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# Understanding non-epileptic attack disorder





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© G18121301W. Design Services, Salford Royal NHS Foundation Trust, All Rights Reserved 2018. Document for issue as handout. Unique Identifier: NOE 42 (18). Review date: January 2021. This leaflet has been designed in collaboration with people who experience **Non-Epileptic Attack Disorder (NEAD)** to help you understand the diagnosis of NEAD. It explains what NEAD is and how it can be managed.

If you have any questions about this leaflet, please ask a member of staff, or email the Clinical Neuropsychology Department at: **reftoneuropsych@srft.nhs.uk** 

### What is Non-Epileptic Attack Disorder?

People with NEAD experience a temporary loss of control and/or awareness that happens when the link between the mind and the body is not working normally for a brief period.

NEAD is not dangerous (though the symptoms are understandably worrying until people are given accurate information).

On rare occasions, episodes can result in minor injuries (e.g. if you fall) but a NEAD episode is not damaging you internally and is not a medical emergency.

NEAD can affect anyone. It often happens to people who are good at "putting up" with difficult or stressful events and "carrying on" under pressure for a long time. There can be many reasons why a person develops NEAD and these are not always obvious at first. Some people worry that being diagnosed with NEAD means that doctors think they are "pretending" or that it is "all in their head". This is **NOT** true. **NEAD symptoms are real.** 

## What does a NEAD episode look/feel like?

NEAD episodes are not always the same. You may experience symptoms that affect your movement, senses or awareness.

Some examples are shown on the diagram opposite (though you may experience other symptoms not in this diagram).



Recovery from a NEAD episode is usually faster in a calmer environment.

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#### Why does NEAD happen? - The Mind-Body Link

Psychological experiences affect the body all the time.

For example:

- Sudden shock = heart beats faster
- Embarrassment = face goes red

• Upset = eyes produce tears It is normal for some changes to happen to the body without a medical cause or disease (e.g. tears when we feel sad are not caused by a disease; it is the mind-body link).

These examples are real effects of the Mind-Body link. They are not always within our control and can happen automatically. NEAD also happens through the Mind-Body link.

### What makes the Mind-Body link cause NEAD?

One way of understanding NEAD is to imagine a pressure cooker.

When heat is turned up under a pressure cooker, steam builds up inside. A pressure cooker needs a valve to release excess steam, but sometimes this valve can be blocked. Difficult life events and on-going stresses affect people in the same way as heat affects a pressure cooker.

Emotional and physical stress builds up inside people, similar to the way that steam builds up in a pressure cooker. This can be sudden (e.g. unexpected bereavement) or gradual (e.g. financial difficulties, living with physical health conditions) Just like a pressure cooker needs a valve to release steam, we all need to have ways of releasing

If we are not able to do things that will help us to release stress, stress is released through the mind-body link and NEAD episodes can happen.

pressure/ stress.



Past stressful<br/>situatonsCurrent stressful<br/>situatonsMental health problems<br/>(e.g. low mood, anxiety)Physical illness<br/>(e.g. pain, fatigue, poor health)

### Why do some people develop NEAD and not others?

NEAD can affect anyone, but it usually happens to people who are good at "carrying on" through difficult experiences that affect their lives.

There can be a number of reasons why a person's pressure cooker fills up and the stress is not released:

- Some people may not notice the build-up of pressure over time and may not feel stressed
- Some people can get into the habit of "bottling up" feelings and emotions or "carry on going" in situations that other people might find too difficult
- Some people may believe they shouldn't burden people by talking about difficult life events
- Some people may feel they must always put others first and are unable to take a break when they need to.

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Often the exact factors affecting a person's pressure cooker are not obvious at first, because everyone's lives are different. People are sometimes concerned that NEAD symptoms are their fault, that they have caused them or that they should be able to control symptoms. This is not true.

You did not bring on the symptoms. BUT, with the right information and support you can learn to manage symptoms and lead an independent lifestyle with little disruption.

#### How is NEAD diagnosed?

NEAD is often thought to be epilepsy at first, but a Neurologist or Neuropsychiatrist can tell the difference.

Sometimes a diagnosis can be made quickly, though it may be necessary to carry out several tests that take time.

People can feel uncomfortable or confused with the diagnosis of NEAD because they have not heard of it before or it has taken a long time to get the diagnosis. A NEAD diagnosis is made from certain signs and symptoms that a Neurologist or Neuropsychiatrist can recognise. It is not made because doctors are "giving up" or "have run out of tests".

People with NEAD are sometimes given anti-epileptic drugs (AEDs), before a Neurologist or Neuropsychiatrist confirms a diagnosis of NEAD.

### How can I learn to manage NEAD?

Research and national guidelines recommend people who experience NEAD episodes work with a psychological therapist specially trained in NEAD.

Some people believe that working with a psychological therapist is a sign that they are thought of as "pretending" or that symptoms are "all in their head". This is NOT true.

A specialist psychological therapist is trained to help you understand how the Mind-Body link works and to manage the causes of NEAD. There is no medical treatment for NEAD because it is not caused by disease or damage to the body. Working with a specialist psychological therapist is the only recommended way to manage symptoms.

Treatment is made up of three stages:

- **1. Information:** Learning about what NEAD is and how it happens.
- **2. Stabilising:** Strategies to reduce and control episodes.
- 3. Support making changes: Find new ways to manage stressful situations and patterns of coping that prevent NEAD returning.

## What will happen in the long term to my NEAD episodes?

Many people find that once they gain an understanding of NEAD and how to manage the symptoms they stop happening as frequently.

**REMEMBER:** NEAD is not dangerous. It can affect anyone

and is not your fault. With the right information and support you can learn to manage symptoms and lead an independent lifestyle with little disruption.

Useful links, associations & contacts www.neurosymptoms.org

www.nonepilepticattacks.info

### **Contact Details**

For more information about our department please visit our website:

### www.srft.nhs.uk/about-us/depts/ neuropsychology

If you have any further questions or concerns please contact us:

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