



MN **Epilepsy**  
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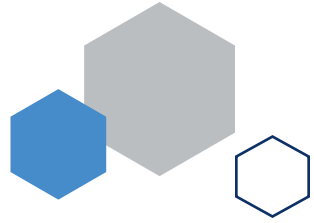


## **Non-epileptic Events**

What to Know - for Patients and  
Family Members

# Quick Overview

If you have been diagnosed with non-epileptic events, you may have several questions and concerns. It is important to understand as much as you can about non-epileptic events as you move forward. This booklet will answer some questions and will help you on your way to recovery.



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## What are non-epileptic events?

Non-epileptic events are episodes that look like epileptic seizures but are not caused by abnormal brain electrical activity. They may involve a wide range of physical symptoms, including changes in awareness, sensation, and/or movement. Some examples of such symptoms are shaking, loss of consciousness, loss of time, or an inability to respond. Episodes may last for a few seconds or many hours.

You may also come across other names such as non-epileptic seizures, stress-related events, functional seizures, conversion disorder, non-epileptic attack disorder, and psychogenic non-epileptic seizures. Some people also use the inaccurate term “pseudoseizures.” There is nothing “pseudo” (fake) about them.

Since non-epileptic events are not a disease of electrical activity of the brain, they are not treated with anti-seizure medications. They can be treated, however, and we will discuss that below.

## I have not heard about them before—are they rare?

No. Non-epileptic events are not rare. As many as 2 to 33 out of every 100,000 people have non-epileptic events. Specialized epilepsy centers such as ours see people with non-epileptic events regularly. About 30%-40% of people referred to epilepsy centers have non-epileptic events.

## How are non-epileptic events different from epileptic seizures and epilepsy?

Epileptic seizures come from an electrical disturbance in the brain. Some causes of these electrical disturbances include old scars on the brain, genetics, or head injuries. Think of an epileptic seizure as a small “electrical storm” or “short-circuit” in the brain. When this happens, a person may have symptoms such as whole body shaking (convulsions) staring, or loss of consciousness.

During a non-epileptic event, there is no “electrical storm” or “short circuit.” In fact, brain electrical activity during a non-epileptic event is calm and normal in most cases.



## How do I know if I have non-epileptic events instead of epileptic seizures?

An epilepsy specialist will help you reach the correct diagnosis and may recommend an EEG, either in the clinic or the hospital. An EEG is a test used to detect abnormal brain activity. During an EEG, wires temporarily attached to your head record your brain's electrical activity. The specialist then checks for abnormalities seen in people who have epilepsy.

During long-term video-EEG monitoring, a person stays in a specialized unit in the hospital. Here, wires record the brain's electrical activity while a video records what the body does. This lets the specialist examine your brain's electrical activity both when you are having an event, and when you are not. Anti-seizure medicine may be reduced or stopped. Triggers may be used to help provoke events. Examples of triggers are strobe lights, deep breathing, and sleep deprivation. Monitoring typically lasts from two to five days.

Early diagnosis will help you on your path to recovery. People who are diagnosed earlier often recover sooner.

## I was told before that I have epilepsy (or I had an abnormal CT head, MRI brain, or EEG). Can I still have non-epileptic events?

Yes. It is not uncommon for people with non-epileptic events to have been diagnosed with and treated for epilepsy in the past. It may take a long time before the diagnosis of non-epileptic events is reached.

The epilepsy center will review previous studies, including images, recordings, and reports. The significance of those results will be considered along with the new information. Each person's case will be reviewed individually.

Some patients with epilepsy also have non-epileptic events. If you have both, it is important to know the difference between your types of events and to treat them with different strategies.



## What causes non-epileptic events?

People develop non-epileptic events for several reasons. Most of the time they are the result of difficulty coping with stress, anxiety, frustration, or other negative emotions. Other times they are due to past frightening or traumatic experiences.

We have all experienced physical symptoms (such as blushing or heart racing) because of emotion, worry, or stress. The mind, body, and emotions are so closely connected that each is affected by the other.

The mind does an amazing job of protecting us when we are overwhelmed. It may “shut-down” our awareness for a time to avoid discomfort or pain. This separates (or “dissociates”) the mind from the discomfort. During the shut-down, we may experience symptoms such as staring off, passing out, or shaking. Because the mind is converting emotional stress to physical symptoms, non-epileptic events are sometimes called “conversion” disorders.

We all are different. How each of us copes with stress, life challenges, or significant emotional pain is a very individual journey. At the same time, however, there are several common things in people with non-epileptic events. Many people with non-epileptic events may have experienced trauma or abuse earlier in life (physical, emotional, or sexual). Other people with non-epileptic events may have overwhelming stress and exhaustion that is happening right now. Stressful events, such as loss of a loved one, a serious new medical diagnosis, chronic pain, or difficult to diagnose health problems, may also contribute. Some people with non-epileptic events have anxiety, depression, or post-traumatic stress disorder (PTSD).

In a small number of people, no previous traumatic experience or stressful event can be identified and therefore the diagnosis is confusing.

By working with your care providers, you may come to a clear understanding of the cause of your non-epileptic events. Even when the cause cannot be found there are helpful treatments available.

Research is ongoing to help us understand the “why” for non-epileptic events. There is still a lot to learn.





## Are they because of anxiety or depression?

No. Although many people with non-epileptic events have anxiety, depression, or other mood-related symptoms, these symptoms do not cause non-epileptic events. If these symptoms are present, however, it is important for them to be treated by a behavioral health specialist. This will likely benefit recovery from non-epileptic events.

Since many people with non-epileptic events have a history of trauma, they may also have a diagnosis of PTSD (post-traumatic stress disorder). Some experts believe that non-epileptic events may be a type of PTSD.

## Does this mean I am faking?

Absolutely not. Most non-epileptic events are involuntary. This means that people do not bring them on and are not in control of the episodes. At the same time, some people may be able to predict an event. With treatment, a person may learn how to control and manage events. This may be useful for alerting others and for helping the person get to a safe place before it starts.

## Are they treatable?

Yes. Many people benefit from specialized forms of psychological therapy. Therapy is performed by a counselor or psychologist. Because people develop non-epileptic events for many reasons, there is not one therapy that is best for everyone. Examples of different types of therapy include Cognitive and Behavioral Therapy (CBT), Dialectical Behavioral Therapy (DBT), Eye Movement Desensitization and Reprocessing (EMDR), and Prolonged Exposure Therapy (PET), but there are many more. Experience in treating non-epileptic events and PTSD is good, but what is most important is that you find a licensed, caring therapist that makes you comfortable. The therapist will determine how many and how often sessions are needed.

You may locate a psychologist or therapist in your area by searching <http://psychologytoday.com/us/therapist>, or by contacting the American Psychological Association (<http://locator.apa.org> or 800-374-2723). We can also help you find a therapist who will be a good fit for you and your situation. Many people find it useful to stay in touch with the doctor who made the diagnosis, to answer questions that might arise. This is even more important if you take anti-seizure medicines.

## Will I get better?

Yes. Non-epileptic events are treatable. With the right kind of treatment, non-epileptic events can go away or can decrease dramatically.

The first step is to reach and understand the correct diagnosis. Sometimes episodes stop completely once people learn about what they are. Usually it takes time and patience. You should not be surprised if the episodes continue for a time. Most people have significant improvement in event control in about six months.

In a few patients, non-epileptic events “flare up” again later. If this happens, they can be controlled with proper treatment, just like before.



## Can I stop my anti-seizure medications?

Maybe. Many patients with non-epileptic events are able to come off their anti-seizure medicines. Your neurologist or epilepsy specialist will tell you whether to stop your medicine. Please do not stop your medicines suddenly or without medical advice.

## Will I be able to drive?

Possibly. Driving restrictions are determined by state. The state of Minnesota restricts driving for three months after events where you are unable stay upright without support or you cannot respond normally. Depending upon your events, driving may be restricted.

## Are they hereditary?

No. There is no current evidence to suggest that non-epileptic events are inherited.

## What should I do if I or my loved one has a non-epileptic event?

Safety first. Remember that non-epileptic events are not voluntary. We want you to be safe while you have a non-epileptic event. This may include being protected from falling or having something fall on you during the event. It may help to have the person rest on a safe surface. Turn the person on their side at the end of the event.

In most cases, non-epileptic events end on their own. Use of medicines such as lorazepam (Ativan®) or diazepam (Valium®) to stop non-epileptic events is not recommended.

If the person is taken to an emergency department, it is important to provide health-care professionals with details about them, including the diagnosis of non-epileptic events.

Your doctor may give you a non-epileptic response plan. This plan helps others know how to respond when you have an episode. We will write these to suit you personally. We will describe your episodes and make specific recommendations about your situation.

## What should I tell others about what I have?

How much you want to tell people about your health is up to you. You may want to tell them that you have non-epileptic events, which are your brain's response to stress and trauma. You can tell them that with treatment you expect to get better and lead a normal productive life. If you feel it is appropriate, it may be a good idea to share safety suggestions and the NEE response plan with responsible family members, friends, or colleagues.

## Where can I get more information?

Epilepsy Foundation of Minnesota

<https://www.epilepsyfoundationmn.org>

Manchester Neurosciences

<https://www.manchesterneurosciences.com/departments/neuropsychology/need#Leaflets>

Suggested Read:

*Psychogenic Non-epileptic Seizures: A Guide* by Lorna Myers, PhD Publisher: CreateSpace Independent Publishing Platform

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