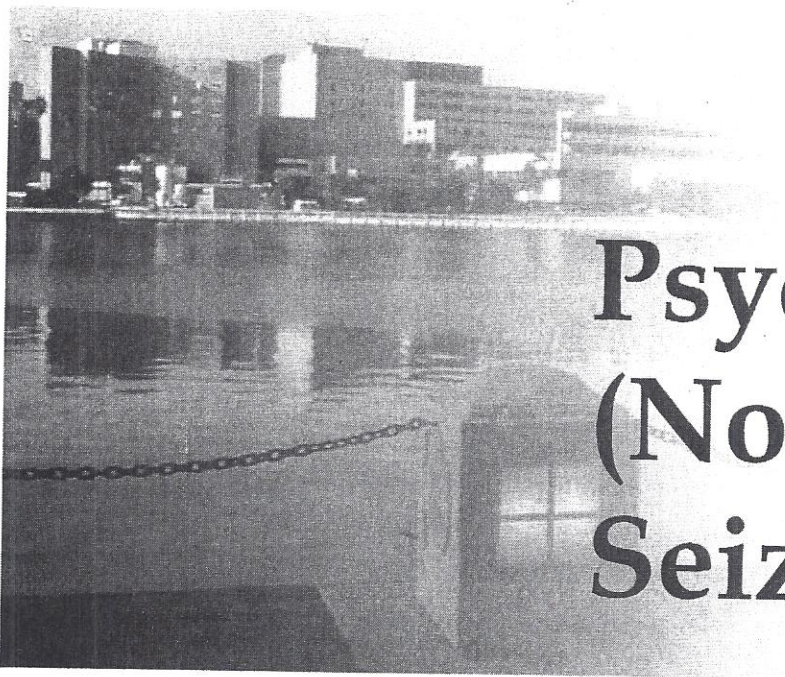
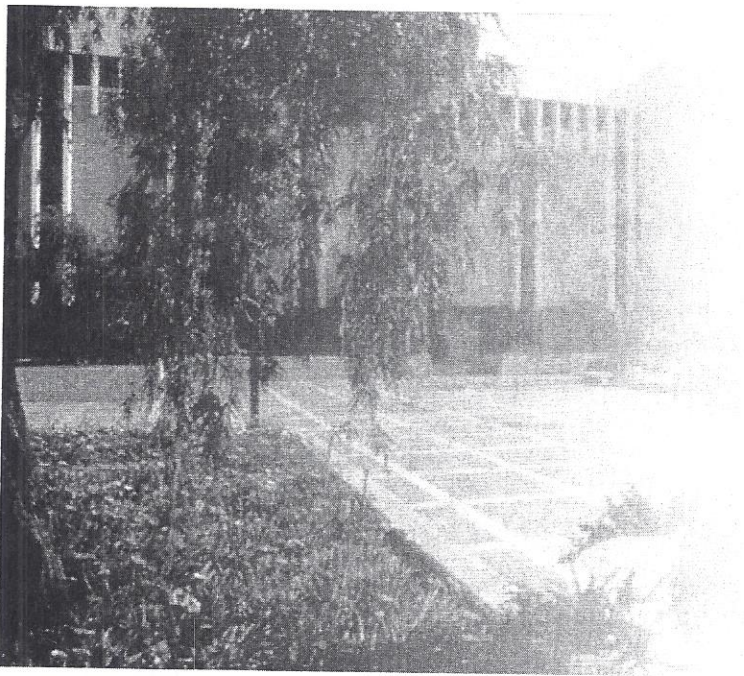


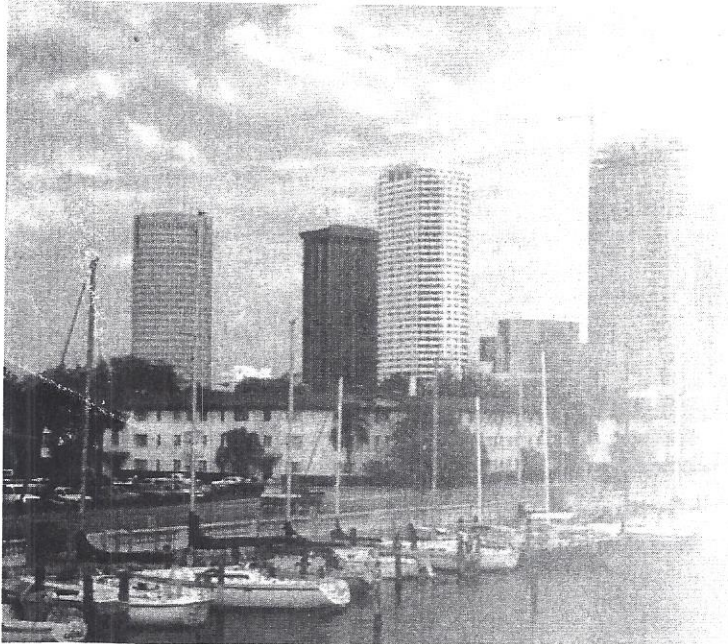


# Psychogenic (Non-Epileptic) Seizures



A Guide  
for Patients  
& Families

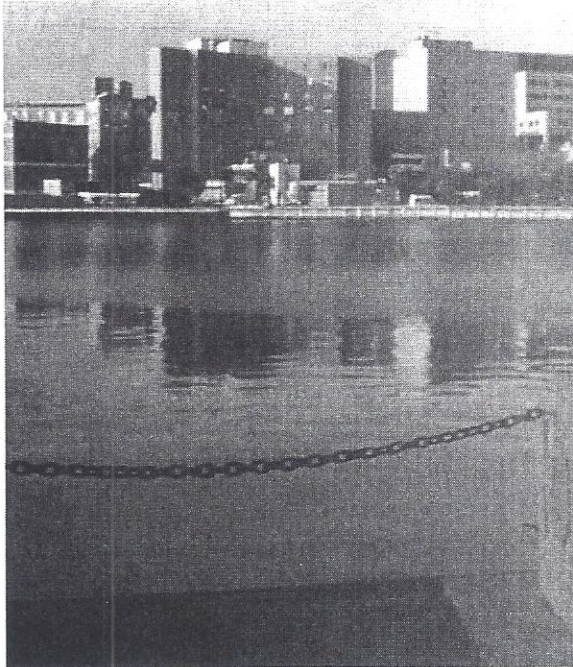
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● Comprehensive Epilepsy  
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## Psychogenic (non-epileptic) seizures: A guide for patients & families

### WHAT ARE PSYCHOGENIC NON-EPILEPTIC SEIZURES?

A seizure is a temporary loss of control, often with abnormal movements, unconsciousness, or both. Epileptic seizures are caused by sudden abnormal electrical discharges in the brain. Psychogenic (non-epileptic) seizures are attacks that look like epileptic seizures, but are not caused by abnormal electrical discharges. They are stress-related or "emotional." They are sometimes called pseudoseizures, but "psychogenic non-epileptic seizures" (PNES) is now the preferred term.

### I HAVE NEVER HEARD OF THIS. IS IT RARE?

PNES are the most common condition misdiagnosed as epilepsy. PNES are not rare, with a frequency comparable to multiple sclerosis. In general, 1 in 5 of patients sent to epilepsy centers for difficult seizures is found to have PNES instead of epileptic seizures.

### HOW CAN WE BE SURE THAT THIS IS THE RIGHT DIAGNOSIS?

Your physician may suspect PNES when the seizures have unusual features (e.g., type of movements, duration, triggers, frequency, etc.). 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."

The routine, 20-minute electroencephalogram (EEG) is often helpful in diagnosing epilepsy because it can detect the abnormal electrical discharges in the brain that indicate epilepsy. 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 to make the diagnosis is EEG-video monitoring, which is the only way to be sure. 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% certainty. However, this can only be done if the episodes in question occur frequently enough (once a week or more). Sometimes techniques can also be used to trigger seizures during monitoring.



## Psychogenic (non-epileptic) seizures: A guide for patients & families

### WHY DID MY OTHER DOCTOR SAY THAT I HAD EPILEPSY?

Most patients (about 80%) with PNES have been treated with antiepileptic drugs for several years before the correct diagnosis is made. This does not mean that doctors who have treated you for epilepsy have been incompetent. Here is why.

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 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%) of patients with PNES also have 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, everyone has blushed in embarrassment or been nervous and anxious as part of a "stage fright" reaction. 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 influ-



## Psychogenic (non-epileptic) seizures: A guide for patients & families

### Psychogenic (Non-epileptic) Seizures, continued...

enced 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 official psychiatric classification (DSM-IV) has a specific category called *conversion disorder with seizures*. This is the category PNES usually fall into.

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 health care 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, which may also be present.

### DO I REALLY NEED PSYCHIATRIC TREATMENT?

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% certainty. This is different from other psychogenic symptoms, are simply a "diagnosis of elimination." With EEG video monitoring performed by an epileptologist, PNES can be shown with near 100% reliability to be of psychological origin.

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.



## Psychogenic (non-epileptic) seizures: A guide for patients & families

### Psychiatric Treatment, continued...

Your neurologist may continue to see 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.

### WHAT IS THE OUTLOOK?

Overall, the outlook is good.

With proper treatment, the seizures eventually disappear in 60-70% of adults; the percentages are even higher 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 sooner patients have carried the wrong diagnosis of epilepsy, the better the chances of 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 carried 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 rather than your neurologist.



## Psychogenic (non-epileptic) seizures: A guide for patients & families

### 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 stresses 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.

### A FINAL THOUGHT

We realize this booklet may not have answered 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.

## ADDITIONAL INFORMATION

PNES are constantly the subject of new research. Each year at the Annual Meeting of the American Epilepsy Society, many presentations are devoted to this topic. Each year, many articles on PNES are published in the medical literature. The following gives some idea of the attention being directed to this well-recognized disorder.

In 2001, there were over 60 articles on PNES published in the medical literature. In 2001, there were 21 presentations on PNES at the Annual Meeting of the American Epilepsy Society.

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