Understanding Non-Epileptic Attack Disorder

Undergraduate Paramedic Teaching

Non-Epileptic Attacks & Other Functional Neurological Disorders

An introduction to working with non-epileptic attacks and other functional neurological presentations

for:

Edgehill University

https://fnd-for-paramedics.netlify.app

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Disclaimers

☹️ Emotionally pertinent areas

📹 Potentially distressing videos

✋ Not about changing protocol

Contents

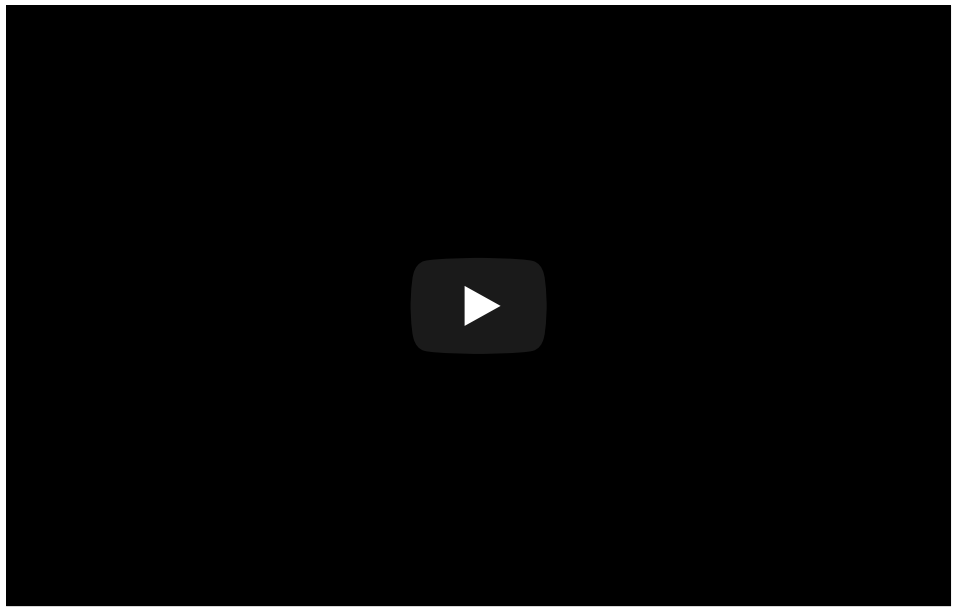
Note: Headings are internal links.

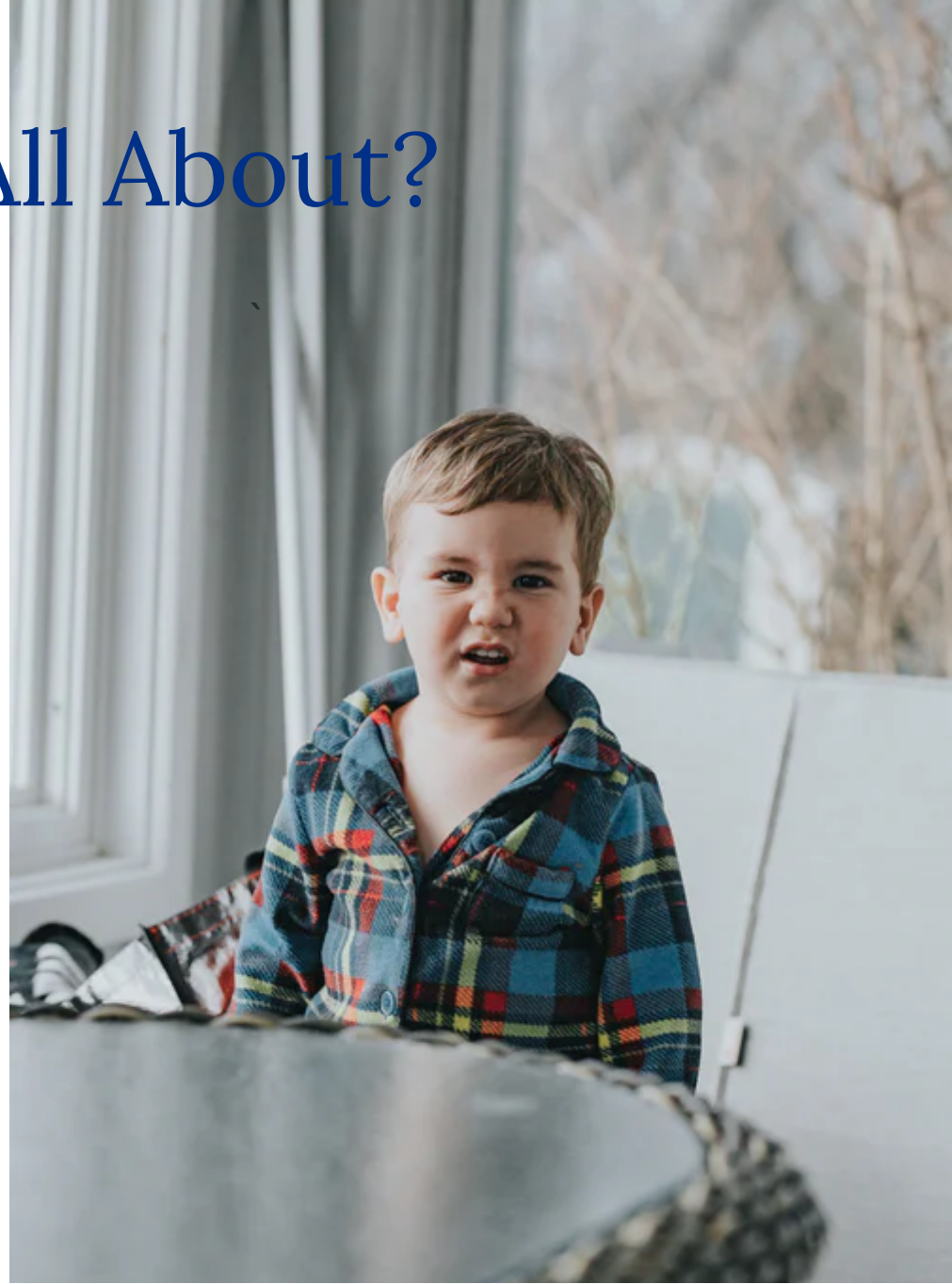
This presentation is also available as a pdf

So What is This All About?

FND = Functional Neurological Disorder

NEAD = Non Epileptic Attack Disorder





Definitions: FND

DSM-5: a patient can be diagnosed with FND if they have motor and/or sensory findings providing "evidence of incompatibility between the symptom and recognized neurological or medical conditions" (American Psychiatric Association, 2013, Stone et al., 2010b).

- The symptom must impair social and/or occupational functioning or lead individuals to seek a medical opinion. There are no duration or severity criteria or explicit rules for exclusion based on additional symptoms.
- In the neurological literature, there are also diagnostic criteria for FND subtypes, such as those for FND-seiz (LaFrance et al., 2013a) and FND-movt (Espay and Lang, 2015, Gasca-Salas and Lang, 2016, Williams et al., 1995).

Above taken from Perez et al 2021

Dissociative Neurological Symptom Disorder the most recent term used in the ICD-11 (World Health Organization International Coding manual) despite pushback from FND Hope and leading FND specialists around the world.

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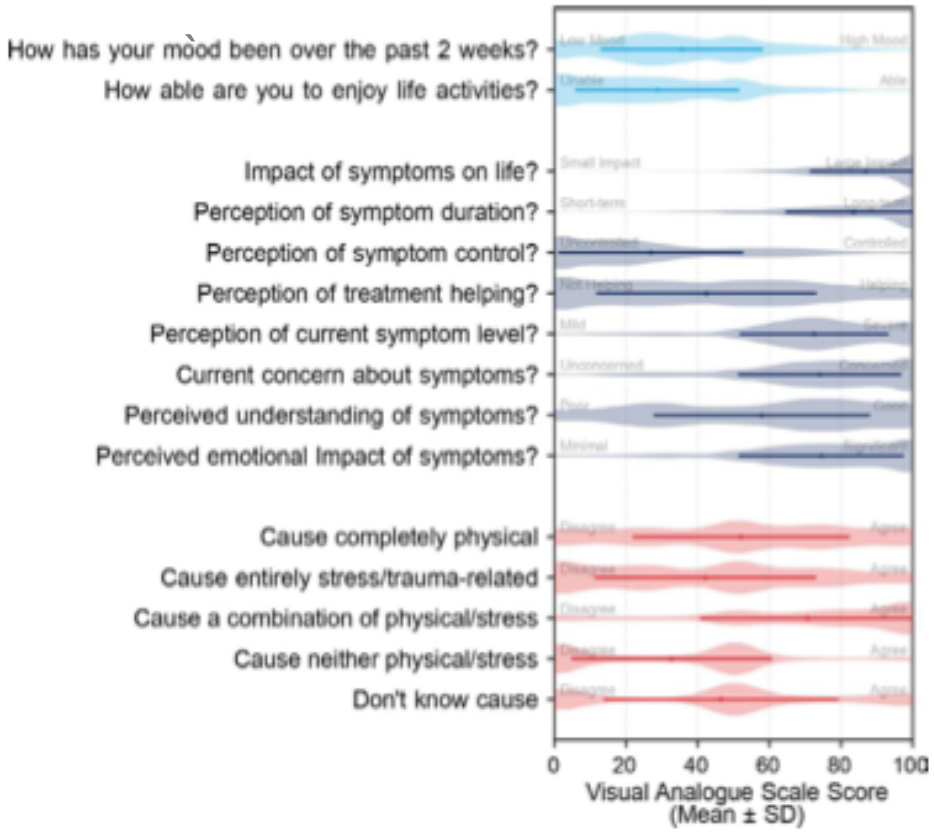
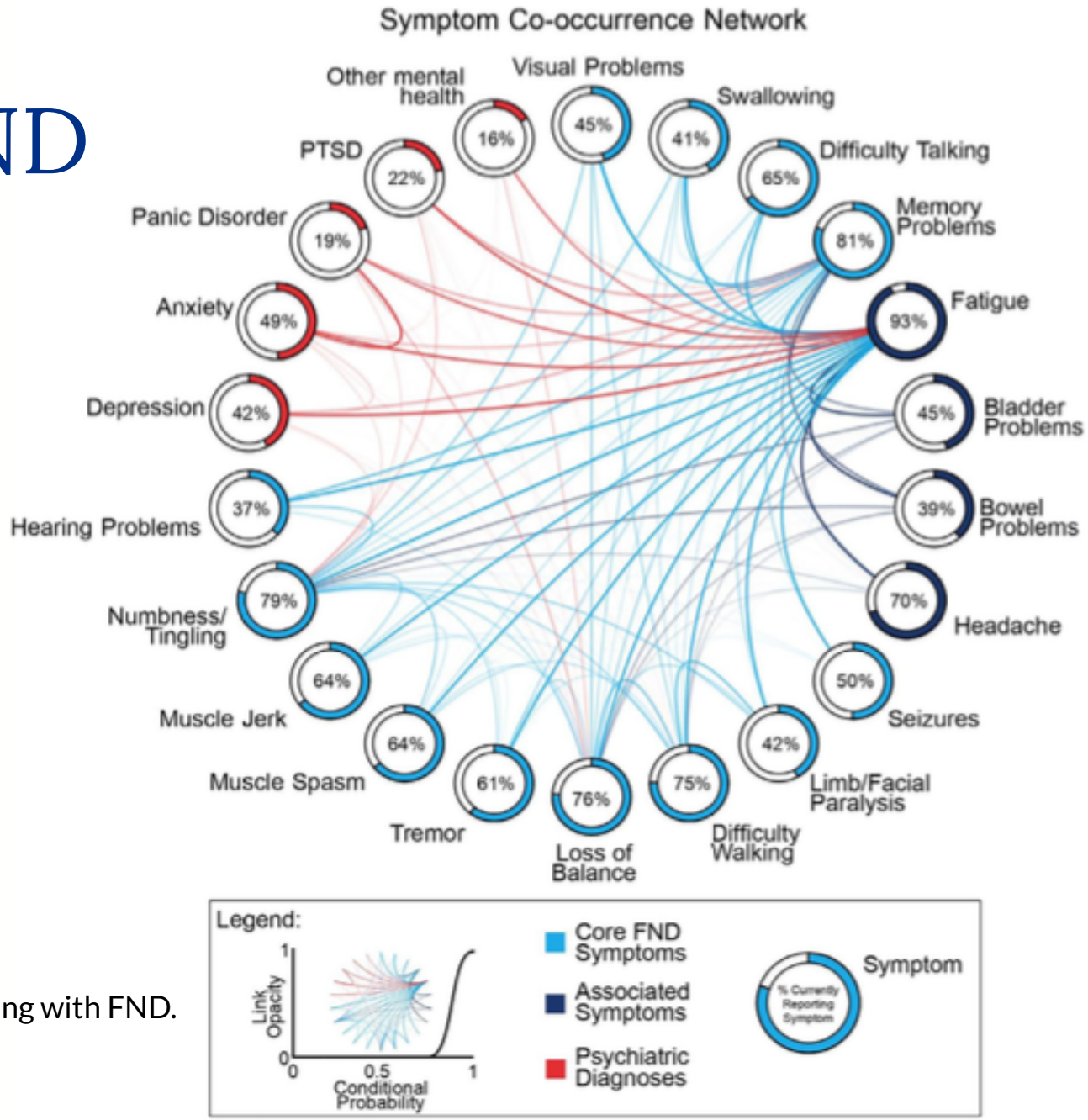
Symptoms of FND





Butler et al (2021) survey of 1048 individuals living with FND.

Types of FND

Classified by neurosymptoms.org, extracted 2021

Functional Limb Weakness

Weakness of an arm or leg.

Functional (Dissociative) Seizures

Dissociative attacks are also called 'non-epileptic attacks'

Functional Sensory Symptoms

Functional Sensory symptoms describe sensory symptoms anywhere in the body that

Functional Movement Disorder

A functional movement disorder means that there is abnormal movement or positioning of

Functional Tremor

Functional tremor is the uncontrollable shaking of a part of the body, usually an arm

Functional Cognitive Disorder

Functional cognitive disorder is a problem with memory or concentration that happens

Functional Speech Swallowing Symptoms

FND speech, swallowing and communication difficulties a consensus recommendation

Functional Dizziness (PPPD)

Dizziness is a common symptom in neurology and has lots of different causes

Functional Drop Attacks

A "Drop attack" is the medical term for a sudden fall to the ground without an obvious

Functional Dystonia

Patients with functional dystonia either have curled fingers or a clenched hand

Functional Gait Disorder

A functional movement disorder means that there is abnormal movement or positioning of

Functional Facial Symptoms

Functional neurological symptoms can have symptoms affecting the face

Functional Jerks and Twitches

Functional myoclonus refers to sudden jerky or shock like movements that occur as part of

Bladder symptoms and FND

Overactive Bladder, Chronic Urinary Retention and Scan negative Cauda Equina

Visual Symptoms

Visual symptoms can be functional or dissociative.

Functional Tics

Tics are a type of repetitive movement or sound

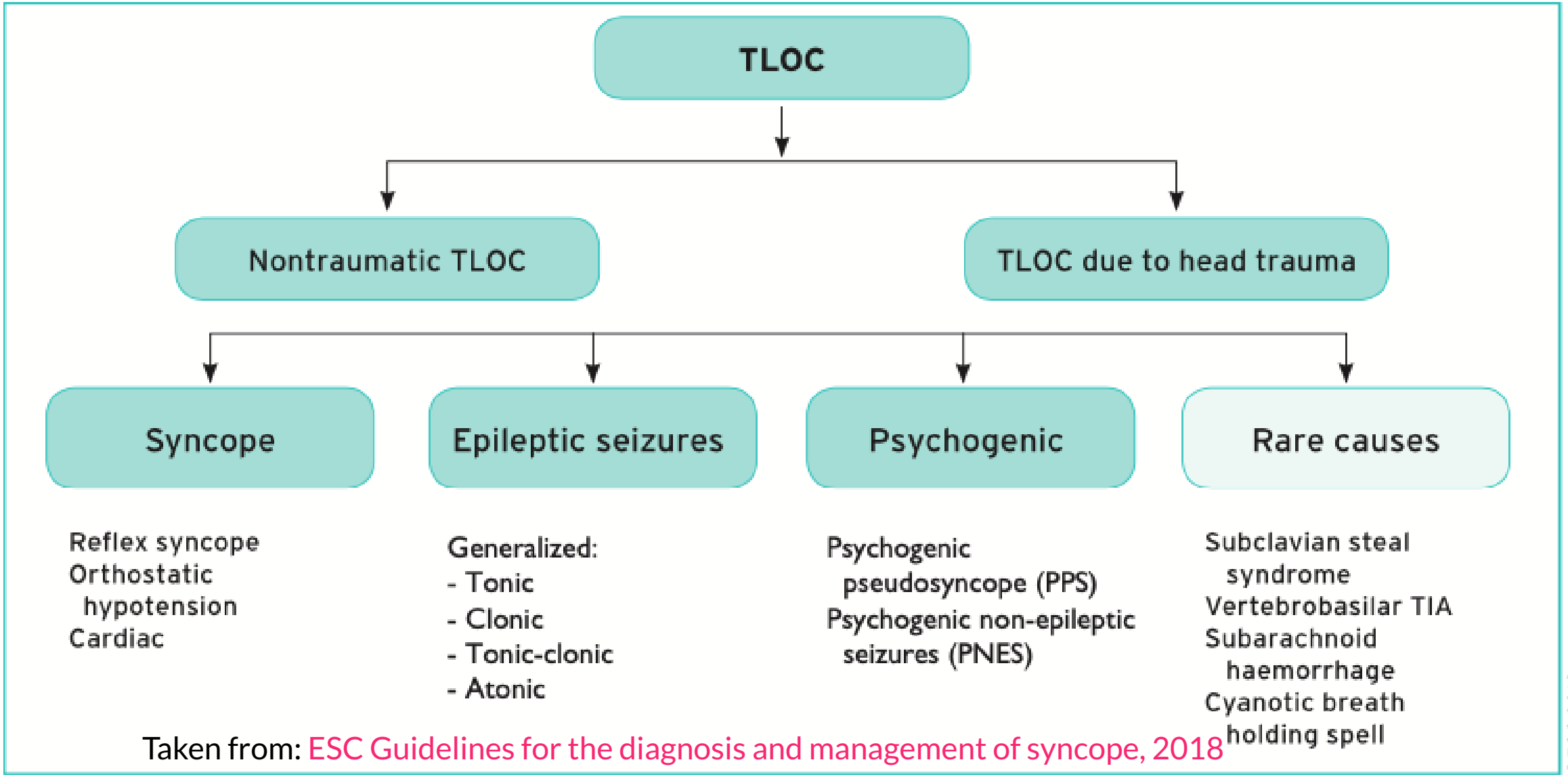
Definitions: Non-epileptic seizures

- One manifestation or constellation of FND.
- In DSM-5, psychogenic nonepileptic seizures are classified as a form of conversion disorder, or functional neurological symptom disorder, with the term "functional" referring to an impairment of normal bodily functioning (3).
- Disruption of usually integrated functions of consciousness, memory, id, or perception (amnesia, fugue, dissociative id disorder, depersonalisation disorder) (Goldstein et al, 2000)

People with NEAD experience **episodes of temporary loss of control and/ or awareness**

Impact of NEAD.

SympomDomains	Examples
Movement	Shaking; Difficulty controlling movement; Falls
Senses	Challenging to senses, Feeling numb
Awareness & thinking skills	Feeling confused; Distant; Disorientated; Blacking out



Taken from: ESC Guidelines for the diagnosis and management of syncope, 2018

Inter and Intra-variability

- Different people experience different symptoms
- NEAD symptoms are not always the same
- Symptoms may change over time

Gregg do you have any furthe info/papers?

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Signs of Non-epileptic Attacks

Taken from: FND in the emergency department

Finkelstein et al., 2021

TABLE 2 Clinical features distinguishing functional from epileptic seizures[38,72-74]

Clinical sign	Notes	Reliability[a]
Highly suggestive of functional seizures		
Closed eyelids during ictal peak	Patients may actively resist eyelid opening.	+++
Prolonged duration	Most epileptic seizures will stop spontaneously in 2 min or less. Particularly useful if it resolves spontaneously after prolonged duration, without significant postictal period. Caution: patients with status epilepticus will have prolonged seizure activity.	++
Fluctuating course	Movements may wax and wane in intensity or stop and start.	++
Ictal awareness/memory of seizure	Only relevant for generalized seizures (abnormal movements of all four limbs). Caution: frontal lobe seizures can involve bizarre movements with retained awareness. Loss of awareness is standard for most functional seizures.	++
Ictal/postictal weeping	Relatively specific for functional seizures, although low sensitivity. May also have other signs of emotional distress.	++
Asynchronous limb movements	Caution: can also be present in frontal lobe seizures.	++
Side to side head shaking	May rarely be present in epileptic seizures. Good differentiator for generalized shaking events only.	++
Response to stimuli during ictal period	Only applies to generalized shaking attacks.	++
Highly suggestive of epileptic seizures		
Figure of four sign	One arm flexed at elbow, other arm extended at the elbow, usually present just before secondary generalization.	+++
Guttural cry/scream	During tonic phase, typically at seizure onset.	++
Prolonged rigid phase with cessation of respiration	Based on authors' experience.	++
Postictal stertorous breathing	Low-pitched sound from back of throat, like sound from nasal congestion or snoring.	+++
Unhelpful features common to both		
Tongue biting Injury (although severe burns and shoulder dislocation should prompt consideration of epilepsy) Urinary incontinence Attack appearing from sleep/no witnesses to seizure Presence of aura or postictal confusion Breath holding High serum lactate after an event[71]		

+++ = highly reliable; ++ = reliable; + = suggestive

[a]Reliability determined based on available clinical data[73,75-77] and author consensus.

Signs of Functional Weakness

Taken from: FND in the emergency department

Finkelstein et al., 2021

Clinical sign	Description	Reliability[a]
Hoover's sign[20,35-37,39]	Weakness of voluntary hip extension that resolves with voluntary contralateral resisted hip flexion. Difficult to detect in bilateral leg weakness.	+++
Platysma overactivation[40]	Contraction of one side of the platysma, creating the effect of a facial droop.	++
Hip abductor sign[37]	Return of strength to hip abduction in the weak leg with contralateral hip abduction against resistance	++
Give-way/collapsing weakness[35,41,42]	Strength is initially normal and then collapses with resistance.	++
Dragging monoplegic leg[20,35]	Plegic leg is dragged behind body often with hip internal or external rotation and without hip circumduction.	++
Drift without pronation[35,43]	Isolated downward arm-drift without associated pronation.	+
Global pattern of weakness[35,44]	Equal weakness of both flexor and extensor muscles, both proximally and distally.	+
Motor inconsistencies[45]	Inability to produce one movement, while using the same muscles to produce a different movement. For example, a patient may have difficulty dorsiflexing while supine, but be able to stand on heels without difficulty.	+

+++ = highly reliable; ++ = reliable; + = suggestive.

[a]Reliability determined based on available clinical data[34] and author consensus.

How common is NEAD?

Approximately:

- 20,000 people in the UK have this diagnosis – but there are likely to be many more.
- 1 out of every 5 people referred to a first seizure clinic go on to have a diagnosis of NEAD.
- NEAD accounts for up to 50% of patients brought to hospital with suspected 'status epilepticus'.

(Howell, Owen, Chadwick, 1989; Kotsoupoulos et al., 2003, Rawlings, Brown & Reuber, 2017)

New paper from Norway Villagrán (2021) - 23.8 per 100,000

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Who is most likely to be affected?

breakdown of key variables for NEA and FND.

- Recent research has shown that young people (15–19) may actually be more at risk Villagrán (2021)] - 59.5 per 100,000.

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Diagnosis

How is it diagnosed?

Diagnosis usually by a Neurologist or Neuropsychiatrist based on:

- Clinical history
- Videos
- Objective signs
- Subjective experience
- EEG (electroencephalogram)
- ECG (electrocardiogram)
- Videotelemetry

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Journey do diagnosis is very long... Enter research here.

Misdiagnosis

Status epilepticus...

New paper showing high rates of misdiagnosis (and treatment) Jungilligens (2021) ... stats

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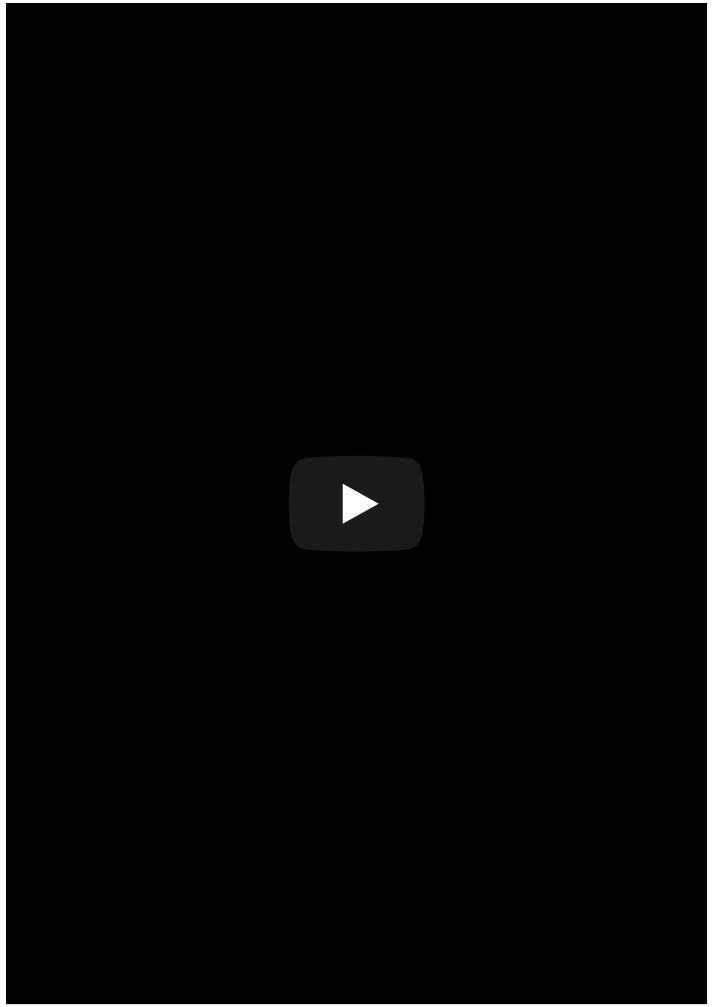
Not a New Condition

Recognised as early as the 18th Century

Studied prominently after the First World War and the recognition of ‘shell shock’

Freud & Charcott



Clearing up confusion

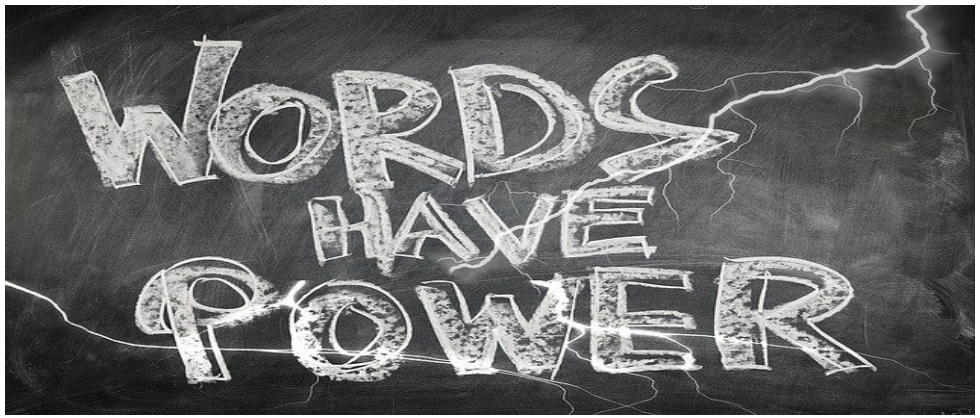
Many terms used to describe the **same experience**.

- Non-epileptic attacks
- Psychogenic seizures
- Psychogenic non-epileptic seizures (PNES)
- Dissociative seizures
- Conversion disorder
- Functional seizures
- Psychological seizures
- Pseudo-seizures

Some terms are more/less **harmful** than others.

Debate and lack of consensus regarding preferred term (see Stone et al., [2003], Barron [2019], FND Society [2020])., , and La France [2010]).

We refer to these events as**"Episodes"** (but are willing to be led by the individual) and our service uses **Non-epileptic Attack Disorder (NEAD)**



What do patients prefer?

Loewenberger, 2021

Epilepsy & Behavior 117 (2021) 107817

Contents lists available at ScienceDirect

Epilepsy & Behavior

journal homepage: www.elsevier.com/locate/yebeh

What do patients prefer their functional seizures to be called, and what are their experiences of diagnosis? – A mixed methods investigation

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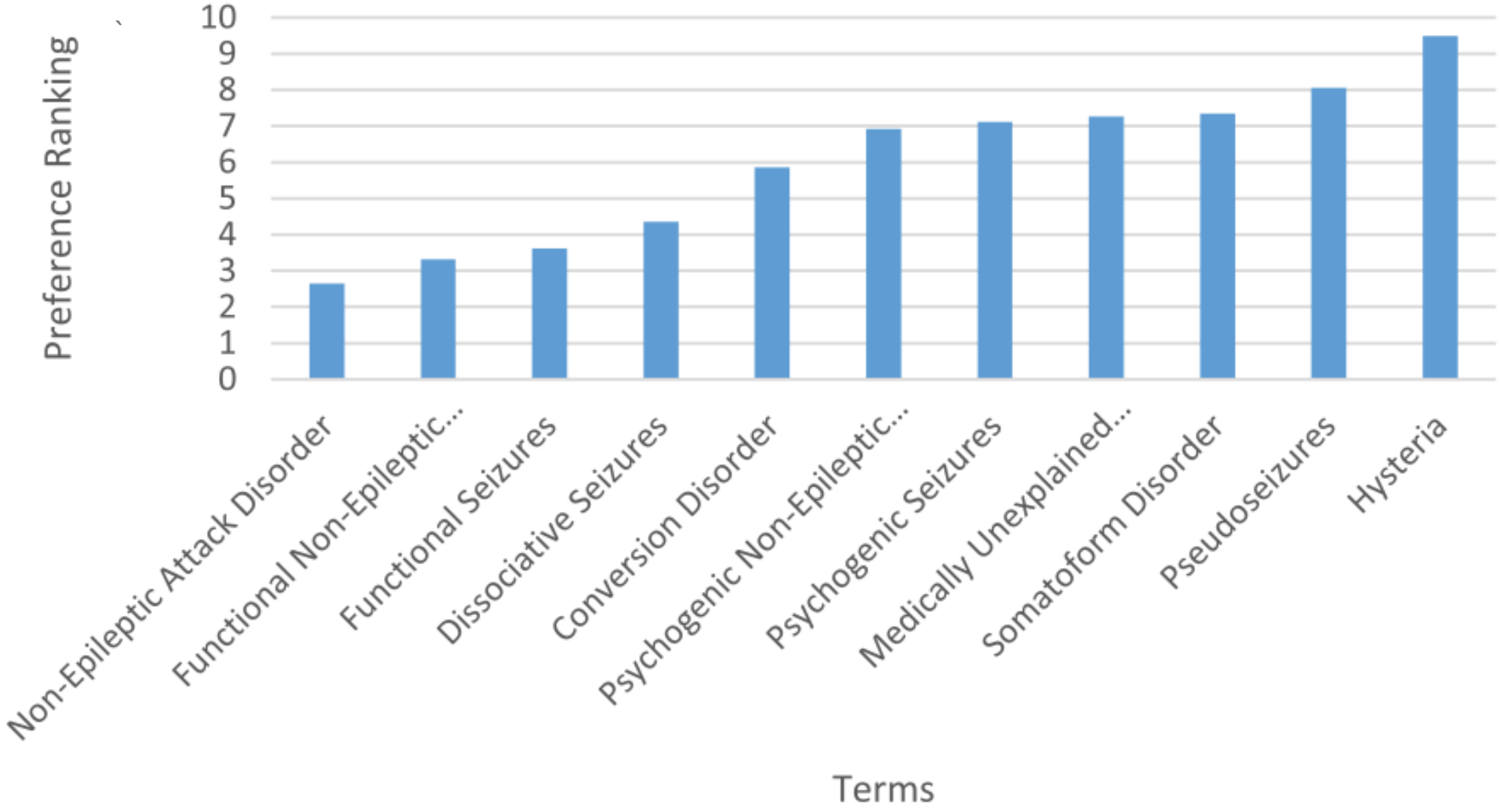
ARTICLE INFO

Article history:
Received 10 October 2020
Revised 21 January 2021
Accepted 21 January 2021

Keywords:
Functional nonepileptic attacks
Dissociative seizures
Nonepileptic attack disorder
Functional seizures
Terminology
Psychogenic nonepileptic seizures

ABSTRACT

This study explored the preferred terms for functional seizures, and the experience of being diagnosed, from the patient's perspective. 39 patients in a neuropsychiatry service diagnosed with functional seizures completed an online survey to investigate preferences for, and offensiveness of, 11 common diagnostic terms used to describe functional seizures. Of these 39 patients, 13 consented to take part in a semistructured interview exploring the experience of receiving a diagnosis. Nonepileptic attack disorder (NEAD), functional seizures, functional nonepileptic attacks (FNEA), and dissociative seizures were ranked the highest preferred terms and did not significantly differ from one another. NEAD was the least offensive term, with functional seizures and FNEA following closely. Significant overlap in confidence intervals was found between the offensiveness of all terms. Terms that indicated a psychological origin were the least preferred and viewed as most offensive. Thematic analysis identified three main themes on the experience of being diagnosed: 'being heard and having a shared understanding', 'feeling alone', and 'sense of hope'. Patients favored diagnostic terms that facilitated and alleviated these themes on a personal basis; however, preferences differed across individuals. Our findings suggest that a range of terms have a similar level of preference and offense rating, with NEAD, functional seizures, and FNEA being the most favorable. Qualitative analysis indicates that a term and its accompanying explanation should facilitate shared acceptance and understanding, and several terms provide this. In combination with our previous study on healthy participants, we propose that one of the two terms researched are adopted by patients, health professionals, and the public: Functional nonepileptic attacks or Functional seizures.


Preference Ranking
10
9
8
7
6
5
4
3
2
1
0
Non-Epileptic Attack Disorder
Functional Non-Epileptic...
Functional Seizures
Dissociative Seizures
Conversion Disorder
Psychogenic Non-Epileptic...
Psychogenic Seizures
Medically Unexplained...
Somatoform Disorder
Pseudoseizures
Hysteria
Terms

Not to be confused with

Malingering:

- Deliberately manufacturing symptoms for material gain e.g. Money

Factitious Disorder

- Deliberately manufacturing symptoms for emotional gain e.g. Attention

Do not mistake NEAD symptoms for factitious/malingering just because it doesn't fit with what you know of epileptic seizures

Gregg paper on health professionals/neurologists perception of the role of alcohol.

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Videos of FND and NEAs

NEA 1 NEA 2 NEA 3 NEA 4 NEA 5 NEA 6 NEA 7

NEAD service patients

Show CG Video

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Why is it happening?

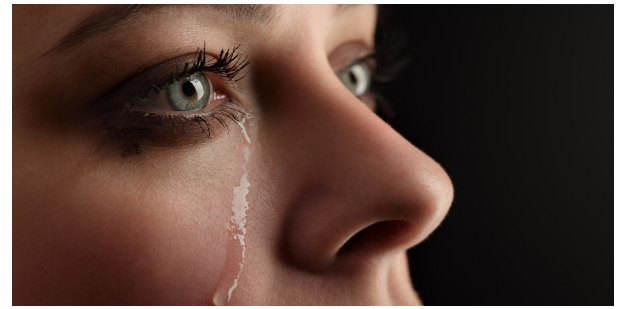
The mind body link

Psychological experiences influence the body **All The Time**

- Sudden shock = heart beats faster
- Embarrassment = face goes red
- Upset = eyes produce tears

It is normal for changes to happen in 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).

NEAD also happens through this Mind-Body link.



The cause is not medical but the impact on the body is **REAL**.

Influence of trauma

- A traumatic event = an incident that causes physical, emotional or psychological harm.
- Can be single event or many unpleasant/threatening incidents
- Could be recent or a long time ago

FACT: It is common for people with NEAD to have experienced some form of trauma

BUT: Many people with NEAD have NOT experienced a trauma

Although many people with NEAD can identify things that have happened/ are happening in their lives that contribute to a build-up of stress, many people do not.

The reasons why an individual develops NEAD is not always obvious at first, because everyone's lives are different.

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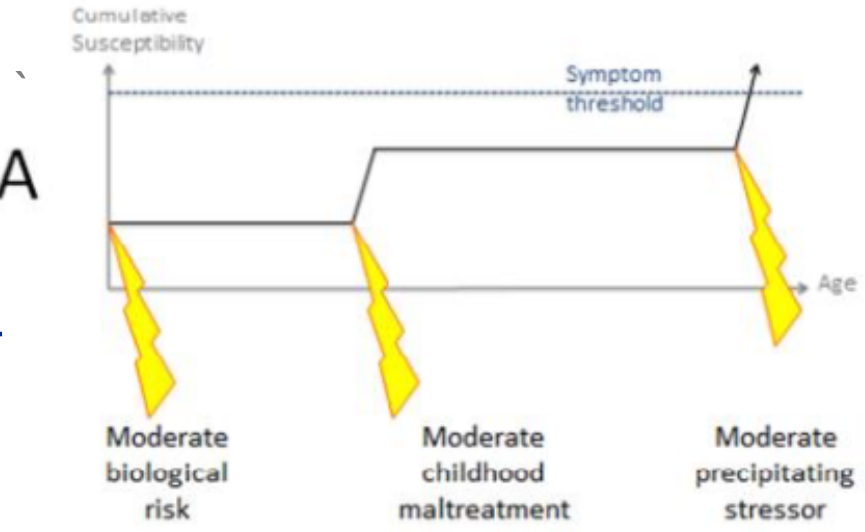
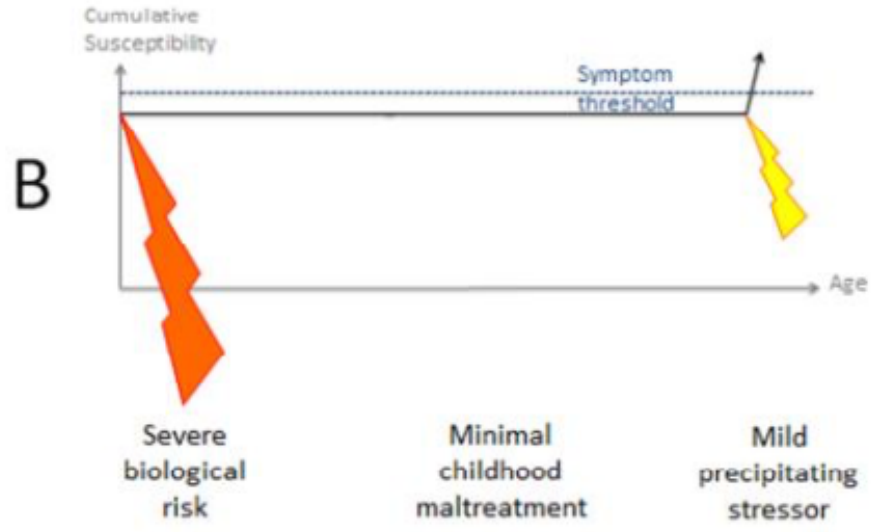
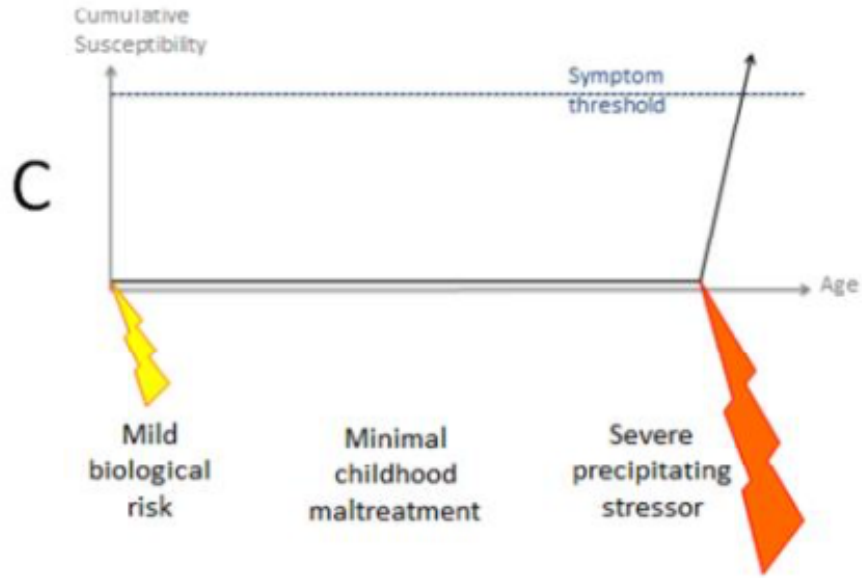
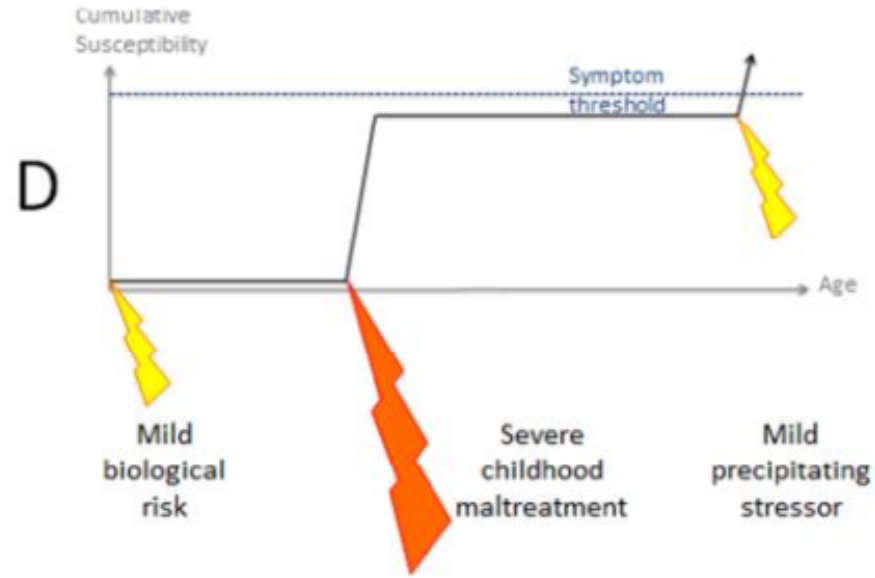
Role of Trauma

Taken from Keynejad, 2021









What is happening during a NEAD episode?

- The fight/flight/freeze response - evolutionary based fear response that is adaptive for survival
- Freezing is one of the main defensive threat reactions across species

(Roelofs, 2017; Rockliffe-Fidler & Mark Willis, 2018)

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

1. Physical stress in the body (e.g., injury, illness, pain).
2. Difficult past experiences (e.g., situations that have felt threatening, loss of a loved one).
3. Current stressful situations (e.g., relating to finances, relationships, difficulty meeting responsibilities, loss of independence).
4. Emotional stress (e.g., worries about the future, difficult memories).

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.

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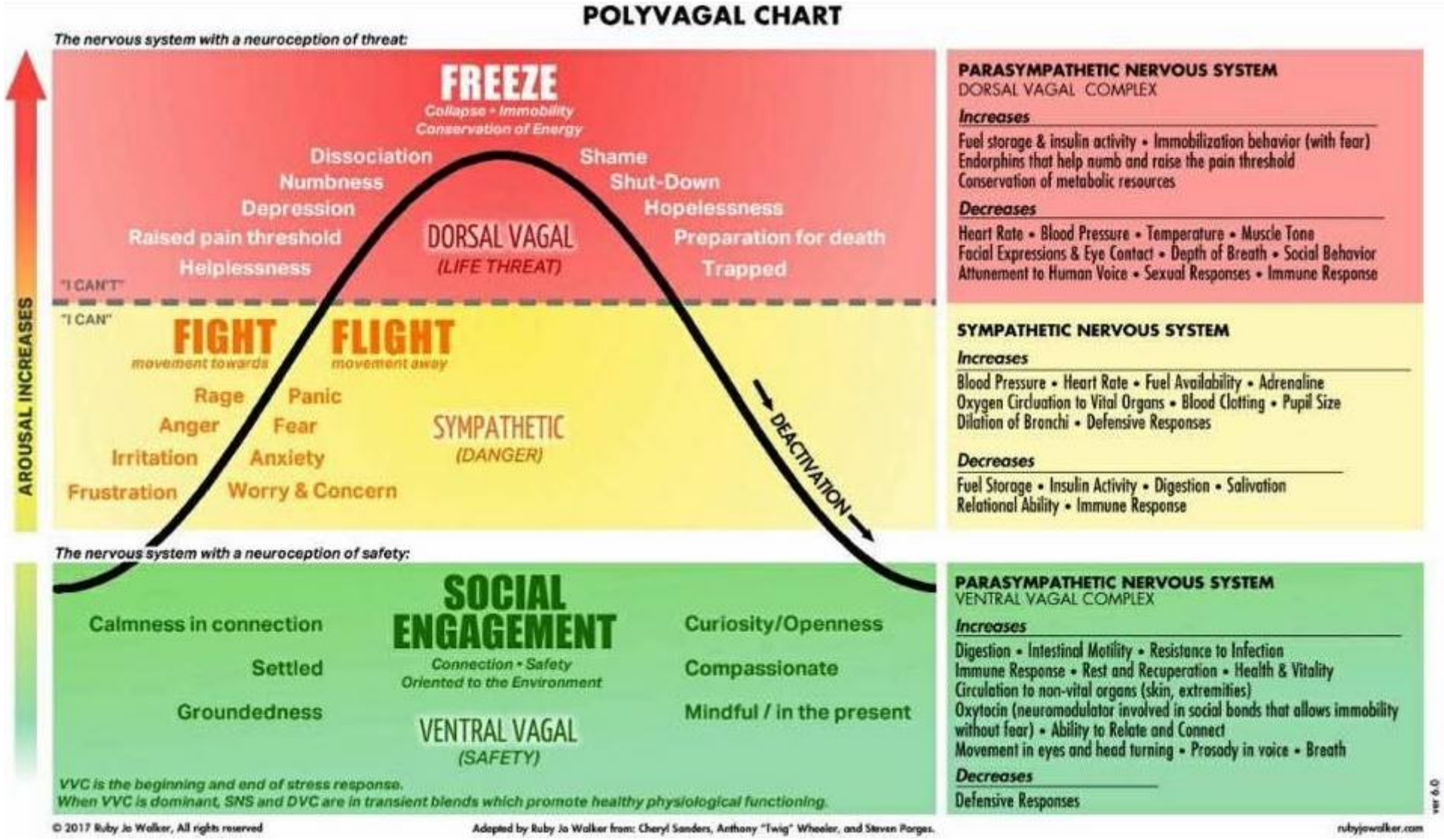
Polyvagal Theory


POLYVAGAL CHART
The nervous system with a neuroception of threat:
FREEZE
Collapse • Immobility
Conservation of Energy
Dissociation
Numbness
Depression
Raised pain threshold
Helplessness
DORSAL VAGAL
(LIFE THREAT)
Shame
Shut-Down
Hopelessness
Preparation for death
Trapped
"I CAN'T"
"I CAN"
AROUSAL INCREASES
FIGHT
movement towards
FLIGHT
movement away
Rage
Anger
Irritation
Frustration
Panic
Fear
Anxiety
Worry & Concern
SYMPATHETIC
(DANGER)
DEACTIVATION
The nervous system with a neuroception of safety:
SOCIAL ENGAGEMENT
Connection • Safety
Oriented to the Environment
Calmness in connection
Settled
Groundedness
Curiosity/Openness
Compassionate
Mindful / in the present
VENTRAL VAGAL
(SAFETY)
VVC is the beginning and end of stress response.
When VVC is dominant, SNS and DVC are in transient blends which promote healthy physiological functioning.
PARASYMPATHETIC NERVOUS SYSTEM
DORSAL VAGAL COMPLEX
Increases
Fuel storage & insulin activity • Immobilization behavior (with fear)
Endorphins that help numb and raise the pain threshold
Conservation of metabolic resources
Decreases
Heart Rate • Blood Pressure • Temperature • Muscle Tone
Facial Expressions & Eye Contact • Depth of Breath • Social Behavior
Attunement to Human Voice • Sexual Responses • Immune Response
SYMPATHETIC NERVOUS SYSTEM
Increases
Blood Pressure • Heart Rate • Fuel Availability • Adrenaline
Oxygen Circluation to Vital Organs • Blood Clotting • Pupil Size
Dilation of Bronchi • Defensive Responses
Decreases
Fuel Storage • Insulin Activity • Digestion • Salivation
Relational Ability • Immune Response
PARASYMPATHETIC NERVOUS SYSTEM
VENTRAL VAGAL COMPLEX
Increases
Digestion • Intestinal Motility • Resistance to Infection
Immune Response • Rest and Recuperation • Health & Vitality
Circulation to non-vital organs (skin, extremities)
Oxytocin (neuromodulator involved in social bonds that allows immobility without fear) • Ability to Relate and Connect
Movement in eyes and head turning • Prosody in voice • Breath
Decreases
Defensive Responses
ver 6.0
© 2017 Ruby Jo Walker, All rights reserved
Adapted by Ruby Jo Walker from: Cheryl Sanders, Anthony "Twig" Wheeler, and Steven Porges.
rubyjowalker.com

Body sensations

Feel strong and at ease
Breathing is comfortable
Muscles relax
Heart rate slower
In control of body movements
Feel relaxed

Thinking

Can learn new information
Aware of the “here and now”
Can shift attention
Able to make decisions
Thinking clearly, clarity
Imagination, creativity

Behaviour

Seek connection with other people
Engage in valued activities
More willing to try new things
Can sleep easily at night

Emotions

Curious, even about challenges
Courageous
Connected
Experience emotions without getting stuck
Compassionate
Confident

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

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)

Emotions

Anger/ frustration/ short temper
Bossed around by emotions
Feel unsafe/ overwhelmed
Anxiety/ panic/ nervous
Agitation/ difficulty being still/ keeping really busy

Thinking

Mental focus narrows
Racing thoughts
Hypervigilance/ increased alertness
Difficulty planning and remembering

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

Behaviour

- Sleeping a lot
- Inactive
- Reduced/ slow movement
- Difficulty controlling movement

Thinking

- Dizziness/ blank
- Feeling distant or “spaced out”
- Changes to vision/ hearing
- Disorientation/ confusion
- No memory or awareness of actions
- Blackout/ unresponsive

Experience

What does NEAD feel like?

“I feel like I am ‘tripping’ without taking nothing. I am in another world short term, and I feel confused, dazed, disorientated and its scary. My head and brain feels like a tin of broken biscuits. I am different and feel weird. Luckily these episodes don’t last long, but they happen ‘out of the blue’, when you least expect it!

Understanding of my environment is lost, and my body changes with my eyes spinning and poor-coordination and my listening is affected. I feel stupid during these episodes and I wonder do people notice or think I am acting or faking it for attention?”

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What does NEAD feel like?

“I feel really spaced out. Like I’m not really there. I try to move but I am like a snail. I try to talk but it’s like my tongue is stuck”

“It feels like I am falling, although my body is still it feels like it is being thrown around. My arms and legs are tensed and cramped up. I can see and hear but I can’t move. It’s so scary”

“I really can’t get up and cannot speak, if I kick out it is not because I am being aggressive, it’s because my body can help it”

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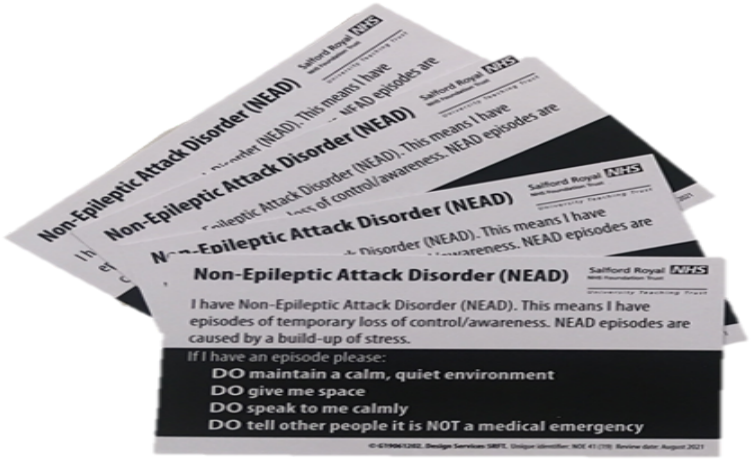
Therapeutic Solutions

Is this NEAD?

- Salford Royal NEAD service guidance letter
- Friends/ family members
- Salford Royal NEAD guidance cards
- Medical alert bracelets

Do not attempt to make a differential diagnosis. If information about the diagnosis is not available, follow epilepsy guidelines.



Common concerns about NEAD

The changes that are experienced before, during and after episodes are caused by the fight/ flight/ freeze response

These changes might look and feel uncomfortable/ unpleasant but are not causing immediate harm:

- Brain activity remains the same
- Having an episode is not caused by and does not cause internal damage.

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Common concerns about NEAD

Risk of injury

- NEAD episodes do not cause internal damage
- Risk of injury from falls during episodes is low (number of injuries VS total number of episodes)

Duration of episodes

- Episodes can last seconds, minutes, hours or even days.
- Even if the episode lasts a long time (or longer than usual), it is still not causing internal damage
- The episode will pass naturally without need for medical intervention

Symptom variation

- Many people experience episodes that feel very different to one another
- It is normal for episodes to change over time

Do

1. Maintain a calm, quiet environment
2. Give me space
3. Speak to me calmly
4. Tell other people it is NOT a medical emergency
5. Help to re-orientate (e.g. tell the person where and who they are, what is happening).
6. Offer water.
7. Encourage noticing what they can see/hear (e.g. count the number of circles/ red things).
8. Maintain a calm environment.
9. Encourage focus on slow, deep breaths.
10. Find out if there is someone who can help them to get home/ to a safe place?
11. Provide support to friends/ family.

Do not

1. Give me medication
2. Touch me (unless to protect my head)
3. Crowd or stand over me
4. let there be more thn one person nearby
5. Try to bring me "out of it"
6. Restrain me
7. Time the episode
8. Take me to hospital, unless I have a significant injurt that needs immediate medical attention
9. try to lift the person up or try to get them moving before they are ready
10. Ask lots of questions

How we talk about NEAD matters

Communication has a significant impact on:

- Patient satisfaction
- Acceptance of the diagnosis
- Frequency/ severity of symptoms
- Future engagement with healthcare services

(Hall-Patch et al., 2010; McKenzie, Russell, Pelosi & Duncan, 2010)

How we talk about NEAD matters

“We know your symptoms are real”

“We do not think your symptoms are “all in your head””

“We know that you are not pretending”

“We know that this is not your fault”

“NEAD is a well-recognised condition”

“It’s like having a software problem in your brain rather than a hardware problem”(Stone)"

“You are (just) stressed”

“You do not have...”

“It’s nothing to worry about”

“You can control this”

“Stop doing this”

Case Vignettes

Case Example 1

You are called to an incident in a shopping centre. The report is of someone experiencing a sudden collapse. You arrive to find a man, approximately 50 years old, on the floor making jerking movements with his arms and legs. His eyes are closed and he is not responding to your questions.

Q: What are the standard assessments and interventions you would carry out in this situation?

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Case Example 2

Whilst you are treating your patient, his care worker arrives. She lets you know that his name is Alan, he has a moderate learning disability, and has a NEAD diagnosis.

She tells you that he started to have NEAD episodes 3 years ago when he was living in an inpatient care facility. He was frequently restrained and sedated and did not understand why. His experiences were very distressing and, as a consequence, he now fears healthcare professionals.

Taking this information into consideration:

1. *Q: How might you change your approach?*
2. *Q: What might you do the same?*

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Case Example 2 - "An Unhelpful Experience"

What could be done differently:

- Don’t assume that I am drunk/ a druggie
- Don’t assume that I am play acting for attention
- Do treat me with compassion – I am a person who is not in control and feeling very scared
- Don’t tell me to get up, talk, stop burbling, telling me there’s no reason why I can’t talk
- Understand that the episodes can come in waves and I, like many people, can be thrown back in to another episode one after another for several hours
- Please offer me a drink with straw and then hold it – I am not able to move and, when episodes last for hours, can get pretty thirsty
- Do provide reassurance
- Do sit next to me, don’t stand over me

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Case Example 2 – "A Helpful Experience"

The most helpful things that the paramedic team did:

- They were calm
- They took on board all the information they could find in my bag and the lanyard
- They worked out that I could sometimes respond by nodding slightly and shaking head very slightly. They were quick to pick that up and the grunts I made! That made a massive difference.
- When I was in the ambulance the paramedic asked me if I wanted the straps on me kept on. I still couldn't talk or respond much but she seemed to understand that I could hear and understand. It was so helpful to keep the straps on because of my violent jerking. She was able to understand that I needed them staying.
- I can't remember if the paramedic asked me if I could hear her and understand her but I think she must have done.
- Paramedics explained my diagnosis to staff at the emergency dept.

Resources

Further information

- Understanding NEAD leaflets, posters and guidance cards
- SRFT NEAD website coming soon...
- http://www.manchesterneurosciences.com/departments/neuropsy chology/nead
- http://neurosymptoms.org/
- https://www.fndaction.org.uk/non-epileptic-attack-disorder/
- http://www.nonepilepticattacks.info/
- https://www.youtube.com/watch?v=MA1EYAg9y5k&feature=youtu. be
- https://www.youtube.com/watch?v=w4obwKD8JLU
- https://www.fndsociety.org/fnd-education

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