

Seizures can be divided into three major categories:

1. Epileptic seizures (ES)
2. Physiologic non-epileptic events (NEE)
3. Psychogenic non-epileptic seizures (PNES)

1. Epileptic seizures. The brain is made up of millions of nerve cells. These cells, called neurons, generate electrical discharges, sending messages to the body to produce thoughts, feelings and actions.

An epileptic seizure is a disruption in the normal pattern of these discharges, caused by the neurons firing all at once and at a much faster rate. This can cause changes in sensation, awareness, and behaviour, or sometimes convulsions and loss of consciousness, depending on where the seizure starts and spreads in the brain.

2. Physiologic non-epileptic events are neither epileptic nor psychogenic. A wide variety of medical conditions or events can be misinterpreted as epileptic seizures, but are essentially caused by body changes that produce a seizure or seizure-like event (e.g., convulsive faint or concussive seizure). Sometimes these are termed reactive seizures because they are the body's reaction to a provocation.

3. Psychogenic non-epileptic seizures are 'sudden, involuntary changes in behaviour, sensation, motor activity, cognitive processing (can include change in level of consciousness) or autonomic function (e.g. blood pressure, heart rate) linked to psychological or social distress.¹ These events look like epileptic seizures, but are not caused by abnormal electrical discharges. The events are often triggered by an emotional or psychological cause rather than a physiological one and can be seen in people with or without epilepsy.

PNES function as a coping mechanism. People with these events are more likely to use poor coping strategies to handle stress. These events are sometimes referred to as pseudoseizures or psychogenic seizures but these are older terms.

PNES are a physical symptom of a psychological disturbance and are usually involuntary.

I have never heard of PNES before. Is it rare?

PNES are the most common condition misdiagnosed as epilepsy. Approximately one in five people referred to a neurologist for investigation of difficult-to-control seizures have PNES instead of epilepsy, and about 10% of people with PNES also have epilepsy.

Three out of four people with PNES are women, and although they can occur at different ages, they most often begin in young adulthood.

The syndrome is also called **Conversion Disorder or Functional Neurological Disorder**.

How do we know that this is the right diagnosis?

A doctor may suspect PNES when the events have unusual features (e.g. type of movements, duration, triggers, frequency, circumstances of events etc.). The best way to find out if an event is an epileptic seizure or not, is to have it recorded on a video electroencephalograph (EEG). Unfortunately capturing the event can be difficult, as they are usually sporadic and unpredictable.

Therefore a careful description of the event is also extremely valuable for diagnosis.

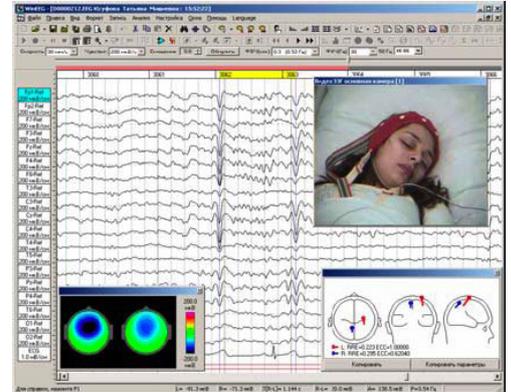
Fact Sheet: Psychogenic Non-Epileptic Seizures

Unfortunately, misdiagnosis often results in antiepileptic medication being prescribed, but is usually ineffective and the “events” do not stop (because they are not epileptic seizures).

It is important to have a correct diagnosis to avoid being unnecessarily treated with anti-epileptic medication.

A doctor may suspect PNES if:

- Antiepileptic medication does not reduce or stop the seizures
- The seizures are always triggered by an emotional or stress response
- The seizures usually occur in the presence of others
- The characteristics of seizures are inconsistent with epileptic seizures. For example, side-to-side head shaking, eyelid fluttering, cycling movements of the legs, pelvic thrusting, back arching, weeping, stuttering and talking and verbally responding
- There are usually no injuries or incontinence
- There is often a history of trauma, abuse or some form of psychiatric disorder such as depression or post-traumatic stress disorder (PTSD)



<http://www.dimachki.com/index.php?catid=391&lang=en>

It is important to know that if someone does not respond to a number of antiepileptic medications that they may not have epilepsy and may need further investigations.

A routine EEG is often helpful in diagnosing epilepsy because it can detect the abnormal electrical discharges in the brain that indicate epilepsy. **However, EEG can be normal in people with epilepsy, so it cannot be used alone to exclude epilepsy.** A more reliable test is video EEG monitoring, which monitors the person for several hours to several days until a seizure occurs. It records the seizures (on video) and the brain's electrical activity (EEG) simultaneously. This combined information is valuable in diagnosing and understanding a person's seizures and their correlation with EEG. Diagnosis can be made with a nearly 100% certainty. However, video EEG can only be done if the person consents and the seizure occur often.

Why did my doctor say I have epilepsy?

Most people (about 80%) with PNES have been treated with antiepileptic medications before the correct diagnosis is made. Most doctors hardly ever witness their patient's events or seizures. Remember that the diagnosis of seizures relies on descriptions of the events or seizures, and PNES and epileptic seizures can sound very similar. Sometimes people may not notice or pass on important details, as it may not seem important to them. Also, access to video EEG monitoring is limited, and is usually done in a specialist unit and reported by a neurologist who specialises in epilepsy (epileptologist).

Because epileptic seizures are potentially more harmful than PNES, doctors, when in doubt, will treat the more serious condition. If seizures continue despite medications, then either the treatment needs to be changed or the diagnosis may not be epilepsy and will need to be reviewed.

Why was my EEG abnormal?

Many people with PNES are diagnosed with epilepsy before being correctly diagnosed. Similarly, many have had EEGs reported as abnormal. This may be because:

- It is possible to have an abnormal EEG without having epilepsy. A small percentage of the population have an abnormal EEG but no physical signs or symptoms of seizures
- EEG is a very complex and specialised area, and sometimes some EEG features that may be within normal range can look abnormal or very similar to epilepsy abnormalities.
- It is also possible to have both PNES and epilepsy. About 10% of people with PNES also have epilepsy. If you have both, it is very important that you and your family learn to distinguish between the epileptic seizures and the psychogenic non-epileptic seizures.

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What causes PNES?

By definition, PNES is a psychiatric disorder. There is usually not a single cause of PNES. Different studies have shown factors such as:

- greater than 80% of people with PNES had experienced trauma
- the frequency of PNES is higher in people with head injuries, learning disabilities, or isolated neuropsychological deficits
- people with PNES have higher than average rates of abnormal results on Magnetic Resonance Imaging (MRI) and EEG. These factors suggest that physical brain disease may play a role in the development of the events
- PNES can also occur in people with brain lesions that are associated with an increased risk of developing epilepsy such as stroke, trauma, infection and malformation.

It is well known that emotional or psychological stress can produce physical reactions in people with no physical illness.

Disorders where emotional stressors cause symptoms that look like physical illness are called somatoform (taking form in the body) disorders and are called either conversion disorder or functional neurological disorder. The official psychiatric classification (DSM-IV) has a specific category called conversion disorder with seizures. This is the category most PNES are included.

It is also known that more extreme emotional stressors can cause physical illness and some physical illnesses can be greatly influenced by psychological or emotional factors. These illnesses are called psychosomatic or mind-body illnesses. Examples include psoriasis, eczema, angina (chest pain), asthma, high blood pressure and headaches. Other conditions thought to be influenced by stress and are often associated with PNES, include some pain syndromes and irritable bowel syndrome.

It is important to remember that somatoform disorders, including conversion disorder, are real conditions that arise in response to real stress and that people 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 people. Often the underlying trauma has been blocked from consciousness, and the person 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.

Non-epileptic events (and other functional neurological disorders) are a defined psychiatric condition and a mental health professional can help the person to manage them.

Getting diagnosed and treated

The first and most important step in initiating treatment is to have a correct diagnosis.

Most people with PNES have previously received a diagnosis of other conditions (such as epilepsy) and therefore, reactions typically include disbelief and denial, as well as anger and hostility. For example, they may ask "Are you accusing me of faking?" or "Are you saying that I am crazy?"

Some doctors are uncomfortable with explaining PNES or uneasy about giving a conclusive diagnosis and consequently the person and their family are often confused and the events can continue. A good understanding of PNES and the affected person's reaction to the diagnosis can greatly affect the outcome; therefore education is crucial.

It is vital for the person to seek treatment from a professional who is most able to help. The psychological factors can best be identified with the help of those with specialist training in psychological issues: psychiatrists, psychologists, or clinical social workers. As with all other medical conditions, sometimes the exact cause remains unknown but the most important goal is to reduce or eliminate the events.

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Although a neurologist may continue to see the person, 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 the person cope with the events during the course of treatment. Sometimes medication may be needed to treat associated anxiety and depression.

Can it happen in children?

PNES can also occur in adolescents and young children. More common symptoms in these age groups include headaches and stomach aches. Most of the points made in this guide apply to children as well as adults. Children and adolescents usually have a better rate of recovery.

What is the outlook?

Overall, the outlook is good but it can depend on a few factors including the age of the person and how long the PNES have been happening.

With appropriate treatment and education, PNES eventually disappear in 60-70% of adults; the percentages are even higher for children and adolescents. Psychiatric treatments are not a quick fix and can take time. A common mistake is to deny the diagnosis and not follow up with the proper treatment. Unfortunately, a person who makes this choice may continue to take antiepileptic medications, which will not stop PNES.

An important factor is early diagnosis. The less time a person has the incorrect diagnosis of epilepsy, the better the chances of full recovery. Outcomes can also be improved with a good understanding of the condition, so education is critical. With the supervision of the neurologist, antiepileptic medications can be gradually (not abruptly) stopped. Where people have epilepsy and non-epileptic events, medications will continue.

Ongoing PNES can severely affect a person's quality of life.

Driving

Many people with PNES have stopped driving because they were diagnosed with epilepsy. There is no law that regulates driving in people with PNES, and neurologists vary in what they recommend. The final decision about 'fitness to drive' is made for each individual by the Driving Licensing Authority based upon information provided by the person and if requested, by a psychiatrist and neurologist.

A final point

This fact sheet may not answer all questions. It is not intended to replace discussions with a doctor, but rather to increase understanding and to let the person know that they are not alone and have a known and treatable condition. Treatment is available and is effective for most people who seek it.

Further reading:

Functional Neurological Disorder <http://fndhope.org/>

References

- [1] Baslet, G. Psychogenic non-epileptic seizures: A model of their pathogenic mechanism. *Seizure* 2011;20: 1-13
- [2] <http://emedicine.medscape.com/article/1184694-clinical>

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This information is given to provide accurate, general information about epilepsy. Medical information and knowledge changes rapidly and you should consult your doctor for more detailed information. This is not medical advice and you should not make any medication or treatment changes without consulting your doctor.

