



What is an epileptic seizure?

The brain is made up of millions of nerve cells. These cells, called neurons, normally generate electrical discharges, sending messages to 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 (NEE)?

NEE, also known as psychogenic non-epileptic seizures, 'are sudden, involuntary changes in behaviour, sensation, motor activity, cognitive processing (including change in level of consciousness) or autonomic function (eg 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. For this reason they are also referred to as *pseudoseizures* or *psychogenic seizures*.

Non-Epileptic Events are a physical symptom of a psychological disturbance and are usually involuntary.

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.

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 Neurologist 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?

A doctor may suspect NEE 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 a seizure or not, is to have it recorded on a video EEG. Unfortunately capturing the event can be difficult, as they are usually sporadic and unpredictable.

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

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

Unfortunately, sometimes antiepileptic medication is prescribed but is usually ineffective with no reduction in the events, essentially because they are not epileptic seizures.

A Doctor may suspect NEE if:

- ◆ There is no response to antiepileptic medications
- ◆ The events are triggered by an emotional or stress response
- ◆ The events usually occur in the presence of others
- ◆ The characteristics of events 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 no injuries or incontinence
- ◆ There is often a history of trauma, abuse or some form of psychiatric disorder

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 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 event occurs. It records the events (on video) and the brains electrical activity (EEG) simultaneously. This combined information is valuable in diagnosing and understanding a person's events 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 events occur frequently.

Why did my doctor say I have epilepsy?

Most people (about 80%) with NEE have been treated with antiepileptic medications before the correct diagnosis is made. Most doctors never witness their patient's events or seizures. Remember that the diagnosis of seizures relies on descriptions of the events or seizures and both can present in a similar way. 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 the more serious condition. If seizures continue despite medications, then either the treatment needs to be changed or the diagnosis is not epilepsy.

Why was my EEG abnormal?

Many people with NEEs have 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.

It is also 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.

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 between the seizures and the non- epileptic events..

What causes NEE?

Recent research suggests that there maybe simultaneous over and under metabolism in the particular areas of the brain involved in the processing of emotion, cognition (perception, learning and reasoning) and motor (muscle) activity in people experiencing NEE. The fundamental reason for this is unknown and more research is needed before any conclusions can be made.

It is known that these events, unlike epileptic seizures, are not the result of excessive electro-chemical activity in the brain. Physical and neurological tests are usually normal. NEE are usually emotional or stress-induced, and result from previous traumatic experiences, sometimes from the forgotten past. In short, they are subconscious presentations 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, include some 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 to have a correct diagnosis.

Most people with NEE 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.

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 events 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.

Unfortunately some people believe being treated by a psychiatrist is a sign of weakness when in fact it is a sign of strength.

It makes sense to seek treatment from a person 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.

Although your Neurologist may continue to see you, 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 events 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 events 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 to take antiepileptic medications, which are not likely to stop the events.

An important factor is early diagnosis. The less time people have 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.

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 because they were diagnosed with epilepsy. There is no law that regulates driving in patients with NEE, 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 yourself and as requested by your psychiatrist and neurologist.

A final point

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.

(1) Baslet, G. Psychogenic non-epileptic seizures: A model of their pathogenic mechanism. *Seizure* 2011;20: 1-13

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.