Functional Seizures & Other Functional Neurological Disorders

An introduction to working with functional seizures (i.e., NEAD) and other functional neurological presentations

for:

Edgehill University

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

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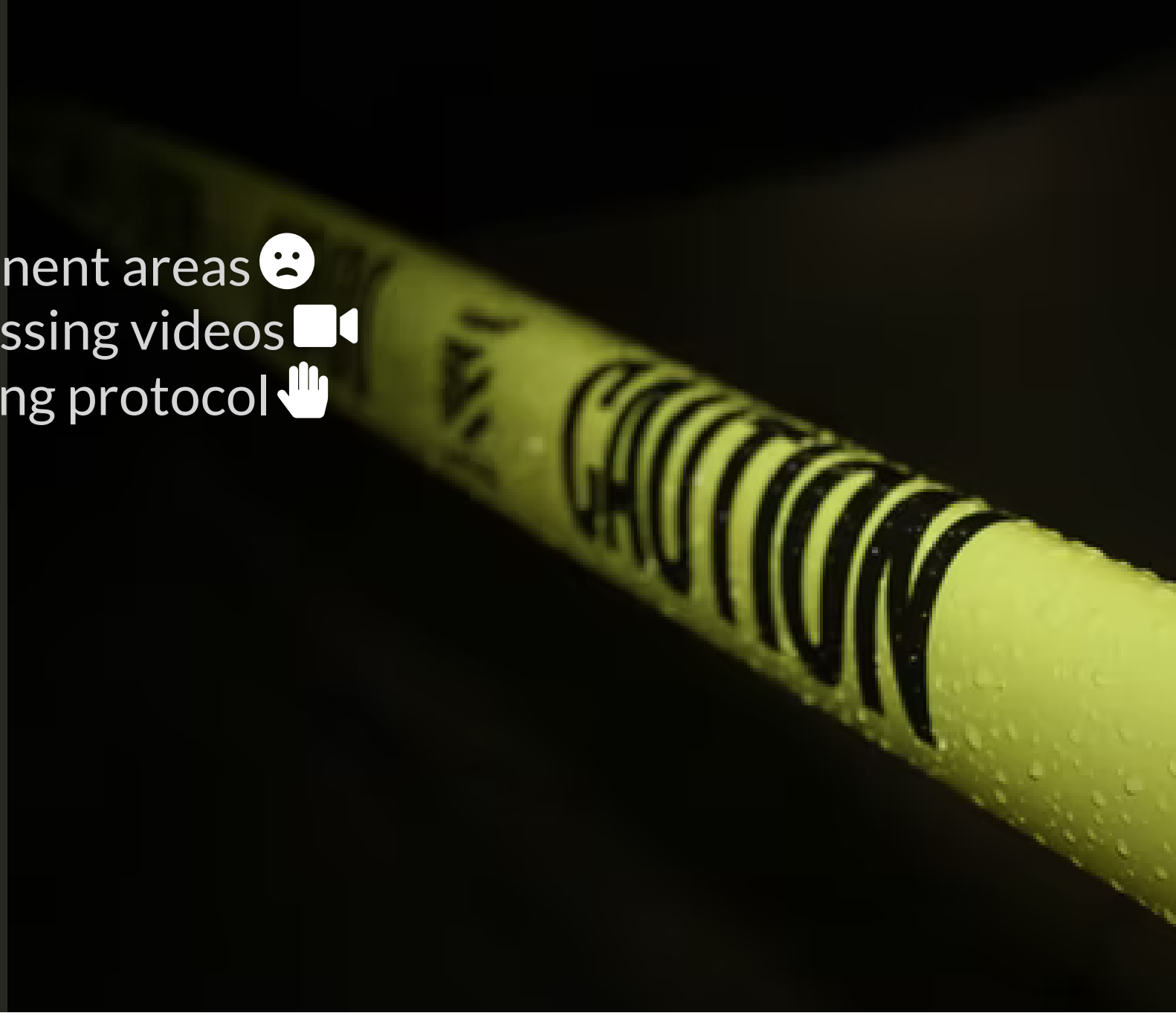
Disclaimers

- Emotionally pertinent areas ☹
- Potentially distressing videos 📹
- Not about changing protocol ✋



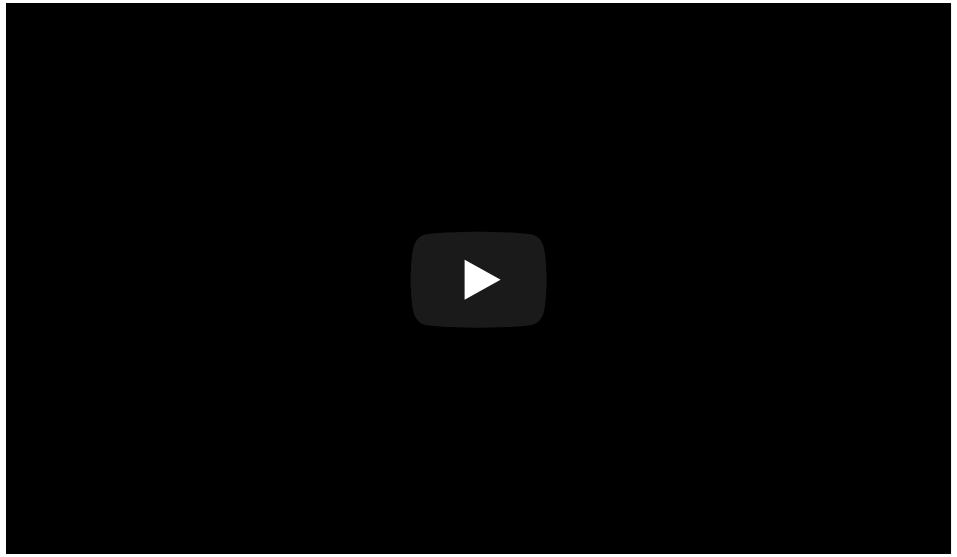
Contents

Note: **Headings** are internal links.

A pdf of this presentation is also available.

So What is This All About?

- **FND** = Functional Neurological Disorder
- **NEAD** = Non Epileptic Attack Disorder

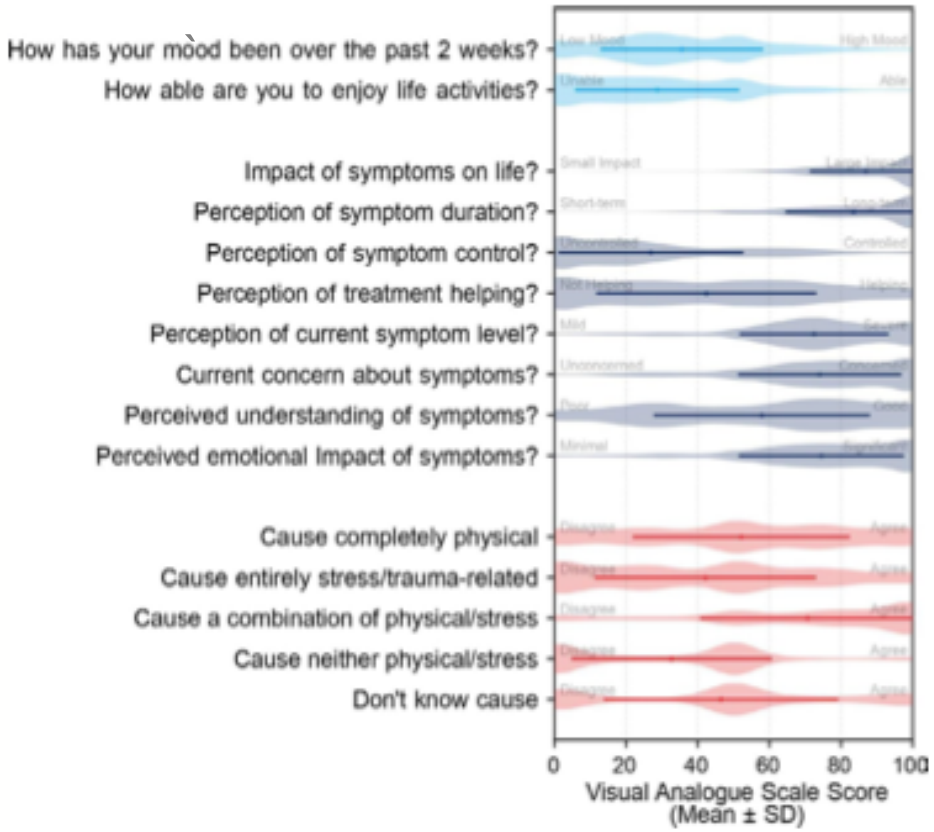


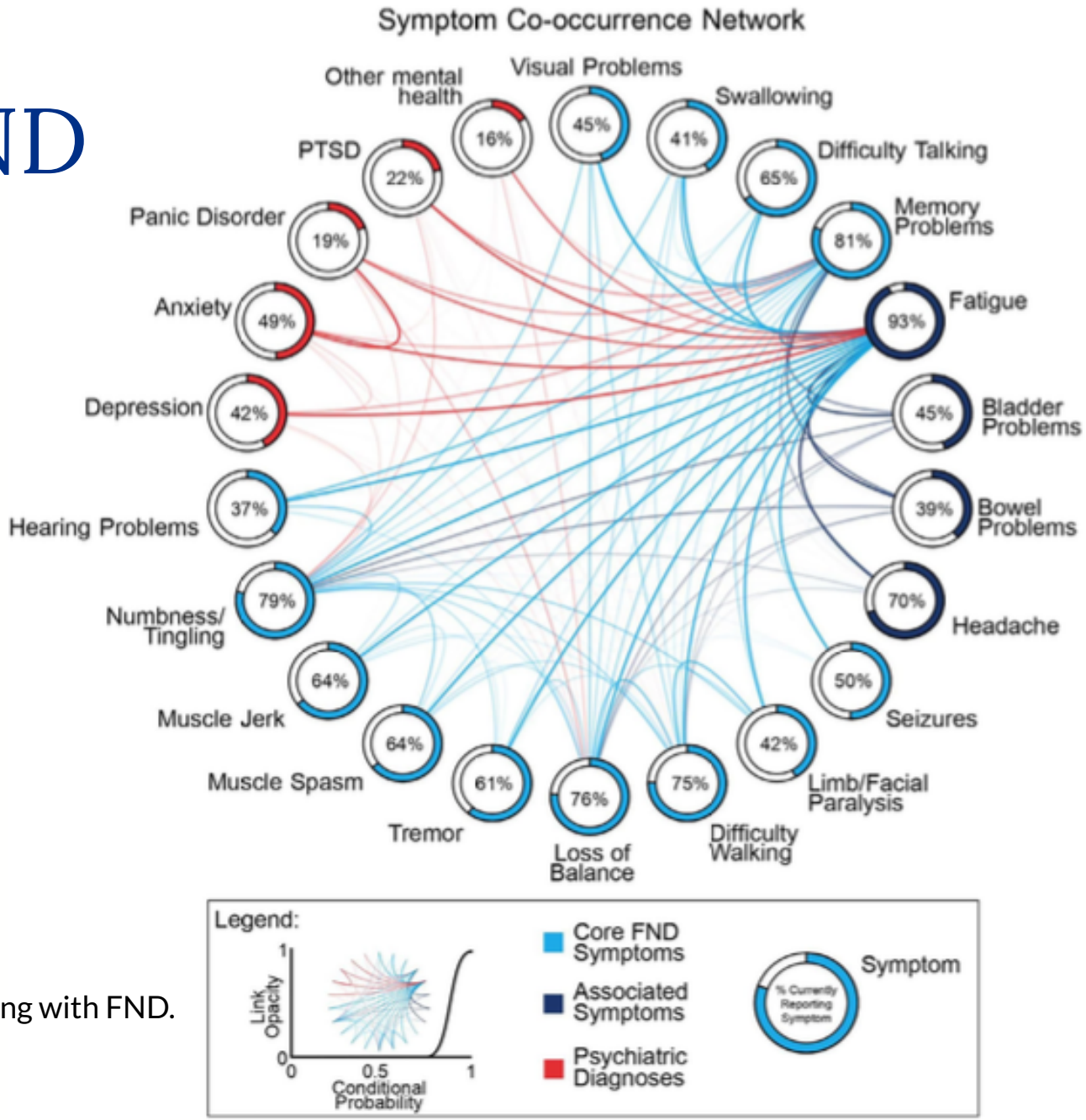
Video by Massachussets General Hospital

Definitions: FND

- Functional Neurological Symptoms Disorder: added as an inclusion term to Conversion Disorder in the DSM-5 (2013).
    - Diagnosis requires FND motor and/or sensory findings.
    - “evidence of incompatibility between the symptom and recognized neurological or medical conditions” (APA, 2013, Stone et al., 2010b).
    - The symptoms must impair social and/or occupational functioning or lead individuals to seek a medical opinion.
    - No duration or severity criteria, or explicit rules for exclusion based on additional symptoms.
- 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.

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

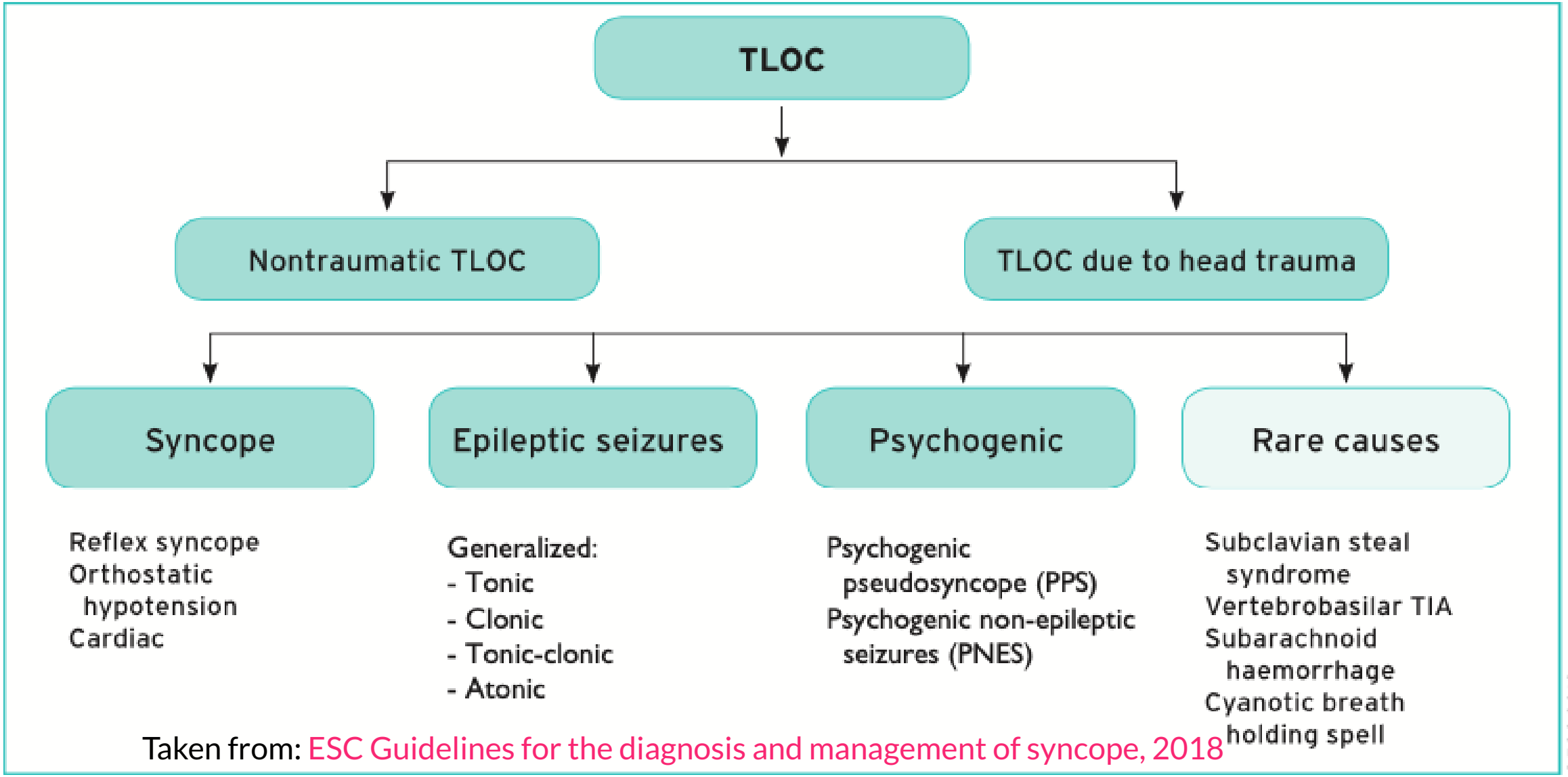
Definitions: Non-epileptic seizures

- One manifestation or constellation of FND.
- In DSM-5, functional 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.
- 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	Challenges 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

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?

Statistics:

- Approximately 20,000 people in the UK have a diagnosis (likely to be many more).
- NEAD accounts for nearly 20% of presentations to seizure clinics (Angus-Leppan 2008)
- NEAD accounts for a proportion of patients brought to hospital with suspected 'status epilepticus'.
- Recent estimate of prevalence (Norway) = 23.8 per 100,000 (Villagrán 2021)

Note: It is hard to accurately quantify prevalence rates in non-epileptic attacks due to common diagnostic delay and patients being lost to follow-up.

Who is most likely to be affected?

1. **Age:** Young people (15–19) has been shown to be the period with greatest rate of onset. Villagrán (2021) - 59.5 per 100,000.
2. **Gender** Female preponderance however disparities less evident in younger/older cohorts (e.g., Jungilligens, 2021)
3. **Epilepsy:** High rate of comorbidity.
4. **Psychiatric comorbdity**
    1. Anxiety and depression
    2. "Personality disorder"
    3. PTSD/Trauma
5. More likely to: be **white, unemployed, lower SES, have an LD**.

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More information later on predisposing, precipitating and perpetuating factors.

Diagnosis

Usually by a Neurologist or Neuropsychiatrist.

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

Table 2. Overview of proposed diagnostic levels of certainty for psychogenic nonepileptic seizures

	History	Witnessed event	EEG
Diagnostic Level			
Possible	+	By witness or self-report/description	No epileptiform activity in routine or sleep-deprived *interictal* EEG
Probable	+	By clinician who reviewed video recording or in person, showing semiology typical of PNES	No epileptiform activity in routine or sleep-deprived *interictal* EEG
Clinically established	+	By clinician experienced in diagnosis of seizure disorders (on video or in person), showing semiology typical of PNES, while not on EEG	No epileptiform activity in routine or ambulatory *ictal* EEG during a typical ictus/event in which the semiology would make ictal epileptiform EEG activity expectable during equivalent epileptic seizures
Documented	+	By clinician experienced in diagnosis of seizure disorders, showing semiology typical of PNES, while on video EEG	No epileptiform activity immediately before, during or after ictus captured on *ictal* video EEG with typical PNES semiology

Key: +, history characteristics consistent with PNES; EEG, electroencephalography (as noted in the text, additional tests may affect the certainty of the diagnosis—for instance, self-protective maneuvers or forced eye closure during unresponsiveness or normal postictal prolactin levels with convulsive seizures).

Epilepsia, 54(11):2005–2018, 2013
doi: 10.1111/epi.12356

Misdiagnosis & delayed diagnosis

Because NEAD can have clinical comparisons to epilepsy it can be difficult to distinguish one from the other.

This can lead to a variety of concerns around:

- Diagnostic delay.
- Response to status epilepticus.
- Prolonged use of anti-convulsants.
- Lack of access to neccersary support.

New paper demonstrating rates of people diagnosed and treated for status epilepticus who infact had non-epileptic attack (Jungilligens et al., 2021)

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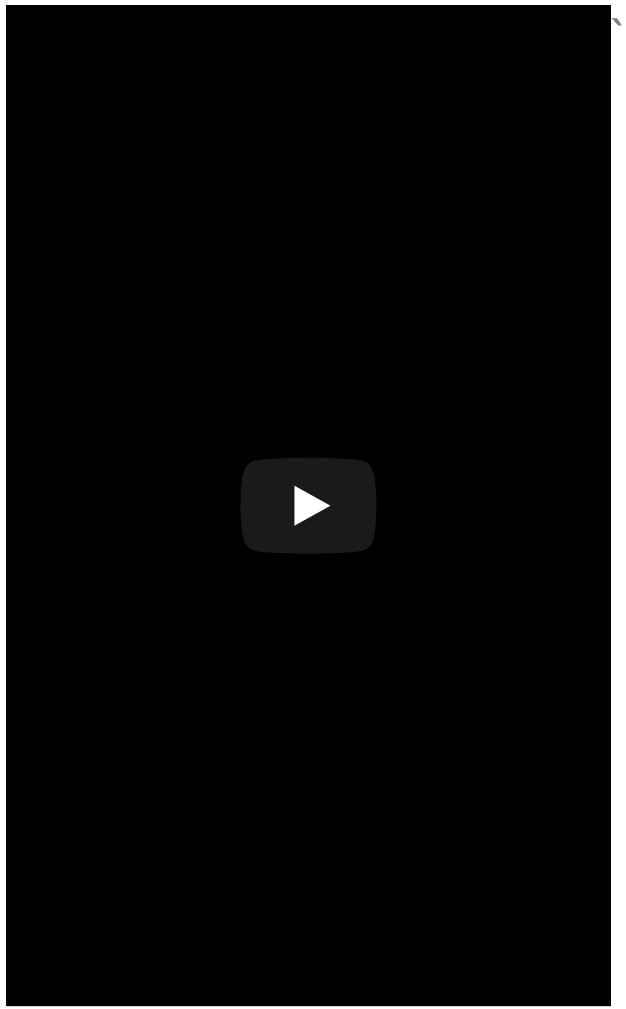
Misdiagnosis & delayed diagnosis

Journey to diagnosis can be very long. Recent estimate of 3.2 years (although 48% in same year).

Getting the diagnostic label

Patients discussed the lengthy process of getting diagnosed [45, 48]. Having to go through a variety of medical investigations was associated with feelings of 'frustration', "limbo" or being "dumped" [61, 62]. This was a particular concern to patients in South Africa due to limited medical insurance [56]. Some explained getting the diagnosis was 'meaningless' [61, 62]. Patients reported feeling 'disappointed' and that "it was like coming back to the beginning again" [48]. Others embraced getting the diagnosis as it 'granted legitimacy to their experiences' [62] and 'facilitated a further search for information' [46]. Some were relieved because it meant there was nothing more sinister [48, 61], such as epilepsy (statement 4) [43]

Not a New Condition



- **400 BC** - Hippocrates -> "hysteria" (hyster = uterus).
- **Pre-1700s** - Considered demonic possession/witchcraft 🧙‍♀️
- **Late-1700s** - Recognised as not gender exclusive ♀♂
- **1800s** - Charcott -> "hysteria major" (functional seizures).
- **1890s** - Freud -> "conversion disorder".
- **1910s** - Studied prominently (First World War -> ‘shell shock’).
- **1980s** - Hysteria retired as a term within the US.

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

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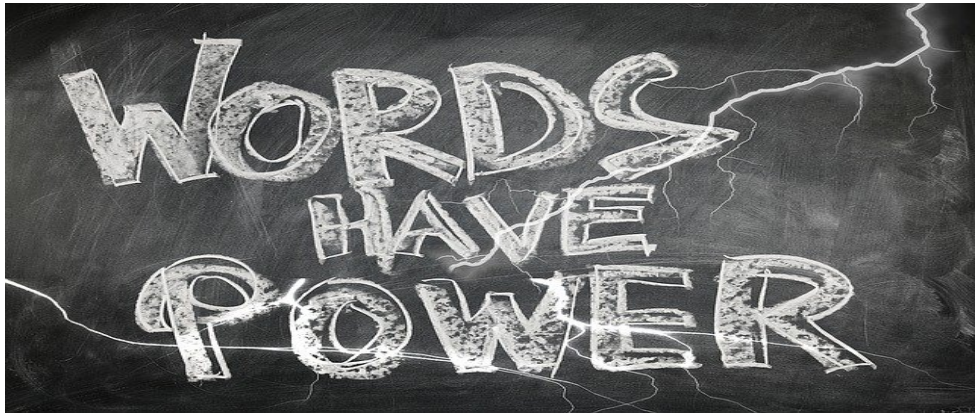
Some terms more **harmful and prejorative**.

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

Be led by the individual.



What do patients prefer?

Loewenberger, 2021

Epilepsy & Behavior 117 (2021) 107817

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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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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.

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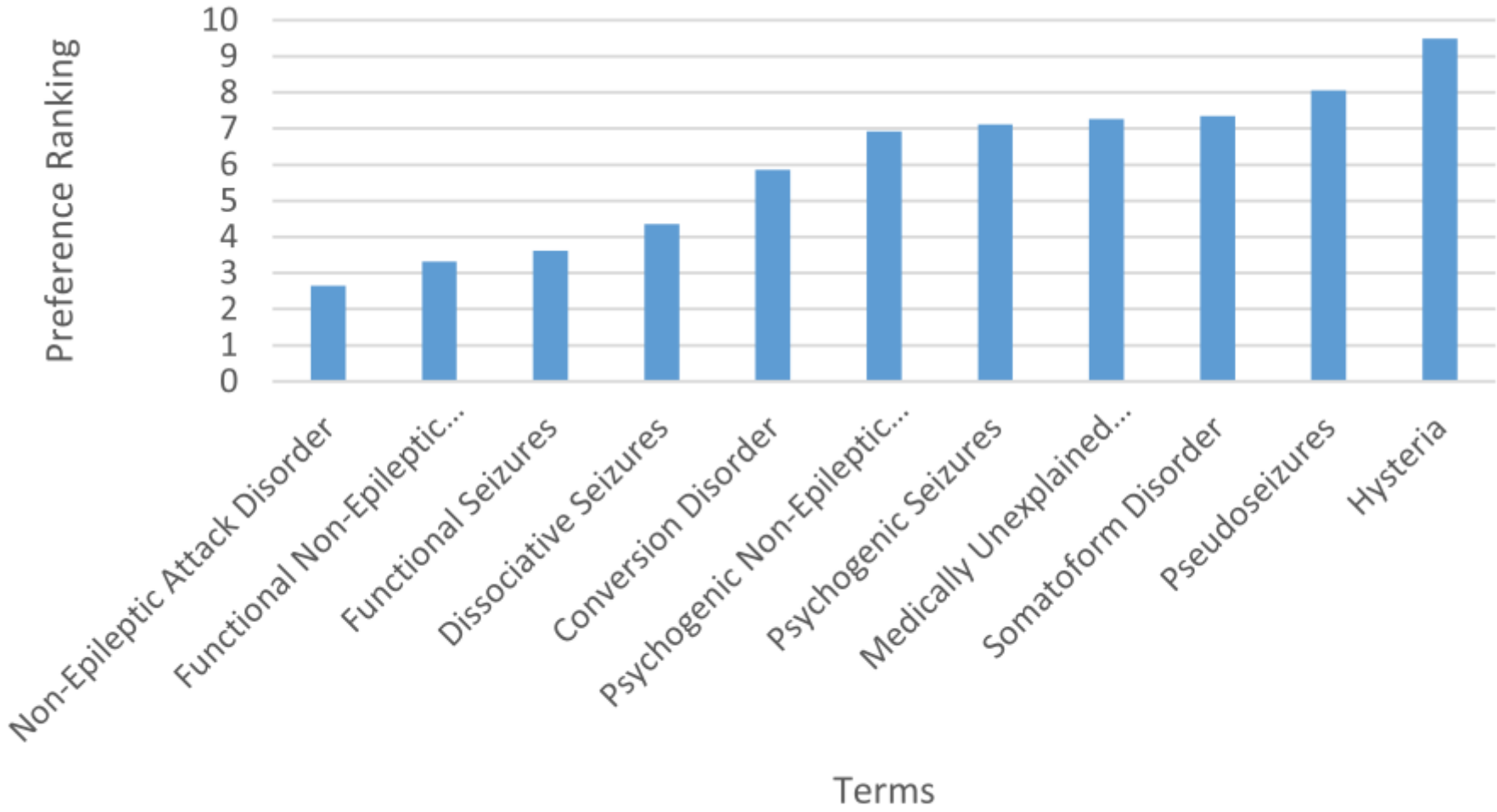
Preference Ranking
10
9
8
7
6
5
4
3
2
1
0
Non-Epileptic Attack Disorder
Functional Non-Epileptic...
Functional Seizures
Dissociative Seizures
Conversion Disorder
Psychogenic Non-Epileptic...
Psychogenic Seizures
Medically Unexplained...
Somatoform Disorder
Pseudoseizures
Hysteria
Terms

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

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Table 5
Number of staff who answered "agree" or "strongly agree" to each cause.

	Number (%) of neurologists		Number (%) of psychiatrists	
	Epilepsy	NEAD	Epilepsy	NEAD
C1 Stress or worry	26.6	95.3	55	**97.5**
C2 Hereditary – it runs in the family	80.0	18.2	85	35.9
C3 A germ or virus	40.0	4.5	37.5	2.5
C4 Diet or eating habits	9.1	0	12.5	2.5
C5 Chance or bad luck	50.0	2.3	45.0	20
C6 Poor medical care in their past	26.7	40.9	41.0	45.0
C7 Pollution in the environment	2.2	2.3	7.5	2.5
C8 Patient's own behaviour	33.3	59.1	22.5	57.5
C9 Patient's mental attitude	6.7	72.8	7.5	60.0
C10 Family problems or worries caused by illness	8.9	88.6	27.5	90.0
C11 Overwork	15.6	46.5	25.0	55.0
C12 Patient's emotional state	13.3	81.9	35.0	92.5
C13 Aging	46.6	4.5	50.0	5.1
C14 Alcohol	**86.6**	25.0	**90.0**	40.0
C15 Smoking	15.6	0	12.5	2.5
C16 Accident or injury	**88.9**	39.6	**94.8**	45.0
C17 Patient's personality	4.4	**97.5**	10.0	92.3
C18 Altered immunity	24.4	2.3	20.0	0
C19 Emotional abuse[a]	6.7	**97.7**	17.5	**95.0**
C20 Physical abuse	28.9	**97.8**	35.9	92.5
C21 Sexual abuse	8.9	95.4	20.5	**95.0**
C22 Poor coping skills	8.9	88.4	15.0	92.5
C23 Malingering	2.3	34.9	10.0	37.5
C24 Mental illness	15.6	59.1	17.5	70.0
C25 Attention seeking	4.4	52.2	10.0	67.5
C26 Childhood neglect	6.7	88.6	20.5	90.0
C27 Bullying	4.4	86.4	7.5	75.0
C28 Learning disability	68.2	50.0	72.5	65.0
C29 Brain lesion	**95.5**	15.9	**100.0**	40.0

The three most commonly endorsed causes in each column are shown in boldface.
[a] The causes C19–29 were added to the original IPQ-R for the purpose of this study.

Videos of FND and NEAs

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

NEAD service patients

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Why is it happening?

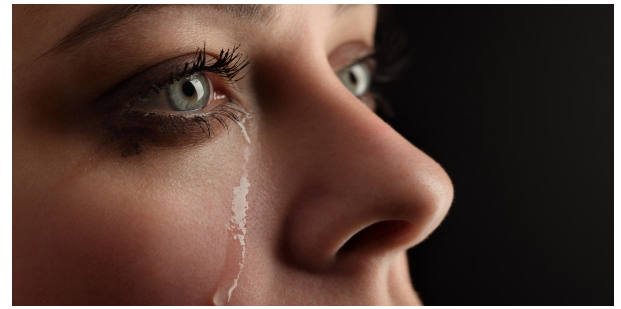
The mind body link

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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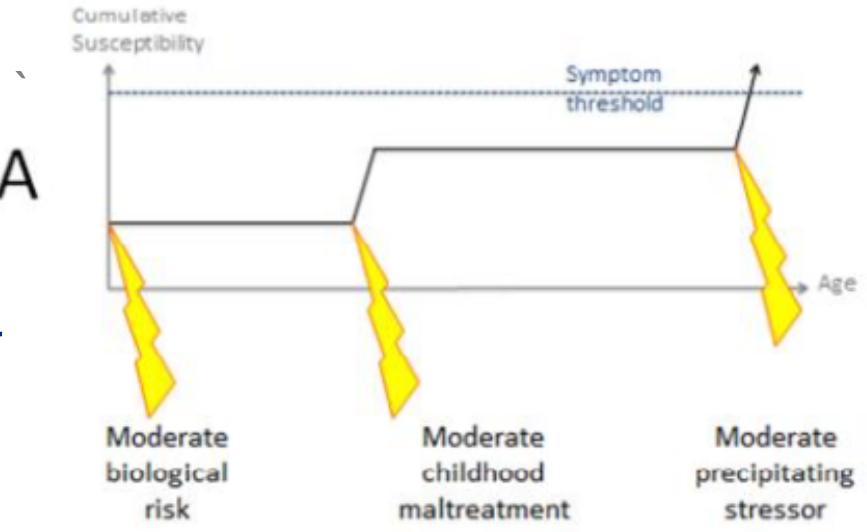
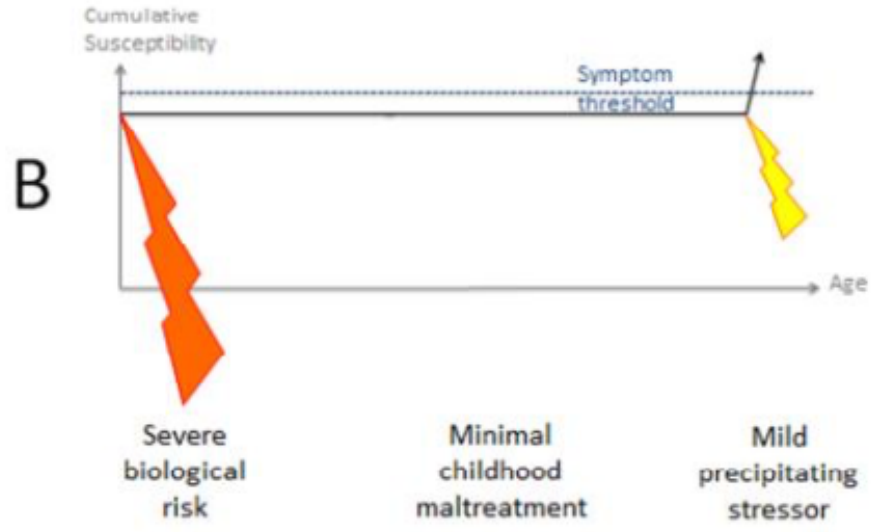
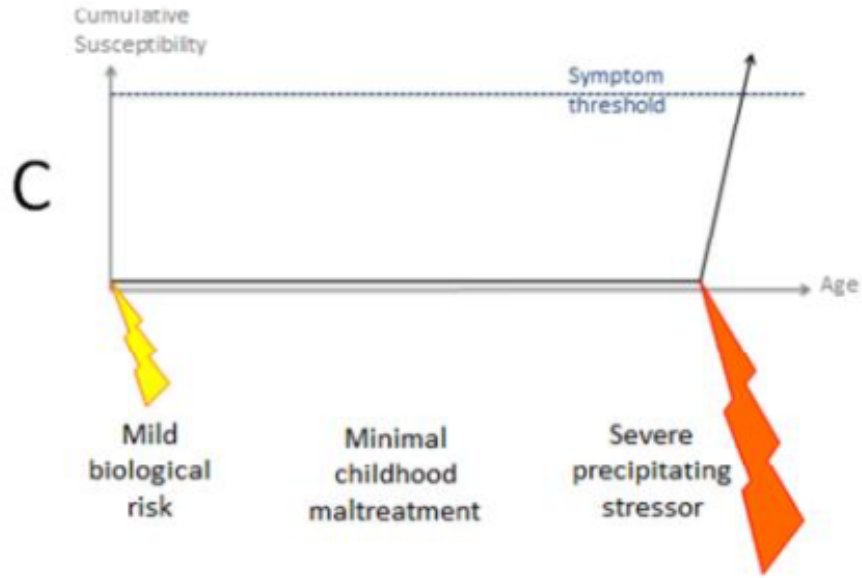
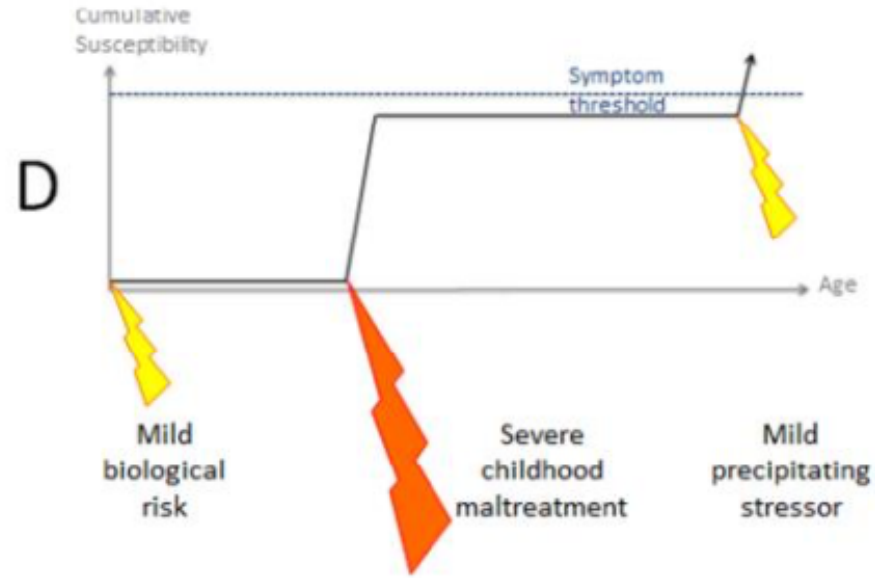
Role of Trauma

Taken from Keynejad, 2021



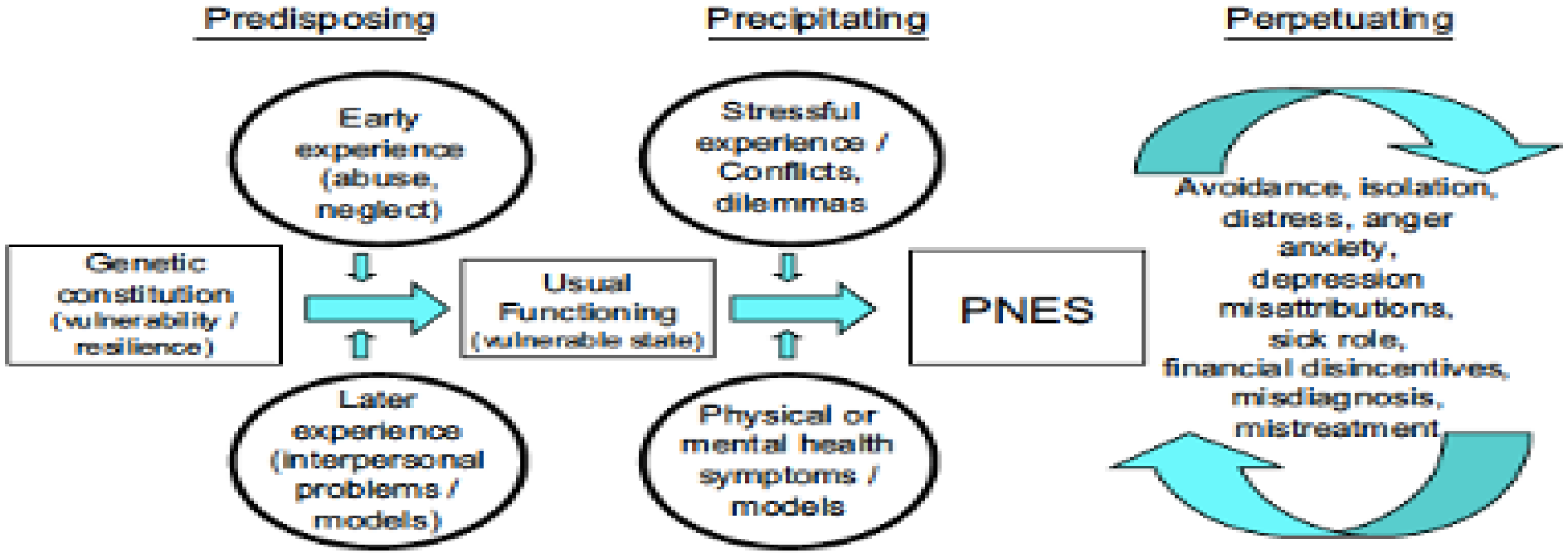






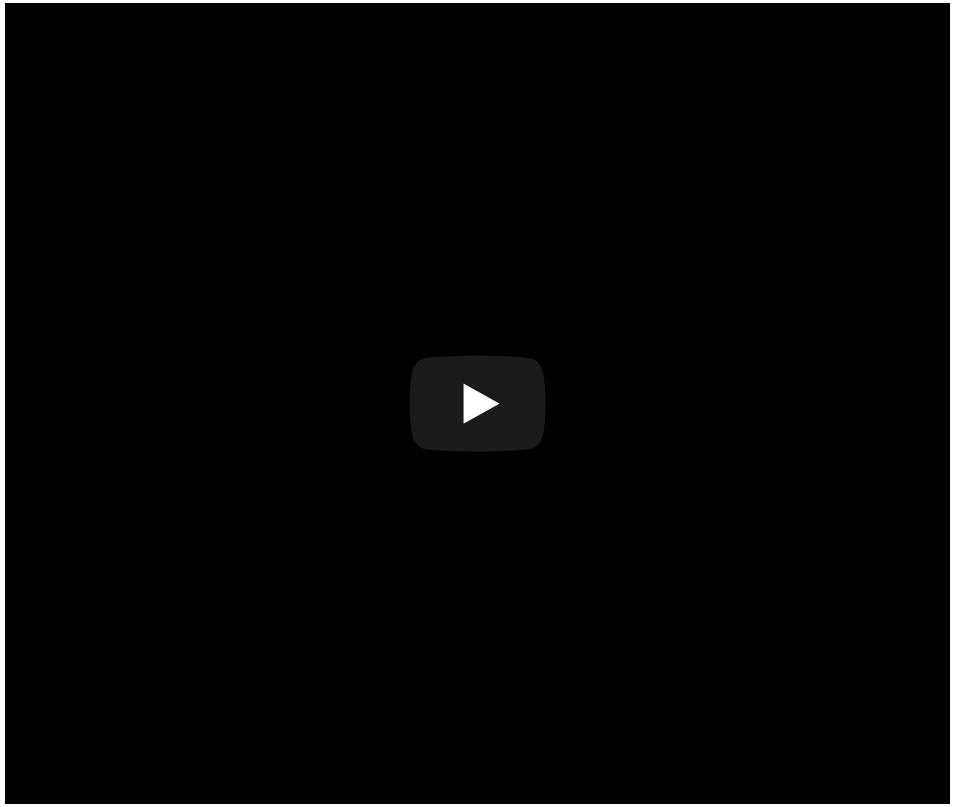
Other relevant factors?

- No single factor explaining functional seizures across all patients.
- People have often (not always) had previous life adversity and stressful life events (e.g., abuse, trauma or neglect).
- Patients can be experiencing acute and ongoing stress, this could also be related to dysfunctional relationships and attachment difficulties.
- Formulation figure from Reuber, 2009



What is happening during NEAD?

- 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)



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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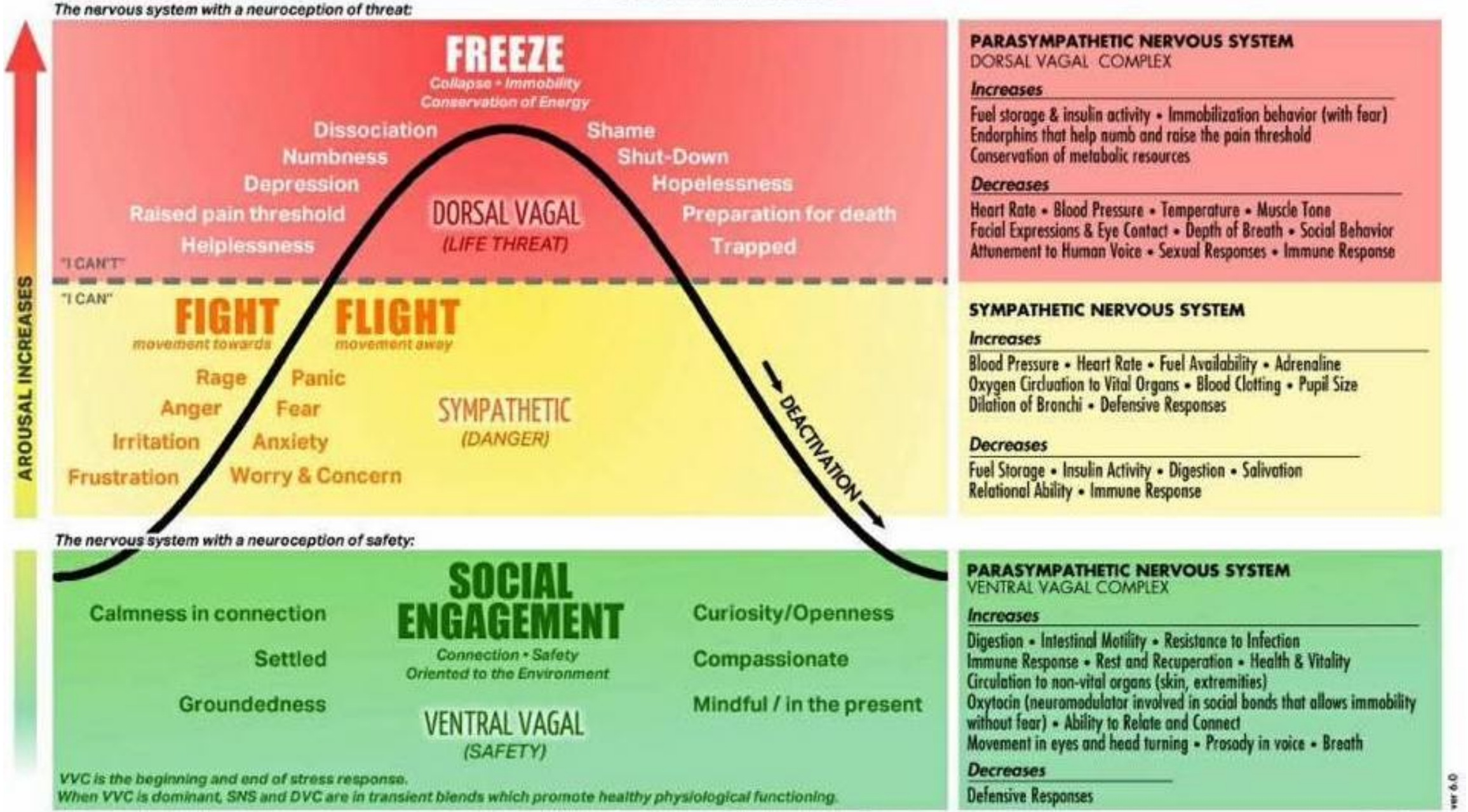
POLYVAGAL CHART



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Adopted by Ruby Jo Walker from: Cheryl Sanders, Anthony "Twig" Wheeler, and Steven Porges.

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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