

Non-Epileptic Attack Disorder Information Course

Session 1

This document goes with the videos you will be sent by e-mail for session 1 of the course. If you do not receive an e-mail with the youtube link on the date stated on your appointment letter please let us know: neadresearch@srft.nhs.uk.

What is Non-Epileptic Attack Disorder (NEAD)?

People with Non-Epileptic Attack Disorder (NEAD) experience episodes of temporary loss of control. During a NEAD episode people can experience symptoms that affect movement (e.g. shaking or falling) as well as changes to their senses (e.g. hearing, vision, taste and smell). Symptoms can also affect awareness (such as feeling confused, being unresponsive or blacking out). NEAD is a natural response to danger and is not an indication that something is medically wrong or that there is damage to the brain or nervous system. Different people experience different symptoms and NEAD symptoms often change over time.

Like many conditions, there are multiple terms used to describe the same experience. Some of the terms that you may have heard: Psychogenic seizures, Psychogenic non-epileptic seizures (PNES), Dissociative seizures, Conversion disorder, Functional seizures and Psychological seizures.

Approximately 20,000 people in the UK have this diagnosis – but it could be more. 1 out of every 5 people who see a doctor because of seizures go on to have a diagnosis of NEAD.

What causes NEAD?

A helpful way to think about NEAD is to imagine a set of traffic lights (see *traffic lights* page 5).

When we are in the green zone we are at our best, feeling strong and capable. We are able to focus on the things that we want to do and feel connected with the people who are important to us. Ideally we want to spend as much time as possible in this zone.

When we experience physical (e.g. pain, illness, injury) and/ or emotional difficulties (e.g. worrying thoughts, feeling under pressure), hormones such as adrenaline and cortisol are released into the body. This is called the “fight or flight” response – a natural response that humans (and most other animals) developed to help us to fight or run away from dangers. During this response, we experience physical changes (e.g. faster heart rate, feeling hot, and butterflies in the stomach) and a shift in our emotions (e.g. fear, panic). We may also experience changes in our thinking (e.g.

racing thoughts, increased alertness) and behaviour (e.g., sticking to set routines and familiar places). This can be thought of as being in the “amber” zone (see traffic lights sheet).

This can be really helpful in situations when we are faced with an immediate physical danger. This is because it means that blood and oxygen is pumped to our muscles so that we can fight or run away. This same response also happens when we are faced with stresses that do not pose an immediate physical danger (e.g. worries about the future, running late for an appointment, sitting an exam).

Once the stress has passed, we usually need more rest than usual to get back into the green zone. This temporary shift from green to amber and back to green is healthy and helps to increase our ability to cope with future stresses. Unfortunately, if we have been or are going through really difficult experiences without the chance to rest and recover, we can get stuck in the amber zone. This can be for many weeks, months, or sometimes even years. It can become so normal to us that we don't even feel it.

Being in the amber zone for too long or at high intensity can cause us to go into the red zone (also known as the freeze response). This is a response that developed as a way to protect us from harm in situations that we are unable to change or escape from. We might notice being inactive, sleeping a lot, feeling numb, having difficulty controlling movement and feeling distant. It is when we are in the red zone that NEAD episodes can happen.

It is important to understand that being in the red zone is your body and mind's natural way of protecting you from danger. Being diagnosed with NEAD means that this protective response is happening much more frequently than it needs to – it has become an involuntary habit for the body and mind to react in this way. This response can become more sensitive over time which means that it may be triggered now by things that seem small. The reasons why this habit has developed are not always obvious at first, because everyone's lives are different.

What can cause us to go into/ stay in the amber zone?

** These are all general factors which may or may not be relevant for you*

- Physical stress in the body
 - *Examples:* injury, illness, pain...
- Difficult past experiences
 - *Examples:* situations that have felt threatening, loss of a loved one...
- Current stressful situations
 - *Examples:* relating to finances, relationships, difficulty meeting responsibilities, loss of independence...
- Emotional stress
 - *Examples:* worries about the future, difficult memories...

- Lifestyle factors also affect our traffic lights:
 - What we eat and drink
 - Caffeine
 - Drinking enough water
 - Not eating enough or eating too much
 - How active we are
 - “Over-doing it” and not having breaks
 - Being inactive
 - Sleep
 - Sleeping for long periods during the day
 - Not getting enough good quality sleep

For many people, it is not one big thing that has caused them to go into and stay in the amber zone. It is often a combination of factors.

Managing NEAD/ my traffic lights involves:

- Noticing which zone you are in
- Learning strategies to help bring you into the green zone
- Increasing time spent in the green zone by looking after ourselves and doing more of the things that are important to us

Strategies

1. Creating an anchor

An anchor is something you can easily pay attention to when you start to feel overwhelmed by difficult thoughts, feelings and/ or sensations.

We used **an object** and **sounds** as an anchor.

Q: Which one was easiest and most enjoyable for you to focus on?

My favourite anchor is (object or sounds):

It had the effect of:

I faced the challenge of:

Grounding means to increase awareness of being in the present moment. When we try to deal with everything that happened in the past and everything that might happen in the future we can become overwhelmed. Going over difficult thoughts can cause stress to build up making it more likely we will go into the red zone (e.g. have a NEAD episode).

How to do it:

- Sit comfortably and upright if possible.
- Join the tips of the thumb on the left hand to the thumb on the right hand, join the tips of the left and right first fingers, middle fingers, ring fingers and little fingers.
- Now the tips of each finger and thumb on the left hand are lightly touching the tips of the same fingers/thumb on the right hand with a space in between.
- Hold this gesture at the level of your heart if possible, or rest it in your lap.
- Let the breath flow naturally. You may notice that it starts to slow down and deepen.
- Observe the breath (this is like your anchor now).
- Notice thoughts, sensations and emotions without judging them or trying to get rid of them. See if it's possible to allow thoughts, feelings and sensations to come and go.
- Whenever you get caught up and carried away by a thought, sensation or emotion, notice that, and bring yourself back to your anchor which is the breath.

Notes

[illegible]

Red Zone <i>Freeze response (energy saving processes)</i>	
Thinking Dizziness/ blank Feeling distant or “spaced out” Changes to vision/ hearing Disorientation/ confusion No memory or awareness of actions Blackout/ unresponsive Behaviour Sleeping a lot Inactive Reduced/ slow movement Difficulty controlling movement	Body sensations Feel weak Numbness Slow, shallow breathing Exhaustion Muscles rigid/ stiff Shaking Collapse/ fall Emotions Feel numb Low mood Lack of motivation Can’t connect with other people Sense of hopelessness
Amber Zone <i>Fight/ flight response (energy consuming processes)</i>	
Body sensations Feel tense Heart rate speeds up Fast/ shallow breathing Throat tightens ‘Butterflies’ Feeling hot Nausea/ feeling sick Urination Change in appetite Dry mouth Difficulty sleeping Digestive changes Headaches Pain Sweating, shaking Changes to bowel movements	Thinking Mental focus narrows Racing thoughts Hypervigilance/ increased alertness Difficulty planning and remembering Emotions Anger/ frustration/ short temper Bossed around by emotions Feel unsafe/ overwhelmed Anxiety/ panic/ nervous Agitation/ difficulty being still/ keeping really busy Behaviour Avoidance of: situations, places, activities... Doing a lot of things at once - quickly Stick to set routines/ familiar places Rely on outside things to relax (e.g. alcohol, smoking, food)
Green Zone <i>Rest/ digest (at your best)</i>	
Behaviour Seek connection with other people Engage in valued activities More willing to try new things Can sleep easily at night Thinking Can learn new information Aware of the “here and now” Can shift attention Able to make decisions Thinking clearly, clarity Imagination, creativity	Emotions Curious, even about challenges Courageous Connected Experience emotions without getting stuck Compassionate Confident Body sensations Feel strong and at ease Breathing is comfortable Muscles relax Heart rate slower In control of body movements Feel relaxed

Noticing

- The process of noticing brings the green zone centres of the brain online.
- When you feel strong emotion, noticing can lift you out of automatic reaction and give you more options.
- By noticing you can change habit patterns which you do not like.
- You can learn to notice when you move out of the green zone so that you can bring yourself back.
- Not noticing stress building up may cause NEAD episodes to keep happening

Noticing practice: which zone are you in?

1. What **physical sensations** do you notice in your body?

2. What do you notice about your **energy level** and/ or **breathing**?

3. What's happening in your **mind**?

4. What **emotion/ s** are you experiencing?

5. What do you notice happening **around you**?

Homework

Stop and Notice

- Look at the traffic light system
- Use the traffic light diary to notice and record which zone you are in

Things that might help:

- Setting alarms
- Having a version of the diary on your phone
- Telling someone about this task

Use your anchor / grounding regularly

I will aim to practice my anchor / grounding ____ times a day for the next week.

Traffic Light Log

	1. What am I experiencing right now? <i>e.g. body sensations, thinking, emotions and/ or behaviours</i> 2. Which zone am I in? <i>Green, Amber or Red</i> 3. What is the situation? <i>e.g. what is going on? where? who with?</i>		
Date	Morning	Afternoon	Evening
<i>Example</i> 24.09.19	1. Fast heartbeat, frustrated 2. Amber 3. In busy shop with a friend	1. Difficulty concentrating, headache 2. Amber 3. On the phone sorting out electric bill	1. Feel more settled, breathing rate steady 2. Green 3. Having dinner with family, talking about the football

