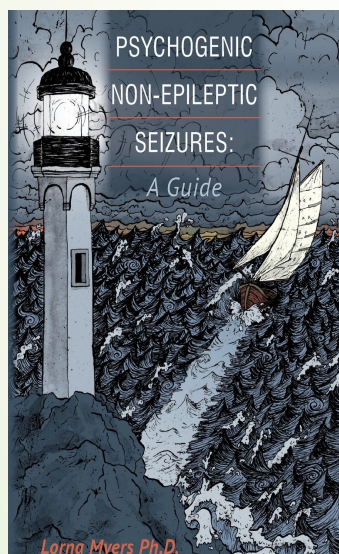


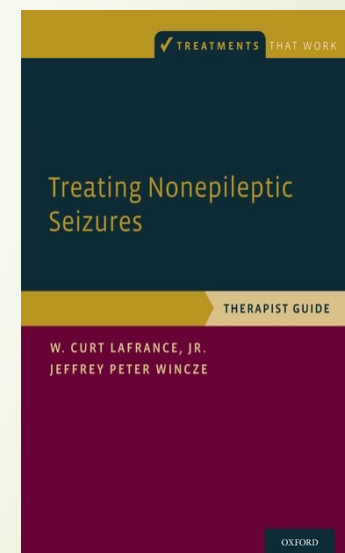
# When Medication Does Not Work

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## Goals/Objectives

- ▶ To understand what PNES are
- ▶ To understand that PNES are common & serious
- ▶ To understand what the causes of PNES are
- ▶ To understand what can be done for people with PNES

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Jean-Martin Charcot, French Neurologist, in 1887 painting by Brouillet

# PNES

- ▶ Events that look like epileptic seizures but are not epileptic seizures
  - ▶ Jean Charcot in Paris (1887) – hysterical seizures
  - ▶ The term “Pseudoseizures” was used for many years
  - ▶ **Psychogenic Non-Epileptic Seizures** (The Official Term): **PNES**
  - ▶ Psychological (?Protective) Non-Epileptic Events (PNEE): Dr. Lorna Myers
- ▶ Diagnosing PNES
  - ▶ Most people with PNES are diagnosed first with epilepsy & treated with anti-seizure medications, which do not work & may lead to more PNES & Emergency Department visits
  - ▶ Average time from onset to correct diagnosis of PNES 7.2 years!!!
  - ▶ Video-EEG is the gold standard for diagnosing PNES but is only done at specialized epilepsy centres like the University of Alberta Hospital
- ▶ If not epilepsy or syncope, what are PNES? And how common are PNES?



## What are PNES?

- ▶ Events that look like seizures but are not epileptic seizures
  - ▶ Abrupt, transient changes in behavior &/or consciousness without changes in EEGs
  - ▶ They are automatic and not consciously generated and involve changes in brain activity (SPECT) different than epileptic activity
- ▶ PNES are heterogeneous and may include:
  - ▶ Unresponsiveness/staring (altered consciousness or awareness)
  - ▶ Shaking (tremor)
  - ▶ Crying out/vocalization
  - ▶ Undulating body movements as in swimmer's butterfly stroke
  - ▶ Worsening after getting anti-seizure medications



## How Common are PNES?

- ▶ Epilepsy Clinics ~ 12% of people with first seizure-like event have PNES (Hitiris et al., 2005)
- ▶ Epilepsy Surgery Centres & Emergency Departments
  - ▶ ~30% of people undergoing Video-EEG in U.S. have PNES
  - ▶ 11% of Emergency patients with convulsive events have PNES
  - ▶ 10% of people who have epileptic seizures also have PNES
- ▶ PNES is most common in people in their 20s or 30s, though children & elderly can have PNES
  - ▶ 75% of adults with PNS are women (excluding military veterans, older adults, and in India)
  - ▶ ~50% report a precipitating event like a mild traumatic brain injury

# Serious Personal & Societal Costs of PNES

## ➤ Personal Costs: Health-Related Quality Of Life (QOL)

- **Physical Health** (energy/fatigue, mobility, activities ...), **Mental Health** (mood, emotional well-being ...), **Social Functioning** (relationships, work/employment ...) are all **poorer than in People with PNES than in people with Epilepsy or Syncope**
- Low QOL in PNES related to chronic psychological distress & somatization (experiencing emotional stress physically)

## ➤ Societal/Healthcare Costs

- Lifetime Cost of Treating Single Patient with PNES = \$100,000
- Annual Costs in U.S.A. of Patient Visits (Outpatient, Emergency Department), Lab/Diagnostic Procedures, and Drugs = \$900,000,000

## What are the Causes of PNES?

### ➤ Risk Factors for PNES

- Up to 50% of People with PNES Report a Precipitating Event like Mild Traumatic Brain Injury\*
- Up to 90% of People Report **Past Trauma** with  $\leq 40\%$  of these of a Sexual Nature
- Current or Past Mental Health and Psychosocial Problems, including **Anxiety, Depression, or Post Traumatic Stress Disorder, are common** though far from universal in people with PNES
- Experience with epilepsy (personal or professional)
- Approximately 70% of People With PNES Have Other Medically Unexplained Symptoms (Chronic Pain, Sleep Disorders ...)
- 75% of people diagnosed with PNES are women
- **Alexithymia** – emotional dyslexia (trouble reading own emotions)
- There are **multiple interacting causes** (biological, social, experiential)



# Trauma is significantly related to Adult PNES

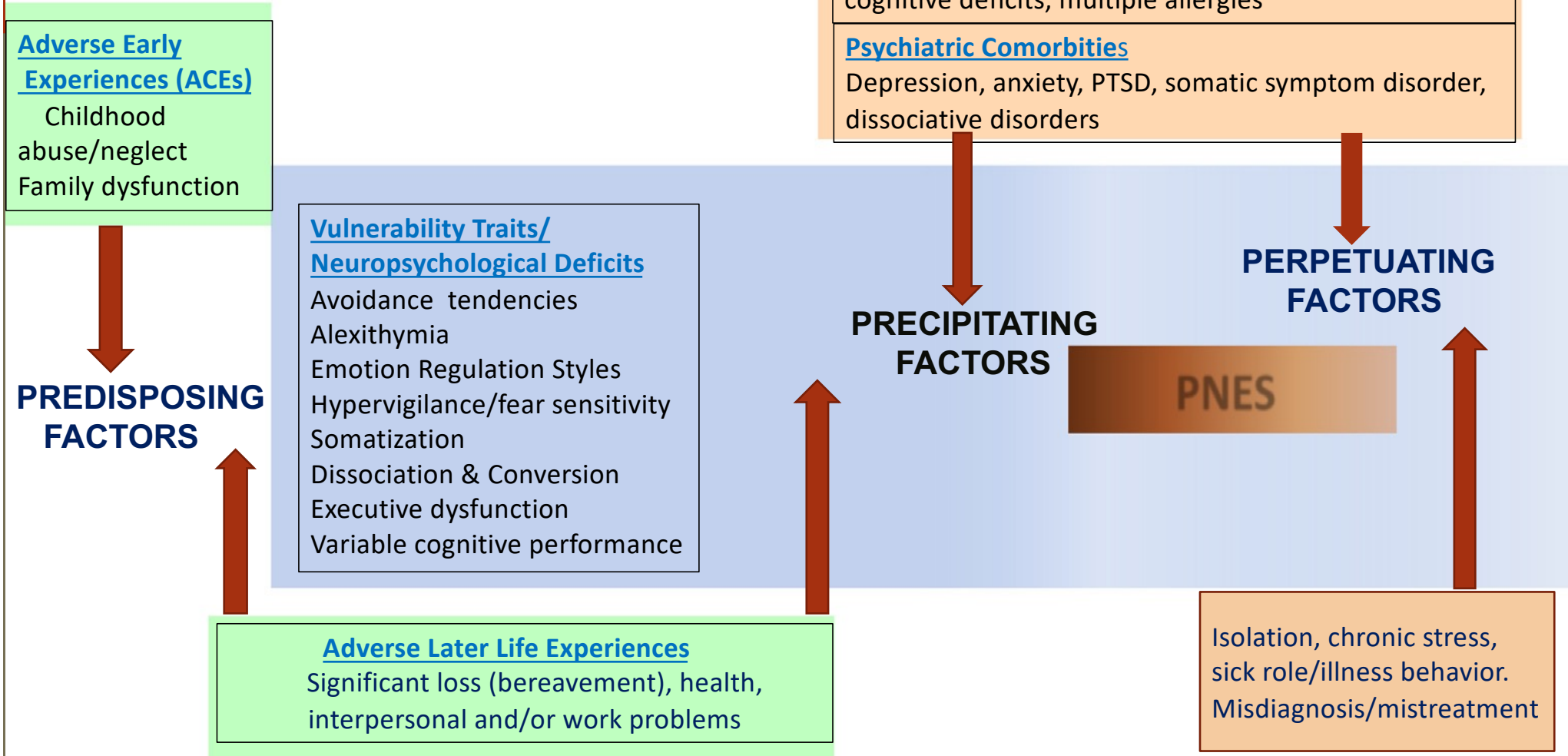
- PNES (transient neurological changes/altered state of consciousness) result from **atypical emotional processing and autonomic arousal**
- 80-90% of people with PNES have a history of trauma; 10-20% of people with PNES report no history of trauma
- What is trauma & the response of the “embodied” brain to trauma?
  - Trauma derives from the Greek word for “wound”
  - Trauma can involve visible, physical wounds and/or invisible emotional/psychological wounds, i.e. injuries
  - What happens to the brain/body when injured physically or emotionally?
    - Pain, inflammation (immune response), & autonomic arousal (stress response) which can resolve with effective treatment
    - How does emotional pain resolve? Naming & talking about emotions + healthy life style with exercise, healthy food, good sleep and exercise


# Common Sources of Psychological Trauma

- ▶ Battlefield Experiences
- ▶ **Being repeatedly bullied\***
- ▶ Being the victim of an accident (MVA+), crime, or torture
- ▶ **Physical or sexual abuse or neglect\***
- ▶ **Contracting a life-threatening disease or other illness\***
- ▶ Death of a loved one (especially loss of a child)
- ▶ **Divorce or break-up of a significant relationship\***
- ▶ Physical Injuries
- ▶ **Childhood Instability (multiple foster homes, refugee status ...)\***
- ▶ Natural disasters (COVID-19 pandemic, floods, tornados ...)
- ▶ Being shunned by family or society
- ▶ Witnessing death or suffering of parent/loved one

**\*ACE = Adverse Childhood Experience**

Baslet et al. (2016), Psychosomatics





According to research at Cambridge University, it doesn't matter in what order the letters in a word are, the only important thing is that the first and last letter be at the right place. The rest can be a total mess and you can still read it without problem. This is because the human mind does not read every letter by itself, but the word as a whole and the brain figures it out anyway.

## PNES & Emotion Processing

- ▶ PNES: Brain's **Automatic Rapid Response** (“reflex”)
  - ▶ To threatening External and/or Internal Triggers (feelings, memories, flashbacks, thoughts, personal Interactions ...) Markus Reuber
  - ▶ **Adaptive**: loss of awareness of threat & reduction of arousal/distress - subjective anxiety no greater in PNES than in Epilepsy & Fear not common in PNES
  - ▶ **Maladaptive over longer term**: loss of control of body & independence
- ▶ PNES are **Learned, Unconscious Responses** to Emotional and/or Social Distress that are Expressed as Neurological Symptoms
  - ▶ “The Body’s Expression of Emotions” Dr. Nizam Ahmed
  - ▶ Key to understanding neurobiological mechanisms of PNES is better understanding of emotion processing (intensity, regulation) \*\*
  - ▶ If PNES is a learned response, it can be replaced by other responses via psychotherapy!!

## Take Home Message

- PNES are behavioral events with altered consciousness experienced by some children, adolescents, & adults in response to past/present psychological/emotional stressors & are often misdiagnosed & treated as epileptic seizures
- Multiple interacting biological & psychosocial factors contribute to the cause, form, & perpetuation of PNES, with past history of trauma/stressful life events common for adults with PNES
- Early diagnosis, appropriate communication of diagnosis, and early involvement of mental health specialists are important for positive outcomes
- Cognitive Behavioral Therapy (CBT) & Mindfulness are the most effective treatments for PNES

**Take care of your body. It's the only place you have to live!**

## Resources for Information about PNES & Treatment

- Edmonton
  - Comprehensive Epilepsy Program – University of Alberta Hospital
  - Edmonton Epilepsy Association
  - Adult Neuropsychiatrists: Dr. Caitlyn Earle & Dr. Michael Martyna
- Calgary
  - Foothills Hospital Epilepsy Centre: Drs. R. Sharma & S. Macrodimetris
  - Alberta Children's Hospital: Dr. Tyson Sawchuk
- Epilepsy Societies: International League Against Epilepsy (ILAE)
- Books/Online
  - Dr. Lorna Myers, Psychogenic Non-Epileptic Seizures: A Guide (2014)
  - PNES Webinar - Psychogenic non epileptic seizures: an Introduction for patients and loved ones

**Thanks for Attending!**