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**Epilepsy at Work: A Course for Employees and Co-workers**

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**TOPIC 1: WELCOME**

## Can You Tell?

One of these five people has epilepsy—but all five are affected in some way by this disability.

**Yuen:** Yuen doesn’t have epilepsy. But as a yoga instructor with a very large clientele, she would like to better understand the disability. The way she sees it, if 1 in 100 people have epilepsy, chances are eventually, someone will have a seizure in her studio, and she wants to know how to help.

**Nancy:** Nancy, an active and successful young lawyer, is about to learn SHE has epilepsy. How will this affect her life? Will she lose her job? Will she need to change careers?

**Tarik:** Tarik doesn’t have epilepsy. He is the Director of Human Resources for his company. It is his job to ensure that employees with disabilities receive the accommodations they require to perform their jobs to the best of their ability. But how do you accommodate someone who’s having a seizure? Can this person still do the job? Will he have to let this individual go?

**Deb:** Deb doesn’t have epilepsy—but her daughter, Nancy, has been living with seizures. As a retired community nurse, she’s met many people with epilepsy through the years, and she’s really worried for her daughter. How will she be treated at work when they find out she has seizures?

**Reuben:** Reuben is the boss. He doesn’t have epilepsy, but he is about to discover that Nancy, a bright young member of his legal department, does. He is likely to wonder how will this impact Nancy’s ability to do her job well. Can she be productive? Does she put the company at risk? What can he do?

## Epilepsy – Understanding Is Key

As you’ve just learned, Nancy’s epilepsy is a matter of some concern for her family, friends, and co-workers.

**The problem isn’t Nancy’s epilepsy; rather, a lack of understanding and awareness of the disability**. Even Nancy has preconceived notions and fears about the condition—which might be making the situation worse than it ever has to be.

## Learning Objectives

In this e-learning course, you and Nancy will learn more about the seizures she’s recently started to experience, and adjustments she and her co-workers can make to ensure her continuing success at work.

By completing this e-learning course, you will:

* Increase your understanding of epilepsy, and
* Learn how to accommodate people in your workplace.

## Credits and Disclaimer

Epilepsy is a complex neurological condition, which can vary widely between individuals. The information contained in this course provides a general overview of the condition and its impact in the workplace, but is in no way intended to address all possible situations.

The intent of **Understanding Epilepsy in the Workplace** is to provide general information about epilepsy and workplace issues. It does not directly or indirectly provide personal, medical or legal advice. In the event that you use any of the information for yourself or your place of employment, the authors, publishers, developers and sponsors assume no responsibility for your actions or outcomes.

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For further information, contact your local epilepsy organization: 1-866-EPILEPSY (1-866-374-5377)

**TOPIC 2: EPILEPSY AND ITS EFFECT**

**Getting to Know Nancy**

Learn more about Nancy and her mom Deb.

**Nancy**

* Late twenties
* Active lifestyle
* Practicing law for the last five years
* Recently started experiencing what she calls “episodes”

**Deb**

* Worked as a community nurse for 25 years
* Taken epilepsy awareness courses for work
* Has not witnessed one of her daughter’s “episodes” but is concerned about them based on Nancy’s description of them

## Getting to Know Epilepsy

Nancy knows very little about epilepsy, so as she waits in the doctor’s waiting room for her appointment, she’s started browsing through a few pamphlets to learn more about the disability.

**It’s Neurological:** Epilepsy is a disorder that results from sudden bursts of electrical activity (misfiring neurons) in one or various parts of the brain. These bursts of electrical activity result in “seizures,” which vary in form, strength, frequency and duration depending on which part of the brain is affected.

**Its Cause is Unknown:** Epilepsy’s effects (seizures) are intermittent and unpredictable. If a person has two or more seizures – which are due to another condition – that person will be diagnosed as having epilepsy. In approximately 70% of all diagnoses, epilepsy’s cause cannot be pinpointed.

**It’s Not Contagious:** Epilepsy is not contagious. There is no way for a person with epilepsy to pass it on in their workplace.

**It’s Not Uncommon:** Each year, on average, 15,500 Canadians are diagnosed as having epilepsy. Epilepsy affects more than 300,000 Canadians. This means 1 of almost every 100 Canadians has epilepsy.

## Knowing is Understanding

**DIALOGUE**

**Nancy:** Hi, Doctor Hernandez.

**Dr. Hernandez:** Hello, Nancy. You’re looking well. What’s new? Anything in particular you’d like to discuss today?

**Nancy:** Thank you. Yes, there is. I’m not sure where to start, though.

**Dr. Hernandez:** You sound worried. Let’s not worry until we know there’s a reason for it, okay? Why don’t you tell me what’s going on these days?

**Nancy:** Well, I’ve been having these . . . episodes. It’s happened a few times in the past month or so. I don’t really know what’s happening to me when they occur—but my friend saw one and she told me I had some kind of fit or seizure.

**Dr. Hernandez:** Well, that’s definitely something we’ll want to explore. I don’t think anyone uses the term “fit” or “episode” anymore, so let’s say they were seizures—and go from there, okay? So tell me, did your friend describe these seizures?

**Nancy:** Yes. She said at first my entire body went stiff. She called it “board-stiff”, and then I fell to the ground. Then she said I started to shake about, and my arms curled.

**Dr. Hernandez:** Hmmm. That certainly sounds like some sort of seizure. And how often has this happened?

**Nancy:** As far as I know, three times over the past five or six weeks. I wanted to ignore it all, but my mom found out and she pretty much insisted I come and talk to you about it. She thinks it may be a sign of epilepsy.

**Dr. Hernandez:** I’m glad she did. Your mom was right. So, let’s take a look at the kinds of seizures caused by epilepsy. We might find a match with what you’ve experienced.

**Nancy:** Okay.

**Epilepsy FYI**

**Seizure Definition:**

* Seizures can look different, depending on the type.
* Seizures may cause involuntary changes in body movements (like convulsing), strange physical sensations or behaviour, and can often cause a loss of consciousness.
* Effects of a seizure can also be as subtle as a fleeting numbness, a loss of memory, visual changes, sensing strange smells, or a sensation of fear and total state of confusion.

## Types of Seizures

**Dr. Hernandez:** So, Nancy, I’ll start by saying that seizures come in a variety of forms. They are categorized by what part and how much of the brain is affected. Different types of seizures also have different characteristics and appearances. These are the four types of epileptic seizures you are most likely to see. Let’s look at each kind—to see if you think you had one of them, okay?”

**Tonic Clonic:**

These types of seizures (formerly called “Grand Mal” seizures) are what most people think of when they think of a seizure. This type of seizure is **a convulsive seizure**. It occurs in **two phases**:

**Tonic Phase**:

* **Stiffening** of muscles
* Person **loses consciousness**
* **Body becomes rigid** as person falls to the ground

**Clonic Phase**:

* Jerking and twitching of the body in **convulsions**

Duration of seizure **(both phases) is about one to three minutes,** and after a seizure the person often feels confused or disoriented.

(Person may also make unusual noises and/or lose bowel or bladder control during this type of seizure).

**DIALOGUE:**

**Dr. Hernandez:** It sounds to me like you may have had a Tonic Clonic seizure. This used to be known as a “Grand Mal” seizure. A Tonic Clonic seizure occurs in two stages. With the first stage, known as the Tonic Phase, your muscles will stiffen and then there will be a loss of consciousness. In the last part of this first phase, the entire body becomes rigid, and the person falls to the ground. The second stage, known as the Clonic Phase, involves a jerking and twitching of the body—we call those convulsions. After the seizure, there can be a period of confusion or disorientation.

**Nancy:** Oh. And how long does this go on? The seizure?

**Dr. Hernandez:** Well, that can vary, Nancy—but the seizures are usually about one to three minutes. Does this sound like what your friend described she saw you experiencing?

**Nancy:** Almost exactly.

**Dr. Hernandez:** Okay, that’s what I thought. But let’s look at the other kinds of seizures too—just to be sure you haven’t experienced those types.

**Absence:**

These kind of seizures were formerly called “Petit Mal” seizures and are a **non-convulsive** seizure. When someone’s experiencing this kind of seizure they:

* Will appear as though the person is **staring blankly into space**
* May repeat many timesthroughout the day
* Usually more **common in childhood**
* Are often **mistaken for daydreaming** or not paying attention

This kind of seizure can last from **5 to 15 seconds.**

**DIALOGUE**

**Dr. Hernandez:** Absence Seizures—they used to be called “Petit Mal” seizures—are a *non*-convulsive type of seizure. If you have an Absence Seizure, you will look as though you’re frozen and staring blankly into space. These kinds of seizures may repeat many times throughout the day and can last from 5 to 15 seconds. They’re more difficult to identify as a seizure— since they can be mistaken for daydreaming or not paying attention.

**Simple Partial:**

Characteristics of a Simple Partial seizure, **motor or sensory,** may include:

* **No loss of consciousness** (usually)
* Unusual visual, smell and sound sensations – these **sensations may be described as an “aura”**
* Unintentional movement of one part of the body
* Overwhelming feelings of fear or joy
* Dizziness and stomach discomfort

This kind of seizure **can last 30 to 60 seconds.**

**DIALOGUE**

**Dr. Hernandez:** With Simple Partial seizures the person will not lose consciousness. Instead, they will experience unusual sensations, such as smells that don’t make sense—like something’s burning when nothing is. Sometimes it involves impaired or distorted vision and hearing. These sensations are sometimes described as an “aura.” Simple Partial seizures can also involve convulsions of one part of the body. This kind of seizure tends to last about 30 to 60 seconds—and here’s something for us to keep in mind—Simple Partial seizures can occur alone, or can be followed by a Tonic Clonic seizure.

**Nancy:** Okay. That does sound sort of familiar. I think I may have felt that kind of thing too. That aura sensation.

**Dr. Hernandez:** Okay, I’m not surprised to hear that. It’s common for people to experience both Simple Partial *and* Tonic Clonic seizures.

**Complex Partial:**

Someone experiencing this type of seizure may:

* Experience an “aura” before the seizure occurs
* Appear dazed and confused or drunk or high on drugs
* Exhibit random walking, mumbling, head turning or pulling at clothing – and then not remember doing this

This type of seizure can last about one to two minutes and the person may feel tired, have a headache or feel nausea afterwards.

**DIALOGUE**

**Dr. Hernandez:** Complex Partial seizures can involve a loss of consciousness as well. When Complex Partial seizures occur, the person may appear dazed and confused—maybe even drunk or high on drugs. There may be random walking, mumbling, head turning or pulling at clothing. Like a lot of seizure types, the person usually can’t remember these repeated motions. Has anyone suggested that you’ve done anything like this Nancy?

**Nancy:** Umm, no, not at all.

**Dr. Hernandez:** Okay—in order to make a proper diagnosis we need to do some neurological testing. So, why don’t we get you scheduled and then we’ll devise our management plan after those results are in. Why don’t you browse through this brochure while I get you slotted in for some testing in the next few days? Then when we’re both finished, I can do a physical assessment and then we can discuss any questions you may still have.

**Nancy:** Okay. Thanks Doctor.

##

## Diagnosis of Epilepsy

**Nancy`s Diagnosis:** There is no single conclusive diagnostic test for epilepsy. A diagnosis is formed from a combination of tests and history such as an investigation of a first seizure, a physical examination, results of EEGs, CT scans and MRIs, and family medical history.

**The Diagnosis:** Nancy’s had her tests done and is meeting with Dr. Hernandez to discuss the results.

**Patient**: Nancy Smith

**Diagnosis**: Tonic Clonic seizures – sometimes preceded by Simple Partial seizures

**Surgery Indicated**: Possibly

**Meds Indicated**: Anti-convulsant

**Recommendations:** Maintain healthy active lifestyle and take steps to manage triggers for seizures

## The Anxiety

*What will everyone think? Will I miss work? Am I going to lose my job?*

Nancy is very anxious about having epilepsy. Nancy confides to her mother, Deb, that she’s really worried about missing a lot of work because of it. What if she has a seizure at work? What if there are side effects from the drugs she has to take? Nancy, like many people diagnosed with epilepsy, fears her condition will do nothing but negatively impact her life.

## Epilepsy is Manageable

Deb assures Nancy that, with the right lifestyle choices and an anti-convulsant medication, she won’t miss any more work than the average person. Deb decides she should try to help Nancy address her worry, so she has Nancy complete a learning game Deb used when she was a community health nurse. The exercise helps those recently diagnosed with epilepsy think about what they can do to help manage their epilepsy.

Let’s work through that exercise with Nancy.

## Treatment and Lifestyle Changes

**Lifestyle Techniques**

|  |  |
| --- | --- |
| **Should** | **Should Not** |
| Keep active and fitManage stressTalk to your doctor about drug therapyTalk to your doctor about surgeryKeep a seizure journalTalk about epilepsy with family and friends | Lose or gain a lot of weightDrink a lot of alcoholStop taking drugs when the seizures stop happeningSkip meals when you’re feeling good |

Taking good care of yourself, and addressing concerns and stresses related to epilepsy can also go a long way to reduce its effects!

Epilepsy is managed in various ways, depending on the nature of the seizures and whether or not the cause of the seizure is known. Although surgery is sometimes an option, single and multiple drug therapies are the most common means of managing epilepsy.

Also, many individuals report a lessening of frequency and severity of seizures by using alternative therapies such as yoga, acupuncture and cognitive behavioural therapy. And just as Deb assured Nancy, when someone with epilepsy takes proper care of themselves—they don’t miss any more work and are just as productive as someone without epilepsy.

## Triggers

Now that Nancy knows more about all the different available approaches and techniques for managing her epilepsy, Deb wants to be sure her daughter knows to avoid exposing herself to common seizure provokers—also known as triggers.

**Epilepsy FYI**

Deb explains to Nancy that a seizure trigger is an external factor, like flashing lights, which can affect brain activity and bring on a seizure in a person who has epilepsy. There are many known possible triggers for seizures.

## Types of Triggers

Deb has Nancy review a list of common triggers and check off the ones she thinks she should try to avoid.

* glass of wine – drinking too much alcohol can be both a trigger for a seizure and interfere with your medications.
* prescription bottle – skipping an anti-convulsant pill—or not taking medication on schedule—can trigger a seizure.
* sleep – failure to get regular or sufficient sleep can trigger seizures too.
* bright light – sometimes people with epilepsy have seizures triggered by bright lights or lights that flash or flicker.
* stress – too much unmanaged stress and anxiety can trigger a seizure.

Deb reminds Nancy that a trigger for one person may not be a trigger for another. Recognizing her triggers and working to avoid them will lessen the likelihood that Nancy has a seizure in the workplace.

## Common Misconceptions

Nancy is still very anxious about how her epilepsy may affect her and be perceived by her co-workers.

Deb suggests that maybe it would be a good idea for Nancy to complete a quiz about epilepsy myths and facts, before Nancy tells her employer about the recent diagnosis—in case anyone at work has any misconceptions about epilepsy in the workplace.

Let’s take the quiz with Nancy now!

**Epilepsy FYI**

Epilepsy & Jobs

Epilepsy is a barrier to employment only when the potential of having a seizure on the job would endanger the person’s or the public’s well-being, such as driving or operating heavy machinery.

Working in dangerous or risky jobs is discouraged, until the person with epilepsy has their seizures completely under control. **However, Deb’s assured Nancy, *most* jobs can be done just as effectively by someone who is living with epilepsy as by someone who is not.**

## Understanding Epilepsy in the Workplace – Quiz #1

**Understanding Epilepsy in the Workplace**

* **Question:** Epilepsy is a contagious condition that may be passed along to others.
* **Answer:** So not true! What is known is that epilepsy can be caused by brain tumours, genetics, interactions with drugs, oxygen deprivation and traumatic brain injuries. There is no way for a person with epilepsy to pass it on.
* **Question:** For a person with epilepsy, the social effects of epilepsy can be more difficult than the seizures themselves.
* **Answer:** Unfortunately—that’s a reality. The unpredictable and traumatic nature of seizures and the ignorance and stigma still associated with epilepsy can lead to depression, frustration and a lack of confidence.
* **Question:** People with epilepsy are physically limited in what they can do.
* **Answer:** Big myth! People with epilepsy have the same range of physical abilities as the general population. And while it is true that some people experience severe and frequent seizures and are unable to work, most are successful and productive in physically challenging careers when suitable precautions are taken.
* **Question:** For people who have seizures, each episode will usually take the same form each time.
* **Answer:** T’is true, yes. A person with epilepsy will have a predominant type of seizure, and with proper response protocol, catered to that person’s type of seizure, co-workers will be able to manage with confidence should they ever need to respond to a seizure.
* **Question:** Some people with epilepsy may appear to be drunk or high on drugs.
* **Answer:** Yessiree Bob! That’s a fact. A seizure type known as Complex Partial seizures can appear as if the person is drunk or high, as they may be mumbling or wandering around. This type of seizure typically lasts a few minutes.

## Epilepsy in the Workplace

Nancy has decided to disclose her diagnosis to her law firm’s HR Rep, Tarik

**Read Nancy’s email to Tarik below:**

Hi Tarik,

I’ve told Reuben I’m working from home for a few days, but wanted to tell you that I’ve recently been diagnosed with epilepsy. I have some thinking to do about all of it—but I *am* thinking I may have to resign from my job. I’m afraid of both having a seizure at work and about what everyone there is going to think if they find out about my epilepsy.

I just wanted to let you know what’s going on—in case I decide over the next few days to resign. Sorry for using email to share this with you. I’m still pretty upset about all the recent news and don’t feel like talking about it in person.

**Read Tarik’s response to Nancy’s email:**

Hi Nancy,

Don’t worry about us here—just take good care of yourself, okay?

Please know that your job is not in jeopardy and you don’t need to resign.

I have worked with people with epilepsy before, and I know they have often experienced discrimination in the workplace, so they may be afraid to tell people at work that they are affected by this very manageable condition. No need to worry about that here though—I have a plan.

What I would like to do, Nancy, if you’re okay with it, is to quickly start to inform and educate your teammates. I think the best approach is to host a Lunch and Learn session—and have a representative from the local epilepsy agency attend, to support us. Also, it would be ideal if you attended too—but that’s not a requirement, if you’re not feeling comfortable enough yet. The kinds of topics I’d like to cover in the session could include:

* Epilepsy basics
* Myths and facts
* How to discuss epilepsy
* How to accommodate an employee with epilepsy
* Creating an inclusive workplace

The idea of the learning session would be to help staff become more knowledgeable about epilepsy in general—and, if you’re okay with it—we’d also let everyone know about your diagnosis. Something for you to think and let me know about Nancy, okay?

Hope all of this helps you feel less anxious. Call me if you need anything—or just want to talk.

Tarik

## Disclosing

A person with a disability, including epilepsy, has no legal obligation to disclose their disability to an employer if the person does not require job accommodation, or if their condition does not affect their occupational health and safety.

According to the Canadian Charter of Rights, an employer cannot deny a person an interview, refuse to hire them, or fire them, because they have a disability, so long as it does not adversely affect job performance. An employer may ask questions or require an employee to have a medical examination only when it has a legitimate reason to believe that epilepsy or some other medical condition may be affecting the employee’s ability to do their job.

Disclosing to an employer (manager or human resources department), however, doesn’t mean that co-workers can be informed. This information is confidential. If safety issues are a factor, the employer may want co-workers to know so that appropriate measures can be taken during or just before a seizure. This is a conversation to be had between the employee with epilepsy and the employer.

## Accommodation

Under the Ontario Human Rights Code, employers have a legal duty to accommodate the needs of a person with a disability. The Employment Standard under the Accessibility for Ontarians with Disabilities Act builds on this requirement. Accommodation is a shared responsibility – employers, unions, and employees must work together in good faith to identify and implement accommodations for people with epilepsy. If providing accommodation will cause an organization undue hardship by way of financial costs, the ability to get outside funding, or a multitude of health and safety risks, an employer can choose not to provide accommodation.

## Breaking the Ice

Nancy felt a little relieved after reading Tarik’s email—but she was still feeling uncomfortable talking about her epilepsy with her boss, Reuben. She called Tarik and asked if he would tell Reuben for her.

**Nancy:** Tarik, could you discuss all this with Reuben?

**Tarik:** Sure, of course, Nancy.

After talking to Nancy, Tarik calls Reuben, to discuss Nancy’s diagnosis and anxiety. Tarik and Reuben both agree that they should schedule a meeting to talk about Nancy’s epilepsy and how it might affect the workplace if she comes back to work.

**Tarik:** Reuben, Nancy asked me to discuss a medically-related matter with you.

**Reuben:** Sure, Let’s schedule a meeting to discuss.

##

## Accommodation and Planning

**DIALOGUE**

**Reuben:** So, first, I wanted to thank you for updating me on Nancy’s situation, Tarik. And now I’m just wondering—how is Nancy’s epilepsy going to affect us here at the office? I mean, I love Nancy’s work and everything, but are we going to have to jump through hoops to keep her here now? I mean I hate to ask, but is this going to be a big disruption around the office—having someone with epilepsy here working with us?

**Tarik:** That’s a fair question, Reuben, and I thought you’d be concerned about what Nancy’s return to work will look like—so I’ve prepared a bit of a presentation to help answer the kinds of questions most employers ask about epilepsy and the workplace.

Employment Accommodation means modifying a job, a job site or the way a job is performed so a person with a disability can have equal access to work and perform to the best of their ability. These modifications should include and integrate people with disabilities into the workforce in ways that respect their dignity and worth.

The types of accommodations vary depending on the needs of the individual with epilepsy. In fact, many people with epilepsy will not need any accommodation at all.

The first step in providing accommodation is to privately discuss needs with the employee and then create both an Accommodation Plan and a First Aid Plan.

For people with epilepsy, discussing and creating an Accommodation Plan—confidentially with managers or HR staff—can be comforting. For co-workers, knowing there’s a First Aid Plan available reduces the fear and mystery of a seizure occurring in the workplace. So, for the person with epilepsy, it provides for their safety and dignity, and allows them to work to the best of their ability. So, Reuben, would you like to know more about an employer’s duty to accommodate and preparing both an Accommodation Plan and a First Aid Plan?

**Employment Accommodation** is an adaption or adjustment made to support a person with a disability in the performance of an essential duty or requirement of a job.

**Duty to Accommodate:**

Under the Ontario Human Rights Code, employers have a legal duty to accommodate the needs of a person with a disability. The Employment Standard under the Accessibility for Ontarians with Disabilities Act builds on this requirement. Accommodation is a shared responsibility – employers, unions, and employees must work together in good faith to identify and implement accommodations for people with epilepsy. If providing accommodation will cause an organization undue hardship by way of financial costs, the ability to get outside funding, or a multitude of health and safety risks, an employer can choose not to provide accommodation.

Remember that epilepsy affects people differently and therefore the types of accommodations required by individuals will also vary.

**Accommodation Plan (Private/Confidential):**

An Accommodation Plan is created jointly by the employee, employer and union (if one exists), and is to be kept confidential. This plan is used to outline strategies to accommodate disability-related concerns such as memory, fatigue and workplace hazards. If in place, the plan will also identify who the primary and secondary responders are and whether or not a medical incident report should be completed after each event. Primary and secondary responders are co-workers who, with the employee’s consent, have agreed to help during a seizure.

Your local Canadian Epilepsy Alliance organization (1-866-EPILEPSY) can be a tremendous source of information for the development of an epilepsy Accommodation and First Aid Plan and for staff awareness and sensitivity training.

**First Aid Plan (Public/Accessible):**

The First Aid Plan is a tool that can be used to prepare for, or respond to, emergency situations that arise when a person has a seizure on the job. The Plan could include information about what the employee’s seizures look like, how to respond to seizures at work, and emergency contact information, of families and friends. Having this kind of visibly accessible plan will help to reduce fear and confusion that co-workers may experience if they see an employee having a seizure on the job.

## Types of Accommodation

Reuben has always liked Nancy’s work and now that he knows accommodating her is fairly straightforward, he is looking forward to her return. He also wants her to feel as welcome as possible when she does. He asks Tarik what kinds of things they might need to do, to be sure Nancy’s safe and comfortable while she’s working.

Review the different types of accommodation to learn with Reuben what kinds of steps the law firm can take to be sure Nancy can return to a positive, productive and safe workplace:

* **Job Carving:** Modifying an existing role so that it can be successfully performed by an individual with a disability, while simultaneously meeting the needs of an employer. This creation or modification process involves assessing a role, task by task, identifying which tasks are suitable and which are not, relevant to the employee’s abilities, and then creating a modified role best suited to the person’s task-related strengths and physical limitations.
* **Flexible Scheduling:** Allowing an employee with epilepsy to work based on a flexible schedule can be an effective way to limit the absences recorded on the person’s employment record, in case their seizures and recovery periods are occurring during regular business hours. Flexible scheduling is also a good way to help the employee to better manage stress levels and workloads, so that they can still achieve their goals, without provoking seizures and unnecessary fatigue.
* **Telecommuting:** Eliminating the stress of commuting and potential office space triggers makes Telecommuting (virtual office, working from home) an effective way to get 100 per cent productivity from the employee with epilepsy. Today’s communications technologies make telecommuting a very effective and productive way to work away from the office site.
* **Rest and Relax Space:** After a seizure occurs (the “postictal state”) a person with epilepsy may experience an altered state of alertness (e.g. grogginess, confusion, fatigue), which usually lasts between five and thirty minutes, but sometimes longer in the case of larger or more severe seizures. It is during this period that the brain recovers from the trauma of the seizure. Providing a quiet, private space for the employee who has had a seizure in the workplace can help lessen the stress of the recovery period and helps other employees feel more calm and relaxed about their co-worker’s recovery after a seizure.
* **Modified Workstation and Areas:** For people working with epilepsy, the following workspace modification may also be required:
* Removing sharp corners and adding padding to the edges of workstations along with the addition of anti-fatigue matting or carpet to hard floors to reduce risk of injury in the event of a seizure
* Avoiding the use of or working around unguarded machinery or tools which could cause injury in the event of a seizure
* Avoiding working from heights such as on scaffolding, ladders or stairs, to reduce risk of injury in the event of a seizure.

For individuals with photosensitive epilepsy, some modifications to workplace lighting and computer screens or equipment may be required, including:

* Flicker-free lighting
* Computer screen filters
* Flat panel monitors
* **General Accommodation:** Some employees may need one or more of the following examples of general accommodations at work:
* Breaks to take medication or avoid a seizure trigger
* Leave to seek or recuperate from treatment or adjust to medication
* A consistent start time
* A checklist to assist in remembering tasks (epilepsy can in some cases cause short term memory issues)
* Someone to drive to off-site meetings and other work-related events

## Acceptance and Support

Tarik and Reuben agree that the next important step in the process of welcoming Nancy back to the office is to help educate her co-workers about epilepsy—to be sure they don’t fear her condition or avoid working closely with her.

Tarik has talked to Nancy and confirmed she’s comfortable with him doing a Lunch and Learn session, but she’s still too uncomfortable about her epilepsy to attend the session. Tarik’s done his research, contacted the local epilepsy organization and they’ve agreed to help facilitate—and Tarik is happy to do the session the next day.

## A Supportive Environment

**DIALOGUE**

**Tarik:** What would you do if one of your co-workers told you they had epilepsy or had a seizure at work? Would you automatically ask if they need any support in their job?

Saying something is better than not saying anything. Don’t be afraid to say the wrong things.

Creating an opportunity to talk about epilepsy and how it affects your co-worker will allow accurate information to be presented and will quickly dispel rumours, myths and misinformation. Open lines of communication will go a long way towards reducing the fear and stress for the person with epilepsy.

Although open dialogue and communication is encouraged, allow your co-worker with epilepsy to lead these discussions, when they have the knowledge and confidence to do so. Practical and emotional support at work can make a big difference to them.

Showing this kind of support can sometimes be as easy as asking thoughtful questions.

Would anyone like to see other examples of the kinds of questions you might ask a co-worker who has epilepsy?

**Questions You Could Ask Your Co-Worker About Their Epilepsy**

1. What type of seizures do you have?
2. What do your seizures usually look like, and how long do they typically last?
3. How often do you have seizures?
4. Are you likely to need any assistance during a seizure?
5. Do you get a warning of any kind so that you can alert me to be ready to assist you?
6. What should I do if you have a seizure?
7. Is there anything about the work we do that acts as a seizure trigger?
8. Is there anything we can do to help you reduce seizure triggers?
9. Is there a formal Accommodation Plan and First Aid Plan that the manager or HR department has developed with you?
10. May I read a copy of your First Aid Plan?
11. Are there certain circumstances where you might like me to contact your family or friends?
12. Are there contact phone numbers on the First Aid Plan?
13. What happens after your seizures? Are you able to continue work or do you need to rest or leave?
14. Does anyone else in the company know that you have epilepsy? Is it common knowledge or just us in the department?
15. Would you be comfortable with me being your primary responder or is there someone else in the company I should contact if I see you having a seizure?
16. Have you thought about taking some time at a staff meeting to provide us with some epilepsy information?
17. Always maintain your co-worker’s privacy and allow them to share what it’s like to live their life with epilepsy.

Always maintain your co-worker’s privacy and allow them to share what it’s like to live their life with epilepsy.

**Why Should We Talk about Epilepsy?**

* Not talking about something important can cause stress for everyone
* You will feel more empowered and more at ease
* Your co-worker with epilepsy will feel the same and will also feel less vulnerable and less isolated

**It Can Come as a Shock**

* Receiving a diagnosis of epilepsy and/or developing seizures can be a shock for everyone
* If a co-worker has been recently diagnosed with epilepsy, they will need time to deal with their condition
* Once they’re ready, they will likely appreciate some open and thoughtful communication

## First Aid Response

At about the same time Tarik is facilitating the Lunch and Learn session, Nancy decides a yoga class would probably help her relax and stay fit, as the doctor encouraged her to do. As she is coming into her friend Yuen’s yoga studio, Nancy has another seizure. Fortunately, Yuen knows Nancy has recently been diagnosed with epilepsy—and Yuen took an epilepsy awareness course a few years ago. So Yuen knows how to respond to Nancy having a seizure.

Learn how Yuen monitors and helps Nancy:

1. Yuen remains calm and times the seizure.
2. She protects Nancy from injury by moving hard or sharp objects out of the way. She places something soft under her head.
3. Yuen does not call 911—unless the seizure lasts longer than five minutes, or Nancy sustains a serious injury as a result of her seizure and fall.
4. She does not attempt to insert anything into Nancy’s mouth, as it is impossible to swallow her tongue. Yuen loosens any tight clothing or jewellery.
5. As the seizure subsides, Yuen gently rolls Nancy on her side, staying with her until she becomes re-oriented.

## Understanding Epilepsy in the Workplace – Quiz #2

As Nancy rests and recovers after her seizure, Tarik is back at the office finishing up a very successful Lunch and Learn. He wraps up the session by having the attendees complete a quiz about the myths and realities of epilepsy in the workplace. Let’s complete that quiz along with the session participants.

* **Question:** People with epilepsy have the same or fewer days away from work than the general population.
* **Answer:** That’s very true! Statistics show that people with epilepsy generally take better care of themselves through diet, exercise and regular sleep patterns than the general population and are less likely to miss time away from work. Statistics show that people with epilepsy generally have fewer lost time accidents in the workplace than the general population.
* **Question:** A person having a seizure will harm those around them.
* **Answer:** Nope! The chance of harm coming to employees and bystanders is almost non-existent. If a co-worker obtains some basic seizure first aid training, it will lessen the chance of harm coming to the person having a seizure as well.
* **Question:** Anyone who has epilepsy has likely had a seizure at work.
* **Answer:** Oh. My. Gosh! So not true! The majority of people who have epilepsy manage their condition well with lifestyle and medication, and understand and avoid seizure triggers thus reducing seizures.
* **Question:** Many people with epilepsy will require no additional support or adjustments in the workplace.
* **Answer:** That’s super true! A positive approach helps boost staff morale and productivity. Some minor accommodation could be as simple as adjusting start and finish times to later in the day or providing a quiet place where a person can rest after a seizure.
* **Question:** People with epilepsy cannot be in a job that is stressful or holds a lot of responsibility.
* **Answer:** Total myth! While it’s true that for some people with epilepsy, high stress situations can act as a trigger for seizures, most people with epilepsy recognize their triggers and have techniques and safeguards in place to reduce and manage them thus eliminating the risk of seizures.

##

## The Inclusive Workplace

**DIALOGUE**

**Tarik:** Supporting an inclusive workplace may require some adjustments; however, the steps you take as a manager and/or co-worker to create an inclusive workplace environment will benefit everyone.

Managers and co-workers should lead by example and show an interest in assisting co-workers and customers with disabilities in the workplace—including sometimes nearly *invisible* disabilities, like epilepsy.

An example of fostering an inclusive workplace, specifically for someone with epilepsy, use language that is respectful and welcoming. For epilepsy that means referring to your co-worker as a person “with”, “affected by,” “living with” epilepsy. Always avoid using words such as “epileptics,” “fit” and “possessed”—these are out dated and should be considered derogatory.

All employees should feel that their contributions to the company are appreciated and valued. If the person can do the job, they must be given the opportunity to do that job, and provided with the support to do it to the best of their ability.

Give your co-workers the chance to use their talents to their fullest and assure them of equal opportunities to move ahead.

An example of fostering an inclusive workplace, specifically for someone with epilepsy:

**What Makes an Inclusive Workplace?**

An inclusive workplace is one where the human right principles of fairness, respect, equality, dignity and autonomy are promoted and are part of the organization’s everyday goals and behaviour. Working in an inclusive workplace means that everyone can succeed in achieving his or her personal and professional goals. A workplace where people are valued because of their differences. A workplace where employees and co-workers understand the needs of people with disabilities such as epilepsy and easily, with a little knowledge and planning, work together to manage epilepsy in the workplace.

**How to create an inclusive workplace:**

* Request training that addresses a co-worker’s epilepsy to gain a better understanding of what your co-worker lives with on a daily basis. New knowledge is powerful and can be achieved with a simple Lunch and Learn session. To find out more, contact a local epilepsy organization or call 1-866-EPILEPSY.
* Be proactive and compassionate in rearranging some specific job tasks.
* Managers and HR staff may examine alternate work options such as flexible time, part-time, job sharing, contract work and leaves of absence.
* Use language that is respectful and welcoming. For epilepsy that means referring to your co-worker as a person “with”, “affected by”, “living with” epilepsy. Avoid terms such as “epileptics”, “fit”, “possessed”.
* Accommodate your co-worker with epilepsy.
* Be accessible and open to communication with managers and co-workers.
* Share work fairly without judging or assuming your co-worker with epilepsy can’t do the job.

##

## Supporting Your Co-Workers

**DIALOGUE**

**Tarik:** So let’s wrap up our Lunch and Learn by considering the kinds of things people sometimes wonder—and even *fear*, when working with someone with a disability like Epilepsy.

Will I have to do more work because my co-worker has epilepsy and can’t pull their load? Will my co-worker with epilepsy miss a lot of days of work? Do I have to walk around all day pretending my co-worker doesn’t have epilepsy? Do we have to call an ambulance every time my co-worker has a seizure at the office?

The answer to all of these questions and concerns is absolutely *not*.

People with epilepsy often work harder —to try to compensate for their condition. People with epilepsy, once they’ve disclosed their condition to their co-workers—will rarely shy away from talking about it, if you have questions. And finally, seizures do not mean we need to call 911. We’ll look at appropriate responses using a seizure simulator at the end of today’s training session.

Finally, before we get back to work, let’s review a useful tool we can use to reflect on what we’ve learned today.

**Considering Your Thoughts About Epilepsy—Co-Worker Reflection Questionnaire**

It is natural to experience anxiety, fear and trepidation after finding out your co-worker has epilepsy. But with open communication, education and examining your own thinking about your co-worker, you can learn to act with confidence as well as positively and appropriately at work beside your co-worker and his/her condition.

Review the following questions and record your responses and thoughts in detail in the spaces provided. Be sure to provide evidence of your thoughts by listing experiences and specific interactions with your co-worker that make you feel and think the ways you are. This is for your own benefit and is not to be shared with others unless you would like it to be.

1. After finding out my co-worker has epilepsy, my thoughts of him/her are:
2. How has my relationship changed with my co-worker after finding out he/she has epilepsy?
	* 1. Positively:
		2. Negatively:

If negatively, how can I make it more positive?

1. Do I resent my co-worker for having to take extra time away from work to deal with his/her condition? List reasons why for both responses to help clarify your thoughts.
2. Do I understand the exchange of specific job tasks because of his/her condition? If no, what am I thinking?
3. What more can I do to support my co-worker at work?
4. What has happened to me in the past that can help me empathize with my co-worker about his/her fear of having a seizure at work?
5. Do I feel confident that I have enough knowledge about epilepsy? If not, what am I still afraid of or feel that I need more information about?

Think about your responses and how you might deal with them. Do you need to set a time to talk one-on-one with your co-worker, your manager, someone from HR or counselling services your benefit package at work provides? Do you think additional training on epilepsy would be useful to you? Based on your responses, take the appropriate action to ensure a productive workplace. Epilepsy is a manageable condition and it does not need to be a stress factor at work.

## Better Than Ever

A few weeks after Tarik’s Lunch and Learn and Nancy’s return to work, she and Tarik met to talk about how she felt her co-workers were responding to her disclosure about her epilepsy.

**DIALOGUE**

**Nancy:** At first, I was very anxious. And I think a lot of the staff were too. I think we were all trying to figure out how we should deal with my epilepsy. You know, face it or ignore it. And then I had that seizure—in the second week back—and that was such an affirming experience for me. Not only did everyone seem to know how to respond, but Reuben even made sure I spent some time resting in the room off his office for awhile—until I felt I was ready to get back to work.

I couldn’t ask for a better group of co-workers and friends. I feel so much more relaxed about the epilepsy now—thanks to the way all of you have welcomed me back and made me feel like I’m the same old Nancy I was before I was diagnosed. Like I said—it’s just been a pretty wonderful experience.

I feel so energized by what’s happened around the office, I’ve even started attending monthly epilepsy support meetings. I’ve heard some great, really positive stories about great workplaces. It makes me very happy to think this isn’t the only work environment out there offering great support to people living with epilepsy.

## Success Stories

**Epilepsy in the Workplace [Video]**

|  |  |
| --- | --- |
| Marylena  | If I was starting a new job, the one piece of advice I would give co-workers is that everyone starts a job with skills, knowledge and uniqueness, not with a disability. |
| Mark McAllister | Obviously your employer is going to be concerned from the get-go if they are aware of this in the first place, they’re going to want to know more. |
| Lindsay Yeo | If you hire someone and keep someone with epilepsy a) is understand exactly what kind of epilepsy they’re coming in with because every person is different, so make sure you know what they’re bringing to the table so that you can be prepared to deal with that and then kind of partial to that is also just to treat them like a regular person because in the end, they’re just a regular person. |
| Marylena  | So I would very much be open to disclosing it at the beginning, which is the interview, and if that company accepts you, then they have accepted someone great.  |
| Mark McAllister | Deal with it on a personal level, make sure you understand everything you need to understand, so that when you’re ready to talk to other people about it – including your employer, including management in your workplace, your immediate boss – you have all the information that they would ever want from you first.  |
| Marylena  | Disclosing my epilepsy in my workplace I think has brought my co-workers together and it`s also inspired them at the same time.  |
| Mark McAllister | If I felt that someone didn’t want to talk to me about it, I made a point of talking to them first.  |
| Marylena  | My workers go above and beyond on a constant basis to show me support for my disability. My current employer provides me many accommodations to ensure that I’m comfortable doing my job with my disability. They know that I’m very sensitive to lighting because of the epilepsy, so they’ve removed lighting above my workstation, as well as added filters to my computer screen so that within an eight hour day of work my eyes will not be stressed.  |
| Lindsay Yeo | Them not being afraid of me mentioning my epilepsy to clients when I’m on the phone – to me I think that’s something that is very accommodating. That’s undying gratitude and undying loyalty at this stage because they have just supported everything from day one and without that support, there’s no way that I would be doing what I do both personally and professionally.  |
| Mark McAllister | If I felt that there was some hesitation or that my employer wasn’t comfortable with the way things were going, I knew that there was other places I could turn to, to help facilitate that. I already had a local organization, Epilepsy Toronto, reach out to me for support services.  |
| Lindsay Yeo | I think it’s really important for everyone in the workplace to know a lot more about epilepsy or what they can expect at least from each person as they come into a new job with epilepsy, because obviously with epilepsy it’s different for everyone, but I think it’s really important for me to explain in a workplace what the situation could be or what they might see that might seem different. |
| Marylena  | A company should hire someone with epilepsy because we tend to be dedicated to our work. |
| Mark McAllister | Those that are living with it are that much more aware of what they’re going through, their surroundings, everything that they have to deal with on a daily basis. And when you become mindful of those types of things you’re that much more focused.  |
| Lindsay Yeo | Going through these kinds of things as part of your lifestyle and learning to manage this and live with this, you’re going to be more accommodating, more comforting, more supportive to other people as they go through other challenges.  |
| Mark McAllister | When you’re going through that personal experience it’s important to know that everyone in your life is there for you. Whether it be a friend, whether it be a family member, but you spend a lot of time at work and to know that your colleagues are there for you if you need them, but to also know that your boss, your manager, the executive within that company are going to be there for you as well is so key because if that’s taken away from you, that’s going to be a huge blow to everything that you’re trying to overcome.  |

## In Closing

What would you do if you found out your co-worker had epilepsy? Would you now feel confident and comfortable enough to ask if they need any support at work? I hope so.

As you’ve just learned, having co-workers with epilepsy doesn’t have to be stressful or scary. Working together, to better understand a fellow employee’s epilepsy, can make for a better, more productive workplace. And knowing how to respond to a seizure can make your co-worker—or your customers with epilepsy—feel confident, safe and valued.”

Having co-workers or customers who have epilepsy doesn’t have to be stressful or scary. Working together, to better understand your fellow employee’s epilepsy, can make for a better, more productive workplace. And knowing how to respond to a seizure can make your co-worker—or your customers with epilepsy—feel confident, safe and valued.

Whether a co-worker discloses their condition to you, or you witness a seizure, as you have now seen and learned, having support at work can make a big difference!

##

## Epilepsy Resources & Links

**CEA PSA 1 [video]**

|  |  |
| --- | --- |
| Female Restaurant Patron 1:  | Oh wow! |
| Female Restaurant Patron 2:  | Is he okay? |
| Female Restaurant Employee:  | Are you okay? |
| Female Restaurant Patron 2:  | Is he wasted? |
| Male Restaurant Patron with Epilepsy:  | People don’t understand. I don’t get wasted. I have epilepsy. |

**CEA PSA 2 [video]**

|  |  |
| --- | --- |
| Male CEO:  | Can we have an update or report on the final candidates for the new position. |
| Female Manager: | I think we should go with this one. |
| Male CEO:  | And, why have you chosen this one? |
| Female Manager:  | Well, the other candidate has epilepsy. |
| Male CEO: | I have epilepsy. |

**Basic Seizure First Aid**

**Convulsive seizures:** Person falls, their body is rigid, muscles jerk, shallow breathing. Usually last 1-3 minutes. Afterwards, the person is confused and tired.

**How you can help:**

1. Stay calm. Let the seizure take its course. Keep track of time.

2. Protect from injury. If necessary, ease the person to the floor. Move hard sharp objects out of the way. Place something soft under the head.

3. Loosen anything tight around neck. Check for Medical I.D.

4. Do not restrain the person.

5. Do not put anything in the mouth. They cannot swallow their tongue (although they may bite it).

6. Gently roll the person onto their side. As the seizure subsides, to allow saliva or other fluids to drain away, helping to keep their airway clear.

7. Afterwards, talk gently to comfort and reassure the person, who will be confused. Stay with them until they become re-orientated. The person may need rest or sleep.

**Non-convulsive seizures:** Person is staring blankly, dazed, unresponsive, movements are purposeless and clumsy. Usually last a few minutes. Afterwards, person remains confused.

**How you can help:**

1. Stay with the person. Do not try to stop the seizure, but let it take its course. The person will be unaware of his or her actions, and may or may not hear you.

2. Move dangerous objects out of the way.

3. Do not restrain the person.

4. Gently guide away from danger or block access to hazards

5. Afterwards, talk gently to reassure the person, who will be confused. Stay with them until complete awareness returns.

**When to Call 911**

• If a convulsive seizure lasts longer than 5 minutes

• If consciousness or regular breathing does not return after seizure has ended

• If seizure repeats without full recovery between seizures

• If it is a first time seizure, or the person is injured, pregnant or has diabetes

## Final Quiz

**Understanding Epilepsy in the Workplace – Final Quiz**

1. The number of people who live with epilepsy is approximately 1 out of 100. **True**
2. To be diagnosed with epilepsy, a person needs to have had two seizures and no other contributing conditions. **True**
3. Epilepsy affects only one part of the brain. **False**.
4. If I see a person having a seizure, I need to call 911 immediately. **False**
5. Epilepsy does not affect the brain between seizures. **True**
6. People with epilepsy under certain conditions can drive a car. **True**
7. Known causes of epilepsy include brain injuries and tumours, stroke, sports injuries, genetics, oxygen deprivation and interactions with drugs. **True**
8. There is a cure for epilepsy. **False**.
9. People who know they have epilepsy must tell their co-workers of their condition. **False**
10. Side effects from medication, discrimination and not knowing when or if another seizure will occur can be more harmful than a seizure itself. **True**
11. A seizure trigger is a factor that can bring on a seizure in a person who has epilepsy. Examples include stress, missing medication, bright or strobing lights, or inconsistent sleep. **True**
12. Managing triggers in the workplace can reduce the chances of a seizure. **True**
13. Epilepsy does not impact a person’s intelligence, creativity nor sense of humour. **True**.
14. People with epilepsy may fear their co-workers will treat them differently after they have disclosed their condition. **True**
15. Having a co-worker with epilepsy does not make for a good team-oriented work environment. **False**
16. A person with epilepsy may choose not to disclose because they haven’t had a seizure for a long time and are unlikely to ever have another. **True**
17. People with epilepsy are often passed up for promotion in their jobs. **True**
18. Companies with 50 or more employees are not required to provide accommodation for employees with epilepsy. **False**
19. Asking questions about your co-workers epilepsy after they have told you about it or you have witnessed a seizure is not appropriate. **False**
20. Creating an Accommodation and First Aid Plan will help in reducing the fear and mystery of a seizure occurring in the workplace. **True**
21. A co-worker newly diagnosed with epilepsy may need both privacy and support from their employer and coworkers. **True**
22. If you witness a person having a convulsive seizure, ease them to the floor, move hard and sharp objects out of their way, put something soft under the person’s head, roll the person onto their side. **True**
23. If you witness a person having a non-convulsive seizure (staring, wandering around), restrain the person to keep them from hurting themselves. **False**
24. Having a diverse workplace including people with disabilities, leads to increased workplace safety, improved company morale and retention of valued employees. **True**
25. Accommodating a person with epilepsy on the job may involve swapping job duties with others, changing work schedules, reducing bright lights, providing a desk chair with arms or other minor adjustments to the workspace. **True**
26. Epilepsy can be considered a disability when it does not significantly affect a person’s everyday activities, but the employer or co-workers treats the individual as if it does. **True**
27. There is no single conclusive diagnostic test for epilepsy. **True**
28. People with epilepsy cannot do their jobs as well as co-workers without epilepsy. **False**