

Often people describe being aware of people around them but being unable to talk to them.

We are beginning to understand why people are vulnerable to non-epileptic attacks and something about their mechanisms in the brain but there is still a lot we do not understand. We also know that in dealing with these symptoms it is important to think about the whole person and not just their attacks.

Sometimes everything would feel a lot simpler if you could just tell people that you had epilepsy, something that most people understand and sympathises with. **Its very important to know that unlike some people with epilepsy you have the potential to get better even if you have had the symptoms for a long time.**

A good way of thinking about your symptoms is:

“You didn’t bring the attacks on but you can help yourself to get better”

What can I do to help myself get better?

If you have had attacks for a long time you cannot get better quickly from them.

These are some of the things that help

- **Feeling sure about the diagnosis.** If you have ongoing doubts that the diagnosis is wrong then it is unlikely that you will get better. Getting better requires dealing with unpredictable symptoms which is very hard to do unless you are sure about the diagnosis.
 - **Learning to stop attacks**– If, like most people with non-epileptic attacks, you find the attacks come on out of the blue then there are some things worth trying to stop the attack
1. **Cover your nose and mouth with a paper bag**– you may not be feeling that you are hyperventilating but this may help reduce feelings of derealisation or depersonalisation that sometimes come before an attack. Breathe in and out of the bag as **slowly** as possible. This increases the amount of carbon dioxide in the blood back to normal and may stop you from blacking out.

2. **Ask yourself—‘what is happening?’** Are you feeling frightened or worried about what is happening to your body. Remind yourself that you do not have epilepsy and that nothing serious is going to happen to you.
3. **Other people should stay calm**–family or friends can be understandably frightened by these attacks. Try to reassure them that you are not going to die during one and you simply need to be placed in a comfortable position until the attack is over.

“Non–Epileptic Attacks can be overcome if you learn to understand them and how to stop them in the early stages”

- **Dealing with situational non-epileptic attacks** If there is something which seems to bring on attacks, like certain situations (or sometimes even certain memories) then talking to family, friends or a professional such as a psychologist or psychiatrist may help in trying to overcome the problem
- **Expecting ‘relapses’ and giving yourself time to get better**– it is not easy to overcome non-epileptic attacks. You may find that just when you thought you had the problem solved, another attack will happen unexpectedly.

If you can keep positive then non-epileptic attacks can be overcome particularly if you believe the diagnosis, can learn to understand the warning signs and gradually learn how to stop them at an early stage of the attack.

Where can I go for more information?

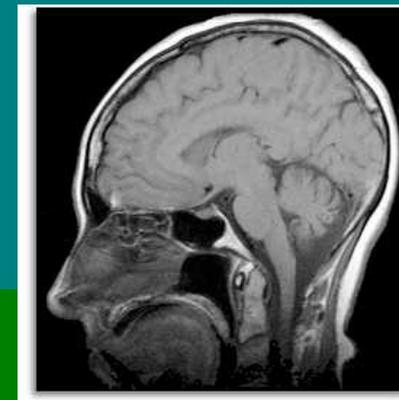
There is little information for patients with non-epileptic attacks. You will find some on the website of the National Epilepsy Society at:

www.epilepsynse.org.uk/PAGES/info/leaflets/factsnea.cfm

You may also find some practical information on coping with fatigue, pain and other symptoms in this book written for people with any diagnosis:

‘Living with a Long Term illness—the facts by Frankie Campling and Michael Sharpe, Oxford University Press’, Oxford 2006. ISBN: 019852882-5

What are Non-Epileptic Attacks?



Patient Information Leaflet

Non Epileptic Attacks

This leaflet aims to explain a bit about non-epileptic attacks and how you might try to overcome them.

Not all of it may apply to you and you should discuss it with the doctor who gave it to you



Patients with non-epileptic attacks often end up not feeling believed by doctors

What are non-epileptic attacks?

Non-epileptic attacks are disabling and frightening attacks that look very similar to epilepsy. People can experience shaking attacks or attacks when they simply 'blackout' often for quite a long time

Unlike epilepsy, non-epileptic attacks are *not* due to abnormal electrical activity in the brain or another neurological disease. They are however due to a *temporary* problem in the way the nervous system is working. They are potentially completely treatable.

Non-epileptic attacks are common. Nearly half of all people brought in to hospital with suspected serious epilepsy have them. Most patients with non-epileptic attacks will have been wrongly diagnosed as epilepsy at some point and may have even taken drugs for epilepsy.

Why are my tests normal?

In non-epileptic attacks all the parts of the nervous system are there, they are just not working properly at certain times. Your doctor will make this diagnosis after listening to what happens during an attack and talking to other people that have seen one

Patients with non-epileptic attacks have normal brain scans and other tests such as an EEG or 'brain wave' test

If you were a computer, it's a bit like having a software problem rather than a hardware problem.

What about my other symptoms?

These are some of the other symptoms that patients with non-epileptic attacks can also sometimes experience as part of their illness. Often these symptoms are also caused by a dysfunction of the nervous system as part of the same illness.

- Numbness or tingling
- Fatigue
- Arm or Leg pain
- Back or Neck pain
- Headache
- Poor concentration
- Sleep disturbance
- Word finding difficulty
- Slurred speech
- Intermittent blurred vision
- A floaty, distant feeling that things around you aren't quite real (derealisation)
- Weakness or Paralysis of a limb
- Frustration, Anger
- Low mood
- Lack of enjoyment
- Worry
- Panic
- Bladder and Bowel

Am I just imagining it then?

One of the big problems patients with non-epileptic attacks experience is a feeling that they are not being believed. This is partly because many doctors and nurses are not trained well in physical symptoms that are not due to disease and research in these areas is very poor. Some doctors really don't believe patients with these symptoms. Others do believe them but find it hard to know how to help.

So if it's a real condition but its not a disease, what is it? Am I just imagining it?

The answer is you are not imagining or making up your

symptoms and you are not 'going crazy'. You have non-epileptic attacks.



Non-epileptic attacks are common but often misdiagnosed

Why do they happen?

Non-epileptic attacks are a complex problem. They arise for different reasons in different people. Often the symptoms are accompanied by feelings of frustration, worry and low mood but these are not the *cause* of the problem.

We recognise a number of different situations in which non-epileptic attacks can arise. Your symptom may fall in to one of these categories although often none of these appear relevant:

1. **Randomly** – One of the most confusing things about these attacks is that they often happen out of the blue without warning.
2. **With hyperventilation** - In some people these attacks can occur at the same time as a shallow and rapid breathing pattern called hyperventilation. You may not even notice that you are breathing too fast but others may do so. If you are hyperventilating this may be making the attack worse. It is useful to know this because it provides a way of stopping future attacks at an earlier stage (see overleaf). Other physical symptoms you may experience during an attack are hot flushes, a tight chest and tingling in your hands.
3. **With depersonalisation/derealisation**—These words describe symptoms that many people have at the same time as their non-epileptic attacks. This is usually a frightening feeling that things around you are not quite real, or that you don't quite feel connected to your body or a feeling that everything is far away and weird. If you have these symptoms it is helpful to know what they are and that they are part of the attack. Many people who have never experienced these symptoms before are so frightened by them that they think they might be dying. You can get an 'out of body experience' with these attacks but you cannot die from them. *Continued.*