

Epilepsy Service Non-Epileptic Seizures

Frequently Asked Questions for patients and families

What are non-epileptic seizures (NES)?

Seizures are brief, time-limited episodes that usually include a combination of abnormal movements, sudden behavioral changes, altered awareness or consciousness, and/or other sets of physical symptoms or experiences. Epilepsy-related seizures result from sudden abnormal electrical discharges in the brain. Non-epileptic seizures (NES) look like epilepsy-related seizures but they are not caused by abnormal electrical discharges. Other names for NES include psychogenic non-epileptic seizures, non-epileptic attacks, non-epileptic events and pseudoseizures. We prefer the term "non-epileptic seizures" (NES) and we refer to each episode of a NES as an "event".

Are NES common?

NES is the most common condition that is mistaken as epilepsy. Approximately one in four patients seen at tertiary epilepsy centers for evaluation of seizures are determined to have NES instead of epilepsy.

NES can greatly affect a person's quality of life, impacting a person's ability to participate in their usual activities, such as work or school. It is common for patients to have been told that their events are or were epileptic. Incorrect diagnosis can sometimes lead to treatment that will not alleviate and may worsen symptoms.

Is it possible to have epilepsy-related seizures and NES?

Yes. Some patients can have a combination of both epilepsy-related seizures and other events that show no epileptic or electrical activity in tests that determine seizures' origins. This requires a careful evaluation by your neurologist.

What tests can confirm my type of seizures or events?

The diagnosis of NES is firmly established when a typical event takes place under video-electroencephalographic (v-EEG) monitoring. During v-EEG monitoring the patient is monitored for a few days with a video camera and an EEG until a seizure or event occurs. This procedure is done under medical supervision in the hospital. The lack of abnormal findings in the EEG during a typical event is highly suggestive, and usually diagnostic, of NES. It is also important to evaluate the EEG tracing during the times that the patient is not having an event.

The diagnosis is also supported by an evaluation involving a multidisciplinary team that includes neurologists, neuropsychiatrists, neuropsychologists and social workers.

But I was told I had an "abnormal EEG" before and that I had epilepsy.

It is very important that past records are reviewed by your neurologist, when available. A past 'abnormal' EEG can mean different things (from showing epileptic discharges to showing abnormalities not diagnostic of epilepsy) and that is why it is important that your neurologist takes a look at those past studies when available. Some patients may have been misdiagnosed as having epilepsy for years and, as explained above, others may have a combination of epilepsy-related seizures and non-epileptic events. Sorting out what kind of episodes you currently experience and what kind of episodes you may have experienced in the past is an essential part of a multidisciplinary evaluation to properly diagnose NES.

What is causing NES?

Our current understanding is that NES are involuntary expressions of distress. It is important for patients and family members to understand that the fact that the events are non-epileptic in origin and that stress may play a role does not mean that they are voluntarily or purposefully fabricated.

Some patients are well aware that they have been struggling with emotional difficulties, or significant emotional or physical stress, and some may have been treated by mental health professionals in the past. Other patients may have never seen a mental health professional and they may not identify any obvious source of stress in their lives. Many people with NES also suffer from other psychiatric problems such as depression, anxiety, problems with relationships, history of childhood abuse, etc.

A clear relationship between an immediately preceding trigger and the event is commonly observed, but this may not always be the case. In contrast, rather than the event being an immediate response to a trigger, NES are thought to be an expression of accumulated distress over time. This accumulated internal hyperarousal may lead to episodes when the brain temporarily loses its ability to integrate sensorimotor, cognitive and behavioral processes.

How can I get treated for NES and how soon am I going to get better?

The most important initial step is to establish the diagnosis correctly through the appropriate tests, including a multidisciplinary evaluation by a team of neurologists, neuropsychiatrists, neuropsychologists and/or social workers, and by v-EEG.

The medical evidence favors psychiatric treatment, especially psychotherapy and in some cases psychopharmacological (medication) interventions. The kinds of psychotherapy treatment shown to be effective in NES are short-term and focus on skills training that can help patients identify stress and manage symptoms and stressors more effectively. Psychotherapy treatment is a process and it may take time, training and effort for results to become evident. Occasionally, family members may participate in treatment as well. It is very difficult to forecast how long it takes for treatment to work. Factors that forecast a positive outcome include correct diagnosis soon after onset of the events, patients' agreement with the diagnosis, commitment to participate in the offered treatment and proper management of other psychiatric diagnoses, when they exist.

If I do not have epilepsy, can I stop taking my anti-epileptic medications?

This will depend on each case and needs to be carefully discussed with your neurologist. If it is clear that you do not need to take anti-epileptic medications, you should follow the instructions of your neurologist and should never stop these medications without their supervision and guidance.

What can family members do to help?

Family members usually want to know how they can help, especially during an event. Ensuring a safe environment where the likelihood of getting physically hurt is minimized is the first priority. In general, ongoing, 24/7 supervision is not recommended, but this should be further discussed with treatment providers. Encouraging participation in treatment and promoting independence and return to functioning (such as work, school or previously routine activities) as much as possible is usually advised.

Family members should carefully discuss with treatment providers when it is recommended or not to call emergency services. In general, if events have been properly diagnosed as NES and continue to present with the same symptoms, emergency room visits are discouraged.

Can I drive?

This will need to be discussed with the professionals treating you for NES in accordance with the laws of the Commonwealth of Massachusetts. The general rule among professionals versed in NES is that driving should not occur until it is determined safe that your events will not recur. Driving can put you and other people at risk especially if your events occur without a warning, involve loss of motor control or involve alteration of consciousness.

How do I set up an appointment and evaluation of my events?

For more information or to set up an appointment, please contact the Brigham and Women's Hospital Neurology Clinic at (617) 732-7547. When you call, please mention that you read this brochure about non-epileptic seizures and would like an evaluation by one of our professionals.