FUNCTIONAL NON-EPILEPTIC SEIZURES
A Guide for Patients and Families

What are functional non-epileptic seizures?

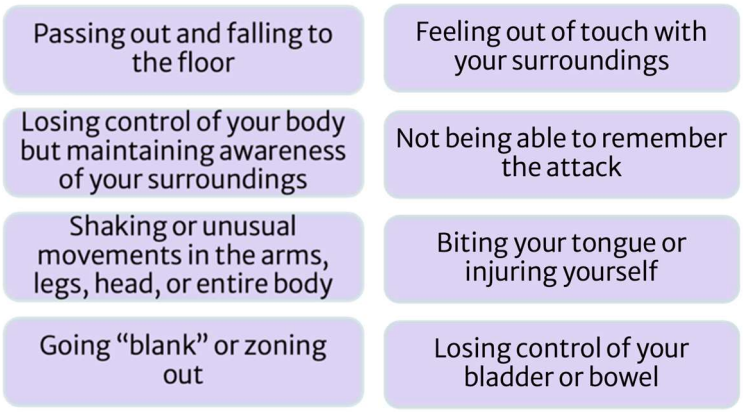
A **seizure** is a word describing any sudden, temporary loss of control over nervous system functioning. Seizures can involve abnormal movements, loss of consciousness, or both. **Epileptic seizures** are caused by sudden abnormal electrical discharges in the brain. **Functional (nonepileptic) seizures** look very similar to epileptic seizures, but they are not caused by abnormal electrical discharges or other structural problems in your brain.

Functional seizures are a subtype of **functional neurological disorder (FND)**. The term "functional" implies that there is a problem with the *functioning* of the brain, as opposed to a problem with the physical *structures* or abnormal electrical (epileptic) activity in the brain.

If we think of our brain as a computer, then functional seizures are like "software glitches" that can occur when the brain is overwhelmed. This is very different than other neurological disorders where there is a problem with the computer "hardware" or physical structures in the brain (e.g., stroke, tumor).

There are many different names for functional seizures. Other names you may hear are psychogenic nonepileptic seizures (PNES), nonepileptic attacks, dissociative seizures, or even pseudoseizures. Some of these terms can be misleading or offensive, so the more neutral term "functional" is usually preferred.

Functional seizures can look very differently from person to person. Some people lose awareness during a seizure. Some are aware but are unable to respond to others around them, and others may be able to speak and follow commands. It is common for people to appear unconscious during a seizure but show signs of being able to react to their environment to some extent (e.g., by turning to a person speaking to them, making gestures or other purposeful movements). Some people fall down and have full body shaking, whereas others just stare or lie still. Some people's functional seizures only last a few seconds, while others go on for much longer, occasionally lasting for hours at a time. Because the symptoms of functional seizures can appear very similar to epileptic seizures or other conditions that cause blackouts or fainting, they can easily be misdiagnosed. Some common presentations of functional seizures include:



I have never heard of this. Is it rare?

Although few people have heard of functional nonepileptic seizures, they are not that rare. It is the most common condition to be misdiagnosed as epilepsy. *Around 30% of patients with suspected epileptic seizures actually have functional seizures.*

How can we be sure that this is the right diagnosis?

In some cases, an epileptologist or neurologist can make a confident diagnosis of functional seizures if they witness the seizure or hear a detailed description of it. Epileptologists can correctly diagnose 9 out of 10 seizures by watching a video recording of the event.

Depending on the nature of your seizures, additional tests may be necessary to confirm the diagnosis and rule out epilepsy or other physical conditions that resemble seizures (e.g., stroke, fainting, and some sleep disorders).

A routine 20-minute electroencephalogram (EEG) can be helpful in diagnosing epilepsy because it can detect the abnormal electrical discharges in the brain. However, a negative EEG by itself is not enough to make a diagnosis of functional seizures. The best way to make a diagnosis is by EEG video monitoring. This procedure requires the patient to spend up to several days in a specialized epilepsy monitoring unit (EMU), where they are monitored with a video camera and an EEG until a seizure occurs. By analyzing the EEG recordings and video while the person has one of their typical events, the diagnosis can usually be made with certainty.

Why did other doctors say I had epilepsy?

It is important to realize that the diagnosis of functional seizures and epileptic seizures is often a gradual process. The information available to the doctor after a first seizure is often limited, but the diagnosis usually becomes clearer as more events are observed. Not all doctors have training or access to EEG and video monitoring facilities that are needed to distinguish between epileptic and nonepileptic seizures.

When the diagnosis is unclear, physicians often prescribe anti-epileptic drugs if there is any question of epilepsy. About 80% of patients with functional seizures are treated with anti-epileptic drugs for several years before the correct diagnosis is made. This is because there are potentially higher risks associated with epilepsy when it is untreated. Ultimately, patients are referred to an epilepsy center like the one at Inova, and this is usually where the diagnosis of functional seizures is made.

What about my abnormal EEG?

Most patients with functional seizures have received a diagnosis of epilepsy before being correctly diagnosed, as described above. Similarly, many have had EEGs read as "abnormal." This is because neurologists who do not specialize in EEG or epilepsy frequently "overread" as abnormal what specialists would consider normal. One in 10 healthy people have minor abnormalities in their EEG, and these can be mistaken as an indication of epilepsy. This is one reason why the diagnosis of functional seizures should only be made by epileptologists.

If you have had abnormal EEGs in the past, it is important that you obtain the actual tracings so the specialist (epileptologist) can review them.

What causes functional seizures?

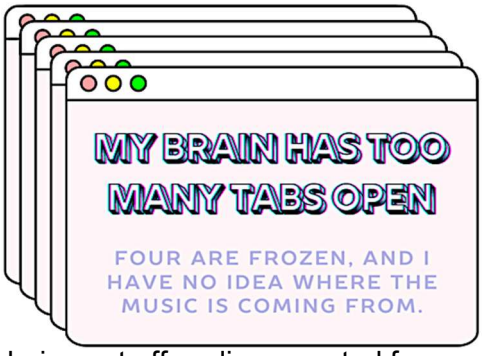
Although functional seizures can look similar to epileptic seizures, the cause is very different. We know that they are not caused by structural or electrical abnormalities in the brain.

It is thought that functional seizures are a mechanism that the brain uses to "shut down" temporarily when it is overloaded. They are an automatic reflexive response to triggers that may come from inside or outside of the body. The specific causes and triggers of functional seizures are different in different people.

In some ways, what happens in functional seizures is similar to what happens when a computer "freezes." Think about the last time your computer crashed. It probably crashed because of a problem with the software (e.g., the programming, coding, or operating system) rather than the hardware (i.e., the physical structures, like the hard drive). If you decided to put your computer into an MRI scanner or x-ray machine, you would not see anything wrong with it. Instead, you may have one or two programs open that are consuming all of the energy or that are not communicating properly with another program. You may not even be aware that these programs are running in the background.

We are not aware of most things that constantly go on in our brain. Many thoughts, actions, and sensations are occurring beneath our conscious awareness all the time. When we are under a lot of stress (or were in the past), have pain, insomnia, headaches, or other physical symptoms, our brains can reach capacity. Each of these things consume valuable mental resources and make us more vulnerable to "crashing."

The lovely thing about computers is that all you usually need to do is press a single button to restart the computer before it starts to work normally again. Human brains, however, are a bit more complex to fix when they are overloaded.



Functional seizures are a mechanism that the brain uses to "shut down" temporarily when it is overloaded.

For some people, functional seizures represent a form of "dissociation," which is a medical word that describes a feeling of being cut off or disconnected from your surroundings or from your own body. Dissociation can be mild

(e.g., when someone is in a daydream, feeling “there but not there”) or severe (e.g., being able to hear but not respond to those around you). Dissociation is a “switching off” process in the brain that happens unconsciously, without you being aware of it. During a functional seizure, the brain switches off and the person loses control of their body. For some people, dissociation happens when they are very tired. For others, it may be their brain’s reaction to something that it feels is intolerable (e.g., a bad migraine or overwhelming stress). In functional seizures, this switching off happens over and over again at times that it is not appropriate and can become disabling.

But why me? Why now?

Usually, several things have to come together for functional seizures to develop. There are certain **risk factors** that make it more likely for someone to develop them. These can include biological factors (e.g., sex, genetics, having another neurological disorder), social factors (e.g., childhood adversity or past trauma), and psychological factors (e.g., certain personality traits, anxiety disorders).

The things that bring on a seizure are called **triggers**. Common triggers include severe pain, overstimulation (e.g., too much noise, too many people), stressful situations (e.g., arguments), or negative emotions (e.g., upsetting thoughts or memories). However, sometimes they can happen without any obvious trigger or warning.

It is common for the first seizure to occur in the context of stress, which can be either physical or psychological. However, sometimes functional seizures occur at times when people do not feel particularly stressed or after the stress was getting better (i.e., during the “come down” after stress). This tends to be more common in people who have had functional seizures for a while. Unfortunately, stress about having another seizure and the lifestyle changes made to avoid more seizures can unintentionally end up making future seizures more likely.

Even though stress often plays an important role in functional seizures, this does NOT mean that you are “crazy” or that you are making it up somehow. Functional seizures are very **REAL** physical conditions that can cause very significant disability. Unfortunately, some doctors and nurses still do not know what functional seizures are and may have a hard time understanding them. This can occasionally lead to them wrongly believing that people with functional seizures somehow have control over them. It is important that functional seizures are always taken seriously.

How are functional seizures treated?

Sometimes functional seizures stop on their own without needing treatment. In other cases, treatment is necessary to help you have fewer seizures or cope with them better.

The first step in treatment is helping you and your loved ones understand the condition and how it is different from epilepsy. Understandably, many people find it difficult to accept the diagnosis, particularly if they have previously been told they have epilepsy. However, coming to terms with the diagnosis is an important step on the road to recovery.

The most important treatment for functional seizures is called cognitive behavioral therapy (CBT), which is a type of skills-based psychotherapy. This is often done with a psychologist, psychotherapist, or counselor. Depending on the individual and the nature of the functional seizures, treatment may include:

- Understanding why the functional seizures are happening
- Identifying triggers and warning signs for seizures
- Learning specific techniques to control or prevent seizures
- Identifying and addressing things that are contributing to seizures
- Learning new ways to calm your autonomic nervous system or cope with stress
- Gradually increasing activity levels
- When relevant, coming to terms with past events that may be related to the seizures

Many people are reluctant to start psychotherapy because they feel like it means they are "crazy" or "weak." However, psychotherapy can help people learn to cope with all kinds of medical illnesses, such as cancer, diabetes, and heart disease. Therapy can be challenging, but it can also be a very positive experience that allows you to return to the things that really matter.

If depression, anxiety, or post-traumatic stress disorder (PTSD) are also present, these can be treated with psychotherapy, medications, or both. When these conditions are present and not treated, the functional seizures may not improve.

Importantly, anti-epileptic drugs do not help functional seizures, so most patients can and should safely stop these medications. They can have harmful side effects and should not be taken unnecessarily. Unless you also have epileptic seizures (which is the case in about 10% of people with functional seizures), anti-epileptic drugs should be reduced and stopped with the support of a neurologist. If you do have both nonepileptic and epileptic seizures, it is important for you and your doctor to know which are epileptic and which are not so that you can be treated appropriately.

Generally, when people have both types of seizures, usually the nonepileptic seizures develop after a person already has a history of epilepsy. So do not fear – having functional seizures does not put you at higher risk of developing epilepsy in the future.

Will I recover?

Most people with functional seizures are capable of a full recovery. A small percentage of people get better just after receiving a diagnosis and good explanation. For other people, recovery happens through treatment, which is usually psychotherapy. It is important to remember that recovery does not happen overnight, and it requires you to take an active role in your treatment. This means that treatment is more challenging than just taking a pill once a day, but ultimately you learn skills to help you live a normal life again.

What about driving?

Many people with functional seizures have stopped driving because they were given a diagnosis of epilepsy. There is no law that specifically regulates driving with functional seizures, and neurologists vary in what they recommend. However, in the state of Virginia, the DMV will suspend driving privileges for a period of 6 months following a seizure, unexplained blackout, or loss of consciousness (under most circumstances).

What about my disability?

If you have received benefits or been unable to work because of your seizures, this should not change based on this new diagnosis. Your seizures are real, and they may be disabling whether they are epileptic or nonepileptic in origin.

Disability paperwork is best completed by a physician who has knowledge of your condition and a long-term relationship with you. It is recommended that you ask your primary care physician, psychiatrist, or doctor who knows you best to assist with disability paperwork.

What about children?

Functional seizures can also occur in children and adolescents. Most of the points made in this guide apply to children as well as to adults. Young patients generally differ from adult patients in that a psychosocial stressor (e.g., at school, with peers, at home) is usually more apparent. Children/adolescents also usually have a higher rate of recovery.

What do I tell people?

Telling people that you have a condition like epilepsy is difficult, but at least most people have heard of epilepsy and know something about it.

Telling people about functional nonepileptic seizures can be much more difficult. Most people have not heard of functional seizures, so it can be difficult to explain what they are. Having a good understanding of the diagnosis can make it easier to explain to others. Here are some useful things you can say:

"I have attacks that I cannot control. They are like epileptic seizures, but they are not caused by the same thing as epilepsy."

"I have been diagnosed with nonepileptic seizures."

"I have a condition similar to epilepsy, which means that I have seizures."

Where can I learn more?

The following websites have helpful information on functional seizures:

www.neurosymptoms.org: A

www.fndhope.org A patient-led organization that offers support to patients

https://www.fndaction.org.uk/non-epileptic-attack-disorder/

https://www.fndsociety.org/ (primarily for healthcare providers, although anyone can join)

What should people do when I have a seizure?

You can keep this card with you in case you have a seizure. You can also give a copy to family or friends. Please check with your doctor that you do not have additional epileptic seizures before you use this card.

I have functional nonepileptic seizures. This is what to do if I have one.

- **Keep me safe from injury**. You may need to guide or move me from an unsafe place, move dangerous objects, or protect my head by carefully placing some soft clothing under it.
- **Do not hold me down or restrict my movement.** This can make the seizure worse or cause injury.
- **Do not put anything in my mouth** or try to give me medication.
- **Speak to me calmly.** I may be able to hear and feel what people are doing when I have a seizure even though I may not be able to respond. Being spoken to in a calm, reassuring manner can help me through the seizure sooner.
- **My seizures do not cause damage to the brain**, even if they go on for several minutes.
- **Do not call an ambulance unless I am injured or the seizure is very different from my typical ones.** It is important that EMS know that my seizures are non-epileptic. Show them this card.