizure triggers, or presence of any side effects or mood changes.

Also, available in an app format, something we mentioned before – a seizure first aid app that be downloaded to a smartphone or tablet. It provides assistance

Section 3: Managing Epilepsy

Self-Management Resources

10

with recognizing different types of seizures, knowing what to do, and timing how long the seizure lasts. It can be found at efmn.org/app.

B. Managing Epilepsy Well (MEW) Network Programs

➤ Talking Points

The CDC supports the Managing Epilepsy Well (MEW) network, a team of people from U.S. universities, community-based organizations and the Centers for Disease Control and Prevention (CDC) who work together to promote epilepsy self-management research and improve the quality of life for people with epilepsy through development and testing of self-management programs and tools for people with epilepsy and healthcare providers. These programs are designed for use in adults with epilepsy with and without comorbidity, and focus on different aspects of epilepsy self-management. The delivery setting also differs among programs. Many of the programs use technology (i.e., phone, internet, tablet, etc.) either as a tool or as a mode of service delivery. Current evidence-based programs and tools address a variety of epilepsy self-management domains.

- **HOBSCOTCH** (Home Based Self-Management and Cognitive Training Changes Lives) is an individual and telephone-based program to improve memory performance and quality of life in adults with epilepsy who have memory problem.
In-person sessions are conducted in a healthcare provider's office. In the future this program may also be offered via the Internet.
- **MINDSET** (Management Information & Support Epilepsy Tool) is a tablet-based tool that is used by an adult with epilepsy in their healthcare provider's waiting room. The tool includes validated instruments to assess attitudes toward and recent behaviors regarding self-management. MINDSET flags problem areas for the provider, thereby facilitating patient-provider communication about self-management behaviors and goals.

Section 3: Managing Epilepsy

Self-Management Resources

10

- **PACES** (Program for Active Consumer Engagement in Self-Management), is a group-based program developed to improve self-management and related health outcomes in adults with epilepsy. It can be administered either in-person or by telephone. Participants take notes, ask questions, share personal stories, and set achievable goals related to managing the challenges of epilepsy for the week.
- **PEARLS** (Program to Encourage Active, Rewarding Lives) uses a team-based care designed to reduce depression and improve quality of life in adults with epilepsy. The program teaches skills across three main components: problem solving, becoming involved in social activities, and planning pleasant activities. The team regularly reviews each case and coordinates care with the person's healthcare provider if necessary.
- **Project UPLIFT** (Using Practice and Learning to Increase Favorable Thoughts) is a telephone-based program based on mindfulness and cognitive therapy to prevent or reduce depression in people with epilepsy. UPLIFT teaches people with epilepsy to recognize how their thoughts affect their mood, how to let go of problem thoughts and pay attention to the present moment.
- **TIME** (Targeted Self-Management for Epilepsy and Mental Illness) was shown to be effective in reducing depressive symptoms. Topics addressed in TIME group sessions included "a summary of facts vs. myths about mental illness and epilepsy, developing an action plan for concurrently coping with mental illness and epilepsy, personal goal-setting, stress management, and training to communicate with care providers." TIME is currently being adapted and tested in individuals with epilepsy who have suffered a negative health event (e.g., breakthrough seizure, recent hospitalization; accident; traumatic injury, etc.) in the past six months. The adapted version of TIME is called SMART (Self-management for People with

Section 3: Managing Epilepsy

Self-Management Resources

10

Epilepsy and a History of Negative Health Events). SMART will be delivered online, but will also include one or more group sessions, telephone coaching, and peer support.

- **WebEase** (Epilepsy, Awareness, Support, and Education) is a web-based self-management program for adults with epilepsy. WebEase is an interactive website that helps people set goals and improve lifestyle skills for managing epilepsy such as taking medication as prescribed, stress-management, and getting enough sleep.

Some of these programs may be available in your community. More information about these programs and tools, can be found on the MEW Network Website at <https://managingepilepsywell.org/programs/index.html>. Your state or local health department might offer free classes for other evidence-based, generic chronic disease self-management programs that you might suggest your clients consider participating in.

C. Social support and support groups

➤ Talking Points

Social support can help people with epilepsy cope with their illness and also make healthier choices. Social supports also means that your clients can access people that you can rely on when needed.

It is important to recognize if clients are feeling stressed or anxious and be helpful in asking them to think about friends or family that they can talk to about their concerns. Suggest other ways that they can get support: spending time with family, attending social activities outside of the home, or attending church or other faith based organizations.

Support groups provide adults with epilepsy a chance to meet others struggling with similar issues, to make friends, to gain from the experience of others.

- The in-person Epilepsy Foundation support groups take several forms, depending on local preference. They can go to the website to locate one in their area.

Section 3: Managing Epilepsy

Self-Management Resources

10

- Some groups are structured with the primary goal of helping their members understand epilepsy better. Others offer an opportunity to discuss key issues. A third group may emphasize fellowship and giving people a chance to enjoy themselves in a setting where seizures are recognized, understood -- and accepted.
- Also, for those without access to a local Epilepsy Foundation affiliate, the epilepsy.com website brings outreach and support to the Internet.
- There, people with epilepsy can connect with others living with seizures in online [Community Forums](#).

D. Epilepsy Foundation resources

As you probably know by now, the National Epilepsy Foundation and the local Epilepsy Foundation Affiliates are an important resource for you, your clients, their families and caregivers, and anyone who wants to learn about epilepsy and how it can be managed.

If you're struggling to help a client with an issue related to their epilepsy, the local Epilepsy Foundation affiliate may be able to help. Most local Epilepsy Foundation affiliates provide information and referral assistance; maintain individual and family support services; serve as advocates for the rights of those with epilepsy; and offer community-based education to employers, emergency first-responders, school nurses, and other allied health professionals.

Also, for those without access to a local Epilepsy Foundation affiliate, the epilepsy.com website brings outreach and support to the Internet.

There, people with epilepsy can connect with others living with seizures in online [Community Forums](#).

The National Epilepsy Foundation offers a 24/7 helpline. The 24/7 Helpline has trained information specialists standing by to answer your questions about epilepsy and seizures and provide help, hope, support, guidance, and access to national and local resources.

Some of the topics the helpline information specialists respond to most often include:

- Current treatment and alternative therapies options

Section 3: Managing Epilepsy

Self-Management Resources

10

- Available medications
- Support groups
- Seizure first aid and safety issues
- Employment and discrimination issues
- Emotional support
- Getting connected with local Epilepsy Foundation affiliates
- Sudden Unexpected Death in Epilepsy (SUDEP)
- Requests for print materials

The helpline number is 1-800-332-1000 (in Spanish 1-866-748-8008).

E. Patient assistance programs

➤ Talking Points

We talked earlier about some of the financial struggles people with epilepsy face, including the high cost of medications. Some drug companies though, offer certain medications at a discount or for free to people who cannot afford them.

Patient assistance programs provide services such as:

- Prescription medicine free of charge or at low cost.
- Medicine sent to the home, doctor's office, or pharmacy, depending on the program.

As a CHW, you may be able to help with the application process, but if your client needs several drugs made by different manufacturers, they must apply to each drug company. You could also refer clients to one of several nonprofit organizations can help them find and apply for patient assistance programs.

On these web sites, you can:

- check if the prescription drugs needed are available from patient assistance programs
- identify the drug manufacturers
- check eligibility
- print applications and instructions

Section 3: Managing Epilepsy

Self-Management Resources

10

Other organizations that help people get assistance with paying for medication include:

- NeedyMeds.org
- The Partnership for Prescription Assistance (PPA) www.pparx.org.
- PatientAssistance.com
- RxAssist.com
- FamilyWize Community Service Partnership

Included in Appendix I is a list of patient assistance programs and their contact information.

F. Additional resources

➤ Talking Points

In addition to community resources that you may already use for clients with other chronic conditions, you or the local Epilepsy Foundation affiliate may be able to refer clients to a variety of other legal, financial, mental health, and employment resources.

VA Epilepsy Centers of Excellence: For veterans, the VA Epilepsy Centers of Excellence (ECoE) are a network of 16 sites that provide comprehensive epilepsy evaluation and care for Veterans with seizure disorders. To improve the care of Veterans nationwide, ECoE partner with a consortium of VA physicians, nurses, therapists, pharmacists and other allied healthcare providers with interest and expertise in improving the health and well-being of Veteran patients with epilepsy. For more information on the VA Epilepsy Centers of Excellence, go to their website at <https://www.epilepsy.va.gov/>.

Section 3: Managing Epilepsy

Self-Management Resources

10

Jeanne A. Carpenter Epilepsy Legal Defense Fund: The Epilepsy Foundation's Jeanne A. Carpenter Epilepsy Legal Defense Fund fights discrimination in:

- Employment
- Education
- Public accommodations (such as camps, childcare facilities, stores, hotels, theaters, fitness clubs)
- Programs and services, including police and first responder training
- Housing
- Insurance
- Criminal justice concerns

For more information, go to <https://www.epilepsy.com/living-epilepsy/legal-help>.

The **J. Kiffin Penry Patient Travel Assistance Fund** provides reimbursement of travel expenses for eligible patients and their families who have had to travel more than 50 miles from their home to receive FDA-approved medical care and/or treatment for their epilepsy, but lack adequate financial resources to meet the cost of this travel without bearing financial hardship. For more information, go to <https://www.epilepsy.com/living-epilepsy/247-helpline/patient-assistance/j-kiffin-penry-patient-travel-assistance-fund>.

The Job Accommodation Network (JAN) is the leading source of free, expert, and confidential guidance on workplace accommodations and disability employment issues. Working toward practical solutions that benefit both employer and employee, JAN helps people with disabilities enhance their employability, and shows employers how to capitalize on the value and talent that people with disabilities add to the workplace. For more information, go to <https://askjan.org/>.

To get help understanding disability discrimination rights, the **Equal Employment Opportunity Commission (EEOC)** has developed a wide range of fact sheets, question & answer documents, and other publications to help employees and employers understand the complex issues surrounding disability discrimination. <https://www.eeoc.gov/laws/types/disability.cfm>

These case studies allow you to apply the knowledge learned in this training and combined with experience to case studies.

Objectives

By the end of this session, community health workers (CHWs) will be able to:

1. Identify area of need or concern of client related to epilepsy self-management
2. Describe actions to address the area of concern related to epilepsy self-management.

Chapter Outline

- A. Case Study #1 – Self-Management Behaviors
- B. Case Study #2 – Lifestyle Management
- C. Case Study #3 – Medication Management and Healthcare Communication
- D. Case Study #4 – Driving and Transportation
- E. Case Study #5 – Work and Disclosure

Session Time:

60 minutes

Materials:

None

Case Study #1 – Self-Management Behaviors

A 36 year old man reports having uncontrolled seizures. How could you help him identify areas in his lifestyle that may improve his seizure control?

- *Ask questions about the self-management domains (Use a screening tool such as the AESMMI-65 – see Appendix H).*
 - *Healthcare communication*
 - *Treatment management*
 - *Coping*
 - *Social support*
 - *Seizure tracking*
 - *Wellness*
 - *Seizure response*
 - *Safety*
 - *Medication adherence*
 - *Stress management*
 - *Proactivity*
- *Help him to set goals*
- *Create a plan to improve self-management skills in identified areas*
- *Teach him about WebEase (<http://www.webease.org>) and show him how to sign-up*

Case Study #2 – Lifestyle Management

A 23-year-old woman with focal aware seizures has trouble maintaining a regular schedule. She sometimes doesn't get enough sleep and is a smoker. When she doesn't get good sleep, she often has seizures. She goes out with her friends every Friday and Saturday night and has 3 or 4 drinks. She tells you that she would like to quit smoking and get better sleep.

How would you help her to better manage her lifestyle?

- *Set a specific time to go to bed and wake up.*
- *Avoid napping during the day.*
- *Avoid caffeine, alcohol and tobacco*
- *Encourage her to quit smoking by educating her about the risks of smoking and benefits of quitting.*

- *Refer her to additional resources to help her quit smoking, like 1-800-QUIT-NOW.*
- *Help her develop a cue that she can use when she's out with her friends to let them know she needs to head home to take care of herself without feeling uncomfortable*

Case Study #3 – Medication Management and Healthcare Communication

A 30 year old client describes feeling especially tired, lonely and depressed and has felt helpless to address his symptoms. He reports not having people close-by whom he can talk with. He sleeps much of the day, and therefore doesn't always take his medicine on time. He sometimes forgets to refill his prescription and runs out of his medicine for a few days. He tells you that he wishes he had someone whom he could talk with about his feelings and who knows what he is going through. He says he wants to better control his seizures.

What are some strategies you would use to help him?

- *Educate him about common emotional problems in epilepsy, and help him identify mental illness symptoms*
- *Ask permission to screen for depression or anxiety, and follow-up as appropriate.*
- *Explain the importance of writing down information about how he's feeling and teach him how to use a medication diary to document side effects and missed doses.*
- *Show him available mobile apps to track medication use, side effects and get reminders to take his medicine on time, and to follow-up on prescription refills.*
- *Show him forms he can use to keep track of questions he has for his doctor*
- *Use motivational interviewing to encourage him to share information about his feelings with his doctor*
- *Help him make appointment with doctor*
- *Ask him to make list of friends/family that he can talk to and help him to set a goal for reaching out to at least one person on the list every day or two.*
- *Help him find support groups in the area*
- *Refer him to Epilepsy Foundation online communities via his home computer or by getting online at a local library*
- *Refer him to the Epilepsy Foundation 24/7 helpline*

Case Study #4 – Driving and Transportation

A 43 year old man became unable to drive because he had some break-through seizures. He lives in a suburb of a large city, 8 miles away from the nearest grocery store. He reported being stressed because he ran out of dog food and had no way to get to the store.

How would you coach him to find solutions to his transportation issues?

- *Use problem solving approaches to help him figure out how to pre-arrange regular transportation for necessary household items, like dog food.*
- *Encourage him to make a list of possible transportation options. Such as:*
 - *Identify people who could give him a ride to the store in exchange for gas money*
 - *Set a regular schedule with family members, friends, neighbors, or a taxi driver to arrange for transportation on a routine schedule to avoid having to ask multiple times*
 - *Identify public transportation routes and learn how to ride public transit*
 - *Call taxi or ride sharing services*
- *Inform him of additional community resources that you are aware of. These may include:*
 - *Call 2-1-1 where available. They often have vans that can take people to appointments or stores for errands.*
 - *Contact the local Epilepsy Foundation affiliate, local churches, the Red Cross, or other nonprofit groups in the area. Many have lists of resources or offer volunteers to help people with transportation.*

Case Study #5 – Work and Disclosure

A 20 year old woman was recently hired as a coffee shop barista, but works irregular hours. She hasn't had a seizure in a year, but since starting the new job, she has not been getting regular sleep and has been stressed about her relationship. She is worried about disclosing to her employer that she has epilepsy, even though she has focal aware seizures and can generally hide the symptoms from others.

How would you work with her to create a comfortable disclosure plan? What would you include in a seizure action plan to prepare for potential seizures at work?

Note to CHW: If the person is unclear about whether/how to disclose—they might contact their local Epilepsy Foundation, the Job Accommodation Network, and/or you can help them think this through by:

- *Creating a list of pros and cons of disclosing*
- *Thinking about possible job accommodations*
- *Encouraging better lifestyle, teaching stress management techniques; maintaining consistent work hours and sleep balance*
- *Consider telling a trusted coworker what to do if she has a seizure*
- *Creating a seizure action plan*

Bibliography

Algreeshah, FS and Benbadis, SR. Psychiatric Disorders Associated with Epilepsy. Medscape. <http://emedicine.medscape.com/article/1186336-overview>. Updated February 4, 2016. Accessed August 29, 2017.

American Public Health Association. Community Health Workers. <http://www.apha.org/apha-communities/member-sections/community-health-workers>. Accessed August 29, 2017.

Centers for Disease Control and Prevention. A Community Health Worker Training Resource for Preventing Heart Disease and Stroke. https://www.cdc.gov/dhdsp/programs/spha/chw_training/pdfs/chw_training.pdf. Published 2015. Accessed August 29, 2017.

Centers for Disease Control and Prevention. Addressing Chronic Disease through Community Health Workers. https://www.cdc.gov/dhdsp/docs/chw_brief.pdf. Published April 2015. Accessed August 29, 2017.

Centers for Disease Control and Prevention. Epilepsy and Smoking. <https://www.cdc.gov/features/epilepsy-smoke/index.html>. Updated February 16, 2016. Accessed August 29, 2017.

Cui W, Kobau R, Zack MM, Buelow JM, Austin JK. Recent changes in attitudes of US adults toward people with epilepsy — Results from the 2005 SummerStyles and 2013 FallStyles surveys. *Epilepsy Behav*. 2015;52:108-18.

Epilepsy Foundation. <https://www.epilepsy.com>. Accessed August 29, 2017.

Escoffery C, Bamps Y, LaFrance WC Jr, et al. Development of the Adult Epilepsy Self-Management Measurement Instrument (AESMMI). *Epilepsy Behav*. 2015;50:172– 183.

Escoffery C, Bamps Y, LaFrance WC Jr, et al. Factor Analyses of an Adult Epilepsy Self-Management Measurement Instrument (AESMMI). *Epilepsy Behav*. 2015;50:184-189.

Institute of Medicine (US) Committee on the Public Health Dimensions of the Epilepsies; England MJ, Liverman CT, Schultz AM, et al., editors. *Epilepsy Across the Spectrum: Promoting Health and Understanding*. Washington DC: National Academies Press (US); 2012. <https://www.ncbi.nlm.nih.gov/books/NBK91506/> doi: 10.17226/13379. Accessed August 29, 2017.

International League Against Epilepsy. Definition and Classification. <http://www.ilae.org/Visitors/Centre/documents/ClassificationSeizures-2017-Scheffer.pptx>. Accessed August 29, 2017.

Bibliography

Kadima NT, Kobau R, Zack MM, Helmers S. Comorbidity in Adults with Epilepsy — United States, 2010. *MMWR*. 2013;62(43):849-853.

Kobau R, Cui W, Kadima N, Zack MM, et al. Tracking psychosocial health in adults with epilepsy—estimates from the 2010 National Health Interview Survey. *Epilepsy Behav*. 2014;41:66-73.

National Association of Epilepsy Centers. What is an Epilepsy Center. <https://www.naepilepsy.org/about-epilepsy-centers/what-is-an-epilepsy-center/>. Accessed August 29, 2017.

Managing Epilepsy Well Network. <https://managingepilepsywell.org/index.html>. Updated January 27, 2017. Accessed August 29, 2017.

PEARLS. Problem Solving Treatment. [http://www.pearlsprogram.org/Conducting-PEARLS/Problem-Solving-Treatment-\(PST\).aspx](http://www.pearlsprogram.org/Conducting-PEARLS/Problem-Solving-Treatment-(PST).aspx). Accessed August 29, 2017.

Selassie AW, Wilson DA, Martz GU, Smith G, Wagner JL, Wannamaker B. Epilepsy beyond seizure: A population-based study of comorbidities. *Epilepsy Res*. 2014;108:305-315.

The Brief Tobacco Intervention.
<https://www.cdc.gov/tobacco/campaign/tips/partners/health/materials/twyd-5a-2a-tobacco-intervention-pocket-card.pdf>. Accessed August 29, 2017.

Thurman DJ, Kobau R, Luo Y, Helmers S, Zack MM. Health-care access among adults with epilepsy: The U.S. National Health Interview Survey, 2010 and 2013. *Epilepsy Behav*. 2015, ePub before print. DOI: 10.1016/j.yebeh.2015.10.028.

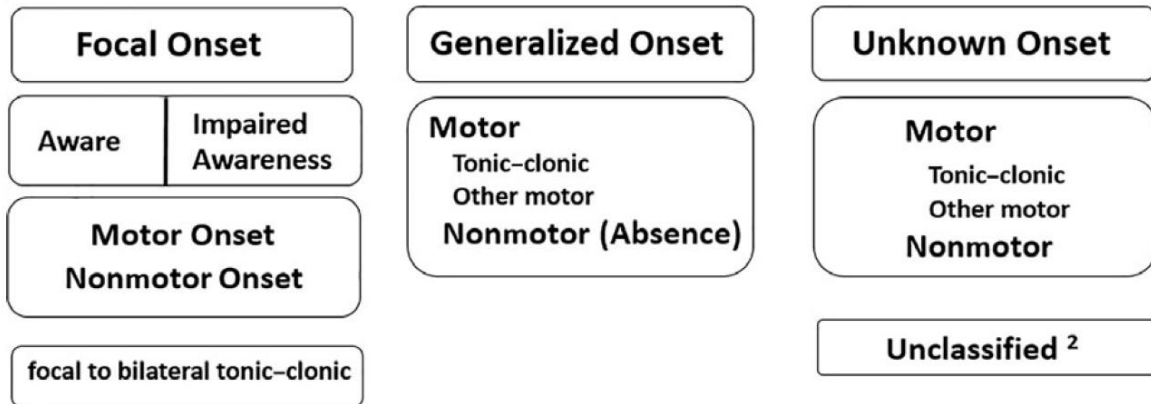
Whetzel, M. Accommodation and Compliance Series: Employees with Epilepsy. Job Accommodation Network. <https://askjan.org/media/epilepsy.html>. Updated March 13, 2013. Accessed August 29, 2017.

Zack MM, Kobau R. National and State Estimates of the Numbers of Adults and Children with Active Epilepsy — United States, 2015. *MMWR*. 2017;66:821–825.
doi: <http://dx.doi.org/10.15585/mmwr.mm6631a1>.

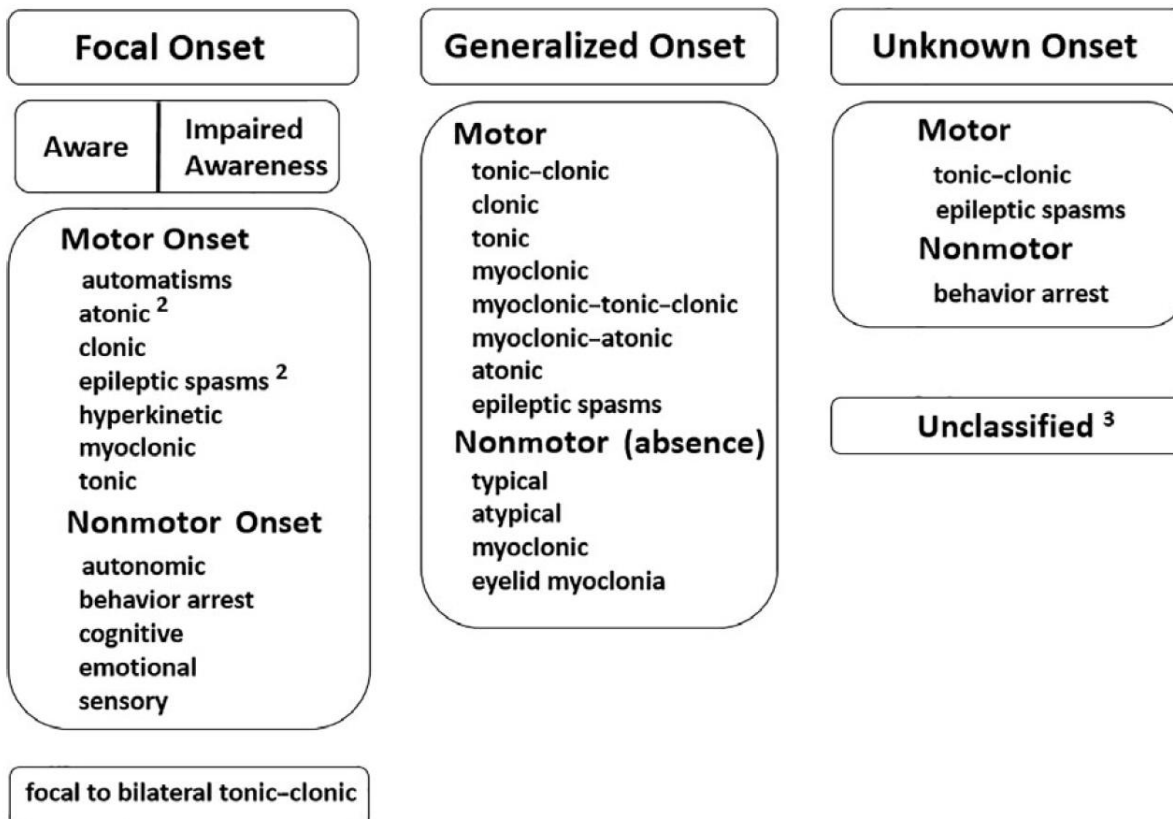
APPENDICES

Appendix A

ILAE 2017 Classification of Seizure Types Basic Version ¹



ILAE 2017 Classification of Seizure Types Expanded Version ¹



Appendix A

The following lists the new terms and whether this is different from before.

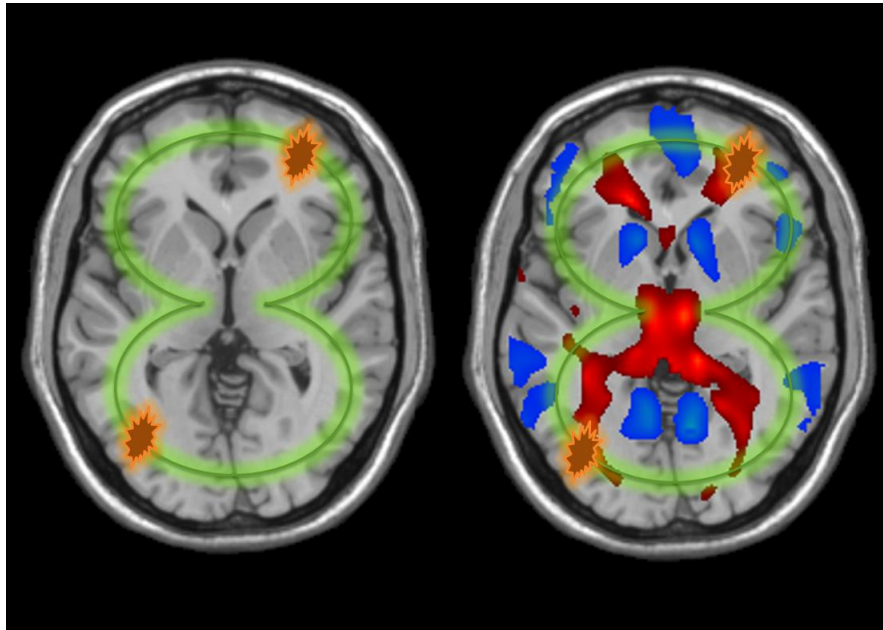
- Generalized Motor Seizures
 - Tonic-clonic – No change (Years ago the term grand mal was used)
 - Clonic – No change
 - Tonic – No change
 - Myoclonic – No change
 - Myoclonic-tonic-clonic – New term
 - Myoclonic-atonic – New term
 - Atonic – No change
 - Epileptic spasms – New term
- Generalized Non-Motor Seizures (Absence)
 - Typical Absence – No change (Years ago the term petit mal was used)
 - Atypical absence – No change
 - Myoclonic absence – New term
 - Eyelid myoclonia – New term

Old Term vs New Terms for Seizures

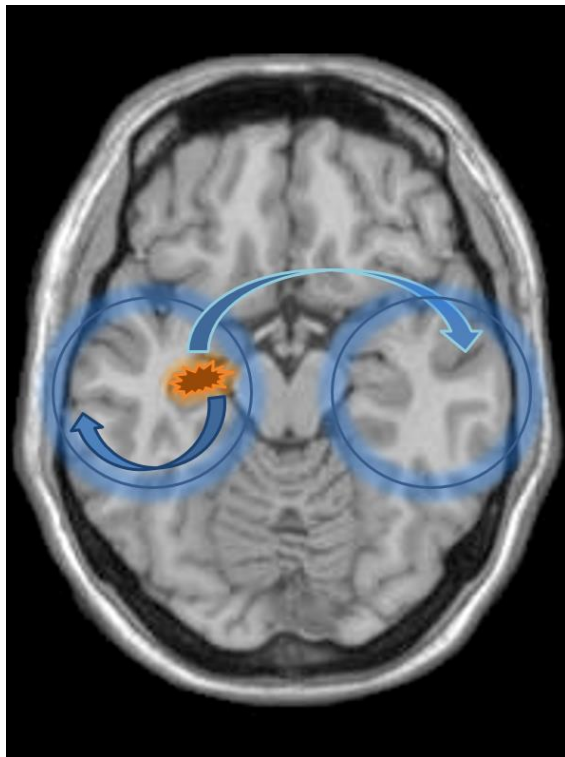
- Absence – Generalized absence
- Atonic or drop attack – Focal or generalized atonic
- Grand mal – Generalized or unknown onset tonic clonic
- Infantile spasms – Focal, generalized, unknown onset epileptic spasms
- Myoclonic – Focal or generalized myoclonic
- Petit mal – Generalized absence
- Tonic clonic – Generalized or unknown onset tonic clonic
- Tonic or drop attack – Focal or generalized tonic
- Complex partial – Focal impaired awareness
- Focal motor – Focal motor aware or impaired awareness
- Focal sensory – Focal sensory aware or impaired awareness
- Limbic – Focal impaired awareness
- Psychomotor – Focal impaired awareness
- Simple partial – Focal aware

Appendix A

Generalized Onset Seizure:



Focal Onset Seizure:



Dietary Therapies for Treating Epilepsy

The Ketogenic Diet

- The ketogenic diet is a special high-fat, low-carbohydrate diet that helps to control seizures in some people with epilepsy.
- Doctors **usually recommend the ketogenic diet for children** whose seizures have not responded to several different seizure medicines.
- The typical ketogenic diet, called the "long-chain triglyceride diet," provides 3 to 4 grams of fat for every 1 gram of carbohydrate and protein.
- Several studies have shown that the ketogenic diet does reduce or prevent seizures in many children whose seizures could not be controlled by medications.

The Modified Adkins Diet (MAD)

The modified Atkins diet is less restrictive than the ketogenic diet. It allows for fewer carbohydrates (15 to 20 g/day) and more strongly encourages fat intake than the traditional Atkins diet. It may be more appropriate for adults because foods can be eaten more freely in restaurants and outside the home well. Studies show it is very similar to the classic ketogenic diet in efficacy.

The Low Glycemic Index Diet (LGIT)

The LGIT monitors the total amount of carbohydrates consumed daily, with particular focus on carbohydrates that have a low Glycemic Index. On the LGIT the percentage of calories from fat is approximately 60%, compared with up to 90% on the ketogenic diet.

For more details on these dietary therapies, go to

<http://www.epilepsy.com/learn/treating-seizures-and-epilepsy/dietary-therapies>

FIRST AID FOR SEIZURES

1. Stay calm, most seizures only last a few minutes.
2. Prevent injury by moving any nearby objects out of the way.
3. Pay attention to the length of the seizure.
4. Make the person as comfortable as possible.
Turn the person on their side.
5. Keep onlookers away.
6. Do **not** hold the person down.
7. Do **not** put anything in the person's mouth.
8. Do **not** give the person water, pills, or food until the person is fully alert.
9. If the seizure continues for longer than five minutes, call 911.
10. Be sensitive and supportive, and ask others to do the same.



Appendix D

Drivers Licensing and Mandatory Reporting

The laws determining which medical conditions may prevent someone from driving varies from state to state. Some states have become more liberal in recent years, basing laws on actual data about risks. This has resulted in fewer restrictions for people with epilepsy.

- In some cases, accidents involving epilepsy are caused by people, especially men, who are driving without a license or who fail to report their epilepsy when applying for a license.

To get a driver's license in most U.S. states, a person with epilepsy must be free of seizures that affect consciousness for a certain period of time, ranging from 3-12 months.

In most states, the medical information and license application is reviewed by the state's department of motor vehicles (DMV). When the decision is not clear, the information is usually forwarded to a consulting doctor or the state's medical advisory board. A medical advisory board may also hear appeals about denying or revoking drivers' licenses.

- Decisions made by the motor vehicle department can be appealed by requesting an administrative hearing with the medical advisory board or another designated body. If the administrative decision is not favorable, the applicant can request a review by a judge within a certain time period.

Some states may allow someone with seizures to drive with certain restrictions such as during the daytime only, to and from work or within a certain distance from the home, or only during an emergency. Situations that may be considered for restricted licenses may include:

Seizures that do not affect consciousness, awareness or control of movement.

- Seizures occur only during sleep.
- Seizures that are consistently preceded by an aura.
- Seizures are restricted to a certain time of the day (such as within an hour after awakening).
- A change in seizures occurred only when seizure medicines have been reduced or stopped on the advice of a doctor.

Appendix D

If a person has been had no seizures for more than 3 to 5 years, most states will no longer require periodic medical reports. However, they may be asked for a letter from their doctor or treating health care professional stating the date of the last seizure or other information when renewing their driver's license.

Potential liability and physician reporting

Personal Liability: A person with epilepsy may be civilly or criminally liable for a motor vehicle accident caused by seizures. Liability may occur when a person drives...

- Against medical advice,
- Without a valid license,
- Without notifying the state department of motor vehicles of the medical condition, or with the knowledge that he or she is prohibited from driving.

Mandatory Physician Reporting: Some states (California, Delaware, Nevada, New Jersey, Oregon, and Pennsylvania) have "mandatory reporting laws" that require doctors and other treating health care providers to report persons with active epilepsy and other disorders that may make driving hazardous. These laws generally order the doctor to notify the department of motor vehicles of the person's name, age, and address.

- In these states, doctors may be liable for negligence if they fail to report a person with epilepsy who is later involved in a motor vehicle accident.
- In states without such laws, however, the question of whether a doctor should report a patient who may be driving unsafely presents a difficult conflict between public safety and the doctor's need to respect the privacy of the patient. In theory, a physician who reports a patient's condition could be sued for disclosing confidential information.

There are some important situations regarding mandatory reporting:

- When a doctor must report someone may be unclear and vary between states that require physician reporting. For example, do all patients with epilepsy have to be reported to the DMV, those with uncontrolled seizures, or those who may have specific risks or situations?
- Mandatory reporting can destroy the doctor-patient relationship. In many cases, those who believe that they "must" drive will lie to the doctor about

Appendix D

their condition in order to avoid mandatory reporting and potential loss of the driver's license.

- If a physician fails to report a patient under mandatory reporting laws, they can be penalized with a monetary fine. However, an accident can lead to a lawsuit charging wrongful death or injury, with a large judgment against the doctor. In states that require mandatory reporting, compliance varies widely among doctors.
- Doctors who state that it is safe for a person with epilepsy to drive and recommend licensure could also face some liability in case of an accident, although it appears to be minimal. Doctors should not be liable for recommendations made to the department of motor vehicles if their opinions are reasonable and consistent with good medical care. Some states grant immunity from liability to doctors who make recommendations about driving privileges.

For information on driving laws in your state, check the **State Driving Laws Database**.

<http://www.epilepsy.com/driving-laws>



The Impact of the Americans with Disabilities Amendments Act on Persons with Epilepsy

What is the Americans with Disabilities Act Amendments Act?

The Americans with Disabilities Act Amendments Act (ADAAA) is a new law that was signed by President Bush on September 25, 2008. It amends the Americans with Disabilities Act (ADA) and restores the original intent of Congress when it drafted the law in 1990 with regard to who is protected from discrimination on the basis of disability.

Why was a new law needed?

When the ADA was enacted it promised to be a vital means of protecting the interests of people who are treated unfairly because of their epilepsy. But a series of Supreme Court decisions severely narrowed who was covered by the law and many individuals with epilepsy and other chronic illnesses found themselves no longer protected by the law. Thus, while some people with epilepsy were able to prove that their condition was a disability under the original ADA, many others – especially workers – had trouble proving to courts that their epilepsy met the Court's narrow definition of "disability," usually because they were able to manage their condition with medication.

Why is it important to be covered by the Americans with Disabilities Act?

If an individual with epilepsy is unable to show that he or she has a disability, is regarded as having a disability, or has a record of a disability, then nothing in federal law protects that person from discrimination. Thus, without the law's protection, an employer could explicitly refuse to hire a person simply because that person has epilepsy.

How does the ADAAA affect people with epilepsy?

The ADAAA now makes it clear that Congress intends for people with conditions such as epilepsy to be covered by the law and protected from discrimination on the basis of their epilepsy.

Does the ADAAA change anything other than who is covered by the law?

No. All other provisions of the ADA – including the requirement for an employee to prove that the discrimination was based on epilepsy and the employer's obligation to provide reasonable accommodations – remain the same.

Does the ADAAA affect the rights of people with epilepsy outside of the workplace?

Yes. While most of the problems with coverage occurred in the workplace, the revised definition of disability applies everywhere that the ADA applies, including day care centers, schools, hotels, restaurants, concert venues, correctional institutions, and public transportation.

8301 Professional Place East, Suite 200
Landover, MD 20785-2353

1-800-332-1000
301-459-3700

FAX: 301-577-2684
epilepsy.com

The Epilepsy Foundation is your unwavering ally on your journey with epilepsy and seizures. The Foundation is a community-based, family-led organization dedicated to improving the lives of all people impacted by seizures.



When does the new law go into effect?

The new law is effective on January 1, 2009. It will apply to acts of discrimination occurring on or after January 1, 2009.

How can I get help to fight discrimination?

Individuals experiencing discrimination based on epilepsy in employment, education and other areas can get legal help from the Epilepsy Foundation's Jeanne A. Carpenter Epilepsy Legal Defense Fund. The mission of the Fund is to work toward ending epilepsy-related discrimination and injustice through education, advocacy and increased access to legal services for individuals with epilepsy. The Fund provides legal guidance to individuals and their families, along with referrals to a nationwide network of cooperating attorneys, who can provide legal advice and representation. These attorneys have agreed to provide at least three hours of free legal help to persons referred by the Fund. Individuals may request legal help through the Fund's Web site, www.epilepsylegal.org, or by calling 1-800-332-1000 (select option 2).

8301 Professional Place East, Suite 200
Landover, MD 20785-2353

1-800-332-1000
301-459-3700

FAX: 301-577-2684
epilepsy.com

The Epilepsy Foundation is your unwavering ally on your journey with epilepsy and seizures.
The foundation is a community-based, family-led organization dedicated to improving the lives of all people impacted by seizures.

Appendix E

The Americans with Disabilities Act and Reasonable Accommodations

The Americans with Disabilities Act (ADA) was enacted to prohibit disability-based discrimination. Title I of the Act prohibits employment discrimination against qualified individuals with disabilities and applies to private employers with 15 or more employees. A "qualified individual" with a disability is one who is able to perform the essential functions of the job, with or without reasonable accommodation. The ADA equally protects all disabled individuals regardless of which state they live in.

An employer must make reasonable accommodation for a known disability unless to do so would impose an undue burden on the employer. Whether a particular accommodation imposes an "undue burden" depends on a variety of factors including

- Overall size of the employer
- Number of employees
- Number and types of facilities
- Budget size
- Nature and cost of the accommodation requested.

In addition, an employer is not required to make an accommodation that would fundamentally alter the job requirements.

Accommodation Categories

There are three separate categories of reasonable accommodations:

1. Modifications to job application process that enables disabled individuals to be considered for jobs
2. Accommodations on the job
3. Accommodations made to allow disabled individuals to enjoy equal benefits and privileges of employment.

What are reasonable accommodations?

Accommodations vary in form and should be individually tailored to suit the person's unique needs.

- Accommodations should be considered on a case-by-case basis with attention to the person's individual limitations or needs.
- There are no so-called "blanket accommodations" that would be appropriate for every individual with epilepsy or seizures. For example, an individual experiencing memory problems, due to side effects of certain medications, may request that specific instructions or directions be put in writing instead of given orally. For the person in the

Appendix E

process of changing medications, the possibility of breakthrough seizures may necessitate a request for flexible hours for a period of time as an accommodation or require a short break if a seizure occurs at work.

It is important to involve the person with epilepsy in the process of determining what accommodation might be needed.

The Equal Employment Opportunity Commission (EEOC), the federal agency in charge of enforcing title I of the ADA, "envisioned an interactive process that requires participation by both parties." While the employee is required to request an accommodation, the specific accommodation requested need not be the one that is specifically granted. Rather, the accommodation need only be "effective." In other words, the accommodation must ultimately meet the objective of permitting the employee to perform the "essential functions" of the position. It need not necessarily have to be the accommodation the employee "preferred."

In addition, the individual's treating physician can play an important and sometimes critical role in the accommodation process. Requests for accommodations will trigger legitimate inquiries by employers for supporting medical data. The job description may assist an employee's or applicant's physician in providing input. In general, courts have determined that employees who fail to provide to their employers *any* medical information regarding their request for reasonable accommodation are considered not to be participating in the "interactive process" intended by the law. However, the scope of the employer's inquiry should be limited and job-related. It is also expected that the medical data sought should support the requested accommodation, thereby establishing that the accommodation is medically indicated.

If an individual is having difficulties in performing job duties due to a disability, it is important for the employee to consider whether an accommodation should be sought. Employers are not responsible for providing accommodations where the disability is not known to the employer. Moreover, the employee experiencing difficulties in performing job duties will want to address the problem *prior* to the employer taking any type of adverse or disciplinary action related to job performance.

Tips for Staying Safe

Safety in the home:

- To give some privacy, place an occupied sign on the bathroom door instead of locking it.
- Hang the bathroom door so that it swings outward (into the hall or bedroom). This prevents the door from being blocked if a person falls during a seizure.
- Sing in the shower so people know you're okay.
- Take showers instead of baths.
- Make sure shower and bath drains work properly so water doesn't build up.
- Keep water temperature low to avoid burns.
- Use nonskid strips in tub or shower - everyone should use these!
- Use a shower curtain instead of a shower door, it's easier to get in and help someone if they fall in the shower.
- Use tub rails or grab bars.
- For people who fall during a seizure or have frequent seizures:
 - Use a shower chair or sit on bottom of tub and use hand held shower nozzle.
 - Take showers when someone else is in the house.
- Use an electric razor to avoid cuts.
- Use shatterproof glass for mirrors.
- Avoid glass tables.
- Avoid scatter rugs. Wall-to-wall carpeting or soft flooring may reduce injuries for individuals who fall.
- Use protective or padded covers on faucet handles, nozzles, or the edges of countertops to help cushion falls and reduce injuries.
- Use covers or enclosed heating units or radiators.
- Electrical equipment such as hair dryers or razors should be used away from any water source.
- Secure televisions, computers or other things that could fall off tables.

Appendix F

- Use fireplace screens at all times.
- Avoid clutter in rooms. Also, look around and make sure there is room to fall safely.
- Have an enclosed yard for children to play and prevent wandering during a seizure.
- Have a way to call for help if you are alone. Look into alarm systems, medic alerts and other safety devices!

Safety while sleeping:

- Remove sharp or potentially dangerous objects from near the bed.
- If there's a danger of falling out of bed, try sleeping on a futon, other low bed, or put a mattress on the floor. Pads can also be placed on the floor next to the bed.
- Limit the number of pillows used so they don't get in the way at night.
- Avoid sleeping on your stomach.
- Share a bedroom or have someone nearby who can help if a seizure occurs.
- Some people place a monitor in the room so a person can hear if a seizure occurs at night.
- Look into seizure alert or detection devices. They may be able to detect when a seizure occurs and alert someone, or call for help.

Safety while eating:

- Make sure that caregivers, friends, or family know basic first-aid such as the Heimlich maneuver to assist someone who is choking.
- Always eat sitting upright.
- Don't let a person eat, drink, or try to swallow pills right after a seizure. Make sure they can swallow first.
- Use chairs with arm-rests to prevent falls.
- Use nonskid surfaces under plates and cups to avoid spills.
- Use a bowl or scoop dish if coordination is a problem.
- Use a cup with a lid and spout (i.e. commuter cup) for hot liquids.

Appendix F

Safety at work:

- Use the elevator instead of stairs.
- Only climb to heights that would not cause injury if a seizure occurred.
- If seizures are not controlled, talk to your doctor or nurse about how seizures should be handled at work.
- Develop a plan for seizure first aid with your employer and involve relevant co-workers (who may be present when seizures occur). Make sure this plan includes when to call for emergency care.

Safety while exercising:

- For those who have uncontrolled seizures, use a buddy system, especially when using equipment such as weights or bike riding.
- When riding a bike, avoid busy streets. Try bike paths or quiet residential streets instead. Don't forget the helmet!
- Walking is even easier and doesn't cost anything. Use the same ideas – avoid busy streets and walk with a buddy.
- Avoid using a treadmill alone because falling can lead to major injuries. It's better to run outside or on a track.
- Start small and don't tackle long periods of exercise right away!
- Take frequent breaks and drink plenty of fluids.
- If you tire easily, exercise in small amounts. Even 15 to 20 minutes at a time helps!
- Always wear a medic alert bracelet or necklace and carry a medic alert card!
- Look at seizure alert systems that are being developed. Using one with GPS locator is a great idea in case you have a seizure and need help.
- A cell phone with GPS locator can help people find you too! Program emergency numbers and key family members or contacts into your phone!
- Wear the right protective gear for each sport.
- Always have a buddy with swimming or water sports.
- At least one person in the activity or observing it should be aware of the possibility of seizures and know basic life-saving techniques.
- Always wear a high-quality, properly fitted life vest when near the water.

Appendix G

SAMPLE Plan of Action.

Consider using this as guidance on how to write a plan of action.

Disability and/or Limitation(s): Epilepsy (simple partial seizures)

Warning Signs for Oncoming Seizure:

- a. John will experience nausea.
- b. John's face or shoulder/arm will jerk involuntarily.
- c. Warning signs give John 3-4 minute before seizure activity begins.
- d. John will signal designated co-worker using 2-way radio (with texting) to inform of oncoming seizure.

Action Plan:

- a. Using his hand or arm, gently lead John to designated safe area.
- b. If necessary, help John into a seated or lying position.
- c. If necessary, loosen any restrictive clothing around the neck (such as a tie or scarf).
- d. During seizure (which lasts from 2 - 5 minutes), John will not need medical attention.
- e. When seizure subsides, offer John a cool cloth for his face or a cool drink.
- f. If John is disoriented, identify yourself and identify his location/surroundings. Let him know what happened.

Additional Comments:

- a. Two designated co-workers will carry radios to hear John's emergency signal.
- b. Supervisor will call John's emergency contact person.
- c. Based upon John's documentation provided by his neurologist, ambulance/medical attention is not required unless John falls or hits his head.

This form may NOT be kept in an employee's personnel file. It must be kept in the employee's confidential medical file.

Appendix H

Self-Management Forms, Tools, and Assessments

Form	Link
Observing Seizures	
Tips for Seizure Observation Recording	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/medicineschedule_0.pdf
Seizure Description Form	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/Seizure-Description-Form-English-Spanish_0.pdf
Seizure Recording/Diaries	
Instructions for Using Seizure Calendar	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/instructions_using_seizure_calendar.pdf
Seizure Calendar	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/seizure_calendar.pdf
My Seizure Event Diary	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/event_calendar_0.pdf
Adult Medication Records	http://www.epilepsy.com/sites/core/files/atoms/files/nomoreseizures.org_adult_meds_record.pdf
Seizure Response Forms	
My Seizure Plan	http://www.epilepsy.com/sites/core/files/atoms/files/myseizureplan.pdf
Seizure Action Plan	http://www.epilepsy.com/sites/core/files/atoms/files/seizure-action-plan-pdf_0.pdf
Seizure First Aid	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/SeizureFirstAid_Page1.pdf http://www.epilepsy.com/sites/core/files/atoms/files/seizure%20first%20aid%20spanish.pdf
Medication Records	
Medicine Schedule	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/medicineschedule_0.pdf
Pharmacist Letter	http://www.epilepsy.com/sites/core/files/atoms/files/nomoreseizures.org_pharma_letter-1.pdf

Appendix H

Form	Link
Communication Tools	
My Healthcare Contacts	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/myhealthcarecontacts_0.pdf
Questions for my Team	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/questionsformyteam.pdf
Doctor Visit Notes	http://www.epilepsy.com/sites/core/files/atoms/files/-8-Doctor-s-Visit-Notes-Epilepsy-Parent-Notebook_English.pdf
My To Do List	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/mytodolist.pdf
Lifestyle and Safety	
Lifestyle Modification Tips	http://epilepsy.prod.acquia-sites.com/sites/core/files/atoms/files/Lifestyle_modification_tips.pdf
Online Tool/App	
WebEase	http://www.webease.org/
Seizure First Aide App	http://www.epilepsyfoundationmn.org/app
Epilepsy Foundation My Seizure Diary (online tool)	https://diary.epilepsy.com/login
Programs	
Managing Epilepsy Well (MEW) Network	https://managingepilepsywell.org/programs/index.html
Assessment/Screening Tool	
Adult Epilepsy Self-Management Instrument (AESMMI-65)	https://managingepilepsywell.org/documents/instruments/AESMMI%2065.pdf
Patient Health Questionnaire-9 (PHQ-9)	http://www.phqscreeners.com/sites/g/files/g10016261/f/201412/PHQ-9_English.pdf
Generalized Anxiety Disorder 7-item (GAD-7) scale	https://www.integration.samhsa.gov/clinical-practice/GAD708.19.08Cartwright.pdf
Neurological Disorders Depression Inventory for Epilepsy (NDDI-E)	http://www.sciencedirect.com/science/article/pii/S1059131109000661



Patient Assistance Programs

A number of drug companies have patient assistance programs and independent websites to help individual's access specific medications.

These programs offer certain medications at a discount or for free to people who cannot afford them. All major drug companies have patient assistance programs.

The Epilepsy Foundation provides these details for informational purposes only. These programs are not run by the Foundation.

Please contact the manufacturer of your epilepsy medication if you don't see it listed.

Questions or
need assistance?
Please call:

Epilepsy & Seizures
24/7 Helpline

800.332.1000
contactus@efa.org

epilepsy.com

AbbVie Patient Assistance Foundation

www.DepakoteER.com or
www.abbviepaf.org

(800) 222-6885

Medications covered: Depakote and Depakote ER

Eisai Fycompa Patient Assistance Program

www.eisaireimbursement.com

(855) 347-2448

Medication covered: Fycompa

GlaxoSmithKline Bridges to Access

www.BridgesToAccess.com

(866) 728-4368

Medications covered: Lamictal, Lamictal XR and Potiga

Johnson & Johnson Patient Assistance Foundation

www.JJPAF.org

(800) 652-6227

Medication covered: Topamax

Lundbeck

Onfi Support Center

www.ONFI.com

(855) 345-6634

Medication covered: Onfi

Lundbeck's SHARE Call Center

www.sabril.net

(888) 457-4273

Medication covered: Sabril

Meda Patient Assistance Program

www.felbatol.com

(800) 593-7923

Medication covered: Felbatol

Novartis Patient Assistance Foundation

www.patientassistanceNOW.com

(800) 277-2254

Medications covered: Tegretol, Tegretol XR and Trileptal

Superus Pharmaceuticals Patient Assistance Program

www.oxtellarxr.com and

www.trokendixr.com

(866) 398-0833

Medication covered: Oxtellar XR and Trokendi XR

Pfizer RxPathways

www.PfizerRxPathways.com

(866) 706-2400

Medications covered: Celontin, Dilantin, Lyrica, Neurontin and Zarontin

Questcor Pharmaceuticals

Acthar Support & Access Program (A.S.A.P.)

www.acthar.com

(888) 435-2284

Medication covered: Acthar Gel (ACTH)

Recordati Rare Diseases

Reimbursement Hotline

www.needymeds.org

(866) 209-7604

Medications covered: Peganone

Shire Cares Patient Assistance & Support

www.rxassist.org

(888) 227-3755

Medication covered: Carbatrol

Sunovion Support

Prescription Assistance Program

www.Aptiom.com/sunovion-answers

(844) 427-8466

Medication covered: Aptiom

Teva Cares Foundation Patient Assistance Program

www.tevacares.org

(877) 237-4881

Medication covered: Gabitril

UCB Patient Assistance Program

www.rxassist.org

(866) 395-8366

Medications covered: Keppra, Keppra XR, Vimpat

Upsher-Smith Laboratories

Qudexy XR Patient Savings & Support Program

www.SaveOnQudexyXR.com; (800) 657-7613

Medication covered: Qudexy XR

Valeant Patient Assistance Program

www.rxassist.org

(800) 511-2120 or (866) 268-7325

Medications covered: Diastat AcuDia and Mysoline

VNS Therapy Access Program

www.cyberonics.com

(877) 610-1180

353PMA Rev. 01/2016