





Patient cases are shared in this session for educational purposes. In some cases, the information does not relate to an individual, and instead represents a compilation of disease presentation.

In cases involving individual patient information, the patients have authorized the discussion of their case in this setting.

# Introductions

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# Objectives

- To challenge prevailing perspectives of primary psych etiology for difficult to diagnose symptoms such as sympathetic overdrive, “cog fog”, fatigue, etc.
- To support more precise determination of primary vs secondary psych presentations. Address genuine (and often secondary) psych implications of chronic, multi-system inflammatory diseases (ME/CFS, POTS, PASC, etc.).
- To provide case examples presented in medical & MH clinic settings.
- To lodge recommendations for concurrent mental health care modalities & imperative of interdisciplinary care.

## CHECKLIST

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# This is challenging (for patients & providers)

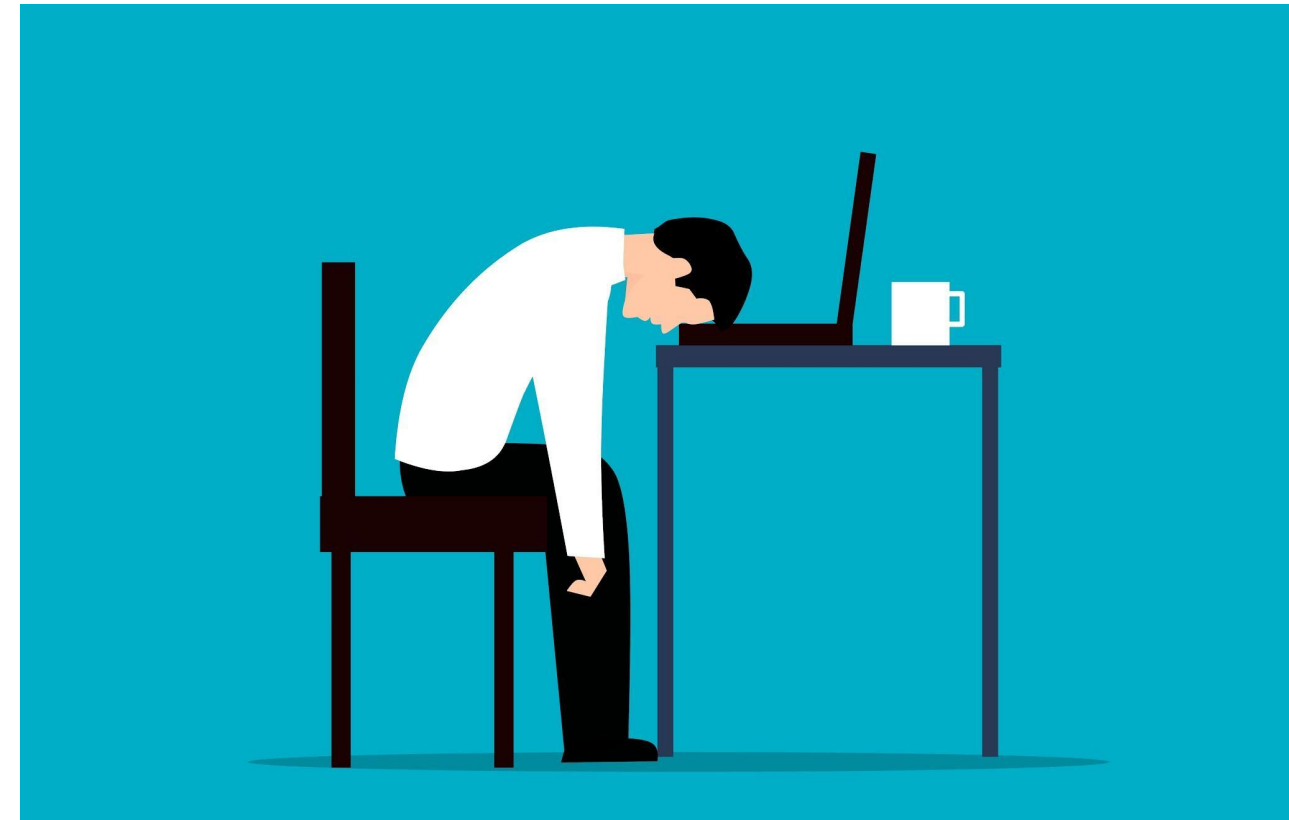
**In a 2018 EULAR study**, 1/3 of respondents with confirmed rheumatological disease reported **duration from seeking care to formal diagnosis was 10+ years.**

96% received at least 1 misdiagnosis, **36% received a dx of psychogenic d/o** (conversion, factitious, health anxiety, etc.)

## **2015 IOM report for ME/CFS**

-84-91% of patients affected are yet to be diagnosed.

-Time to diagnosis from onset of symptoms 5 - 10 yrs, if at all. Also frequently misdiagnosed as psychiatric etiology.



# Co-Occurring Psych Presentations (Yes-And...)

CI patients commonly present with co-occurring psych symptoms, often due to several frequently reported factors including:

- longitudinal experiences of medical dismissal and/or misdiagnosis
- stressors related to process of receiving proper medical ddx (incl. cost, burden of frequent care visits, wait times)
- loss, grief and adjustment disorders due to acknowledging & navigating accrual of disability & comorbidities



# Primary vs Secondary Psych Symptom Drivers

- **Functional Neurologic Disorder (FND)**, aka Conversion Disorder per the NINDS - “refers to a group of common neurological movement disorders caused by an abnormality in how the brain functions.” FND is not caused by another disorder and there is no significant structural damage in the brain.
  - Symptoms: Weakness, tremors, syncope, seizure, fatigue, sensory issues, balance issues, tics, difficulty with speech, extreme slowness and fatigue, pain (including migraine). Attributed to prior stress or trauma and possible reaction to their chronic illness.
  - Symptoms can come and go and be triggered by stress or emotional or physical trauma.
- **Anxiety** per APA - “is an emotion characterized by feelings of tension, worried thoughts, and physical changes”
  - Symptoms: Racing heart, sweating, trembling/tingling, chest pain, fatigue, difficulty with concentration, headaches, muscle aches, unexplained pain, insomnia, OCD symptoms, PTSD symptoms.
- **Depression** per the NIMH - “Is a common but serious mood disorder that can cause severe symptoms that affect how a person feels, thinks, and handles daily activities, such as sleeping, eating, or working.”
  - Common symptoms: Fatigue, hypersomnia, body pain, headaches, impaired physical and cognitive function.

# HOWEVER.....

❖ Symptoms may offer a clue as to what is driving their chronic illness.

## **Some alternate diagnoses to consider**

-**Dysautonomia** - POTS, orthostatic hypotension, neurogenic orthostatic hypotension, syncope, slow GI motility, insomnia, PTSD/Anxiety, sensory sensitivities.

-**PEM of ME/CFS** - fatigue, cognitive impairment, decreased function, neurologic issues.

-**Fibromyalgia** - diffuse pain, fatigue, headaches

-**SFN** - numbness, weakness, OI (orthostatic intolerance)

-**MCAS** - Hives/rashes, GI issues, food intolerance, vitamin/mineral deficiencies, SOB, headaches, recurrent URI and flu-like symptoms.

-**Hypermobility w/ CCI** - body and joint pain, headaches, cognitive impairment, worsened sympathetic overdrive.

-A Note on recent NIH study\*\* “alteration of effort preference” → **could we consider ‘exertional constriction’ as alternative terminology not connoting pt volition?**

+\*\*Walitt, B., Singh, K., LaMunion, S.R. *et al.* Deep phenotyping of post-infectious myalgic encephalomyelitis/chronic fatigue syndrome. *Nat Commun* 15, 907 (2024).

<https://doi.org/10.1038/s41467-024-45107-3>



# Case Example #1

- ❖ 55 yro woman with Long COVID. Acute COVID infection with Pnx 06/2020. Hospitalized x 3 days in ICU but not intubated.
- ❖ Pertinent comorbid conditions - T1D, HTN, OSA, MS, CKD 3b, obesity.
- ❖ Post COVID diagnoses - Post COVID ME/CFS, debilitating PTSD and anxiety, SOB and low O2 sat, dysautonomia/OI, cognitive impairment, meat intolerance.
- ❖ NLT - Increased “fight or flight”, SOB, anxiety, dizziness, dry mouth. Moderate HTN response, Increased HR 22bpm.
- ❖ Cognitive testing - unable to complete.
- ❖ PE - Impaired balance
- ❖ Psych Meds: Escitalopram, Prazosin
- ❖ Cognitive Impairment - Cog/emotional exertion very fatiguing. Poor STM, confusion, overwhelmed, poor processing. Sensory stim, stress, pressure worsen symptoms as well.

## IMPRESSION

- Cognitive impairment driving a lot of her anxiety secondary to concerns about performance.
- Physical and cognitive exertion → PEM → increased cognitive impairment/fatigue → worse PTSD/Anxiety.

# Case #1 continued

## TREATMENTS

### CI

- ❖ Low Dose Naltrexone - 4.5 mg in am
- ❖ Aripiprazole 2mg later on
- ❖ NAC 900mg QD

### Dysautonomia

- ❖ Dextromethorphan 15mg BID
- ❖ Initiated Clonidine 0.05mg QHS later
- ❖ Stellate Ganglion Block May 2023
- ❖ Neuroplasticity/Neuro-Biofeedback programs

### MCAS

- ❖ Gastrocrom - off now as symptoms have resolved

### Psych

- ❖ Escitalopram
- ❖ Prazosin 1mg QHS

## OUTCOMES

- ❖ Anxiety/PTSD improved.
- ❖ Cognition improved, less sensory overload.
- ❖ Back to work FT.
- ❖ Stress and exertion still can exacerbate PTSD symptoms but not as severe.
- ❖ Continues to have physical exertion impairment but better than before.

# Case Example #2

- ❖ 37 yro woman with Post COVID ME/CFS. Sick since 10/2020. Very healthy prior to COVID.
- ❖ Co-morbid conditions: POTS, MCAS, CCI, FM, anxiety/depression
- ❖ Overall condition - severely ill, bedbound

## Situation:

1. 8/2021 worsening depression, suicidal ideation, verbal tics
  - Hospitalized for suicidal ideation and major depression
  - Discharged on 80mg fluoxetine

\*In hindsight - PEM with worsened neuroinflammation. Some secondary depression and anxiety but not the driver of symptoms.

2. 12/2022 experiencing severe PEM x 2 months with severe headaches.
  - Initiated Indomethacin 25mg and had severe reaction - nausea, faint, heart racing, chills/sweats, eyes rolling back. Then panic, slurred speech, couldn't walk.
  - EMS called went to ER - Labs, head CT and exam all normal.
  - Symptoms resolved in 3-4 hrs
  - Dx'd with FND

\*In hindsight - Drug reaction secondary to severe dysautonomia

# Case Examples presenting to MH

## “Example 1”

- AFAB female, early 30's, white
- prior dx of **psychogenic seizures, panic d/o & MDD** by family medicine & psychiatry
- Began MH therapy (somatic, polyvagal, MBCT & ACT) to address the chronic depressive symptoms she experienced secondary to accrual of disability & family hostility towards her attempts to receive proper medical DDX.
- Referred to BHC within first 6 months of MH care with increasing disability incl OI & PEM, Dx'd with ME/CFS *5 years after initial psychiatric DX.*
- 5 years into ME/CFS care, pt is able to ride her horse, drive short distances and has relocated away from family of origin who unanimously remain convinced she's malingering.

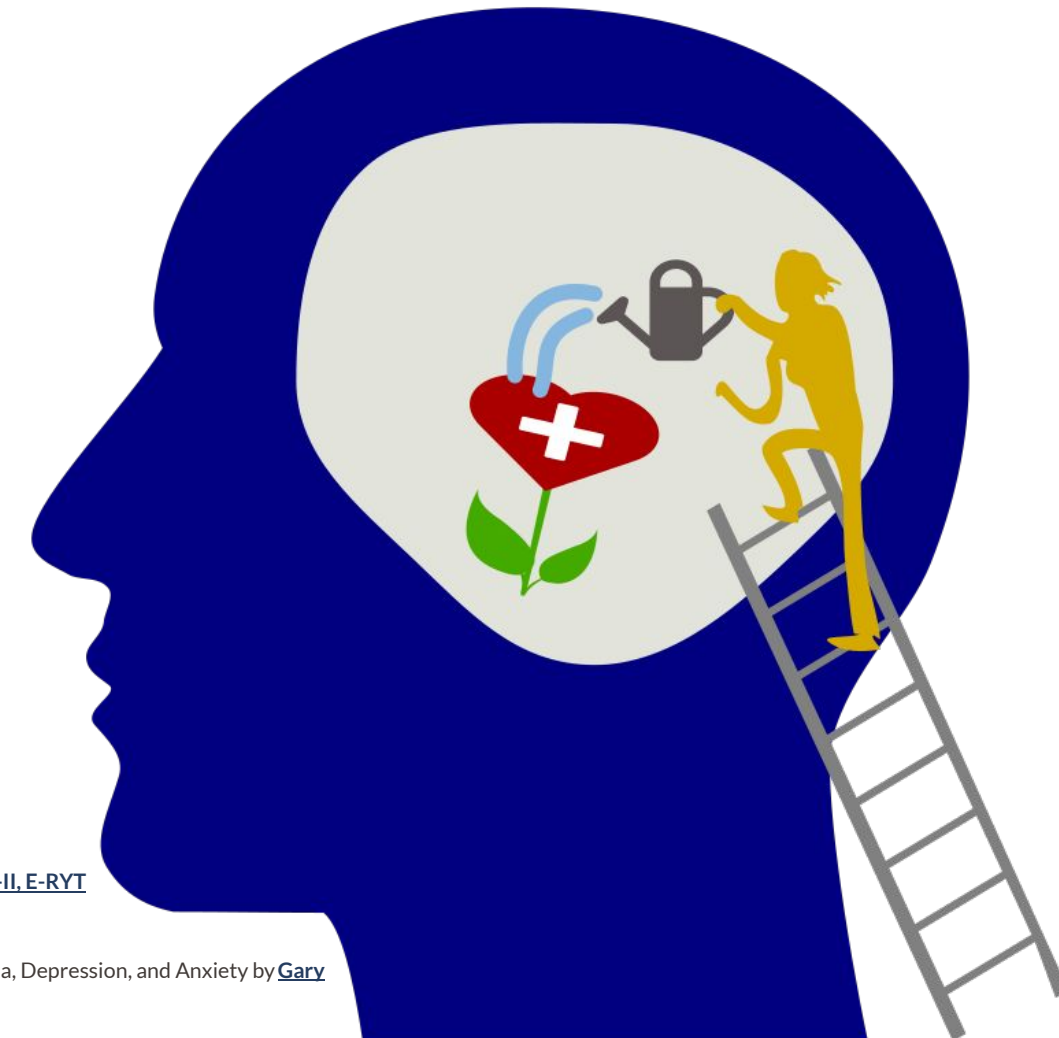
## “Example 2”

- AFAB female, mid 40's, white
- prior dx **conversion d/o**
- referred to MH care for chronic depression and 'isolation behaviors'
- pt subjectively required c-collar, was moderately ambulatory w/ waxing & waning non-specific neuro symptoms w/ “normal” brain/c-spine MRI. Pt reported diffuse, chronic pathologic pruritus, with occasional urticaria, flushing, GI distress & unrefreshing sleep.
- during first months of MH care, pt's depression & anxiety were intractable. Therapist encouraged Pt several times to request their PCP refer or order mast cell panel. PCP denied initially, eventually capitulated after several requests by Pt & therapist w/ ROI.
- Shortly thereafter, Pt dx'd with Systemic Mastocytosis & currently seeking DDX for CCI or Tethered cord. Treatment of SM showed marked reduction of 'psych' symptoms.

# Mental Health Modalities of Relevance

Somatic & Trauma Therapies as a subclass of MH tx are useful, especially with a clinician who is competent with co-occurring CI, CP & medical trauma populations:

- Somatic EMDR
- Somatic Experiencing
- ACT with somatic mindfulness emphasis
- MBCT
- DBT-PE (*esp. when health anxiety or OCD symptoms are present*)
  
- Brain Spotting
- Mind-Body Bridging
- Grief & Loss therapies (existential, Francis Weller, etc.)
- Neurofeedback
- TMS
- KAP (**avoid KAT**)
- \*Emerging data on psilocybin TBD\* (*ask me in 5 years...*)



# Interdisciplinary Care Matters

- healthcare silos prevent proper DDX and may over-rely on psychiatric explanations of symptoms (obtain ROI & reach out to other providers)
- lack of communication between distinct providers restricts comprehensive care (stay in contact re shared pt's)
- treatment planning is myopic without collaboration & overlap of medical & MH (follow up & follow-through on pt progress)
- inter-disciplinary care should be standard, not aspirational (take the time or ask for it if your system doesn't standardize it, consider a collaborative care model)
- specialist providers in MH & medical and should be sourced for best practice with these patients (establish & maintain trusted referent relationships)

*Questions are welcome!*

*Thank You!*