Epilepsy is a treatable medical condition!

The development of this material has been possible thanks to subsidy from the CDC (Centers for Disease Control and Prevention) # 1U58 DP000606-01.
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Introduction

In August of 2006, we formally initiated Epilepsy training for Community Health Workers, PROMOTERS. Our meeting point was San Diego, California, and the reason, the best of the reasons for the Promoters, “The Ninth Annual National Conference of CHWNNA” (Community Health Workers National Network Association). During the epilepsy session, the Promoters in attendance received the best and clearest information possible that can be provided in 8 hours, as well as exceptional support materials created and produced by the Epilepsy Foundation, in collaboration with important professionals in medicine and education.

Subsequently, in November of 2006, our meeting point with another wonderful group of Promoters was Albuquerque, New Mexico, where we participated in the “16th Annual Midwest Stream Farmworker Health Forum”, organized by the National Center for Farmworker Health (NCFH). Again, those in attendance received important information during the 4-hour training, and as in San Diego, high quality support materials.

At the Epilepsy Foundation, we are grateful and we feel proud to work with CHWNNA and the NCFH. These organizations, and above all, their human resources, have literally stolen the respect and commitment of our organization, not only to continue participating in their national events, but to educate and update their Promoters in the ever fascinating field of epilepsy.

Talking about epilepsy is not easy, and the myths and misinterpretations that for generations have been created around it make it more difficult for those who have epilepsy to come out of the shadows. Nevertheless, it is vital for us to combine our efforts to tell the Hispanic community that epilepsy is a treatable medical condition, that is not contagious, that is not the result of possession by the devil or payment for sins.

At the Foundation, we have wanted to develop this curriculum, because we recognize the importance of the Promoters’ daily work. We have entrusted to Martha Londoño the task of translating this subject into simple material that is easy to understand and share. Martha has created material that goes beyond our expectations and doubtless will attract your attention and commitment.

Promoter Friend, with your help, we can impact the lives of the 400,000 Hispanics with epilepsy in the United States and their families. Remember... anyone, at any time, anywhere... Epilepsy is more common than you think.
Credits

The start of this curriculum was the HOPE (Helping Other People with Epilepsy) Mentors Program, whereby people with epilepsy have educated family, friends, and members of their communities about their condition. The HOPE program mentors have shared their own experiences, giving HOPE to other people with epilepsy who have probably experienced loneliness, fear, rejection, and misunderstanding living with this condition.

Then the Epilepsy Foundation Arizona developed an initial curriculum for Promoters under the Promising Strategies Program, sponsored by the CDC during 2005 and 2006.

Mary Macleish, Laura Linam and Dr. Joe Sirven, were unstinting in their commitment and professionalism in carrying out this project and its final material. As expected, it was a basic piece for Martha Londoño, who, with the support of health professionals, members of the Hispanic Council of the Foundation, and other executives, combined the initial resources in the best way, and added her educational and professional experience to create this important material.

The Epilepsy Foundation of San Diego County, with its “champion”, Healy Vigderson, has also played an important role in our project with Promoters. Healy was the first person who coordinated a training with Promoters, and also the best spokesperson for her cause.

Organizations such as CHWNNA and NCFH also deserve to be mentioned in this section. Without them, our “meeting moments” with Promoters would be practically fruitless.

The materials that you will receive today are not perfect pieces and do not contain the absolute truth about epilepsy. Your comments and suggestions are very valuable for the ongoing improvement of these working tools. Do not hesitate to let us know how we can make our materials masterpieces, and rest assured that your contributions will allow you to shine in our next credits.

August, 2007

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Acknowledgments

The Epilepsy Foundation thanks the CDC – Centers for Disease Control and Prevention for its sponsorship in the development of this curriculum.

Moreover, we thank Medtronic Foundation and Quest Diagnostics for their support during the different stages of the Hispanic Community Outreach Initiative.

The various working teams of the National Office and the 54 branches around the United States, as well as member of the Hispanic Council of the Foundation also played an important role in conceiving and developing this material.

Thank you to Martha Londoño for her professional commitment, for the love whereby she joined the pieces of material that at the beginning seemed like a puzzle, to form a curriculum where the academic is combined with the human and the Hispanic.

We would also like to thank Dr. Jose Gonzalez, the Medical Director of the Epilepsy Foundation of Florida, who reviewed this material and contributed his invaluable experience of over 15 years with the Foundation.

Lastly, thank you to the team of Promoters and to all those Providers of health information and services for Hispanics in urban and rural communities; this material will offer them the guidance they need and will allow them to impact the lives of thousands of people with epilepsy and their families.
Introduction

Do you know someone who has epilepsy? You probably do. Epilepsy is more common than most people think.

Epilepsy is a treatable medical condition that can happen to anyone anywhere at any time. In fact, one in ten persons will have convulsions during their lifetime, and one in every 100 people in the United States, including one in every 100 Hispanics, has epilepsy.

But despite how common epilepsy is, many people have mistaken and even harmful ideas about this condition and its seizures. It is important to know the truth about epilepsy to make sure that people who have it receive the treatment and respect that they need and deserve.

Justification

The Epilepsy Foundation works to ensure that every person who has epilepsy may participate in all life experiences. The development of this educational strategy is a commitment of the Foundation to carry its message to the Hispanic community.

“For many years, I tried to hide [the epilepsy] from everyone, thinking that I would be judged... they would erase me from their list of friends. Gradually I learned that people aren't like that... it has opened a number of doors to me that I had previously closed by myself.”

Brainstorm: Epilepsy in our own words

Goal

With this curriculum, we hope to increase the information and education of the Hispanic community and to reduce fears and myths about epilepsy and its treatments.

Objectives

At the end of the training, the participants will be able to:

1. Describe the difference between a seizure (or convulsion) and epilepsy
2. Demonstrate an ability to overcome fear and the myths that the Hispanic community has about epilepsy
3. Demonstrate a commitment to help people with epilepsy to lead active and productive lives
4. Recognize the factors that trigger seizures
5. Identify the main symptoms of epilepsy
6. Give first aid to persons having an epileptic seizure
7. Recognize the main types of treatment
8. Recognize the main social effects of epilepsy

For whom is this curriculum intended?

For health Promoters, community health educators, persons with epilepsy, their families and friends, and anyone who wants to help people with epilepsy.

Methodology

Although the subject is complicated, the curriculum is written in an easily understandable language. In this material, questions are used as a resource for involving the participants and using one’s experiences, also using technical and scientific research content.

Instructions for managing curriculum

The curriculum is designed in two columns: the right column provides notes and instructions for the Promoter; the left column, for its part, has the content and the slides.

The content has been written in short paragraphs that contain all the information necessary so that each of the points developed can be explained.

When it is necessary to emphasize a given point, it is highlighted as Important; so that the Promoter can reinforce this concept.

The slides are a summary of the content, also used to reinforce learning and in turn allow easy management for the Promoter.

Time to perform the activities

In order to uniformly handle all the activities, it has been determined that each activity will take 5 minutes; in any event it is flexible and one should take into account the number of participants and their characteristics in order to expand or not expand the assigned time, as well as to define which modules of the curriculum should be presented.
Content

- Beginning
- A Story
- Overview
  - What epilepsy is NOT
  - People with epilepsy can...
  - Introduction
  - Who has epilepsy?
  - Groups at higher risk of developing epilepsy
  - The difference between epilepsy and seizures
- The Human Brain
  - The brain and its functions
  - The nervous system
  - Epilepsy and the brain
  - What causes epilepsy?
  - Cysticercosis
  - Cysticercosis and epilepsy
  - Prevalence of cysticercosis worldwide
- Classification of epilepsy, symptoms and first aid
  - Criteria used to classify epilepsy
  - Classification of epileptic seizures
  - Symptoms that may indicate a partial seizure
  - Symptoms that may indicate a generalized seizure
  - Factors that trigger seizures
  - First aid for a partial seizure
  - First aid for a generalized seizure
  - These things are dangerous when a person is having a seizure
  - Call 911 or emergency medical services...
- Diagnosis and treatment of epilepsy
  - What should you tell your doctor about your seizures?
  - How is epilepsy diagnosed?
  - Treatment for epilepsy
  - What factors influence the decision to treat?
  - Types of treatments for epilepsy:
    - Treatment with medications
    - Treatment with surgery
    - Treatment through Vagus nerve stimulation
    - Treatment with the Ketogenic diet
  - The relationship between the medical staff and the person with epilepsy
- How is epilepsy perceived?
  - What do you know about epilepsy?
  - What do you think are the causes of epilepsy?
  - Do you agree with the treatment?
  - Myths and beliefs about epilepsy
- The impact of epilepsy
  - A spectrum of severity
  - Social aspects of epilepsy
  - Fear and ways to overcome it
  - Emotions: Depression
- The financial impact
- Whom should you tell?
- Employment and epilepsy
- Driving
- Safety tips
- Utilizing resources

- Epilepsy and Children
  - Education
  - Developing a relationship with the school
  - Information you should provide regarding your child’s epilepsy
  - Education: resources for parents

- Epilepsy and women
  - Reproductive health aspects
  - Conception and contraception
  - Pregnancy and epilepsy
  - Parents and newborns

- Epilepsy and the elderly
  - Epileptic seizures in later life: causes
  - Complex partial seizures
  - Is it a seizure or not?
  - Social aspects

- And, finally, be aware of...
  - National and local resources
  - For more information

Supporting educational material

At the end of the curriculum you will find a package containing a wide range of our Spanish materials. You will also find a request form to be sent to our national office in case you need to order more copies. In order to reduce the shipment cost, we suggest placing joint orders together with other Promoters.

Here is a review of the materials:

**Short Story, “Beyond the Storm”**
This is the story of 4 people with different types of epilepsy. Each character shows the challenges that he/she has to face day after day as well as his/her treatment option. This material provides important
information about Epilepsy and has been most welcome by the community in general. It is available in English and in Spanish. English-speaking Hispanic children prefer the material in English, while Hispanic adults prefer the Spanish version. It can be used as basic training material for volunteers, people with Epilepsy, family and friends.

**Bilingual Brochure (English – Spanish), “The Truth about Epilepsy”**

This brochure offers suitable information to help clarify myths and misinterpretations associated with epilepsy. It also provides basic statistical information related to this condition. Since this brochure contains information both in English and in Spanish, it may be distributed among people who feel comfortable reading in any of these languages. Additionally, it may be distributed in schools and workplaces for the purposes of educating employees about this condition.

**Brochure, “Epilepsy is more common than you think”**

This material is available only in Spanish and uses the same characters as those appearing in the “Beyond the Storm” short story. It is very easy to read and may be distributed to any audience, especially among people with a low level of education.

**First Aid Wallet/ Pocket Card**

This card is bilingual and contains excellent information on first aid for tonic-clonic seizures. This is an excellent material to be distributed at health fairs, conferences, etc.
**Bookmarks**
These two bookmarks provide first aid information. While one addresses tonic-clonic seizures the other one addresses partial seizures. They both explain the most common symptoms associated with such seizures and what the person offering help should do. These materials are the Spanish version of the already known English bookmarks. Just like the pocket cards, these bookmarks may be distributed at mass events.

**Information Sheet, “Epilepsy; Get to know it”**
This material contains general information about Epilepsy and may be distributed in any type of events.

**Information Sheet about Epilepsy in the Latin Community “Epilepsy and the Latino Community”**
Even though this material is in English, it provides important information for non-Hispanics working with Hispanics. It may be distributed at doctors’ offices, to nurses, teachers, among others.
Brochures in Spanish (10 brochures)
These brochures contain detailed information about epilepsy in different scenarios. They should only be distributed among people who have already been diagnosed with Epilepsy, their families, health professionals, medical interpreters and other members of the patient’s healthcare team. This material is not to be distributed massively or at health fairs, unless the person taking it has epilepsy or knows someone close who has such condition.

Important Information

Even though we are sure that as a Promoter you will provide the best information about epilepsy to the members of your community, we would like to emphasize the following aspects:

- Make it clear, before each presentation, that you are not a medical professional, neurologist or Epilepsy Foundation representative.

- That the information you will provide is not a diagnosis or treatment and that if any person in the audience has epilepsy or knows someone who has epilepsy, he or she may not alter his or her treatment based on your presentation.

- That epilepsy is diagnosed after performing a series of tests and evaluations on the patient. A person who believes he or she has a symptom may not self-diagnose as a person with epilepsy.

- Any person who has had epilepsy symptoms must consult a doctor for evaluation and treatment.
# 5 Minutes

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<tr>
<th><strong>Notes / Instructions</strong></th>
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<tbody>
<tr>
<td>Greet the audience ...</td>
<td>Welcome the audience with music ...</td>
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<tr>
<td>Present slide 1</td>
<td><img src="image" alt="Epilepsy is more common than you think!" /></td>
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</table>

Introduce yourself, welcome and thank everybody for attending.

Good morning / good afternoon / good evening. My name is ___________ and I’m a Promoter / volunteer / or I work for the Epilepsy Foundation.

Welcome and thanks for participating!

I am here today to share with you basic information about epilepsy or, how some prefer to call it, seizure disorders, and in this way help you better understand the impact that epilepsy has on the lives of those who have it and their families.

Before beginning, on behalf of the Epilepsy Foundation, I would like to thank the organization that has made this training possible, the CDC.

# Thank You For Your Support

The Epilepsy Foundation wishes to acknowledge the support of the Centers for Disease Control and Prevention (CDC) during the development of this project.

400,000 Thanks to CDC
### Notes / Instructions

**5 Minutes**

Tell your personal experience with epilepsy if you have it, and if not, continue...

Ask:
If no one answers, tell Claudia’s story. Present slides 3, 4, 5

---

**5 Minutes**

Read the first slide about Claudia’s story...

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**Claudia’s Story**

“Once my seizure is over and I’ve regained consciousness, I can see the fear on the faces of the people around.”

Claudia Ochoa is one of the 400,000 Hispanics with epilepsy in the United States, and one of the 3 million people with epilepsy throughout the country.

It has not been easy for Claudia to live with epilepsy, but her desire to lead a normal life has motivated her. Her drive and discipline allowed her to attend the Engineering School at the Autonomous University of Tamaulipas, in Tampico (Mexico), where she earned a degree as an Industrial and Systems Engineer in 1998.

---

Seventeen years ago, Claudia was a young girl like any other girl, but at the onset of puberty, her life “literally changed.” Not only because of all the changes that normally occur during this period in life, but also because it was when Claudia suffered her first epileptic seizure.

Claudia has always had her family's unconditional support. However, she realizes that some people treat her differently after witnessing one of her seizures or, simply, upon learning that she has epilepsy.

“I understand that people often look at me in a different way because they do not know what is really happening with me, because they think that what I have is contagious, or simply because my seizures scare them.”
Claudia’s Story

Claudia has lived in the United States for 5 years now, is studying English and works at a printer shop.

Her main wish is to become fully bilingual and further her studies.

After suffering an epileptic seizure in June, 2004, Claudia went to the local Epilepsy Foundation office for help. There, Claudia found more than help; she also found understanding and the opportunity to work with them “for her cause.”

Currently, Claudia is a spokeswoman for the Foundation by helping to educate her local Hispanic community on epilepsy.

What Epilepsy is Not:

- NOT contagious
- NOT punishment for sins, lack of faith, or demonic possession.
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<td>Continue by saying...</td>
<td>People with epilepsy can...........indicate the different activities on the slide, and ask the participants to share their experiences, don't take too long, because later on each of these situations will be explained.</td>
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5 Minutes Introduction

Present slide 9...

**Introduction**

- Many people have misconceptions and fears about the convulsive episodes called seizures and epilepsy.
- It is important to understand the truth about epilepsy, to ensure that people with this condition receive the proper treatment and the respect they need and deserve.
- Epilepsy can be a serious condition if it is not treated properly.

Continue with slide 10...

**Introduction**

- Through treatment and understanding, people with epilepsy are capable of living their lives without major problems.
- For other people, epilepsy may affect almost any aspect of their lives, interfering with their ability to hold a job and carry out their daily activities.
- If you or someone you know has epilepsy, please take advantage of this session to learn more about epilepsy and be able to share this information with others.
Why am I here? The reason I’m here today is because I believe that good medical care is based on a partnership between the doctor, the patient and his/her family, all of whom of course need to be well-informed.

My goal is to help you learn more about this condition and encourage you to discuss the options that may be helpful for you.

As we develop the subject, please ask any questions that may clarify the various subjects discussed.

5 Minutes
Who has epilepsy?

Continue...

There are many people in the United States who have epilepsy, and remember: in each of the countries where we are from it is also a big problem.

Present slide 11

The most important thing for people with epilepsy to know is that they are not alone and that advances in medical science have made various medical treatment options available.

Who Has Epilepsy?

- Around 3 million people in the United States have epilepsy and 400,000 of them are Hispanic
- Also, 180,000 new cases of seizures and epilepsy are diagnosed every year
- 50% of all persons with epilepsy have seizures before they turn 25; however, anyone can develop epilepsy at any time
- Currently, there are as many people over 60 with epilepsy as there are children under 10 with epilepsy

It is surprising to learn that so many people have epilepsy.

The incidence of epilepsy is higher among older people and this is mainly related to their greater incidence of cardiovascular disease, Alzheimer’s disease, stroke and brain tumors.

5 Minutes
Who is at risk?

Continue...

It is estimated that epilepsy may develop in:

* 10% of children with mental retardation or autism
* 1 in 3 children with cerebral palsy
* 50% of children with cerebral palsy and mental retardation
* 10% of patients with Alzheimer’s disease
* 22% of patients who have had a stroke
In short, the groups that are at greater risk are:

- Approximately 1% of the general population has epilepsy
- The risk is greater in people who already have certain medical conditions:
  - Mental retardation
  - Cerebral Palsy
  - Alzheimer’s disease
  - Stroke
  - Autism

Let us look at where epilepsy comes from...

**Remembering a bit of history.** Epilepsy was one of the first brain disorders described over 3,000 years ago.

The behavior caused by some types of seizures has throughout history created many superstitions and prejudices. People came to believe that they were people possessed by demons or gods. Nevertheless, Hippocrates, a physician in ancient times, indicated that it was a brain disorder, and now we know that this is true.

In order to understand epilepsy, it is important to know the difference between epilepsy and seizures.

**Who would like to explain what epilepsy is?** Now, What is a convulsion?

**The word epilepsy** is derived from a Greek term that means “seizure”.

**Epilepsy** is a generic term used to define a variety of disorders characterized by recurring seizures.

A diagnosis of epilepsy means that a person has an underlying condition, such as a brain injury, affecting the delicate systems that control the way electrical energy behaves in the brain, making it susceptible to recurring seizures.

**A seizure - or convulsion -** is a brief, temporary disturbance in the electrical activity of the brain.

Seizures are a **symptom** of epilepsy. However, having a seizure does not necessarily mean that a person has epilepsy.
There are other causes such as high fever, kidney failure and lack of oxygen.

### The difference between epilepsy and seizures

- **Epilepsy** is a medical condition characterized by recurrent seizures (which means that they occur more than once). Epilepsy is also known as “seizure disorder.”

- A **Seizure** is a brief, temporary disturbance in the brain’s electrical activity.

  _A seizure is a symptom of epilepsy_

### Important:

- Epilepsy is not contagious. One cannot get epilepsy through contact with people who have epilepsy.
- There are many misconceptions with regard to epilepsy and sometimes people unintentionally contribute to the negative image of this disorder by using certain language.
- Like all individuals with a disability, people who have epilepsy do not like to be labeled, for example, “he is epileptic”.
- The preferred terminology is a “person with epilepsy”.

**Epilepsy is a condition that a person has**

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<td>In order to understand the way epilepsy originates, we should briefly examine the way the brain normally functions.</td>
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### The Human Brain
All of the brain’s functions, including our feelings, vision, thoughts, and all our muscle movements depend upon the electrical signals that nerve cells in the brain send to each other.

The brain consists of millions of nerve cells, called neurons, and their supporting structures. Each neuron can receive electrical signals from other neurons and pass them on to others.

This is the brain, and it is divided into several parts; giving or receiving orders is done through neurons.

The neuron is the cell of the nervous system, and each cell is connected to another, and they form groups to perform the various functions of the body.

What phenomenon in nature is similar to epilepsy?

Lightening flashes......electrical discharge......electrical storm
Epilepsy and the Brain

An epileptic seizure occurs when too many neurons “trigger” electrical signals too fast, thus causing an “electrical storm.”

The normal brain is constantly generating electrical signals in an orderly way. In epilepsy, this order is altered by some neurons that discharge the signals inappropriately.

**But how can this happen?**

A brief “electrical storm” can arise from:

- Neurons that are in themselves unstable due to a genetic defect (like in the various types of hereditary epilepsy).
- Neurons that became unstable due to metabolic abnormalities, for example, low blood sugar concentrations or the presence of alcohol.
- Also, the abnormal discharge may come from a specific part of the brain, as in the case of epilepsy caused by a head trauma or a brain tumor.

5 Minutes Causes of Epilepsy

Does anyone know what the causes of epilepsy are?

Most people with epilepsy wonder what caused their disorder.

In 7 out of 10 people with epilepsy, no specific cause can be found. Among the rest, the cause may be any one of a number of things that may affect the way in which the brain works, such as:

1. Head trauma that occur for numerous reasons, among them:
   - Automobile accidents
   - Firearm wounds
   - Sports accidents
   - Falls or blows.

   The more serious the injury, the greater the risk that epilepsy will occur.
   - Lead and alcohol are examples of toxins that may harm the brain. In fact, every year, more than 5,000 people have a seizure caused by alcoholism.
2. A number of serious infections and causes of inflammation may lead to brain injury, including:
   - Meningitis
   - Viral encephalitis
   - Lupus erythematosus

3. The brain of a fetus may not develop properly during pregnancy, or a lack of oxygen during birth may damage the delicate electrical systems within the brain.

4. Lastly, heredity also plays its role. People may inherit varying degrees of a predisposition for seizures. When no other specific cause of seizures can be identified, it is assumed that this is the most probable cause.

5. In people of advanced age, epilepsy may be owing to a stroke, Alzheimer's disease, or other head traumas.

Epilepsy is a disorder that may have many possible causes, anything that disturbs the normal pattern of the neurons activity.

**Important:** Since the cause is unknown in so many people with epilepsy.  
✓ We need to remember that the most important aspect is **how to live well with a seizure disorder.**  
✓ We need to focus on the best way to control the seizures.  
✓ We need to learn how to cope with the issues that having a seizure disorder creates.  
✓ We need to help people with epilepsy, by spreading and educating our communities about this condition.

Present slide 18
And add... in short...

**What Causes Epilepsy?**

- In approximately 70% of all cases, the cause of the epilepsy is unknown.

- In the remaining 30%, the most common causes are:
  - Head trauma
  - Infection of the brain tissue
  - Brain tumor and stroke
  - Heredity
  - Lead poisoning
  - Prenatal brain development problems
As we have seen, one of the causes of epilepsy is infections; let’s look at what cysticercosis is and the role it plays in epilepsy.

Does anyone know what cysticercosis is?

When a person eats pork that has not been well cooked or that has not been raised under proper hygienic conditions, it is very likely that he will get from this meat the eggs of the tenia or tapeworm.

The tenia is a parasite that, when it enters the organism of a person, forms a series of blisters or cysts full of larva that reproduce and which through circulation lodge in the intestine and move to the lungs, eyes, and brain.

When these blisters reach the brain, cysticercosis occurs, and this harm to the brain may cause seizures or convulsions.

**Important:** the larva of the tapeworm may be transmitted from one person to another.

How are the tapeworm larva transmitted to another person?

1. The person who has the tapeworm in his organism eliminates its larva through fecal matter.
2. If this person has poor hygienic habits, like going to the bathroom and not washing his hands, he is likely to have larva on his hands.
3. When preparing food, this person contaminates it with the larva and passes it to others through food.

This is the cycle of the cysticercosis......

A person ingests the eggs or larva through pork. These eggs and larva go through an embryonic and multiplication stage to become cysts, through circulation they attach to the intestine and go to the lungs, brain, and eyes.

It is important to note that some eggs leave the body through fecal
matter, which, in inappropriate hygienic situations, constitutes a danger to others.

Present slide 20 and continue...

in short...

Cysticercosis and Epilepsy

- Cysticercosis is a common cause of epilepsy among first-generation Mexican-Americans.
- It can also occur in members of the second and third generations who live in contact with people who have recently arrived in this country.
- 10% of all persons admitted to the neurology department in Los Angeles County, California, are admitted due to Cysticercosis.

Present slide 21

5 Minutes Cysticercosis in the World

Remark...

The presence of Cysticercosis in the world is concentrated in Mexico, Central America, South America, Central and Southern Africa, and a large part of Asia. Cysticercosis is a worldwide problem, which develops particularly in poor countries.
The classification of epilepsy includes more than the type of seizure and there are some criteria that should be taken into account.

- The type of seizure
- EEG (electroencephalogram) results
- Clinical characteristics such as:
  - Behavior during the seizure
  - Expected course of the disorder
  - Triggering events
  - Expected reaction to treatment
  - Genetic characteristics.

Physicians have described over 30 types of epileptic seizures, grouped into two main categories; but within each category, there are many types of seizures.
Inform...

- Partial seizures, also called focal seizures, occur only in one part of the brain.
- Around 60% of people with epilepsy have partial seizures.
- Generalized seizures are caused by the activity of abnormal neurons on both sides of the brain.
- A person with epilepsy may have more than one type of seizures.
- The type of seizure depends on the part of the brain that is affected by the sudden electrical discharge, and on its intensity.
- Partial seizures are the most common type of seizures experienced by people with epilepsy.
- Seizures that start early in life may change into different types as the child grows older.
- If a relative or the person who cares for a person with epilepsy notes new patterns in the seizures, he/she should inform the physician, this may help determine the most effective medication and provide a more accurate picture of how the condition is progressing.

Continue...

Just as there are many different types of seizures, there are also many types of epilepsy. Your doctor will tell you which type of epilepsy you have.

### 5 Minutes

**Symptoms of Epilepsy**

**What are the symptoms of epilepsy?**

A seizure is a massive disruption of the electrical communication among neurons. If enough neurons are involved, the electrical impulses discharge will cause symptoms. The result may be any number of different sensations or behaviors, such as sudden muscle jerk, an abrupt fall, or vision disorders.

The symptoms depend on the type of seizure the person has, that is, partial or generalized.
Only a doctor can determine for certain whether a person has epilepsy or not. But many people are not able to detect the more subtle signs of the condition and, therefore, miss the opportunity for early diagnosis and treatment.

**Symptoms that May Indicate a Partial Seizure**

- Wandering
- Clumsiness
- Difficulty speaking
- Trembling
- Staring into space
- Chewing

**Symptoms that May Indicate a Generalized Seizure**

- Sudden moan or cry
- Falling to the ground
- Rigidity
- Shallow breathing
- Muscle spasms
- Loss of consciousness

The symptoms mentioned on the slides are not necessarily indicators of epilepsy, but are the most recognized ones. These symptoms may be caused by another unrelated condition. However, if one or more of these symptoms are present, a medical evaluation is recommended.

Early detection of epilepsy and taking steps to control the seizures, can often help minimize the impact of this condition.
<table>
<thead>
<tr>
<th>5 Minutes</th>
<th>Content</th>
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<tbody>
<tr>
<td>Ask...</td>
<td>Have any of you identified activities or substances that seem to trigger the seizures?</td>
</tr>
<tr>
<td>Wait for answers</td>
<td><strong>Important:</strong> 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.</td>
</tr>
<tr>
<td>Add...</td>
<td><strong>Note:</strong> 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.</td>
</tr>
<tr>
<td>Remark...</td>
<td>Other possible triggers include:</td>
</tr>
<tr>
<td></td>
<td>- Stress/anxiety</td>
</tr>
<tr>
<td></td>
<td>- Exertion or fatigue, or dehydration</td>
</tr>
<tr>
<td></td>
<td>- Lack of sleep/ time to sleep</td>
</tr>
<tr>
<td></td>
<td>- Hormonal cycles in women</td>
</tr>
<tr>
<td></td>
<td>- Some individuals have photosensitive epilepsy. If so, flashing lights or alternating shade/sun may trigger seizures</td>
</tr>
<tr>
<td></td>
<td>- The use of alcohol should be discussed with the doctor</td>
</tr>
<tr>
<td></td>
<td>- The use of illegal drugs should be avoided</td>
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<tr>
<td></td>
<td>- Even some over-the-counter medicines should be avoided when taking epilepsy medication, unless under the advice of a doctor.</td>
</tr>
<tr>
<td></td>
<td>- Electronic games.</td>
</tr>
<tr>
<td>Present slide 23</td>
<td></td>
</tr>
<tr>
<td>In short...</td>
<td>- Just as with the causes of epilepsy, the triggers are often unknown or nonexistent.</td>
</tr>
<tr>
<td></td>
<td>- It is important that children and adults with epilepsy not be blamed for having a seizure</td>
</tr>
<tr>
<td></td>
<td>- Nor should they be prevented from taking part in a full range of activities unless they or their parents or their doctors request accommodations.</td>
</tr>
</tbody>
</table>
5 Minutes

Ask...

Present slide 28

First Aid for Seizures

When you think about helping someone having a seizure, what is your first instinct?

First Aid for a Partial Seizure

- Do not hold the person down or restrain him or her
- Explain what is happening to other people
- Protect the person from danger
- Speak calmly
- Stay with the person until the seizure is over
- Offer to help

Important: Some measures to help someone having a partial seizure:

- First of all, stay calm
- Measure how long the seizure lasts.
- Do not restrain or hold the person, it is likely that the person, as a defense mechanism, will react by moving violently.
- Calm other people and explain what is happening.
- Block possible dangers like letting him/her walk in front of cars, stairs, etc.
- Speak to the person calmly and tell him/her that it will all soon pass.
- Stay with the person until the seizure ends and ask his/her name, the day, where he/she lives and where he/she is going.
- After a seizure, the person is usually confused and it may be dangerous to let him/her leave while still confused.
- To finish, help the person get oriented or if he/she needs to contact someone.

Present slide 29

First Aid for a Generalized Seizure

- Cushion the person’s head
- Loosen any tight clothing around the person’s neck
- Turn the person onto his or her side
- Do not put anything in the person’s mouth
- Look for an identification
- Do not hold the person down on his/her stomach
- Once the seizure is over, calmly offer your help
### Review...

Reinforce safe actions and answer questions.

### Important:

During a generalized seizure, bear in mind the following:

- Measure its duration
- Protect the persons’ head, by putting something soft underneath.
- Loosen the tie, necklace, or collar of tight shirts
- Remove eyeglasses
- Turn the person onto his or her side to keep his or her airways clear

### Important:

Do not put anything in the person’s mouth. This includes spoons, sticks, water, medicine... the person is not going to swallow his/her tongue.

- Look for identification to verify whether the person has epilepsy or whether the seizure is happening for some other reason, like diabetes, for example.
- Do not restrain the person, allow the arms and legs to move
- When the seizure is over, offer to help
- Just like in the first aid for partial seizures, it is important to bear in mind that the person is rather confused after the seizure, do not leave him/her alone while still confused.

### Important:

Do not put anything in the person’s mouth. One of the myths about giving first aid to people experiencing a seizure is that you must put something in their mouths to prevent them from swallowing their tongues. Actually, this is one of the most harmful unnecessary responses to a tonic-clonic seizure. The person’s tongue is attached and cannot be swallowed.

- Do not attempt to give the person anti-seizure medication by mouth and do not give food or drink until the person has fully recovered.
- Do not hold down or restrain the person. During a seizure, the brain is sending instructions to various parts of the body. Even if that part of the body is restrained, for example, an arm or a leg, it will still follow the instructions received from the brain. Hence, a restraint could lead to sprained or torn muscles or even broken bones.
- Do not keep the person on his/her back during a seizure. This may increase the risk that the person will inhale (aspirate) gastric fluids and suffocate.
**These things are dangerous when a person is having a seizure:**

- **DO NOT**
  - Put anything in the person’s mouth
  - Try to restrain the person
  - Try to give any antiepileptic medication by mouth
  - Keep the person on his or her back during the entire seizure

<table>
<thead>
<tr>
<th>5 Minutes</th>
<th>When to Call 911 or Emergency Services</th>
</tr>
</thead>
<tbody>
<tr>
<td>Continue...</td>
<td>Calling 911 or emergency services unnecessarily may be quite expensive for the person with epilepsy or his/her family; however, not asking for help in certain circumstances may be fatal.</td>
</tr>
</tbody>
</table>

Most epilepsy seizures are not medical emergencies; they usually end after a minute or two without any harm.

**Important:** Call an ambulance when:

- When a person has a seizure for the first time
- When the seizure lasts longer than 5 minutes
- When a complex partial seizure lasts longer than 5 minutes
- When another seizure begins before the person has regained consciousness
- Also call when the person having the seizure:
  - Is injured or is a pregnant woman
  - Has diabetes/other medical condition
  - Does not resume normal breathing

First aid for epileptic seizures, by the Epilepsy Foundation.
### Diagnosis and Treatment of Epilepsy

How is epilepsy diagnosed?

There is no one test to diagnose epilepsy. In fact, the most important tool for its diagnosis is a detailed description of the seizures. Therefore, it is essential for the patient to visit the neurologist accompanied by a relative or any person who has witnessed a seizure.

**Clinical history**: it is the main element that the physician uses to diagnose epilepsy. Taking a detailed medical history, with as much information as possible on the aspect of the seizures and what happened immediately before it began is vital.

**The determination of the type of seizure** is important information for the physician, due to the fact that the efficacy of various medications against epilepsy is specific for partial or generalized seizures. Normally, a detailed description of what happened during the seizure is the most trustworthy indicator of whether a seizure was partial or generalized.

What are some of the things that you think are important to tell your doctor about the seizures?

**Consider keeping a record of your seizures**

- Symptoms
- Seizure patterns
- Activity before the seizure (what you were doing right before the seizure)
What other tests does the doctor do?

Once the diagnosis is made, it is supplemented with tests that help detect the origin of the seizures. The most important tests are:

- The cerebral Computerized Axial Tomography (or CAT)
- The Magnetic Resonance Imaging of the Brain (Brain MRI)
- The electroencephalogram. (EEG)

The first two tests are useful to see the structure of the brain and may detect the presence of tumors, scars, cysts, cerebral malformations, etc.

The electroencephalogram (EEG) obtains the record of the cerebral electrical activity that indicates possible excitability of the brain and the location of this excessive excitability. On occasion, it is necessary to have a record of the epileptic seizures through a closed circuit video-electroencephalogram system to be able to diagnose epilepsy with certainty or to be able to determine the cerebral location of the origin of the seizures.

When doctors try to discover what caused a seizure, they look for certain chemical imbalances in the blood, infections, and any event in the person’s medical history that could have injured the brain in any way. The information from each analysis and examination adds a piece of evidence to help the physician put the puzzle together.

The physician’s evaluation probably also includes useful analyses, such as those of the blood and other clinical analyses, to check whether the person is having epileptic seizures and not any other type of episode, such as fainting, holding one’s breath (in children) or low concentrations of sugar in the blood.

In short, the diagnosis of epilepsy is made taking into account:

- Medical Evaluation
  - Patient’s medical history
- Blood test
- EEG (electroencephalogram)
- CAT (Computerized Axial Tomography)
- Brain MRI (Magnetic Resonance Imaging of the brain) or PET (Positron Emission Tomography)
- Neurological evaluation
- Identifying the type of seizure
- Medical evaluation seeking to determine the causes
5 Minutes

Continue...

The purpose of treating epilepsy is:

To prevent seizures, through medical, surgical or dietary measures, and to lessen the consequences of epilepsy and seizures.

Add...

1. **Treatment goal**: Help the person with epilepsy lead an active and productive life. This is why the first issue is to determine what has happened, its possible cause and the prognosis.

2. **Treatment goal**: Eliminate seizures without causing side effects. Analyze whether to treat the underlying condition - if any has been identified and it is treatable - or whether to treat the symptoms by prescribing an antiepileptic (seizure-preventing) drug.

In short...

Prescribing one or more antiepileptic drugs to prevent seizures is currently the most commonly used treatment for most forms of epilepsy.

Present slide 35

### Treatment for Epilepsy

**Goals of Epilepsy Treatment:**

- Help people with epilepsy live active and productive lives
- Eliminate seizures without causing side effects

Add...

In order to decide whether the person having seizures should be treated, the physician considers a number of factors.

- Unless the EEG or Brain MRI is clearly abnormal, which is related to a greater probability of subsequent seizures, doctors tend to wait for a second or even a third seizure before prescribing the antiepileptic medication.

- Studies have shown that a normal person, who has had only one seizure, has a relatively low risk (15%) of having another one. On the contrary, the risk of having another seizure, for a person with an abnormal EEG, may be of up to 50 to 60%. The doctor also weighs the risks against potential benefits.
Risks vary based on the age of the patient and his/her activity level. For instance, waiting to see if another generalized tonic-clonic seizure occurs is less risky for a child living in a safe home environment than for a salesman who lives most of his life driving a car, or for an elderly person with brittle bones.

What factors influence the decision to treat?

<table>
<thead>
<tr>
<th>The treatment may be appropriate</th>
<th>The treatment may NOT be appropriate</th>
</tr>
</thead>
<tbody>
<tr>
<td>Abnormal EEG</td>
<td>A single seizure</td>
</tr>
<tr>
<td>Previous seizure</td>
<td>No previous history</td>
</tr>
<tr>
<td>Partial seizure</td>
<td>Neurologically normal</td>
</tr>
<tr>
<td>Driver</td>
<td>Side effects</td>
</tr>
<tr>
<td>Other neurological disorders</td>
<td></td>
</tr>
<tr>
<td>Elderly patient</td>
<td></td>
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</tbody>
</table>

What are the treatments for epilepsy?

Types of treatments for epilepsy:

- Medication
- Surgery
- Non-pharmacologic treatment
  - Ketogenic Diet
  - Vagus Nerve Stimulation
  - Lifestyle modifications

Current treatment methods can achieve a full or partial control of seizures in about 80% of people with epilepsy.

The four main forms of treatment include medication, surgery, diet and vagus nerve stimulation.
Medication
- Long-term anticonvulsant (or antiepileptic) drug therapy is the main form of treatment.
- More than 20 antiepileptic drugs are currently in use. Most people are treated with one of these drugs; however, some may need two or more in order to obtain the best control of their seizures.

Surgery
- Surgery may be used when medication fails.
- Often, surgery is used when the brain tissue causing the seizures is located in a small area of the brain, which can be safely removed without damaging personality or function.

Diet
- Some people have good luck with the ketogenic diet.
- It is a special high-fat, restricted-calorie diet.
- This diet may be tried in children who do not respond to standard medications.

Vagus nerve stimulation
- 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.

Lifestyle modifications
- Identify factors that trigger seizures
- Avoid triggering factors to minimize the potential for seizures.

5 Minutes

Treatment with Medications

Ask...
Wait for answers and add...

Does anyone want to share their experience with medications for treating epilepsy?
Like many medications, the ones used for epilepsy have side effects.
- Some are related to the dosage: the higher the dose, the more likely the effect.
- Sedation, slurred speech, and a lack of balance are common effects of high dosages of antiepileptic medications.
- With normal dosages, similar effects may occur at the start of treatment and then disappear slowly as the organism becomes accustomed to the medication.

Other side effects are associated with specific medications and occur quite frequently, regardless of the dose.
- Drowsiness
- Irritability
- Nausea
- Rash
- Clumsiness.

Some drugs produce changes in:
- Emotions
- Memory
- Behavior
- Affect learning.
Add...

Ask... Wait and clarify with slide 39

Important:

- Persons taking antiepileptic drugs should be aware of the individual side effects and report changes in health, behavior or mood to their doctor.

- Instances of prolonged fever, rashes, severe sore throat, mouth ulcers, easy bruising or pinpoint bleeding under the skin, weakness, fatigue, swollen glands or lack of appetite may be signs that serious problems are developing and should be reported to the doctor immediately.

- What should the physician be told when there is something that is believed to be a side effect of the medication? All the changes I feel or see in my body once I start the medication.

Present slide 39
Does anyone have experience with surgery as a treatment for epilepsy?

When antiepileptic drugs fail to control or substantially reduce seizures, brain surgery may be considered.

Brain surgery for epilepsy involves:
1) The removal of tissue from the area where seizures originate
2) The interruption of nerve impulses along which seizure impulses spread.
   • Although some of the techniques have been developed recently, surgical removal of seizure-producing areas of the brain has been an accepted form of treatment for over 50 years.
   • Most surgical patients are adults who have fought long and unsuccessful battles to control their seizures. However, children with severe seizures are also treated with surgery.

Doctors take into consideration various factors when deciding whether to use surgery as a treatment:

- Are seizures due to epilepsy?
- Will surgery help?
- Can the focus of seizures be identified?
- Other attempted treatments failed
- Do benefits outweigh risks?

Finally, doctors try to consider whether the condition might get better or worse with surgery, and assess the potential benefits to the person versus the potential risks. It has been reported that surgery is successful in many patients, although such success depends on numerous factors.
Another useful treatment for people with epilepsy is the vagus nerve stimulation.

Vagus nerve stimulation is a relatively new procedure. It involves implanting an electronic device in the upper chest to deliver electrical stimulation to the vagus nerve in the neck.

The procedure has been approved by the US Food and Drug Administration for use in treating partial seizures in adults and adolescents over 12 after other treatments have failed to control the seizures.

Once implanted, the device delivers a regular pattern of stimulation. Persons can turn the device on if they feel a seizure coming on by using a special magnet which, in some cases, may prevent the seizures. Medical studies of the device suggest that some patients will gain some benefit from the device, although complete seizure control is rare. Most people continue taking antiepileptic drugs while receiving vagus nerve stimulation. The most commonly reported side effects are hoarseness, coughing and breathlessness.

Based on the finding that starvation, which burns fat to produce energy, has an antiepileptic effect

Mainly used to treat severe childhood epilepsy, has also proved effective in some adults and adolescents

High-fat, low-carbohydrate and -protein intake

Normally started in the hospital

Needs strong family commitment
The ketogenic diet is not a drug; however, it helps the body to produce substances that have an antiepileptic effect.

The diet is based on the observation that starvation, which burns fat to obtain energy and produce ketones, has an antiepileptic effect.

The purpose of the diet is to make the body get its energy from fat and enter a state of ketosis.

The diet is primarily used to treat severe childhood epilepsy.

People who follow the diet are instructed to prepare food with high amounts of fat and small amounts of carbohydrates and protein.

Normally, the diet is started in the hospital so that doctors can monitor the progress.

The exact reasons why the diet works are still unclear.

Medical studies suggest that about one third of patients are substantially helped, another third have some reduction in their seizures and the remaining third have no change at all.

Children may be kept on the diet for months or years. There are side effects, but not all children experience them.

Just like antiepileptic drugs, the ketogenic diet should not be stopped abruptly, but instead, little by little.

Great care must be taken when this diet is used in children taking medications, since these may contain sugar to make them taste better.

Parent and family education and a strong family commitment to the diet, plus administration by a doctor and a dietitian trained in its use, are generally considered vital to success.

Important:

✓ People with epilepsy should not fast thinking that it will help their seizures; in fact, fasting may trigger seizures.

✓ The ketogenic diet is a serious medicine; it has its own set of side effects, and should never be tried without medical advice.

A good relationship between the doctor, the treatment team and the patient should be established to get the greatest benefits from the treatment.
In short...

- Get the maximum benefit
  - Prepare your questions before your appointment
  - Arrive on time
  - If you have any questions, ask for clarification, especially of difficult terms
- Ask all of the members of the healthcare team (nurses, therapists, etc.) for their support

5 Minutes How is epilepsy perceived?

Continue...

Present slide 44

Add...

Present slide 45

We are going to review an investigation conducted by the Epilepsy Foundation in February of 2004. The Foundation, with the research support of the company Hispanic Research, Inc. conducted a telephone survey in Spanish among 760 Hispanics in the 7 cities in the United States with the highest number of Hispanics.

When the people were asked what they knew about epilepsy, they answered:

<table>
<thead>
<tr>
<th>What people think</th>
<th>Hispanics</th>
<th>Non-Hispanics</th>
</tr>
</thead>
<tbody>
<tr>
<td>Needs full time supervision</td>
<td>65%</td>
<td>11%</td>
</tr>
<tr>
<td>The family hides the condition</td>
<td>56%</td>
<td>27%</td>
</tr>
<tr>
<td>They do not get married</td>
<td>32%</td>
<td>3%</td>
</tr>
<tr>
<td>They cannot hold a job</td>
<td>31%</td>
<td>4%</td>
</tr>
<tr>
<td>They generally die young</td>
<td>25%</td>
<td>3%</td>
</tr>
<tr>
<td>May be contagious</td>
<td>6%</td>
<td>1%</td>
</tr>
</tbody>
</table>
The concept of “overprotection” is very common among Hispanics. And, sometimes, because of the great love we have for our families, and because we don’t want them to be hurt, we isolate them and we don’t let them enjoy important stages of life.

Imagine how a Hispanic person with epilepsy can feel when the favorite word he gets from his family is NO. NO, you can’t be alone; NO, don’t tell anyone you have epilepsy; NO, don’t even think about getting married, because what spouse is going to want to deal with your seizures; NO, you can’t work; NO, you aren’t going to live a long life and, of course, NO, don’t get close to anyone, because they can catch epilepsy.

However, we should also think about the rest of the family; parents, in their love, do not enjoy their own lives, their marriage, nor their other children; because of fear and a lack of guidance, they do not want to give their child with epilepsy a little bit of independence.

The siblings feel that they aren’t important, because their parents don’t have time for them, they don’t feel at ease with inviting friends to their home, because how embarrassing if my brother has a seizure; and lastly, in their love, they also tend to overprotect the sibling with epilepsy.

When asked what they believe to be the causes of epilepsy, they responded:

We spoke previously about Cysticercosis and we know its relation to the act of eating half-cooked pork.

But if we come to aspects of faith, we realize that the person with epilepsy is simply defined as a “bad” person, “he got epilepsy because of a lack of faith”. According to the answers of those interviewed.

When asked if they agreed with the treatment, they responded:
Notes / Instructions

Present slide 47

Add...

Important:
Do not sponsor the use of medications not authorized by the physician, if home remedies are used, the physician must be informed. It is common to hear parents speak about a person with epilepsy who resorts to home remedies that are successful; such as the grandmothers’ recipes.

5 Minutes

Myths and Realities of Epilepsy

Present slide 48 and explain each of the statements.

Add...

- There are more than 2.7 million people with epilepsy in the United States.
- No, it is not contagious.
- No, it is a medical condition; seizures are the result of an excessive and disorderly discharge of electrical energy in the brain.
- It frequently appears in children (infancy) and young adults, but anyone at any age at any time may develop it.
- Although for most people the cause of epilepsy is unknown, some of these people have had head injuries or blows to the head caused by bicycle and automobile accidents, that's why it's important to make
<table>
<thead>
<tr>
<th>Notes / Instructions</th>
<th>Content</th>
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<tbody>
<tr>
<td></td>
<td>use of safety measures for children with the use of helmets when riding bicycles and seat belts when driving or riding in a car.</td>
</tr>
<tr>
<td></td>
<td>• There is no known cure for epilepsy. However, there are modern treatment methods that can control seizures in most cases.</td>
</tr>
<tr>
<td></td>
<td>• Epilepsy is a physical condition, not a mental illness, and the person is not disabled.</td>
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</table>

People having epilepsy and their families already have enough trying to control their seizures, let’s help them by erasing from our culture the myths and misunderstandings about this condition, through education.

<table>
<thead>
<tr>
<th>5 Minutes</th>
<th>The Impact of Epilepsy</th>
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<tbody>
<tr>
<td>Present slide 49</td>
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</tbody>
</table>

<table>
<thead>
<tr>
<th>Ask...</th>
<th>Who would like to say what effects epilepsy has caused?</th>
</tr>
</thead>
<tbody>
<tr>
<td>To the answers, add...</td>
<td>• Epilepsy is a disorder that has many effects on families and each of its members.</td>
</tr>
<tr>
<td></td>
<td>• In some cases, the impact of epilepsy depends on the severity of the disorder; however, this does not fully explain how families cope with seizures.</td>
</tr>
<tr>
<td></td>
<td>• We have found that being open and honest when talking about epilepsy helps face its challenges.</td>
</tr>
<tr>
<td></td>
<td>• Moreover, families who are in contact with other people to get support and encouragement tend to achieve better results.</td>
</tr>
<tr>
<td>Add...</td>
<td>• Lastly, families that accept epilepsy as a part of life, even with frequent seizures, and enjoy life to the fullest extent, tend to do better.</td>
</tr>
<tr>
<td></td>
<td>Epilepsy affects individuals to varying degrees.</td>
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</tbody>
</table>
Present slide 50

A Spectrum of Severity:

Non-complicated epilepsy
Seizures controlled with medication

Seizures that do not respond to treatment; epilepsy is disabling due to frequent seizures and other problems

Seizures not fully controlled by treatment; epilepsy lowers the standard of living due to social, emotional and educational problems

Add...

- The severity of the disability that epilepsy creates is wide; it varies from a minimum impact to the individual to a devastating impact on all aspects of the life of the person.

- For the majority (maybe up to 80%) of persons with epilepsy, the seizures can be considerably reduced or fully controlled exercising a limited effect on the quality of life, although memory and attention may pose additional difficulties.

- In the remaining 20%, epilepsy is really disabling, characterized by frequent seizures and other disorders, and by a drastic reduction in the quality of life.

- Children whose seizures are not well controlled often face social, emotional, and academic problems, which compromise various stages of their development. These problems may extend into adulthood, where they become barriers to finding employment and achieving independence.

5 Minutes Social Aspects of Epilepsy

Ask...

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

Add...

The physical manifestations of epilepsy, combined with the 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.

For a variety of reasons, epilepsy has measurable effects on the most important areas of life, among them:
Notes / Instructions

Present slide 51

Social Aspects of Epilepsy:

- Fear and other emotions
- Interpersonal relationships
- Financial costs
- Schools
- Employment
- Driving
- Recreational activities

5 Minutes  Fear and Other Emotions

Add...

- For most people, the diagnosis of epilepsy is accompanied by a strong emotional reaction.
- It is common to feel fear, anger, worry, guilt, sadness and helplessness. All of these reactions are understandable and normal.
- Allowing yourself to experience your feelings is a good way to start accepting epilepsy. It is often a first step towards coping with the diagnosis.

Add...

Many people with epilepsy fear:

Present slide 52

Emotions: Fear

- It is normal to feel fear. Most people with epilepsy fear:
  - Risk of injury or death
  - Not knowing when or where a seizure will occur
  - Impact on the family and finances
  - Reactions from others

Ask...

Does anyone know how to reduce the fears associated with epilepsy?

Wait for answers and add...

There are several measures that can be very helpful in dealing with fears related to epilepsy.
• First, learn as much as you can about this condition.

• Consider consulting a counselor after epilepsy has been diagnosed in your family, if your family members cannot cope with their fears, or if such fears start affecting your family. The collaboration of a family counselor can help family members acknowledge their feelings and identify strategies to overcome them.

• Participating in a support group may also be very helpful.

• One of the common fears is that you will harm yourself or even die during a seizure. One good way to minimize the risk of harming yourself during a seizure is to become educated about first aid for seizures, and to make sure others around you know what to do as well.

• Unfortunately, injury may occur during a seizure. And it may be necessary to limit your activities or alter your environment for safety reasons. For instance, someone who has impaired consciousness during a seizure needs to avoid driving if he/she has not been seizure-free for a certain period of time as required in the state where he/she resides.

• Fortunately, seizures that cause a fatal injury are extremely rare. And the average person with epilepsy lives a normal lifespan. The great majority of people with epilepsy are able to balance the need for safety with an active, productive and enjoyable life.

Ways to overcome fear:

- Learn more about epilepsy
- Know how to improve safety at home in case of a seizure
- Proper first aid for seizures
- Join a support group
- Talk with a counselor
<table>
<thead>
<tr>
<th>Notes / Instructions</th>
<th>Content</th>
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<tr>
<td><strong>5 Minutes</strong></td>
<td><strong>Emotions: Isolation</strong></td>
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<tr>
<td>Add...</td>
<td>We have to consider not only the person with epilepsy but also his/her family. People with epilepsy are often isolated during their childhood and remain isolated during their adulthood. Older people who are diagnosed with epilepsy often feel quite isolated and, furthermore, the appearance of seizures may be the final event that leads to loss of independence and entering a nursing home.</td>
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</table>

| **5 Minutes**        | **Emotions: Depression** |
| Add...               | • 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 a few days or weeks, it may be a sign of serious depression.  
• Excessive worrying about seizures may lead to depression.  
• Depressed people usually feel:  
  o Powerless  
  o Hopeless with themselves and their future  
  o They feel that nothing they can do will improve their lives  
  o They feel that there is nothing that others can do either.  
• 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.  
Add... |
| Important:           | ➢ For some people, seizure medication may be a cause of depression. This and other side effects need to be discussed with the doctor.  
➢ When a person with epilepsy is very depressed he/she may think about suicide; that's why it is so important to watch for signs in his/her behavior and in the way he/she expresses feelings.  
➢ The local Epilepsy Foundation offices can connect the person with epilepsy and his/her family with support groups that may help them overcome their difficulties. |
Emotions: Depression

- Signs to watch for:
  - Excessive sleep or being tired all the time
  - Isolate oneself from others
  - Losing interest in personal appearance
  - Neglecting personal hygiene
  - Excessive crying
  - Being angry all the time
  - Unable to make decisions
  - Feeling worthless

Participating in Social Activities

- Identify activities you enjoy and try doing them in organized groups

Consider:
- Support groups
- Recreational groups
- Religious groups
- Social or political advocacy
- Patient’s rights

Add...

- Establishing interpersonal and social relationships and participating in different activities can be very good for people with epilepsy.

- Meeting other people and sharing interests and activities with them may make it easier to establish personal relationships and talk about epilepsy when appropriate.

Add...

Important:
In certain social environments, there may be the temptation to drink beer or other alcoholic beverages. In general, alcohol and antiepileptic medications depress the central nervous system and should not be mixed. Moreover, drinking alcohol in excess may lead to seizures in people with epilepsy.
Notes / Instructions  

Ask…  

What other resources do you know that may help a person with epilepsy in his/her interpersonal relationships and social activities?

---

5 Minutes  

The Financial Impact

Present slide 56

Financial Impact

- Medical insurance
- Employment
- Supplemental income benefits

**Potential resources for financial aid**
- United Way
- Social services at clinic or hospital
- City or County Health Department
- Social Security
- Subsidized housing

Add…

Besides the emotional impact, epilepsy is likely to have a financial impact on the patient and his/her family, although this will vary according to the frequency and severity of seizures.

People with epilepsy may have to pay more for health and life insurance.

- You may find that there are marked differences in costs among different insurance companies, and it will probably be advisable to shop around in order to get the best insurance at the most reasonable cost.

- The local Epilepsy Foundation may recommend people who can help you compare and select insurance companies.

**Important:**

A positive aspect is that most people with epilepsy can work.

Finally, the person with epilepsy may be eligible for supplemental income benefits, depending on his/her degree of disability and annual income.

It is important for the person to consult with his/her local Social Security office to find out whether he/she qualifies for social security disability income or supplemental security income.

---

5 Minutes  

Whom should you tell?

Ask…

Whom should a person with epilepsy inform about his/her condition?
Wait for answers and ask again...

Present slide 57

What are some of the strategies that you feel that a person with epilepsy should use to inform others about his/her condition?

- Department of Motor Vehicles
- Sports team coach
- School nurse
- Friends and potential lovers

“For many years, I tried to hide [the epilepsy] from everyone, thinking that I would be judged... they would erase me from their list of friends. Gradually I learned that people aren't like that... it has opened a number of doors to me that I had previously closed by myself.”

-Brainstorms: Epilepsy in our own words

Whom should you tell?

Add...

Most people find it difficult to decide who they should tell about their epilepsy.

- They worry about whether people will judge them unfairly.
- Even though there are no easy answers for whom to tell about epilepsy, the need to tell someone depends on:
  - How well controlled seizures are
  - How close you are to the person
  - What kinds of things you want to do
  - How other people will be affected if they are not informed
  - Safety issues and common sense.

Important:

Undoubtedly, Epilepsy should be disclosed:

1. when applying for a driver’s license.
2. when starting to participate in a sport, at least tell the coach for safety reasons.
3. To the school nurse.
4. Possibly those who work, to their employer.
5. It is not necessary to disclose your epilepsy to a prospective employer during an interview or on the employment application UNLESS you would be unable to perform essential job functions because of your seizures.

Continue...
6. Finally, you may want to tell close friends and people with whom you have an emotional bond, because having a seizure in front of someone who is not informed may harm your relationship and jeopardize your safety.

<table>
<thead>
<tr>
<th>Add...</th>
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<tbody>
<tr>
<td>• In most cases, the person with epilepsy may decide whom to tell about his/her epilepsy. If you haven’t had a seizure for a long time, there is probably no reason to tell casual acquaintances.</td>
<td></td>
</tr>
<tr>
<td>• Keeping secrets from close people and friends can be stressful. When you realize epilepsy is not such a rare condition and it is nothing to be ashamed of, you’ll feel better about yourselves and discussing epilepsy with people who care about you.</td>
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<tr>
<td>• Once you decide to tell someone, choose a quiet time, free from distractions. Also, make sure to give the other person all the facts and to show that you have a positive attitude towards epilepsy.</td>
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<table>
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<th>5 Minutes Safety</th>
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<td>Add...</td>
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<tr>
<td>• People with epilepsy fear injury as a result of a seizure, and with good reasons.</td>
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<tr>
<td>• Seizures that occur in potentially dangerous environments such as, in the water, near fire or hot surfaces, near machinery, at heights or near traffic, can cause serious injuries and even death.</td>
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<tr>
<td>• People also fear dying from seizures and, although this is unusual, this also is a valid concern.</td>
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<td>Add...</td>
<td>Important:</td>
</tr>
<tr>
<td></td>
<td>➢ To live well and use common sense regarding the kinds of activities that the person with epilepsy can do. The risk of injury during an activity should be assessed and an individual decision should be made according to the type of seizures experienced and how well they are controlled with medications.</td>
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<td>➢ If there is a possibility that a seizure will occur, the person with epilepsy must make sure that people who know what to do are nearby.</td>
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<td>➢ People with epilepsy can participate in typical activities, within the limits of their individual abilities. For instance, most can participate in sports (although the coach should know that a seizure might occur).</td>
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<td>➢ Swimming is also a good choice, but only if the person is accompanied by someone who, in case of a seizure, can give first aid. If seizures are not controlled, avoid activities that could be potentially fatal during a seizure, for example, sailing on a boat alone or rock climbing.</td>
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</table>
Persons with any kind of medical or chronic health condition should consider wearing or carrying a form of identification, such as a MedicAlert® bracelet or necklace, in case of an emergency situation. This will allow proper action to be taken in case of an accident.

Likewise, the use of a helmet in certain activities and a seat belt in the car is important for everyone.

For people with epilepsy, whether to restrict the daily activities - and if so, how much - is a very real question. Most have to balance the need for safety with their ability to carry out activities associated with their employment, household tasks and leisure time.

We all have to make decisions about the risks and benefits associated with different activities; for instance, relatively few people think the benefits of bungee jumping are worth the risks. But many feel comfortable with low-risk activities, such as driving a car or swimming. People with epilepsy should evaluate the risks of an activity in conjunction with their doctors, while considering their seizure control.

If seizures are well controlled, the analysis is essentially the same for people who do not have epilepsy.

If seizures occur frequently, the risks increase. For example, a person with frequent uncontrolled seizures should be careful about riding a bike or swimming and should avoid driving a car or piloting a plane. These decisions are relatively easy. But it is more difficult when the person has occasional seizures.

Common sense should be used to decide whether sports or other potentially dangerous physical activities would be appropriate.

Certain precautions, such as being accompanied by buddies, can minimize the risk of injury for persons with occasional seizures.

All states have laws dealing with seizure control and driver licensing, which are designed to protect public safety while allowing people who are unlikely to have an accident to drive.

People who experience episodes of loss of consciousness should avoid smoking in order to reduce the risk of a fire.

What can be some important safety tips for people with epilepsy?
Here are some safety tips.

**Bathroom**
- Install doors that open outward
- Install padded carpets on the floor
- Make sure drain works properly in bath/shower
- Consider using a shower seat
- Lower water temperature to avoid scalding

**Kitchen**
- Use plastic dishes and cups with lids
- Use microwave instead of stove

**House**
- Install carpets
- Pad sharp corners of tables and other furniture
- Do not smoke or light fires when alone
- Make sure iron has auto shut-off

**Work**
- Try to keep regular work hours
- Check safety features of machinery

---

5 Minutes

**Overcome Fears, Utilize Resources**

**Important:**
For the person with epilepsy, it is important to take charge and responsibility for his life and medical care.

- The seizure disorder can be managed in association with one's doctor and by taking an active role in the treatment.
- One can also take responsibility by getting enough rest and maintaining a healthy lifestyle without danger.
- Part of assuming responsibility for controlling epilepsy requires an active focus on medical care. When the person with epilepsy visits the doctor, we recommend that he/she:
  - Write down the questions he/she wants to ask.
  - When speaking to the doctor, try to make sure that the doctor understands everything that is being said.
Although the doctor seems to be busy, all the questions must be answered so that they can be understood. If they are not understood, the question should be repeated. It is also important for the person with epilepsy to know the resources that are available.

**Important:**
The first step is finding the local Epilepsy Foundation; there one can be helped to get access to numerous resources, among them, groups that will help with educational, medical, and financial needs.

The best way to face daily problems with epilepsy is contact with other people suffering the same disorder. That is the reason why support groups can be useful.

The Epilepsy Foundation may help the person with epilepsy and his family find the appropriate support group or maybe the doctor can suggest someone to talk to. An excellent way to keep one's perspective is to share problems and successes with others.

---

**Utilizing Resources:**

- Take responsibility for your life, including taking care of your health
- Be aware of available resources
- Cooperate with doctor and healthcare team
- Find support group networks
  - Epilepsy Foundation
  - Other resources

---

How should a person with epilepsy prepare for a doctor visit? What is the name of the specialist that should treat a person with epilepsy?

The neurologist is the specialist who should treat a person with epilepsy.
Present slide 61

The relationship between the medical staff and the person with epilepsy:

- Be prepared with questions to clarify questions and concerns
- Tell your doctor about any changes you observe or reactions to medications
- Ask your doctor to explain anything you don’t understand
- Ask for a professional translator/interpreter when you don’t understand the language
- Talk with the nurse and other members of the healthcare team

Summarize...

➢ The person with epilepsy and his/her family should periodically evaluate how they feel with the medical team.

➢ Evaluating whether they feel comfortable with the doctors’ and nurses’ professional abilities.

➢ Whether they are comfortable with the treatment and the degree of control over seizures.

It is important for the patient and his/her family to take the best advantage of the medical consultation; that is why we recommend that the person:

- Explain the reason for the visit when the appointment is requested
- Make sure that the clinical history is up-to-date
- Make a list of what he/she feels or questions he/she wants to ask
- Make sure that he/she understands everything that the doctor explains
- Repeat to the doctor what he/she understands in his/her own words
- If he/she does not feel comfortable with the doctor, tell him, with all due respect, that he/she would like to get a second opinion; medical ethics requires that they authorize this request

It is also very important to communicate with other members of the medical team, for example, the nurse and the pharmacist. These people can give a lot of information and help use the time with the doctor efficiently.
5 Minutes

Education and Epilepsy

Present slide 62

Epilepsy and Children:

Education

- Most children with epilepsy have IQ's within the normal range
- However, the risk of having learning problems is three times greater than the average
- Students with epilepsy are eligible for special education and related services

Encourage children with epilepsy to develop their abilities and reach their potential

Add...

- An important subject for the vast majority of families is the education of their children. The parents of a child with epilepsy wish to protect him, but ensure, at the same time, that the child will take the best advantage of his educational experience.

- Most children with epilepsy are, on the other hand, healthy and have a normal capacity to learn.

- As a group, children with epilepsy run triple the risk of having problems learning. Children who manage to control their seizures relatively quickly, with few side effects and without cognitive disorders, generally have a better likelihood of normal or superior achievement in education.

- Some children may not reach their potential and attention problems have been identified at all degrees of seriousness of epilepsy.
Missing school time due to seizures not previously diagnosed or analyzed medically may affect performance, even in children who otherwise progress appropriately.

Some students with epilepsy or seizure disorders may be eligible for special education and related services pursuant to the Individual with Disabilities Education Act (IDEA). Epilepsy is classified as “other health impaired” and an Individualized Education program (IEP) is developed to specify the appropriate services when children need additional help.

Meet all of your child’s teachers
Inform teachers and staff about:
- Your child’s seizure disorder
- The possible effects of medication
- What to do in case a seizure occurs at school
Encourage your local Epilepsy Foundation affiliate office to provide education to students, teachers and other staff
Let your child know that you will notify the school about his/her condition. It will give him/her peace of mind.

Important: When the school personnel are not informed about a child's
seizure disorder, they may not realize that the child is having a seizure and they may not know to question whether epilepsy plays a role in changes in the child’s behavior or academic performance.

Present slide 65

Information you should provide regarding your child’s epilepsy:

- General information about epilepsy
- Describe the type of seizures your child has, whether the seizures are controlled, how often your child has them
- What seizures look like, how long they last, and what the proper first aid procedures are

How can a parent become an advocate for his/her child with epilepsy?

Most children with epilepsy have normal intelligence; however, some have difficulty reaching academic goals.

When the child has academic difficulties, it is important to find out why and to look for resources that may be helpful.

Resources may include a parent advocacy group.

When a parent advocacy group is not available or additional help is needed, it is important to know your child’s rights under the law, and to use diplomatic assertiveness to help ensure the best education possible for your child.

Important: There are two laws: the Individuals with Disabilities Education Act and the Rehabilitation Act, which provide education rights for children and adults with disabilities. These laws stipulate that children have the right to be taught in a regular classroom environment, as much as possible, and to be included in social activities and other types of activities offered by the school.

Additionally, parents have the right to participate in the planning of their child’s education.

Children with disabilities should have a written individualized education plan, created by parents and school staff.
**Important:** The Rehabilitation Act is primarily a law that prohibits discrimination. This Act states that it is illegal for any program or activity that receives federal funds to exclude or discriminate against certain people with disabilities.

The Act typically includes adult education such as college, graduate and technical schools and prohibits them from making a preadmission inquiry about whether an applicant has a disability.

Parents are not alone. There are laws and organizations that protect children and people with epilepsy, so we need to know them in order to be able to use them for the benefit of the person and his/her family.

Present slides 66 and 67

The IEP describes the child's present level of development and establishes short-term and annual goals for his/her education, the specific educational services that the child will receive, the starting date and duration of services, the evaluation criteria and the extent to which the child will be able to participate in regular educational programs.

- **IEP's:** Individualized Education Plans
  - Developed by parents and school staff
  - May include specific services, physical or speech therapy, psychological evaluation and treatment, social work services and counseling
  - Related services that may include education for the school staff and classmates
The IEP is normally prepared in meetings between parents and school representatives. For support, parents may bring a doctor or an advocate to these meetings.

Add...

It is important for parents to know that the IEP covers a wide variety of services. In some cases, the needs of a child with epilepsy may go unnoticed unless parents request specific services.

**Important:** The IEP includes services such as physical or speech therapy, transportation, psychological evaluation and treatment, physical and occupational therapy, recreation, social work services, counseling (which includes rehabilitation counseling when appropriate), early identification and assessment of disabling conditions, and medical evaluations. Advocacy training about the IEP process is available to help parents prepare to advocate on behalf of their child; parents should talk to their Epilepsy Foundation representative about finding a training program.

For children with epilepsy, the IEP may also include education about epilepsy for the school staff, for example, how to administer medication and first aid for seizures. Whenever possible, it is desirable to extend this education to classmates as well, since social acceptance is often one of the major difficulties for children with epilepsy.

Ask...

Does anyone have experience with an IEP to share?

---

**5 Minutes Employment and Epilepsy**

Add...  
- Finding and keeping a job can be a problem for adults with epilepsy.
- Surveys indicate that people with epilepsy are unemployed or underemployed at four times the national unemployment average.

Ask... Wait for answers and add...  
- What is the reason that there is more unemployment among people with epilepsy?
- It may be due to various factors.
- Transportation
- Lack of social agencies
- The legacy of childhood.
  - Loneliness
  - Overprotection
  - Underlying neurologic and cognitive deficits
- The attitudes of employers and coworkers
Assuming that the person with epilepsy will have more absences from work

Assuming that the person with epilepsy can have a poor performance at work

Fortunately, the new laws provide protection for people with disabilities, including people with epilepsy.

The ADA prohibits:
- Most employers from asking job applicants whether they have certain disabilities and how severe they are.
- Most employers from discriminating on the basis of disability if the applicant or employee is qualified to perform the essential job functions.

The employer must provide any reasonable accommodations which would enable an otherwise qualified person with a disability to do the job, examples;
- Modifying work schedules to avoid sleep disruption
- Installing safety devices around machinery.

The fact that people with seizure disorders can and do work effectively at a variety of jobs has been proved in a limited number of demonstration projects funded by the US Department of Labor.

Getting a job may be difficult

Americans with Disabilities Act (ADA)
- It prohibits discrimination based on the disability, if the applicant is qualified for the job
- The employer must provide reasonable accommodations

Do you think that a person with epilepsy can drive a car?
Under what conditions can a person with epilepsy drive a car?

Another issue for many people with epilepsy is driving.

- In many cases, it is possible for a person with epilepsy to get a driver’s license if seizures are controlled.
- Most states have certain restrictions and may require that the applicant
submit a doctor's statement declaring that the person has been seizure-free for a certain period of time (usually between 6 months and 1 year).

- Some states also rely on the doctor to inform about any seizure and to verify, every year, that the driver remains seizure-free.

- The right to drive can be a powerful motivation for taking medications and doing whatever is necessary to control seizures. It can also serve as an incentive to talk to your doctor about the various therapies, when you are not happy with your seizure control.

- Even though it can be difficult not to drive, there are alternatives available. These include public transportation, carpooling, or friends or family that can provide transportation.

**Important:** For information on the present regulations, people with epilepsy should contact their local Department of Motor Vehicles or the Department of Transportation.

Present slide 69 and summarize...

**Driving:**

- Each state has specific restrictions
  - Usually, being seizure-free for 6 months to 1 year
  - You may need a statement from your doctor
  - You will probably need to report any seizures
  - You are not eligible for commercial driver’s licenses

- For information, contact your local DMV and Epilepsy Foundation office

- Alternatives
  - Public transportation
  - Friends, family

Continue...

There are many aspects that a woman with epilepsy should pay attention to, for example, hormonal changes, family planning, pregnancy, breastfeeding, among others.
Epilepsy and Women:

Hormonal effects
- Hormonal changes during puberty, menopause and the menstrual cycle may affect seizure frequency
- Polycystic ovary syndrome

Sexuality and contraception
- Sexual dysfunction
- Birth control pills may be less effective

Pregnancy and maternity
- Need to continue with medication
- Slight increased risk for birth defects

Important: More than one million women and girls in the United States have epilepsy.

Although many of the problems they face are common to both sexes, women with epilepsy must deal with different difficulties at various stages of their reproductive lives:

- Hormonal changes in the balance between estrogen and progesterone in women's monthly menstrual cycles may affect seizure frequency.

- Hormonal changes during puberty may affect seizure control, making it more important for the family and the doctor to provide support and information to growing girls.

- Fertility is reduced among women with epilepsy, possibly because of the greater risk of suffering from reproductive disorders, such as
Epilepsy – Curriculum for Facilitators

Add… in short…

Women of reproductive age that have epilepsy should take greater care during the following stages of life:

Important: Women with epilepsy can and do have normal and healthy babies.

• In the past, marriage and maternity were considered inappropriate activities for women with epilepsy. Some beliefs were based on the mistaken idea that epilepsy was always inherited and that the behavior of people with epilepsy was unpredictable, and therefore, unsuitable for parenting. Nothing can be further from the truth.

• The risk for epilepsy in the children of people with this disorder is small.

• More effective antiepileptic drugs, the ability to monitor therapeutic agents, as well as a better understanding of the risk factors for pregnancy have lead to a considerably improved care for women with epilepsy.

• However, there are certain special problems that such women face which should be discussed with the doctor.

Women and men with epilepsy may experience:

• Sexual dysfunctions that may be due to epilepsy, its treatment or the psychological impact of the disorder.

• Antiepileptic drugs may lower the effectiveness of birth control pills; fortunately, this can normally be overcome by taking higher doses of birth control pills under the doctor’s instruction.

• There is an increased risk for birth defects in children of women with epilepsy. Antiepileptic drugs and seizures are believed to be the causes of such increase.

• Epilepsy will probably add an extra difficulty to dating and marriage. Normally, epilepsy and its treatment do not affect sexual or reproductive functions although epilepsy in women may affect these areas.

• Sexual activity by either sex is unlikely to affect epilepsy or the frequency of seizures.

• A person’s sexual desire may be reduced if medication causes an excess of sedation or impotence. This can be improved by reducing or changing the dosage of the medication, but it can only be done under medical supervision.

Important: Women with epilepsy can and do have normal and healthy babies.

• In the past, marriage and maternity were considered inappropriate activities for women with epilepsy. Some beliefs were based on the mistaken idea that epilepsy was always inherited and that the behavior of people with epilepsy was unpredictable, and therefore, unsuitable for parenting. Nothing can be further from the truth.

• The risk for epilepsy in the children of people with this disorder is small.

• More effective antiepileptic drugs, the ability to monitor therapeutic agents, as well as a better understanding of the risk factors for pregnancy have lead to a considerably improved care for women with epilepsy.

• However, there are certain special problems that such women face which should be discussed with the doctor.
Women with epilepsy have 25% to 33% fewer children than women in the general population.

Social pressures on women with epilepsy to refrain from having children may be a factor in their lower rate of pregnancy.

Biological factors may also be the cause. For instance, menstrual irregularities occur more frequently in women with epilepsy.

A number of other factors, including the type of seizures, their frequency, and the location in the brain where they originate, may also contribute to infertility. Some antiepileptic medications may reduce fertility.

**Important:** Antiepileptic drugs can also complicate birth control. Some of these drugs (including carbamazepine, phenytoin, phenobarbital, felbamate and topiramate) lower estrogen levels and reduce the effectiveness of hormonal birth control methods such as birth control pills or Norplant®.

Midcycle spotting or bleeding may indicate that ovulation is not being prevented and should be informed to the doctor, since it may be a sign that alternative or supplementary methods of birth control are needed.

If a woman with epilepsy is taking an oral contraceptive, she may need to ask her doctor to monitor her hormone levels in order to ensure the contraceptive effectiveness.
Women with epilepsy have fewer children than women in the general population.

Antiepileptic drugs may reduce the effectiveness of birth control pills.

Plan your pregnancy in advance.

The risk for birth defects is low (4 to 6% compared to 2 to 3% in the general population).

Take prenatal vitamins and folic acid.

Do not discontinue antiepileptic drugs.

Your doctor may be able to adjust your dosage.

Pregnancy can affect seizure frequency.

Register with the medication program for epilepsy and pregnancy - (888) 233-2334 - Massachusetts General Hospital - Harvard Medical School.

**Important:** Planning a family and expecting a baby should be happy occasions. For a person with epilepsy, defining the potential dangers and ways of reducing them are a good starting point.

**Important:** Many of the measures to reduce the problems for both the mother and the baby should be taken before pregnancy.

- A good communication among the couple, the neurologist and the obstetrician is essential. Together, this team can make sure that the need to control seizures and the desire for a healthy baby are met to the highest degree possible and are well balanced.

- Most women with epilepsy can conceive and deliver healthy babies. Even though the rate of birth defects is low (4 to 6%), it almost doubles that of the general population (2 to 3%).

**Important:** Studies have shown that the use of antiepileptic drugs during pregnancy is likely to increase birth defects, especially at higher doses or when the mother is treated with multiple antiepileptic drugs.
Add...

**Important:** Folic acid supplement has been proved to reduce the risk of certain defects and is important for all women who are planning to become pregnant or who are already pregnant.

- Folic acid is particularly important for women with epilepsy because some antiepileptic drugs may lower the level of folic acid in the body.

- It should be noted that seizures are a more serious concern during pregnancy than the exposure to antiepileptic medications.

In short...

During pregnancy, between one quarter and one third of women with epilepsy show an increase in the frequency of seizures.

**Important:** The increase in seizure frequency, observed during pregnancy, is related to the changing blood levels of antiepileptic medication during pregnancy. For this reason, it is important to work closely with the doctor during pregnancy.

**Important:**
- In general, when a woman works with her doctor and takes folic acid supplements before conception, she has the best chance of minimizing the risks to her baby.
- All women, including those with epilepsy, should supplement their diet with folic acid before and during pregnancy.
- Finally, it is important for a woman with epilepsy to discuss with her doctor the issue about antiepileptic drugs when she is considering becoming pregnant, and to not stop them on her own.
- The woman’s neurologist and obstetrician need to establish a plan for treating acute seizures, if they occur, especially during labor.

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**5 Minutes**

**Breastfeeding and Epilepsy**

Present slide 75

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**Parents and Newborns:**

- Breastfeeding does not seem to be dangerous and is generally recommended
- Talk to your doctor about reducing the risk of injury during a seizure

“Over 90% of women with epilepsy have perfectly healthy babies”

Dr. Orrín Devinsky
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<tr>
<th>Notes / Instructions</th>
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<tr>
<td>Add...</td>
<td>In general, breastfeeding is recommended for most women with epilepsy.</td>
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<tr>
<td></td>
<td>Breastfeeding provides a variety of benefits to the baby, including protection against infections.</td>
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<td>The benefits should be weighed against the risks when the mother is taking antiepileptic medication. Her doctors can work with her to determine whether breastfeeding is convenient or not in her case.</td>
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<td>Drug levels should be monitored closely and dosage adjusted as necessary in order to prevent seizures during pregnancy.</td>
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<td>Drug levels need to be monitored until the 8th week after the baby is born because they tend to rise during this period and may cause uncomfortable side effects.</td>
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<td>Add...</td>
<td><strong>Important:</strong></td>
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<td>• When the mother is breastfeeding her baby the safety not only for the mother but also for the baby must be improved.</td>
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<td>• Preferably, the mother should not be alone when breastfeeding her baby if she has frequent seizures.</td>
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<td>• The baby’s safety should be maximized, for example, as the baby gets old enough to crawl and move around, gates and playpens should be used to restrict his/her access to dangerous areas of the house (such as staircases.)</td>
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<td>Ask... Wait for answers and reinforce if necessary.</td>
<td>Has anyone had an experience with a pregnant woman with epilepsy?</td>
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### 5 Minutes

Epilepsy and the Older Adult

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Epilepsy and the Elderly:
The incidence of seizures and epilepsy increases after age 60, and, due to age, they may need modifications in treatment and/or require special care considering issues of independence and safety.

Let's review a bit what we have already seen.

What can be the causes of epilepsy in older persons?

There are many possible reasons why an older adult may have epilepsy. Healthy older people have a lower threshold for seizures, which means their brains are more vulnerable to situations leading to seizures.

In younger people, the causes of epilepsy are often unknown.

In most cases of older people who develop epilepsy, a cause can be identified.

Stroke is the main cause of new cases of epilepsy among the elderly.

Among those who develop epilepsy after age 65, the most common causes are:

- Cerebrovascular disease (33%),
- Degenerative disorders, such as Alzheimer's disease (11.7%)
- Brain tumors (4.5%).
- It is much higher among people with Down syndrome who develop early Alzheimer's disease (after age 50), amounting to 75 to 85% of these individuals.
Seizures in older adults are classified into 2 big groups:

- Complex partial seizures
- Generalized seizures

Primary challenges
- Symptoms misinterpreted as effects of aging
- Symptoms may be linked to other disorders
- Lack of awareness during the seizure

Complex partial seizure symptoms often include:
- Staring
- Twitching of the face
- Chewing movements
- Mumbling
- Compulsion to move
- Unresponsiveness and lost time during the seizure.

Important: If a person who is alert and aware of his/her surroundings experiences sudden changes in behavior, is unresponsive for a brief time and then looks confused for a relatively short period of time, it is a good idea to consider the possibility that a seizure may be the cause.

- The change in feelings or sensations that precedes a more extensive seizure may be described by the elderly in different ways, depending on how it is experienced.
- The seizure itself is more likely to alter the way of thinking or cause periods of staring, unresponsiveness or loss of awareness.
Episodic changes and confusion should be evaluated by a doctor specialized in geriatrics or epilepsy.

**Important:** A generalized tonic-clonic seizure is usually defined as the loss of consciousness that causes a sudden fall and body stiffening, followed by major spasms of all the muscles.

- Elderly people with osteoporosis run a higher risk of breaking their bones due to seizures, both from falls and the stress of muscular contractions.
- Complex partial seizures affect awareness and cause an abnormal behavior which is not under conscious control.
- The status epilepticus (non-stop seizures) is a medical emergency, and older people have the highest mortality rates from this condition (30%).
- Even though non-stop seizures can be easily recognized, there is also a type of status epilepticus in which there is constant confusion.
- Long periods of confusion also require emergency medical treatment.

What safety measures may be taken with an older adult with epilepsy?

**Important:** An older person with epilepsy living alone may enhance his/her safety and independence by wearing a device that he/she can use to call for help if a seizure occurs and he/she is injured or unable to get up afterwards.
The treatment for older people with epilepsy poses major challenges, including:

- Start of slurred speech, excessive sleeping and other signs of toxicity should be informed to the doctor in case the dose needs to be reduced.

- Studies reveal that the most common side effects of antiepileptic drugs in older people are unsteadiness, tremor, visual disorders and sedation.

- Older people may also be taking many other medications, such as, for high blood pressure and high cholesterol, blood thinners, diuretics, laxatives, painkillers and sedatives. Adding anticonvulsant medications may lead to interactions.

- Taking the necessary medications at the right time is difficult for many people, especially for elderly people who take a number of medications and struggle with declining short-term memory.

Here are some tips to improve the treatments of the elderly people:

- Help the older person understand the significance of keeping a regular intake of the medication as prescribed by the doctor.

- Talk with the pharmacist and provide him/her with a list of all prescription and non-prescription medications including vitamins and herbal products that the person is taking.

- Elderly people with limited vision may need help reading dosing instructions on medicine bottles, removing safety caps and loading pill boxes.

- Calendars can be helpful, as can segmented pill boxes in which a caregiver or family member can count out tablets for a day or even a week.

- Alarm watches and other reminders may also help.

**Important:** The appearance of epilepsy affects one's social life at any age. With the start of epilepsy at an advanced age, there is a group of effects that may plague the older person:
Social Aspects:
- Lack of self-confidence
- Embarrassment at effects of seizures
- Increased dependency
- Loss of driving privileges
- Decreased mobility
- Depression/stigma
- Loss of independence

What can be done for an older person who has epilepsy?
Promote solidarity and commitment to older people with epilepsy.

Remember, the most important thing is to know that there are various organizations that have several alternatives to help people face the challenges posed by epilepsy. It is essential to identify these organizations and utilize them. Some of these are:

And, finally, be aware of...
Continue...

Add...

Bear in mind during all the training...

Do not forget...

And to conclude...

Bring the activity to an end.

The Epilepsy Foundation is the national organization that works for people affected by epileptic seizures. The national office and a network of affiliated Epilepsy Foundations throughout the country support many programs, including research, community support, patient and family education, advocacy, and services such as information and referral to healthcare professionals, public and professional education, employment assistance and the Women and Epilepsy Initiative.

Today we have reviewed the most important points about epilepsy. Now I would like each of you to tell something important that you learned during this educational session. Let’s concentrate and not repeat what others have said. For this purpose, I will hand out cards with one word, and the one with that card will say what he understands by that word. The other persons can help him.

If anyone does not wish to speak, don’t force them, but take advantage of the opportunity to reinforce the subject in question.

Hand out brochures and educational materials and make sure every member of the audience completes the evaluation and the attendance form.

Thank attendees for participating.

Dismiss the audience with soft music.
Bibliography


