



FAQs about PNES

Frequently Asked Questions about
Psychogenic nonepileptic seizures



PNES

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Illuminating, Helping, Empowering.

Most likely if you were given the diagnosis of psychogenic nonepileptic seizures (PNES), you and your family will have many questions. This section of frequently asked questions (FAQs) is meant to answer some of them. Not all answers may apply to you, and you should bring up any questions about the information provided here to your doctor or treatment team.

1- Epileptic seizures and nonepileptic seizures - what is the difference?

An **epileptic seizure** is a sudden, involuntary, and usually short change in behavior, movement, sensation, and/or consciousness (alertness) associated to an abnormal electrical pattern (like an electrical "storm") in the brain. The abnormal electrical pattern can usually be seen at the time of the seizure in an EEG (electro-encephalogram).

A **nonepileptic seizure** is an episode or event that may look and feel similar to what is described above (epileptic seizures), but it happens without the abnormal electrical changes that happen during epileptic seizures.

This means that to an observer, a nonepileptic seizure might look very similar to an epileptic seizure, but if you were to connect an EEG to record electrical activity in the brain during the nonepileptic seizure, you would not see the type of abnormal electrical activity seen in epilepsy with a nonepileptic seizure.

2- What is the difference between nonepileptic seizures and psychogenic nonepileptic seizures (PNES)?

Episodes that look like seizures but are not epileptic (nonepileptic seizures) can have many different causes. The most common type of nonepileptic seizure is psychogenic (PNES), and this website will answer questions about PNES.

There are some nonepileptic seizures or events that are caused by specific physiological or medical conditions. A few examples of those conditions are:

- Syncope (a temporary loss of consciousness, also known as "fainting" or "passing out" and usually due to insufficient supply of oxygen to the brain);
- Sleep disorders, such as narcolepsy ("sleep attacks"), or daytime sleepiness due to sleep apnea (period of pauses in breathing while the person is asleep);
- Certain movement disorders can be confused with seizures;
- Other medical conditions.

Usually, the description or observation of the seizure or event itself will help your doctor distinguish if the nonepileptic episode is PNES or may be explained by another medical condition. When necessary, your medical doctor may need to rule out these other possibilities and run an extra series of tests.

3- What are psychogenic nonepileptic seizures (PNES)?

Psychogenic nonepileptic seizures (PNES) are sudden, involuntary and usually short changes in behavior, movement, sensation and/or consciousness, that represent a reflex-like response to physical and/or emotional distress that the brain is detecting.

You may or may not be aware of the distressing factors that can be associated with PNES. The brain automatically uses physical symptoms (e.g., PNES or other functional neurological symptoms) as a way to involuntarily channel the

expression of distress or discomfort.

These automatic brain responses may develop due to:

- an accumulation of stressful factors or troubling experiences over time and/or
- patterns of learned behaviors over time and/or
- the way your brain tends to respond to challenging thoughts or emotions.

People do NOT always feel distressed or upset right before a PNES episode. They may not even recall any major distress months or years before the onset of PNES. In those cases, it is possible that PNES develop due to some of the following reasons:

- difficulty recognizing that one is under stress;
- denial of distress (recent or remote);
- speedy dissociation (detachment from physical and emotional experiences) eliminating a subjective warning phase;
- having learned over time to associate emotion fluctuation / arousal fluctuation as threatening, and therefore the brain automatically engages in dissociation and/or PNES.

In other words, PNES is a response to stimuli not entering conscious awareness (in the same way as one may step out of the way of a puddle while walking on a sidewalk and talking to someone without ever becoming aware of the puddle).

4- Some doctors told me that my seizures are “not real” or that I am “faking them”? Am I “going crazy”?

NO, and if a doctor told you that, he/she was mistaken.

PNES episodes are very real and you are not volitionally bringing them on (although with treatment, the patient can gain control over them).

Unfortunately, many doctors and nurses are not well-trained in what PNES are and think that because emotional factors or stress are frequently associated to PNES, patients “must have control” over them. This misunderstanding is slowly changing.

You are not going “crazy” either. The fact that your brain is dealing with underlying emotional difficulties through these episodes only means that your brain is using your body as a way to express something (instead of expressing it in a different way). There are other conditions where stress is thought to play a part in the development of physical symptoms, such as panic attacks, fibromyalgia, irritable bowel syndrome, chronic fatigue and tension headaches.

5- How many people have PNES?

The number of people affected with PNES is not exactly known. It has been reported that out of 10 patients seen in epilepsy inpatient units for difficult-to-treat seizures, 2 to 5 actually have a diagnosis of PNES.

About one in eight people newly referred to an epilepsy specialist turn out to have PNES.

Therefore, PNES are commonly seen by doctors who evaluate and treat patients with seizures.

6- What triggers PNES?

PNES may seemingly happen spontaneously (out of the blue) or may be triggered. Triggers may be inside or outside the body. Examples of inside triggers are physical symptoms, emotions, thoughts, and memories. Examples of outside triggers include something picked up by the senses (sounds, smells, lights, etc.), or difficult experiences that are encountered.

However, PNES can also happen when you are resting and relaxed and removed from any detectable trigger.

Usually, with the help of treatment, many patients become more aware of vulnerable states, environmental triggers and changes in thoughts and emotions that predispose them to experience a PNES episode.

7- Can PNES cause brain damage or be fatal?

A PNES episode cannot by itself cause brain injury or death. However, if during the episode, the patient suffers a blow or physical injury, the situation changes.

It is usually not necessary to call an ambulance or visit a hospital UNLESS there has been an injury suffered during the episode or the episode is markedly different than the typical ones.

8- Can you still be diagnosed with PNES if you also have a neurological condition?

Yes. People with PNES may also suffer from neurological conditions. For instance, a past history of head injury is common in people who suffer from epilepsy. Surprisingly, it is also commonly reported in people with PNES (up to 50% in some studies). It is not yet clear why head injuries are frequent in PNES, but it is intriguing and needs to be studied more.

Also, some patients have both epileptic seizures and PNES. Approximately 10-25% of adults with PNES and up to 25% of children with PNES may also have epilepsy.

9- Is it possible for someone to have both epilepsy and PNES or to have an abnormal EEG but still be diagnosed with PNES?

Some patients have both epileptic seizures and PNES.

Approximately 10-25% of people with PNES also have epilepsy. It is extremely important in these cases to work with your team to help you distinguish which seizures are epileptic and which are PNES, how to tell them apart, and what treatment you should receive for each.

If there is epilepsy-like activity on EEG and abnormalities in neuroimaging studies (brain MRI or other techniques) in someone with proven PNES, the possibility of a "dual diagnosis" (having both PNES and epilepsy) needs to be thoroughly explored.

Sometimes there are slight changes in EEG that happen in healthy people (about 10-20% of healthy people have those changes in EEG). Those EEG changes do not mean that the patient has epilepsy and may confuse some doctors. That is why an expert in epilepsy and EEG is necessary to confirm what those changes really mean.

10- What are some of the other physical and psychological problems that people with PNES have?

Research has shown that other physical and psychological problems can frequently happen in patients with PNES. These include:

- A history of one or more head injuries;

- Fibromyalgia, headaches and other pain syndromes;
 - Fatigue and cognitive changes (including problems with concentration, word finding difficulties, slurred speech, forgetfulness);
 - Weakness or paralysis of a limb, numbness or tingling;
 - Changes in vision, hearing or speech;
 - Bowel and bladder problems;
 - Significant problems with anger management, impulse control and/or assertiveness;
 - High anxiety (including panic and worrying) and problems with stress coping;
 - Depression and difficulty with keeping emotions steady;
 - A past history of traumatic experiences (such as emotional, physical and/or sexual abuse);
 - Difficulties in relationships, family dysfunction;
 - Alexithymia (a difficulty in recognizing and/or verbalizing emotional experiences).
- Some patients have none, a few or many of these other problems.

Treatment with PNES may also help relieving some of these other symptoms or problems.

11- How common are traumatic experiences in patients with PNES?

History of traumatic experiences has been observed in a high percentage of PNES patients (ranging from 40 to 100%, according to different studies).

In adults with PNES, one quarter to three quarters of patients with PNES report a history of childhood physical or sexual abuse. Psychological trauma can also result from other experiences including childhood neglect, combat, witnessing or being the victim of a violent crime as an adult, suffering major accidents or natural disasters, significant medical/health issues, sudden loss of a loved one (e.g. a parent or a child), etc.

In children and adolescents with PNES, traumatic experiences can also occur prior to onset of PNES, although physical and sexual abuse occurs only in about 9-14% of patients (less frequent than adults). Pediatric patients often report traumatic experiences of bullying (up to 50%), family struggles including witnessing violence, and death or loss of a parents or caregiver.

Around 50% of patients with PNES carry a diagnosis of post-traumatic stress disorder (PTSD).

Although common, having a history of past traumatic experiences is not a requirement for the diagnosis of PNES. In fact, psychological trauma and PTSD can also be observed in persons with epilepsy.

12- How do you feel about the diagnosis of PNES?

You may experience a range of emotional reactions when you find out that you have PNES. This is understandable.

“I feel CONFUSED” - It can be confusing to be diagnosed with PNES, especially if you believed you had epilepsy. Epilepsy is quite well known and understood, while PNES is a condition that can be difficult to understand and is not so publicly known.

“I feel ANGRY” - Some people may feel angry that they were diagnosed with a different diagnosis in the past. Also, some people may become angry because it is hard to accept that they do not have epilepsy or some other neurological condition they believed they could have. They may feel angry with the doctor who diagnosed them with PNES because they continue to feel this is a wrong diagnosis.

“I have DOUBTS” - Some people do not accept the explanation of PNES because they do not see any clear emotional difficulty in their lives or they do not feel stressed right before each episode. PNES episodes may occur without a clearly identifiable trigger or significant life stressor at the time of their onset. People sometimes think that if there are emotional factors at play, they “should be able to control the seizures” – not true; people do not choose when they

become depressed or have a panic attack, and it is the same for PNES.

“I feel RELIEVED” - Some people are glad that a clear diagnosis was finally made so they can receive the right treatment for their condition.

It is often helpful to think about how you feel about your diagnosis. This can make it easier to discuss the problem with other people and to ask friends, family, and your doctor for help.

13- Will I get better?

You can recover fully and lead a normal life. Recognizing that the episodes are nonepileptic is the first step of recovery. It may also mean that unnecessary treatments could be stopped (always under your doctor’s supervision).

Sometimes just being diagnosed with PNES is enough for people to get better. For many other patients with PNES, specific treatments (such as psychotherapy) are necessary for the episodes to improve. For a number of patients, the episodes can become a long-term problem. However, even if the episodes continue, many people can learn to live a full and active life.

14- What forms of treatment are available for PNES?

The first step towards recovery comes through the conversation that you, as a patient, have with your neurologist and mental health professional (usually a psychologist or psychiatrist) when you are first told that your diagnosis is PNES. It is incredibly important that this conversation include a thorough and clear explanation about PNES: what it is, what is known about its origins, how it fits with your history and how it can be treated. Ideally, you should not leave the hospital or clinic without a treatment referral or plan in hand.

Next, the most successful treatment interventions may be those conducted by a mental health professional that works in close collaboration with the diagnosing epilepsy center. In this way, the patient is treated by professionals who are familiar with the disorder, who can consult each other if there are questions and among whom there is an open and frequent communication about any new developments with the patient. When this is not logistically possible, efforts to keep your health care professionals in communication (especially neurologists and mental health professionals) are needed.

In the last ten years, a number of psychological interventions have been studied in patients with PNES and many of them are becoming gradually and broadly available. They are summarized here:

- **Cognitive behavioral therapy (CBT)** is the most widely studied form of psychotherapy for PNES. CBT is a type of therapy where patients learn and apply skills to change thoughts and behaviors that facilitate the development of PNES, therefore reducing their frequency.
- **Mindfulness based psychotherapy** (which usually include elements of dialectical-behavioral therapy, acceptance and commitment therapy, mindfulness-based stress reduction, mindfulness-based cognitive therapy or some combination of these) is also a type of therapy where patients learn and apply skills to relate effectively to internal experiences such as thoughts and feelings. By improving awareness of these relationships, there is improved control of behaviors and symptoms, including PNES.
- **Interpersonal and psychodynamic psychotherapy** (regarded as “talk therapy” by some) aims to help patients identify the underlying emotional conflicts thought to lead to PNES. By expressing these internal conflicts in a more effective way, PNES are less likely to occur.
- **Prolonged exposure (PE)** is a specific type of CBT for patients that suffer from both PNES and PTSD. PE helps patients emotionally process past traumatic experiences by confronting distressing memories and situations in a safe context.

- **Family therapy** is an adjunct to any of the above therapies, especially when working with children or adolescents presenting with PNES. An important component is therapy with the parent or caregiver, separate from the child, to address coping with symptoms, improving the child's functioning and identifying and managing contributing family stressors.

Regardless of the specific type of psychotherapy to treat PNES, there are common elements that should be included in any kind of treatment for PNES. These are:

- learning about the disorder,
- being proactive about making positive changes,
- maintaining as much independence and engagement in life as possible;
- taking care of one's own health (emphasizing a healthy diet, exercise, and sleep hygiene) and
- improving connection with others.

Most of the above treatments (CBT, mindfulness-based psychotherapy, PE) can be completed in a short-term basis (for example, 12 sessions), although some treatment modalities may be longer. Many patients require maintenance psychotherapy treatment or longer-term treatment after completion of the initial short-term phase of treatment.

Mental health professionals usually trained to deliver these kinds of treatments include psychiatrists, psychologists, clinical social workers, licensed mental health counselors. When selecting a mental health professional for treatment, you should discuss if she/he is familiar with the diagnosis and treatment approach.

Studies show that there is no effective medication to treat PNES. However, medications may be recommended to treat other disorders that frequently happen in patients with PNES.

Anti-epileptic drugs often may worsen PNES. Unless there is another indication for which an anti-epileptic drug is being prescribed, your doctor should work with you in discontinuing this kind of medication.

Cessation of PNES episodes or significant reduction in frequency has been reported in over half of cases using any of the above-mentioned techniques.

It is not always easy to find mental health professionals (psychiatrists and psychologists) who are comfortable with functional neurological disorders, so it may require some research. This link takes you to a referral list of mental health professionals in the United States and Canada who have an interest in or specialize in PNES (it does not include all states and provinces yet; it is a work in progress). <http://nonepilepticseizures.com/epilepsy-psychogenic-NES-information-referral-sites.php>

15- How do we know if the treatment is working?

Improvement measures vary, but almost always the first measure that the patient and therapist will look at is whether there has been a reduction in the frequency, duration, or intensity of the PNES episodes.

Some patients will experience a reduction in episodes as soon as they receive the diagnosis of PNES and understand and reflect on situations present at the time symptoms began to happen. However, most patients with PNES should complete a course of psychotherapy. Generally, most studies show that more than half of patients experience an improvement after 3 months of psychotherapeutic treatment. Unfortunately, there is a small percentage of patients with PNES (a quarter or less) that may not improve their PNES episodes with the treatments we currently have available.

Some patients may experience a transient increase in episode frequency (especially during the first therapy sessions) as they begin to explore emotions, behaviors, thoughts and life factors related to their symptoms. This does not necessarily mean that "treatment is not working" but rather can be a sign that treatment is beginning to identify some of the factors related to an individual's PNES episodes.

Other areas of improvement seen with participation in treatment and important to focus on:

- Positive changes in quality of life;

- Improvements in coping strategies to address difficult problems that come up in day-to-day life;
- Reduced levels of psychological problems or symptoms (for example, improvement in depressive or anxious symptoms);
- Greater connection with feelings, being less "shut off" and being able to enjoy life more;
- Gaining independence back;
- Being able to return to daily life (work, education, and/or driving).

16- Should I be driving if I have PNES?

Driving issues should be addressed with your doctor and will likely need to be consistent with your state laws for seizures.

In most states, regardless of what the cause is, if someone loses consciousness or awareness or loses control of movements, there are regulations that require a certain time period of symptom freedom (epileptic seizure or PNES episode) before the person is allowed to drive again.

Because PNES symptoms can be so variable, this should be discussed with your doctor.

17- What can I do to make an episode stop?

We recommend that you start treatment as recommended by your doctor. In the meantime, there are some tools that can help you manage the episodes when they happen. These techniques are NOT a replacement to the treatment for PNES recommended by your doctor.

You may experience some "warning symptoms" before experiencing one of your episodes. The presence of warning symptoms should prompt you to try to do some of these activities that may help prevent further progression of the episode. You may also practice these techniques in the absence of warning symptoms, if there is something that makes you feel you may be going into one of your episodes.

1) First of all, make sure you go to a **safe place**, where the risk of injury is minimal. For instance, if there are intense movements during your episodes, make sure you sit down or lay down and are away from furniture that your body may hit against and cause an injury.

2) If there are people around you and they get scared, and you realize this is one of your typical episodes, tell them or make a sign to **reassure them** so that they do not get too alarmed and monitor that you are safe. The main points to communicate to people around you are to:

a) Keep you safe from injury by moving you from an unsafe place or dangerous objects and protect your head by placing soft clothing underneath.

b) Not hold you down.

c) Not put anything in your mouth or give you medication.

d) Speak to you calmly.

e) NOT CALL AN AMBULANCE UNLESS you get injured, the episodes go for longer than usual and/or they look very different from the usual presentation.

You can show people around you a letter explaining what they can do (<http://nonepilepticseizures.com/epilepsy-psychogenic-NES-faqs-should-other-people-do.php>).

3) **Distraction:** if you can learn to focus on something else or distract yourself, this may help.

Examples of distraction techniques include:

a) Count backwards from 100 to 0 in sevens, "100, 93, 86, 79" or fours, "100, 96, 92, etc.", or count forward alternating numbers and letters.

b) Pick up a magazine and start reading it.

c) Talk to someone, stay concentrated on the conversation or topic.

d) Try playing a computer game on a cell phone or some other device.

e) Try singing your favorite song.

4) **Sensory grounding:** it is important to practice these techniques also outside of when you are experiencing an

episode, so you become proficient at them:

a) Feel something, preferably something rough or textured, with your fingers and thumbs. Really focus on what it feels like. For instance, fold a frozen orange (that you can keep in the freezer) and transfer from hand to hand. As you do this, also put your feet flat on the floor and be aware of the ground solid under your feet. If you are sitting down, be aware of the chair solid underneath you. You can alternate your attention between what you are holding in your hands and other points of contact in your body with the chair, floor, etc.

b) Look around and really focus on the things you can see. Describe them to yourself in detail. You can alternate between two objects, describing one characteristic of each object to yourself and then move your attention to the other object.

c) Listen and see what sounds you can hear, e.g. people talking, birds singing, traffic noise.

d) 3-2-1 technique: alternate between sensory modalities; use any 3 senses and focus on 3, 2 and 1 object for each of them. For instance, touch 3 objects, observe 2 objects and hear one noise.

5) **Maintaining attention focus:** beyond sensory-driven attention, you may remind yourself where you are, what day of the week it is, what year it is, who you are with, etc. Keep going through this list, alternating with other distraction or sensory grounding techniques.

6) Remind yourself that you are **safe**.

To get more information about PNES, visit our comprehensive website:
www.nonepilepticseizures.com