

# Seizure Smart

## NON-EPILEPTIC EVENTS

Serving Australians with Seizures

### What Is An Epileptic Seizure?

The brain is made up of millions of nerve cells. These cells, called neurons, normally generate electrochemical discharges, sending messages to other regions of the body to produce thoughts, feelings and actions. A 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.

### What Are Non-Epileptic Events?

Non-epileptic events are attacks that look like epileptic seizures, but are not caused by abnormal electrical discharges. They usually have a stress-related or emotional cause. They are sometimes called *pseudoseizures* or non-epileptic events (NEE).

*These attacks are a physical symptom of a psychological disturbance and are usually involuntary.*

They are characterised by a change in a person's behaviour, perception, thinking, or feeling which can resemble, or is mistaken for, a seizure. However, there are no characteristic EEG changes that accompany a true epileptic seizure. This attack is triggered from an emotional or psychological cause rather than a physiological one and can be seen in people with or without epilepsy.

### I Have Never Heard Of This Before. Is It Rare?

NEE are the most common condition misdiagnosed as epilepsy. Approximately one in five people referred to epilepsy centre's for investigation of difficult-to-control seizures have NEE instead of epilepsy. Approximately 70% of NEE occur in women, and they can occur at different ages, but frequently begin in young adulthood.

### How Can We Be Sure That This Is The Right Diagnosis?

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

Therefore a careful description of the attack becomes extremely valuable. Diagnosis is more difficult without this eyewitness account.

*It is important to have a correct diagnosis to avoid being treated with medication unnecessarily.*

Unfortunately, sometimes this does happen. In these cases, treatment with medication usually demonstrates no reduction in the attacks mainly because they are not true seizures.

Things to possibly consider (collectively) when diagnosing NEE are:

- ▶ Resistance to antiepileptic drugs - when medication has no effect on attacks
- ▶ The presence of specific triggers that is unusual for epilepsy. For example, emotional triggers or attacks when becoming upset are common in NEE.
- ▶ The circumstances in which the attacks occur. For example, do they only occur in the presence or absence of people or certain people?
- ▶ Absence of attacks during sleep
- ▶ Characteristics of attacks that are inconsistent with epileptic seizures. For example, side-to-side shaking of the head, fluttering of the eyelids, bilateral asynchronous movements (eg, bicycling), weeping, stuttering, ability to talk and respond, and arching of the back.
- ▶ Lack of injury or incontinence during major attacks
- ▶ Previous history of trauma or abuse or psychiatric history

A routine electroencephalogram (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 confirmed epilepsy, so it cannot be used alone to exclude epilepsy.** The most reliable test is video EEG monitoring, which monitors the person for several hours to several days until an attack occurs. It records the attacks (on video) and the brain's electrical activity (EEG) simultaneously. This combined information is valuable in diagnosing and understanding a person's attacks and their correlation with EEG. Diagnosis can be made with a nearly 100% certainty. However, video EEG can only be done if the attacks in question occur often enough (once a week or more). Sometimes techniques can also be used to provoke or trigger attacks during monitoring.

Therefore it is necessary to be aware that sometimes if a person does not respond to a number of antiepileptic drugs one possibility may be due to the fact that they do not have epilepsy. But

rather they may need to be further investigated for another possible diagnosis. However sometimes the doctor may decide to wait and see if a similar attack occurs before undertaking further testing.

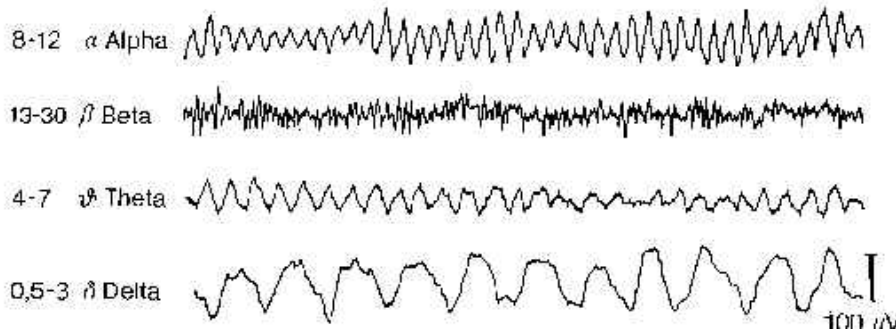
### Why Did My Other Doctor Say I Have Epilepsy?

Most people (about 80%) with non-epileptic events 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.

Most doctors never witness their patient's attacks or seizures. Remember that the diagnosis of seizures heavily relies on descriptions of the events or seizures. Sometimes people may not notice or relay important details, as it may not seem important to them. Also, access to video EEG monitoring is limited, and is usually performed in a specialist unit and reported by a neurologist who specialises in epilepsy (epileptologist).

Because epileptic seizures are potentially more harmful than NEE, doctors, 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 often sent to an epilepsy centre, where the correct diagnosis is usually determined.

### Why Was My EEG Abnormal?



Many people with non-epileptic events have been given a diagnosis of epilepsy before being correctly diagnosed. Similarly, many have had EEGs reported as abnormal. This may be because neurologists who do not specialise in EEG or epilepsy have possibly misinterpreted as abnormal what specialists would consider normal. EEG is a very complex and specialised area, and it can take years to become proficient at reading them. This is one reason why the diagnosis of NEE should only be made by epileptologists.

It is possible to have an abnormal EEG without having epilepsy. A small percentage of the population has abnormal EEGs with no physical signs or symptoms. It is also possible to have both NEE and epilepsy. A small proportion (only about 10%) of people with NEE also have epilepsy. If you have both types, it is very important that you and your family learn to distinguish the two different seizure types.

If you have had abnormal EEGs in the past, it is important to try and obtain the actual tracings so the specialist (epileptologist) can review them.

## What Causes Psychogenic Non-Epileptic Events?

Unlike epileptic seizures, these events are not the result of a physical brain abnormality. Physical and neurological tests are usually normal. Rather, they are usually emotional or stress-induced, and result from previous traumatic experiences, sometimes from the forgotten past. In short, they are an unconscious presentation of physical symptoms due to psychological factors.

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

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 thought to be influenced by stress and are often associated with NEE, 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*. The official psychiatric classification (DSM-IV) has a specific category called *conversion disorder with seizures*. This is the category most NEE fall into.

It is important to remember that somatoform disorders, including conversion disorder, are real conditions that arise in response to real stresses; people are not faking them. The fact that the vast majority of NEE 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 people can recall the event only with help from a trained therapist. The unconscious processes that cause NEE may also cause or contribute to other conditions, such as depression and anxiety.

## Do I Really Need Psychiatric Treatment?

The first and most important step in initiating treatment is delivering and explaining the diagnosis to the person and their family. Most people with non-epileptic events symptoms have previously received a diagnosis of organic disease (eg, 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?"

*Non-epileptic events (and other conversion disorders) are a defined psychiatric condition and a mental health professional should manage them.*



It is important NEE should be explained clearly, in clear terms that people can understand. Some doctors are uncomfortable with explaining NEE or uneasy about giving a conclusive diagnosis and consequently people and their families are left typically confused, and the attacks can continue. A good understanding of NEE and the affected person's reaction to the diagnosis can greatly affect the outcome; therefore education is crucial.

*Some people believe being treated by a psychiatrist is a sign of being crazy or mentally incompetent. This is not the case with non-epileptic events.*

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 specialist 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 attacks.

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 attacks during the course of treatment. Sometimes medication may be needed to treat associated anxiety and depression.

### **What Is The Outlook?**

Overall, the outlook is good. With appropriate treatment, the attacks 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 deny the diagnosis and not follow up with the proper treatment. Unfortunately, people who make this choice may continue antiepileptic drugs, which have already failed and are not likely to work.

An important factor is early diagnosis. The less time people have carried the wrong 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 drugs should be gradually (not abruptly) stopped. In the case of people who have epilepsy and non-epileptic events, medications will continue, but will possibly be reduced or changed under the doctor's supervision.

### **Can It Happen In Children?**

NEE can also occur in adolescents and young children. More common non-epileptic events (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. Children and adolescents usually have a better rate of recovery.

## Can I Drive?

Many people with NEE have stopped driving, since they have carried a diagnosis of epilepsy. There is no law that regulates driving in patients with NEE, 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.

## A Final Thought

We realise this fact sheet may not have answered all your questions. It is not intended to replace discussions with your doctor, but rather to help you understand that you are not alone and have a known and treatable condition. Treatment is available and is effective for most of the people who seek it.

*Special thanks for their assistance in developing this pamphlet to:*



### Reference:

Selim R Benbadis, MD, Professor, Director of Comprehensive Epilepsy Program, Departments of Neurology and Neurosurgery, University of South Florida College of Medicine. *Psychogenic Non-epileptic Seizures*. Updated September 2005. <http://www.emedicine.com/NEURO/topic403.htm>