

# 30 Minute Lesson: Epilepsy

## Non-Facilitated Group Version

Epilepsy is a term used to describe a condition characterized by seizures (unusual electrical activity in the brain causing behavioral changes). This lesson focuses on building an understanding of epilepsy, particularly from an employment standpoint.

### *Learning Objectives*

- < Build an understanding of epilepsy: causes, prevalence, management strategies, characteristics
- < Review information about the types of seizures
- < Review information about successful employment approaches for people with epilepsy



### Test Your Knowledge!

1. What are three types of seizures experienced by people with epilepsy?
  
  
  
  
  
  
  
  
  
  
2. True or False: “Epileptics” is an appropriate label for people with epilepsy, just like people with diabetes are called diabetics.
  
  
  
  
  
  
  
  
  
  
3. True or False: For most people with epilepsy, the cause is not known.
  
  
  
  
  
  
  
  
  
  
4. **“Matt has epilepsy.”** What characteristics come to mind when you hear that phrase? Write your list below, and then compare notes with the others in your small group.

# Epilepsy (Seizure Disorder)

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## What is epilepsy?

There is a balance in the brain between factors that begin electrical activity and factors that restrict it, and there are also systems that limit the spread of electrical activity. During a seizure, these limits break down, and abnormal electrical discharges can occur and spread to whole groups of neighboring cells at once. This linkage of electrical discharges creates a "storm" of electrical activity in the brain. This is a seizure.

Epilepsy, or seizure disorder, is usually diagnosed after a person has had at least two seizures that were not caused by some known medical condition like alcohol withdrawal or extremely low blood sugar.

The seizures in epilepsy may be related to a brain injury or a family tendency, but most of the time the cause is unknown. The word "epilepsy" does not indicate anything about the cause of the person's seizures, what type they are, or how severe they are.

Like any other group of people, people with epilepsy have different intellectual abilities. Some are brilliant and some score below average on intelligence tests, but most are somewhere in the middle. They have normal intelligence and lead productive lives.

Some people, however, may have epilepsy associated with brain injuries or other conditions (such as cerebral palsy or mental retardation) that may cause neurological difficulties that affect their thinking, remembering, or other cognitive abilities. Most people with epilepsy are not intellectually or developmentally challenged; however, people with epilepsy who are served by community rehabilitation programs almost always experience significant cognitive disabilities in addition to the seizures.

## People with epilepsy are not "epileptics."

The word "epileptic" should not be used to describe someone who has epilepsy, as it defines a person by one trait or problem. A label is powerful and can create a limiting and negative stereotype. It is better to refer to someone as "a person with epilepsy" or to a group of people as "people with epilepsy."

# Causes and incidence

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## What causes epilepsy?

Causes of epilepsy are divided into two categories. *Symptomatic* epilepsy is caused by some structural or metabolic abnormality in the brain, such as:

- Genetic conditions
- Complications during pregnancy or birth
- Stroke or brain tumor
- Head injury
- Operations
- Encephalitis or other infections
- Alcohol
- Anoxia from other causes (such as near drowning)

*Idiopathic* epilepsy means that no cause has been identified. This is the case for most people with epilepsy.

## Who gets epilepsy?

Epilepsy can develop in any person at any age.

About 2.7 million Americans have been treated for epilepsy in the past 5 years. That's 8 or 9 out of every 1,000 people. In other words, out of 60,000 people filling a big stadium, about 500 have epilepsy. More men than women have epilepsy. <sup>1</sup>.

***How many of the people you support have epilepsy? How many of these individuals also have other diagnosed disabilities, and what are they?***

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<sup>1</sup> [http://www.epilepsy.com/101/ep101\\_who.html](http://www.epilepsy.com/101/ep101_who.html)

# Types of seizures

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This terminology is taken in part or in whole from the Epilepsy Foundation at <http://www.efa.org> and the National Society for Epilepsy <http://www.epilepsynse.org.uk/pages/index/home/>.

**Generalized tonic clonic (grand mal) seizures**, begin with a sudden cry or fall; the individual may lose consciousness. The individual will become rigid, followed by muscle jerks, shallow or temporarily suspended breathing, bluish skin, and possible loss of bladder control. This seizure may last a couple of minutes. The individual may experience some confusion and/or fatigue, followed by a return to full consciousness.

**Generalized absence (petit mal) seizures** look like a blank stare, beginning and ending abruptly, lasting only a few seconds. Other behaviors exhibited may include rapid blinking or some chewing movements of the mouth.

**Complex partial seizures**, also called psychomotor seizures or temporal lobe seizures, usually start with a blank stare, followed by chewing, then followed by random activity. The person appears unaware of surroundings, may seem dazed, mumble, be unresponsive and clumsy, pick at or try to remove clothes, run or appear afraid, struggle or resist restraint. This seizure lasts a few minutes, but confusion can last longer.

Simple **partial seizures** begin with involuntary jerking movement in the arm, leg, or face. This may spread to become a convulsive seizure. The individual remains awake and aware throughout this type of seizure. The individual may see or hear things that are not there, and may feel unexplained sadness, anger, fear, or joy. The individual may also experience nausea, identify odd smells, or have a "funny" feeling in the stomach.

**Atonic seizures**, also known as drop attacks, occur when an individual suddenly drops and falls. This type of seizure generally lasts between 10 seconds and one minute. The individual will regain consciousness and can eventually stand and walk again.

**Myoclonic seizures** are sudden, brief, but massive muscle jerks that may involve the whole body or parts of the body. This type of seizure activity may cause an individual to spill what he/she is holding, or fall from a chair.

**Photosensitivity epilepsy seizures** can occur when an individual views or is exposed to, flashing or flickering lights or moving geometric shapes or patterns. Some triggers include watching television, playing video games, using a computer, and viewing strobe lights. Other natural occurrences of flashing or flickering lights include sunlight coming through a line of trees, looking out of a window, or sunlight reflecting on water.

*What kind of seizures have you seen? How did they impact the person?*

## Symptoms of a seizure (<http://www.epilepsy.com/>)

A seizure is usually defined as a sudden alteration of behavior due to a temporary change in the electrical functioning of the brain, in particular the outside rim of the brain called the *cortex*. Seizures can take on many different forms and seizures affect different people in different ways. Not every person with seizures will experience every symptom described below.

Seizures have a beginning, middle, and end. When an individual is aware of the beginning, it may be thought of as a warning or aura. On the other hand, an individual may not be aware of the beginning and therefore have no warning.

<b>Sensory/Thought:</b>	<b>Emotional:</b>	<b>Physical:</b>	<b>No warning:</b>
Deja vu Jamais vu Smell Sound Taste Visual loss or blurring Racing thoughts Stomach feelings Strange feelings Tingling feeling	Fear/Panic Pleasant feeling	Dizziness Headache Lightheadedness Nausea Numbness	Sometimes seizures come with no warning

The middle of the seizure may take several different forms. For people who have warnings, the aura may simply continue or it may turn into a complex partial seizure or a convulsion. For those who do not have a warning, the seizure may continue as a complex partial seizure or it may evolve into a convulsion.

<b>Sensory/Thought:</b>	<b>Emotional:</b>	<b>Physical:</b>	
Black out Confusion Deafness/Sounds Electric Shock Feeling Loss of consciousness Smell Spacing out Out of body experience Visual loss or blurring	Fear/Panic  <table border="1" data-bbox="509 1432 927 1499"> <tr> <td><b>Physical:</b></td> </tr> </table> Chewing movements Convulsion Difficulty talking Drooling Eyelid fluttering Eyes rolling up Falling down Foot stomping Hand waving	<b>Physical:</b>	Inability to move Incontinence Lip smacking Making sounds Shaking Staring Stiffening Swallowing Sweating Teeth clenching/grinding Tongue biting Tremors Twitching movements Breathing difficulty Heart racing
<b>Physical:</b>			

The end to a seizure represents a transition from the seizure back to the individual's normal state. This period is referred to as the "post-ictal period" (an ictus is a seizure) and signifies the recovery period for the brain. It may last from seconds to minutes to hours, depending on several factors including which part(s) of the brain were affected by the seizure and whether the individual was on anti-seizure medication. If a person has a complex partial seizure or a convulsion, their level of awareness gradually improves during the post-ictal period, much like a person waking up from anesthesia after an operation.

<b>Thought:</b>	<b>Emotional:</b>	<b>Physical:</b>
Memory loss Writing difficulty	Confusion Depression and sadness Fear Frustration Shame/Embarrassment	Bruising Difficulty talking Injuries Sleeping Exhaustion Headache Nausea Pain Thirst Weakness Urge to urinate/defecate

*Which of these symptoms are exhibited by the people with epilepsy that you support? How does this list match the issues you identified in your quiz?*

# Seizure triggers and treatment

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Some people find that certain experiences or stimuli will make a seizure more likely. These triggers may include:

- Missed medication
- Sleep deprivation, tiredness
- Stress or illness
- Alcohol or other drugs
- Reading
- Heat or cold
- Perfume or other strong smells
- Hot water on the head
- Menstrual cycle
- Nutritional deficiencies
- Over the counter medications
- Flashing or flickering lights

*Which of these triggers might be issues in employment?*

Antiepileptic (also called "anticonvulsant") drugs control the symptoms of seizures and are effective in 60-80% of the cases. Many of these drugs have side effects such as drowsiness, dizziness and nausea so doctors must balance these undesirable effects with seizure control. Surgery is usually only attempted when epilepsy has not been controlled by medications.

Ketogenic (high-fat, low carb) diets may occasionally be effective in controlling some types of epilepsy; although the mechanism behind the effect is not fully understood. They are sometimes prescribed in severe cases where drugs have proven ineffective.

Vagus nerve stimulation is a recently developed form of seizure control which uses an implanted electrical device which connects to the vagus nerve in the neck. Once in place the device can be set to emit electronic pulses, stimulating the vagus nerve at pre-set intervals and milliamp levels. Approximately 50% of the time people will show significant seizure reduction.

Some people with epilepsy receive a special dog which is trained to sense the onset of a seizure and to alert the human so they can reach a safe location before their seizure puts them in danger. Other epilepsy care dogs do not sense seizures, but serve as companions and guardians during the loss of consciousness accompanying a seizure.<sup>2</sup>

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<sup>2</sup> <http://goldbamboo.com/topic-t1311-a1-6Epilepsy.html>

## How do seizures impact thinking and memory?<sup>3</sup>

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*This section provides detailed information on the impact of seizures on thinking and memory. Feel free to set it aside for later and move on to p. 9 if time is short.*

Epilepsy and its treatment affect the way that some people think and behave. If seizures happen repeatedly they can have a lasting effect on many of the brain's functions, including memory, language, planning and reasoning.

**How do seizures change thinking?** Seizures can disrupt the area of the brain in charge of a particular function; for example, if seizures happen in the area in charge of language, you may not be able to name an object when you see it. Seizures can also stop the communication between different areas. Even though you may know the name of an object, the part of the brain that knows can't tell the rest of your brain. If seizures start in several areas, or are generalized, they may affect many different functions.

**How do seizures affect language?** The primary language problem caused by seizures is with finding words. Many people cannot think of the name of something, even when it is right in front of them. This is because seizures can damage the area where the word is stored, as well as the communication lines that carry or transport the word.

**How do seizures affect executive function?** The largest part of our brain is the part that handles executive function: the frontal lobe. This goes from the front tip of the brain to about halfway back (just in front of your ears). The frontal lobe has a major role in decision making.

Seizures that happen in the frontal lobe can cause the planning ability to become weaker. A person may not be able to organize thoughts or actions in the best way. If a person is making a list, for instance, he may think or write the same item over and over.

The frontal lobe regulates how a person interacts with other people. Some people claim this is where personality comes from. The frontal lobe also helps to stop unwanted behavior.

It may be harder to interact with people. Attention may drift much sooner than before. Some people say their personality has changed after having seizures for many years. It also may be harder to stop unwanted behavior. A person may say what's on his mind even when it's not the right time.

*What implications do these issues have for employment? Do you work with anyone whose only disability is epilepsy, and if so, does he/she have thinking or memory challenges?*

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<sup>3</sup> [http://www.epilepsy.com/epilepsy/thinking\\_memory\\_epilepsy.html](http://www.epilepsy.com/epilepsy/thinking_memory_epilepsy.html)

# Responding to a seizure

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Here are some tips from the Epilepsy Foundation:

(<http://www.epilepsyfoundation.org/answerplace/Medical/firstaid/firstaidkeys.cfm>)

- Keep calm and reassure other people who may be nearby.
- Don't hold the person down or try to stop his movements.
- Time the seizure with your watch.
- Clear the area around the person of anything hard or sharp.
- Loosen ties or anything around the neck that may make breathing difficult.
- Put something flat and soft, like a folded jacket, under the head.
- Turn him or her gently onto one side. This will help keep the airway clear. Do not try to force the mouth open with any hard implement or with fingers. **It is not true that a person having a seizure can swallow his tongue.** Efforts to hold the tongue down can injure teeth or jaw.
- Don't attempt artificial respiration except in the unlikely event that a person does not start breathing again after the seizure has stopped.
- Stay with the person until the seizure ends naturally.
- Be friendly and reassuring as consciousness returns.
- Offer to call a taxi, friend or relative to help the person get home if he seems confused or unable to get home by himself.

After a seizure, it is typical for a person to be confused, disoriented, and possibly agitated or sleepy. Many people will sleep deeply for a few hours after a seizure. About 50% of people with epilepsy get migraine-like headaches after a seizure.

Prolonged (more than 5 minutes or so), continuous, or repetitive tonic-clonic seizures require emergency services.

The Job Accommodation Network suggests working with the employer to develop a plan of action including:

- emergency contact information
- visual or audible warning signs
- how/when to provide on-site medical assistance
- when to call 9-1-1
- how to provide environmental support
- who to designate as emergency responders
- who to go to for help
- how to educate co-workers about epilepsy

***What policies and procedures does your agency have in place for dealing with seizures in the office or on the job?***

## Disclosure and accommodations

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Many employers are not knowledgeable about epilepsy and will be disconcerted if their new employee unexpectedly has a seizure on the job! Some employers also fear hiring individuals with epilepsy because they are concerned about higher workplace insurance rates or believe that employees with epilepsy will use a lot of sick leave.

Workplace insurance rates are determined by how hazardous the type of work is and by an employer's overall claims record in the past, not by the physical condition of individual employees. There is no evidence that people with epilepsy are more prone to accidents on the job than anyone else. Because medications usually can control seizures for most people, they do not need to take extra time off from work because of their epilepsy.

For many of the people you are supporting, their epilepsy may be invisible compared to their other disabilities such as cerebral palsy or mental retardation. When and how should the employee share information with the employer and/or supervisor?

It can be helpful to consider the following:

(from <http://www.epilepsynse.org.uk/pages/info/leaflets/employer.cfm>)

- Does the person still have seizures?
- If they have seizures, what type(s) do they have?
- What happens during the seizures?
- How frequent are the seizures and do they occur at any particular time?
- Are the seizures triggered by anything?
- How long does the person need to recover? Some people can return to work immediately after a seizure, others may need time to recover.

In general, if you think there is any reasonable chance that the person will have a seizure on the job, you will want to counsel him/her to disclose information to the employer. Our experience is that employers have been willing to deal with some pretty significant seizures and accommodations, but were REALLY unhappy if they felt like we had been untruthful with them.

***How would these circumstances impact your advice about disclosure?***

***a. The person hasn't had a seizure in a year***

***b. The person seizures, but only at night***

***c. Stress makes it more likely for this person to have a seizure***

***d. The person has absence seizures, which might not even be noticed by others at the workplace.***

**Exercise: Accommodation Strategies  
(5 minutes to develop list)**

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What are strategies and approaches you've found successful in supporting individuals with epilepsy? Brainstorm a list with your group.

# Accommodation Ideas for People with Epilepsy

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<http://www.jan.wvu.edu/media/epilepsy.html>

People with epilepsy may experience limitations in cognitive abilities, motor abilities, and sensory abilities that can affect workplace performance. The degree of limitation will vary from individual to individual, and therefore, so will the accommodation.

## **Memory:**

- ✓ Provide written information to employee
- ✓ Post written information in a central location
- ✓ Use a wall calendar
- ✓ Use a daily or weekly task list
- ✓ Provide verbal prompts or reminders
- ✓ Use electronic organizer on computer or hand-held device
- ✓ Tell employee what activities were taking place at time of seizure (you were on the phone, in a meeting, working on project, etc.)

## **Disorientation/Disorganization:**

- ✓ Put employee's name plate on desk and/or door
- ✓ Provide building directory or employee directory by name, floor, unit, etc.
- ✓ Label items at desk (in-box, this week's videos, etc.)
- ✓ Use nametags (or other identification) for all employees
- ✓ Have auto-dial programmed on phone that connects to supervisor or other frequently used numbers

## **Time Management/Performing or Completing Tasks:**

- ✓ Provide verbal prompts or reminders
- ✓ Provide written or symbolic reminders
- ✓ Use alarm watch or beeper
- ✓ Avoid isolated workstations
- ✓ Work in teams of two or more
- ✓ Use clear timeframes or deadlines
- ✓ Make daily/weekly task list

## **Using Office Equipment (telephone, copier, fax, computers, etc.)**

- ✓ Post directions on how to use equipment
- ✓ Write down access codes, long distance account number, etc
- ✓ Use pictures illustrating directions
- ✓ Identify contact person to answer questions (example: secretary)
- ✓ Write down passwords/access codes
- ✓ Use large-button phone
- ✓ Use phone with universal symbols (fire, police, doctor)
- ✓ Use phone that is clearly labeled

- ✓ Use headset instead of handset for simplicity purposes
- ✓ Provide list of names/extension numbers

### **Driving:**

- ✓ Pair employee with co-worker who can drive to meetings or events
- ✓ Reassign it to another employee, if driving is not an essential job function,
- ✓ Transfer employee to a position that does not require driving
- ✓ Adjust schedule so employee can access public transportation
- ✓ Form a carpool with co-workers (to/from work)

### **Balancing/Climbing:**

- ✓ Use rubber matting on floor area to cushion a fall
- ✓ Use stepping stands with handrails
- ✓ Use rolling safety ladders with handrails and locking casters
- ✓ Reassign climbing duty to another employee,
- ✓ Provide head protection
- ✓ Provide eye protection
- ✓ Have arm rests on chairs to prevent falling out of chair

### **Fatigue:**

- ✓ Use anti-fatigue matting on the floor
- ✓ Provide flexible start or ending times, or adjust workweek
- ✓ Provide area to take nap during breaks or lunch

### **Ensuring safety in the workplace:**

- ✓ Designate a person to respond to emergencies
- ✓ Keep aisles clear of clutter and provide a quick, unobstructed exit
- ✓ Post clearly marked directions for exits, fire doors, etc.
- ✓ Know plan of action (practice)
- ✓ Provide sensitivity training to employees
- ✓ Know when to (or not to) call 9-1-1

### **Photosensitivity**

- ✓ Use flicker-free monitor (LCD display, flat screen)
- ✓ Use monitor glare guard
- ✓ Use "computer glasses"
- ✓ Take frequent breaks from tasks involving computer
- ✓ Replace fluorescent lights with full spectrum lighting or turn them off
- ✓ Use desk or floor lamps
- ✓ Use natural lighting source (window) instead of electric light

### **Seeing/Hearing/Communicating**

- ✓ Allow employee time to recuperate from seizure (leave employee alone)

- ✓ Identify hand signals or other universal signals that employee might use to communicate with another person
- ✓ Assist employee in discontinuing activity such as carrying, climbing, or driving
- ✓ Educate coworkers and supervisors on how to respond/react when employee has a seizure on the job
- ✓ Consult employee's plan of action to determine how to respond/react when employee has a seizure on the job

**Attendance/Absenteeism:**

- ✓ Allow employee to remain on the job after a seizure, if possible
- ✓ Provide flexible schedule or workweek, if possible
- ✓ Count all absences due to seizure activity as one occurrence

**Schedule Issues:**

- ✓ Allow flexible start time or end time
- ✓ Give employee time off while adjusting to medications
- ✓ Work day shift instead of night shift
- ✓ Work straight shift instead of rotating shift

**Exhibiting Appropriate Behavior:**

- ✓ Understand employee's limitations, and be prepared for behaviors such as drooling or spitting, urination on self or on furniture, inappropriate behavior such as trying to push or kiss someone
- ✓ Allow employee to keep change of clothes at the workplace
- ✓ Provide private space for employee to go when exhibiting such behavior
- ✓ Have employee alert co-worker/supervisor when seizure is about to occur
- ✓ Provide sensitivity training/disability awareness to coworkers

**Avoiding Seizures on the Job:** Employees who have epilepsy may be able to control seizure activity by using medications. However, other situations occur in the workplace that could create the onset of seizures. Try to reduce or eliminate these situations so seizure activity does not occur. Some triggers include:

- ✓ Hormonal changes (pregnancy, menstruation, aging)
- ✓ Sensitivity to fragrances or other chemicals in the workplace
- ✓ Stress on the job
- ✓ Disruption in daily activities due to working varied shifts (such as sleeping, taking medications, or eating)

*How did this list compare to your ideas?*

## Online Resources on Epilepsy and Employment

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[Epilepsy](#) - Neuroscience for Kids  
[EpiCentre](#)  
[Epilepsy.com](#)  
[Epilepsy - World Health Organization \(WHO\)](#)  
[Epilepsy Treatment - WHO](#)  
[Epilepsy History- WHO](#)  
[Epilepsy - Social/Economic - WHO](#)  
[Epilepsy Fact Sheet](#) - NINDS, NIH  
[Epilepsy Foundation of America](#)  
[Frequently Asked Questions about Epilepsy](#)  
[Epilepsy - Genes may build the road in treatment](#)  
<http://www.nichcy.org/pubs/factshe/fs6txt.htm>  
<http://www.epilepsyfoundation.org/>

### Quiz Answers

What are three types of seizures experienced by people with epilepsy?

**Absence (petit mal), tonic-clonic (grand mal), atonic, simple partial, complex partial, myoclonic**

True or False: "Epileptics" is an appropriate label for people with epilepsy, just like people with diabetes are called diabetics.

**False: The word "epileptic" should not be used to describe someone who has epilepsy, as it defines a person by one trait or problem. It is better to refer to someone as "a person with epilepsy" or to a group of people as "people with epilepsy."**

True or False: For most people with epilepsy, the cause is not known.

❖ **True.**



# 30 Minute Lesson: Feedback Form

Please let us know what you think of this product, so we can continue to better meet your training needs. Fax or mail to Laurie Ford at 6912 220<sup>th</sup> SW, Suite 105, Mountlake Terrace, WA 98043; Fax (425) 774-9303

Topic of Lesson \_\_\_\_\_

- Facilitator Version
- Participant Version
- Non-Facilitated Group Version
- Self-Study Version

1. On a scale of 1 to 5, please rate the relevancy of these materials to your job \_\_\_\_\_ (1 is worst, 5 is best)
2. On a scale of 1 to 5, please rate the positive impact of these materials on your professional skills, knowledge, and abilities (1 is worst, 5 is best) \_\_\_\_\_
3. On a scale of 1 to 5, please rate the positive impact of these materials on your organization (1 is worst, 5 is best) \_\_\_\_\_
4. What was the most useful part of the lesson?
5. What was the least useful part of the lesson?
6. How could this lesson be improved?
7. What additional topics would you like to see in a 30 Minute Lesson?