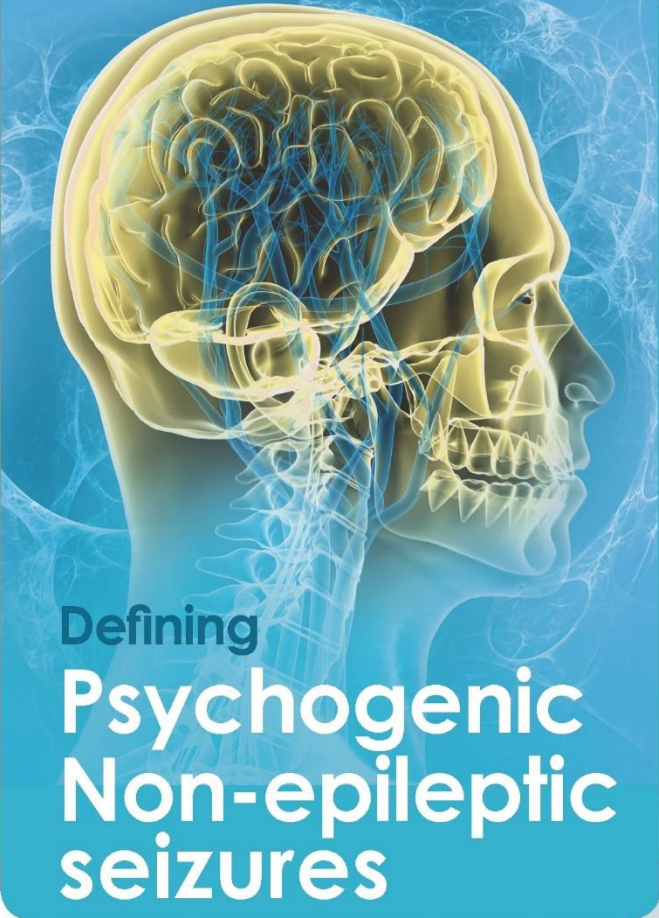


## A GUIDE FOR PATIENTS & FAMILIES

### WHAT ARE PSYCHOGENIC NON-EPILEPTIC SEIZURES?

A seizure is a temporary loss of control, often with abnormal movements, loss of consciousness, or both. Epileptic seizures are caused by sudden abnormal electrical discharges in the brain. Psychogenic non-epileptic seizures (**PNES**) are attacks that look like epileptic seizures, but are not caused by abnormal electrical discharges. They are, instead, stress-related, psychological, or emotional.

They are sometimes called pseudoseizures.



# Defining Psychogenic Non-epileptic seizures

PNES are the most common condition misdiagnosed as epilepsy. They are not rare and are as common as multiple sclerosis. In general, 20 to 30 percent of patients sent to epilepsy centers for difficult seizures are found to have PNES instead of epileptic seizures.

Your physician may suspect PNES when the seizures have unusual features, such as type of movements, duration, triggers, and frequency. PNES may look like generalized convulsions (similar to grand-mal seizures) with falling and shaking. Less often, they may mimic petit mal or complex partial seizures with temporary loss of attention, or staring.

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

The routine, 20-minute electroencephalogram (EEG) is often helpful in diagnosing epilepsy because it can detect the abnormal electrical (epileptic) discharges in the brain. However, the EEG is very often normal in patients with proven epilepsy, so it cannot be used alone to exclude epilepsy.

The most reliable test, and in fact **the only test**, that can make a PNES diagnosis is EEG-video monitoring. This procedure monitors a patient for several hours to several days with a video camera and an

EEG until a seizure occurs. By analyzing the video and EEG recordings, the diagnosis can be made with a nearly 100 percent certainty by experienced epilepsy specialists. However, this can only be done if the episodes in question occur frequently enough (once a week or more) to be recorded. Sometimes techniques can also be used to trigger seizures during monitoring.

#### Why did my other doctor say I have epilepsy?

Most patients with PNES, about 80 percent, have been treated with antiepileptic drugs for several years before the correct diagnosis of PNES made. This does not mean that doctors who have treated you for epilepsy have been incompetent. Remember that the diagnosis of seizures relies on the descriptions by observers, who may not notice important details. Few physicians have access to EEG-video monitoring, which has to be performed by a neurologist who specializes in epilepsy (epileptologist).

Because epileptic seizures are potentially more harmful than PNES, physicians, when in doubt, will treat for the more serious condition. If seizures continue despite medications, then either

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# Defining Psychogenic Non-Epileptic Seizures

the treatment needs to be changed or the diagnosis is not epilepsy. At that point, patients are sent to an epilepsy center, where the diagnosis is usually made.

## What about my abnormal EEG?

As mentioned above, most patients with PNES have received a diagnosis of epilepsy before being correctly diagnosed. Similarly, many have had EEGs reported as abnormal. This is because neurologists who do not specialize in EEG or epilepsy frequently over-read as abnormal what specialists would consider normal. This is one reason why the diagnosis of PNES 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.

A small proportion (only about 10 percent) of patients with PNES also has epilepsy. If you have both types, it is very important that you and your family learn to distinguish the two types.

## What causes psychogenic non-epileptic seizures?

PNES, unlike epileptic seizures, are not the result of a physical brain disease. Rather, they are emotional, stress-induced, and result from traumatic psychological experiences, sometimes from the forgotten past. It is well known that emotional or psychological stresses can produce physical reactions in people with no physical illness. For example, most everyone has blushed in embarrassment or been nervous and anxious as a reaction to stage fright. Today, we also know that more extreme emotional stresses can actually cause physical illnesses.

Some physical illnesses can be greatly influenced by psychological or emotional factors. These illnesses are called psychosomatic or mind-body illnesses. Examples include angina (chest pain), asthma, and headaches. Other conditions are thought to be influenced by stress and are often associated with PNES, including fibromyalgia and other pain syndromes, and irritable bowel syndrome.

Disorders where emotional stresses cause symptoms that look like physical illnesses are called somatoform (taking form in the body) disorders, and the most common type is conversion disorder. In fact the offi-

cial psychiatric classification had a specific category called conversion disorder with seizures. This is the category PNES usually fall into. This terminology has since been revised, but whatever term is used, it is clear that emotions or psychological stress can cause physical symptoms.

It is important to remember that somatoform disorders, including conversion disorder, are real conditions that arise in response to real stresses; patients are not faking them. The fact that the vast majority of PNES are not consciously produced is often poorly understood by family members and even by healthcare professionals. A specific traumatic event, such as physical or sexual abuse, incest, divorce, death of a loved one, or other great loss or sudden change, can be identified in many patients. Often the underlying trauma has been blocked from consciousness and patients can recall the event only with help from a trained therapist. The unconscious processes that cause PNES may also cause or contribute to other conditions, such as depression and anxiety.

Thus, as mentioned above, PNES (and other conversion disorders) are a psychiatric condition. Some patients are reluctant to believe the diagnosis. Keep in mind that PNES represent a well-recognized condition that can be diagnosed with nearly 100 percent certainty. This is different from other psychogenic symptoms, which are simply a diagnosis of elimination. With EEG-video monitoring performed by an epileptologist, PNES can be shown with near 100 percent reliability to be of psychological origin.

## What about children?

PNES can also occur in adolescents and young children. More common psychogenic (stress-induced) symptoms in these age groups include headaches and stomach aches. Most of the points made in this guide apply to children as well as to adults. Young patients generally differ from adult patients only in that the triggers are typically less severe and are often related to the stresses experienced by younger patients, such as school or dating. Children and adolescents also have a higher rate of recovery.

# Defining Psychogenic Non-Epileptic Seizures

## You are not alone

We realize this booklet may not answer all your questions. It is not intended to replace discussions with your physician, but rather to help you understand that you have a known and treatable condition. You are not alone in having this. Treatment is available and is effective for most of the patients who seek it.

## Do I really need psychiatric treatment?

Some people believe that treatment by a psychiatrist is a sign of being “crazy” or otherwise mentally incompetent. Such is not the case with PNES. Many patients become upset when told that their seizures are psychological. Remember that PNES are not purposely produced — it is not your fault that you have them.

It makes sense to seek treatment from a person most able to help you. The psychological factors can best be identified with the help of those with special training in psychological issues: psychiatrists, psychologists, or clinical social workers. As with all other medical conditions, sometimes the exact cause remains unknown. Even then we can concentrate on the most important goal: reducing or eliminating the seizures.

Your neurologist may continue to follow you, but treatment will be provided primarily by a mental health professional. Treatment may involve psychotherapy, stress-reduction techniques (such as relaxation and biofeedback training), and personal support to help you cope with the seizures during the course of treatment. Some medications, such as antidepressants, may also be helpful.

## What is the outlook?

With proper treatment, the seizures eventually disappear in 60 to 70 percent of adults, and even higher percentages for children and adolescents. Keep in mind that psychiatric treatments are not a quick fix and take time. A common mistake is to refuse the diagnosis and not follow up with the proper treatment. Unfortunately, patients who make this choice will continue antiepileptic drugs, which have already failed and are not likely to work.

An important factor is early diagnosis. The shorter amount of time patients carry the wrong diagnosis of epilepsy, the better the chances are for full recovery.

With the supervision of the neurologist, antiepileptic drugs should be gradually (not abruptly) stopped.

## CAN I DRIVE?

Many people with PNES have stopped driving, since they have received a diagnosis of epilepsy. There is no law that regulates driving in patients with PNES and neurologists vary in what they recommend. The decision as to whether you should be driving has to be made individually with both your psychiatrist and your neurologist.

## 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 psychological in origin. However, if your disability is now related to PNES (and not epilepsy), decisions are best made by your psychiatrist or psychologist rather than your neurologist.

## More information

PNES are constantly the subject of new research. Each year at the Annual Meeting of the American Epilepsy Society ([www.aesnet.org](http://www.aesnet.org)), many presentations are devoted to this topic. And each year, 50 to 100 articles on PNES are published in the medical literature.

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## Your experts:

### Selim R. Benbadis, MD

Professor of Neurology  
Director, Comprehensive Epilepsy  
University of South Florida & Tampa  
General Hospital  
813-259-8577  
[sbenbadi@health.usf.edu](mailto:sbenbadi@health.usf.edu)

### Gina Dunn, RN

Coordinator, Comprehensive Epilepsy  
Program  
University of South Florida & Tampa  
813-259-0922  
Fax # 813-259-8822

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to replace medical evaluation, advice, diagnosis  
or treatment by a healthcare professional.

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