

Non-Epileptic Events

*A guide to help you understand
your diagnosis*



About your diagnosis

Is this the right diagnosis?

The best way to diagnose non-epileptic events is to stay in an Epilepsy Monitoring Unit (EMU). While you were here, we videotaped you and gave you a test called an electroencephalogram (EEG). This let us watch your brain's electrical signals when you had an event. The results from the video and EEG help us make a diagnosis of non-epileptic events.

As many as 1 out of 3 patients who come to our EMU are diagnosed with non-epileptic events. This also happens in EMUs across the United States and the world.

What is an epileptic seizure?

Your brain uses electrical signals to send messages throughout your body. Signals sent from different parts of your brain control different things. For example, one part of your brain controls balance and another part controls how you talk.

If these electrical signals don't work the way they should, your brain loses control over parts of your body. When this happens, it's called an epileptic seizure. Patients who have these events over and over are diagnosed with a condition called epilepsy.

The results of the video-EEG showed that your brain's electrical signals worked fine during your events. This means your events were non-epileptic. These results also tell us that you don't have epileptic seizures. Because of this, you have a diagnosis called non-epileptic events.

What are non-epileptic events?

During a non-epileptic event, there may be a change in how a patient acts. Their body may move in a way they can't control. These events may look like an epileptic seizure. But non-epileptic events and epileptic seizures don't have the same cause or treatment.

Non-epileptic events aren't caused by your brain's electrical signals. They are caused by very strong emotions or feelings in your body from past and current experiences such as:

- the death of a loved one
- an unhealthy relationship
- physical, emotional, or sexual abuse
- violent military or police combat.

It's important to remember that your condition is very real and you don't have control over your body during an event.

Patients who have non-epileptic events often have other conditions such as:

- post-traumatic stress disorder (PTSD)
- personality or mood disorders
- anxiety
- depression
- very bad headaches (migraines)
- sleep issues
- constant pain.



Treatment and lifestyle

Why was I first told that I have epilepsy?

Non-epileptic events may look like epileptic seizures. Many health care providers who aren't trained on epilepsy and EEG may not be able to tell the difference between these two events. This is usually when they make the wrong diagnosis.

Research shows up to 80% of patients with non-epileptic events first get diagnosed with epilepsy. These patients start to take medicine for epilepsy but it doesn't stop their events. Or there are bad side effects which make their events worse. This may go on for years before patients are finally referred to us.

Is there a treatment?

Yes! There is treatment and even a cure for many patients who have non-epileptic events. Because these events are caused by emotions and stress, your treatment is different than epilepsy patients.

The best known treatment is called **Cognitive Behavioral Therapy (CBT)**. CBT is a common type of talk therapy, also called psychotherapy. You'll work with a mental health provider who can help you understand how you think about and deal with stressful things.



Another treatment that may help you is called **Eye Movement Desensitization and Reprocessing (EMDR) therapy**. EMDR uses movements of your eyes, ears, and hands to help you heal from trauma.

You may also get medicine to help treat depression or anxiety. This medicine won't stop your events, but it can help your mood.

Your non-epileptic events may stop for a short time, but if your emotions and stress aren't treated first, the events will happen again later. Or you may have other symptoms such as:

- body aches and pain
- headaches
- anxiety attacks
- body movements that aren't normal.

Remember—non-epileptic events don't happen by choice. But you can learn to control them with the right type of therapy. There is nothing wrong with getting the help you need to treat your condition.

Will I be able to drive?

Under Tennessee law, any person who has events where they lose control of their body, or their body moves on its own, shouldn't drive until they've gone 6 months without an event.

This law doesn't make a difference between epilepsy and non-epileptic events. This means that with your diagnosis, you shouldn't drive until you've gone 6 months without an event or your provider tells you it's okay to drive.



How do I talk about my condition?

It's important for people around you to understand that this is a real diagnosis. You aren't pretending or "faking" these events. Many patients feel ashamed or embarrassed. It can also be frustrating to try to explain what's happening in your body.

Remember—these events are not your fault. You can always talk to your health care team about any feelings or questions you have.

How can my family help me?

There are several things your family can do to support you:

- Make sure your home is safe so you won't get hurt during an event.
- Be patient.
- Know who and how to ask for help if they have questions or concerns.

Contact us

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Resources

Website

nonepilepticseizures.com

Video

Epilepsy Webinar (YouTube) by Lorna Myers

Books

- *Psychogenic Non-Epileptic Seizures: A Guide* by Lorna Myers
- *In Our Own Words: Stories of those living with, learning from and overcoming the challenges of psychogenic non-epileptic seizures (PNES)* by Mary Martiros and Lorna Myers
- *Lowering the Shield—Overcoming Psychogenic Nonepileptic Seizures* (Kindle book edition) by John Dougherty
- *View From the Floor: Psychogenic Non-Epileptic Seizures: A Patient's Perspective* by Kate Berger
- *In Our Words: Personal Accounts of Living with Non-Epileptic Seizures* (The Brainstorms Series) by Markus Reuber, Gregg Rawlings, and Steven C. Schachter
- *On the floor again: A Raw Look at Life with Nonepileptic Seizures* by Mia Montgomery