Clinical Tools for ME/CFS, POTS and Fibromyalgia Care

Lunch & Learn Webinar | May 20, 2026

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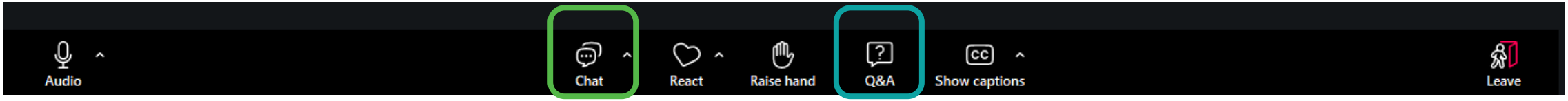
CareNow ONTARIO

Alliance for Healthier Communities
Alliance pour des communautés en santé

Housekeeping



- Audience **microphones are muted** and will remain muted throughout.
- Please submit questions using the **Q&A panel**.
  - Questions may be answered **in writing within the Q&A panel**, **verbally during the Q&A period**, or in a **follow-up email**
- Please use the **Chat window** **for technical assistance only.**
- The webinar is being **recorded**. A link to the recording and slide deck will be shared by email next week.
- Please **turn off** all recording devices and note-taking assistants (AI bots)

Acknowledgement of Traditional Indigenous Territories

We recognize that the work of the Alliance for Healthier Communities and Alliance members takes place across what is now called Ontario on traditional territories of the Indigenous people who have lived here since time immemorial and have deep connections to these lands. We further acknowledge that Ontario is covered by 46 treaties, agreements and land purchases, as well as unceded territories. We are grateful for the opportunity to live, meet and work on this territory.

Ontario continues to be home to vibrant, diverse Indigenous communities who have distinct and specific histories, needs, and assets, as well as constitutionally protected and treaty rights. We honour this diversity and respect the knowledge, leadership and governance frameworks within Indigenous communities. In recognition of this, we commit to building allyship relationships with First Nation, Inuit and Métis peoples in order to enhance our knowledge and appreciation of the many histories and voices within Ontario. We also commit to sharing and upholding responsibilities to all who now live on these lands, the land itself and the resources that make our lives possible.

Presenters

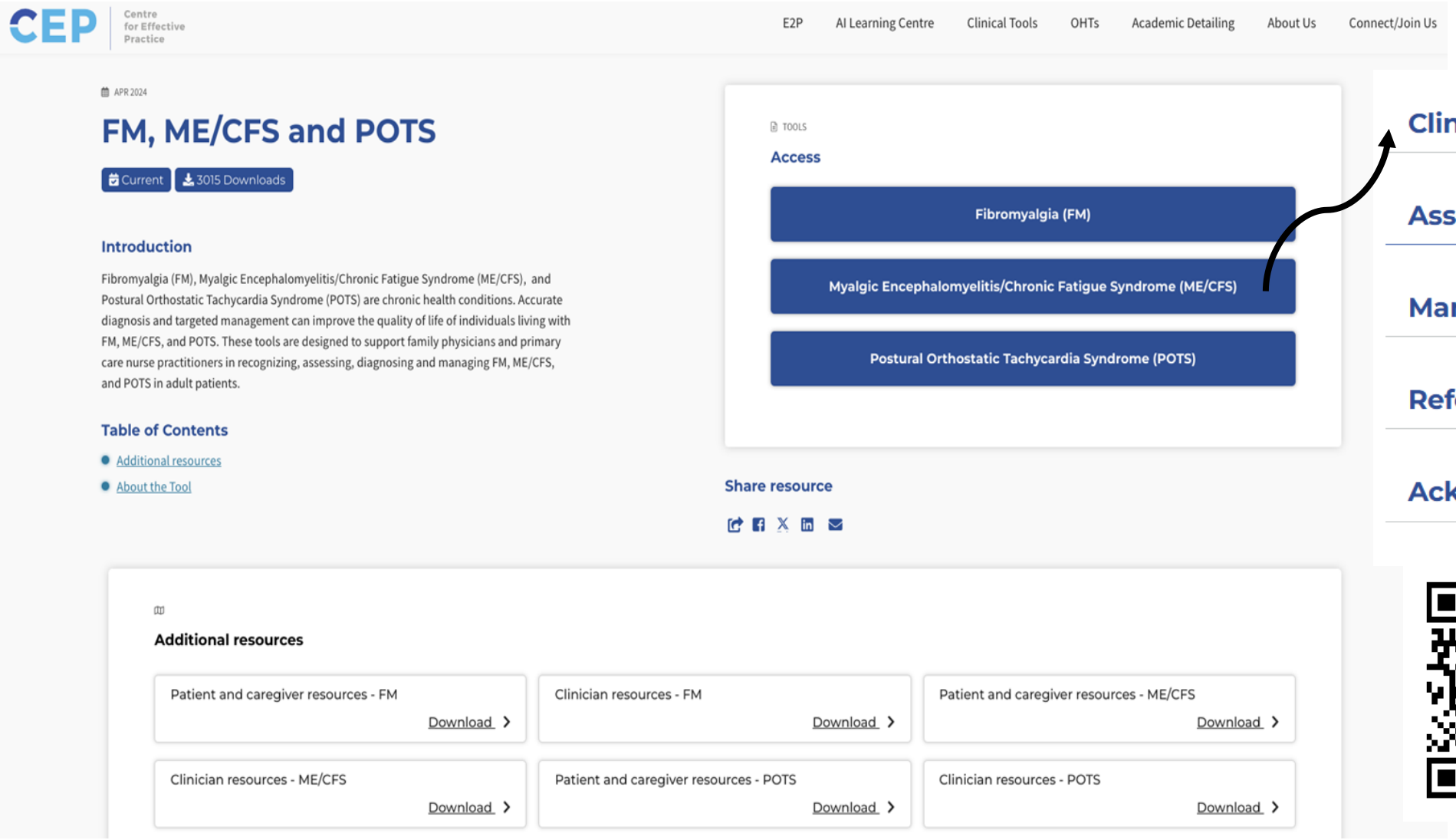
Dr. Farah Tabassum

Environmental Health Clinic, Women's College Hospital

Kathleen Dennis

CareNow Ontario

Centre for Effective Practice Primary Care Tools



Scan me!

Objectives

1. Determine how to **diagnose** and **prioritize management** for ME, Fibromyalgia, and POTS

2. Understand how management changes if the conditions are **comorbidly** present.

3. **Apply** the **tools** from the **Center for Effective Practice** to support diagnosis, and management of ME, Fibromyalgia, and POTS

4. Learn about **disability related supports** that can be helpful and how interprofessional health care providers can support care

Overall Goal ➡ **Add ME, FM and POTS to your differential diagnosis list**

Cases to guide our discussion today

CASE 1 - Kat

- 51F with hx of Mosquito bites → headache, fever + rash on chest
- Progression: Severe headache, photophobia, fatigue, upper body muscle weakness disorientation
  → confirmed neuroinvasive **West Nile virus infection**
  → Initial recovery ~3 weeks

Persistent Symptoms

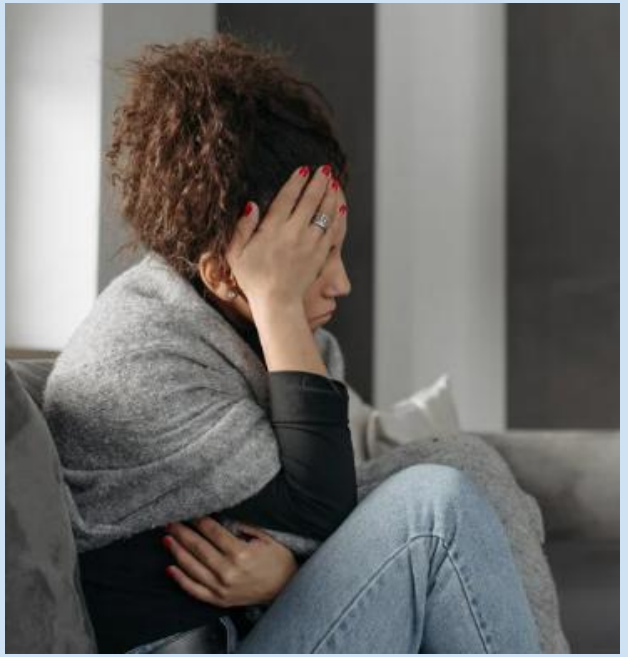
- Severe fatigue, cognitive dysfunction, orthostatic intolerance + palpitations, musculoskeletal pain, unrefreshing sleep and exacerbation of symptoms roughly 1 to 2 days after activities

CASE 2 - Bridget

- 52 year old female longstanding history of **chronic pain after an MVA.**
- She initially had pain in her neck and shoulders but then developed **pain in arms, legs, and lower back**.
- Inflammatory markers are negative and imaging is normal.
- She was diagnosed with **Fibromyalgia**.
- Despite appropriate pharmacological management for Fibromyalgia she reports ongoing **uncontrolled pain**, **poor sleep**, and **debilitating fatigue**.

How would you approach **diagnosis?**

How would you approach **management?**



Background

What are ME, FM and POTS?

Myalgic Encephalomyelitis (ME)

- Profound fatigue, cognitive dysfunction, sleep abnormalities, often with autonomic manifestations, pain, and other symptoms.
- Made worse by exertion which can be physical, cognitive, emotional, or orthostatic stressors.

Fibromyalgia (FM)

- Widespread MSK pain and other associated symptoms (sleep disturbances, fatigue, and impaired cognitive and physical function).
- Symptoms vary from person to person and may fluctuate from day to day

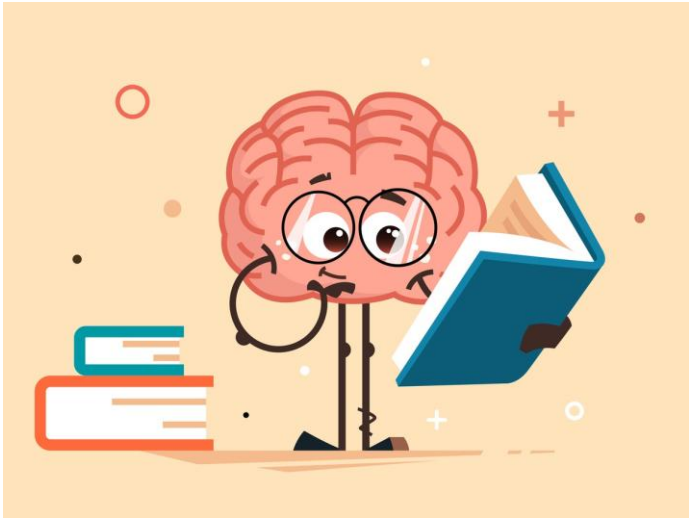
Postural Orthostatic Tachycardia Syndrome (POTS)

- Form of dysautonomia
- Excessive orthostatic tachycardia and orthostatic intolerance

***These 3 conditions are commonly comorbid**
***ALL 3 conditions are more common in women**

Why learn about this?

- These illnesses are **not commonly taught** in medical school or residency
- Many patients are **undiagnosed and poorly managed**
- These conditions can lead to **severe disability** and poor quality of life
- These conditions are often **post-infection sequelae**
  - For example, for COVID infections - 20% of people with acute infection went on to have longer term symptoms (beyond 3 months) and of those, about 50% were meeting diagnostic criteria for ME (Jason and Dorri, 2022)



Why learn about this?

Family medicine is in a unique position to recognize these conditions

- There is no single specialty designated for these conditions
- Unifying diagnosis can be missed as symptoms affect multiple organ systems

Why ME, FM and POTS can be challenging to diagnose?

Canadian Consensus Criteria (CCC) for Myalgic Encephalomyelitis

2003 Canadian Consensus Criteria

☐ **Pathological Fatigue**
A significant degree of new onset, unexplained, persistent or recurrent physical and/or mental fatigue that substantially reduces activity levels and which is not the result of ongoing exertion and is not relieved by rest

☐ **Post-exertional Malaise and Worsening of Symptoms**
Mild exertion or even normal activity is followed by malaise: the loss of physical and mental stamina and/or worsening of other symptoms. Recovery is delayed, taking more than 24 hours

☐ **Sleep Dysfunction**
Sleep is un-refreshing: disturbed quantity - daytime hypersomnia or nighttime insomnia and/or disturbed rhythm - day/night reversal. Rarely, there is no sleep problem.

☐ **Pain**
Pain is widespread, migratory or localized: myalgia; arthralgia (without signs of inflammation); and/or headache - a new type, pattern or severity. Rarely, there is no pain

☐ **Neurocognitive Manifestations (2 or more)**

- ☐ confusion
- ☐ impaired concentration
- ☐ short-term memory
- ☐ disorientation
- ☐ categorizing and word retrieval
- ☐ perceptual and sensory disturbances
- ☐ ataxia
- ☐ muscle weakness
- ☐ fasciculation
- ☐ cognitive overload
- ☐ emotional overload
- ☐ hypersensitivity to light or sound

☐ **At least one symptom from two of the three following categories:**

Autonomic Manifestations

- ☐ orthostatic intolerance–neurally mediated hypotension (NMH)
- ☐ postural orthostatic tachycardia syndrome (POTS)
- ☐ delayed postural hypotension
- ☐ light-headedness, vertigo
- ☐ extreme pallor
- ☐ nausea and IBS
- ☐ urinary frequency and bladder dysfunction
- ☐ palpitations with or without cardiac arrhythmias
- ☐ exertional dyspnea.

Neuroendocrine Manifestations

- ☐ loss of thermostatic stability–subnormal body temp; marked diurnal fluctuation
- ☐ sweating episodes
- ☐ recurrent feelings of feverishness
- ☐ cold extremities
- ☐ intolerance heat and cold
- ☐ marked weight change
- ☐ anorexia or abnormal appetite
- ☐ loss of adaptability and worsening of symptoms with stress

Immune Manifestations

- ☐ tender lymph nodes
- ☐ recurrent sore throat
- ☐ recurrent flu-like symptoms
- ☐ general malaise
- ☐ new sensitivities to food, medications and/or chemicals.

☐ **The illness has persisted for at least 6 months**

Family Medicine
Internal Medicine

Neurology

Sleep Medicine

Rheumatology
Physiatry
Anesthesiology
(Chronic Pain Specialists)

Cardiology
Otolaryngology
Gastroenterology
Urology
Respirology

Endocrinology
Psychiatry
Psychology

Hematology/Oncology
Infectious Disease
Allergy & Immunology

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Fibromyalgia

Fibromyalgia - **Background**

- **Onset:** Gradual or sudden
  - Often after a period of physical or psychological stress.
    e.g. viral infection, accident/injury (eg MVA), operation, etc.
  - Sometimes no specific stressor is easily identified.
- **Epidemiology:** Fibromyalgia disproportionately affects women (~80-90%) (Rusu et al, 2015)
- **Typical symptoms:**
  - widespread pain, fatigue, poor sleep, cognitive difficulties, plus other symptoms (sensory sensitivities, headaches, mood symptoms, etc.)

Image from CEP Tool - Fibromyalgia

Fibromyalgia - **Diagnosis**

- **Investigations**: CBC, ESR, CRP, CK, LFTs, TSH, glucose, urea, electrolytes, etc.
- **Evaluate** for conditions that can worsen pain - sleep disorders, meds (e.g. lipid lowering agents)
- *Reminder: FM is not a diagnosis of exclusion and can co-exist with other conditions*
- **2016 Fibromyalgia Diagnostic Criteria**

Adapted from the Royal College of Physicians' The diagnosis of Fibromyalgia syndrome: UK clinical guidelines, 2022

2016 Fibromyalgia Diagnostic Criteria

1. Widespread pain index (WPI) and symptom severity score (SSS)
   - WPI ≥ 7 and SSS ≥ 5 OR WPI 4-6 and SSS ≥ 9
2. Generalized pain: pain in 4/5 regions
3. Symptoms present ≥ 3 months

The fibromyalgia diagnosis can now be made irrespective of other diagnoses (you do not need to rule out all other conditions that could explain the symptoms, if criteria 1-3 are all met).

1. Widespread pain index (WPI)

In the past week, where have you had pain? (check all that apply)

Left upper region (1)
- ☐ *L jaw*
- ☐ L shoulder girdle
- ☐ L upper arm
- ☐ L lower arm

Right upper region (2)
- ☐ *R jaw*
- ☐ R shoulder girdle
- ☐ R upper arm
- ☐ R lower arm

Axial region (5)
- ☐ Neck
- ☐ Upper back
- ☐ Lower back
- ☐ *Chest*
- ☐ *Abdomen*

Left lower region (3)
- ☐ L hip (buttock/trochanter)
- ☐ L upper leg
- ☐ L lower leg

Right lower region (4)
- ☐ R hip (buttock/trochanter)
- ☐ R upper leg
- ☐ R lower leg

Total: _____ WPI score (add up boxes checked, 0-19)

_____Number of regions checked (excluding items in italics); use this for criterion #2.

Symptoms Severity Score (SSS)

For each of the following, for the past week, rate

	0=No problem	1=slight or mild problem, often mild or intermittent	2=moderate, considerable problem, often present	3=severe, pervasive, continuous, life-disturbing
Fatigue	☐	☐	☐	☐
Waking unrefreshed	☐	☐	☐	☐
Cognitive symptoms	☐	☐	☐	☐

In the past week, have you been bothered by any of the following?

	0=No problem	1=Problem
Headaches	☐	☐
Pain or cramps in lower abdomen	☐	☐
Depression	☐	☐

Total SSS: _____(0-12)

Summary:

☐ **1. Criterion 1 is met if you have EITHER**
- ☐ WPI ≥ 7 and SSS ≥ 5 OR
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☐ **2. Generalized pain: met if you checked pain in 4/5 regions (not including items in italics)**

☐ **3. Symptoms present ≥ 3 months**

Fibromyalgia is diagnosed if you meet all 3 criteria 1-3, independent of whether other diagnoses contribute to these symptoms. This is new: FMS diagnosis used to require that there be no other diagnosis to explain the findings.

Adapted from the American College of Rheumatology (ACR) 2016 Diagnostic Criteria for Fibromyalgia

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		mild or intermittent	problem, often present	continuous, life-disturbing
	☐	☐	☐	☐
	☐	☐	☐	☐
	☐	☐	☐	☐

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	☐	☐

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SS ≥ 9
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≥ 3 months

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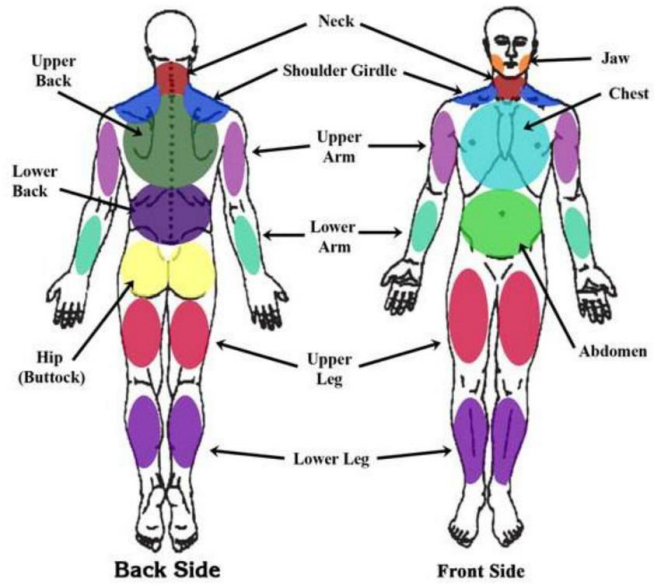
Clinical Pearl

Patients may not describe widespread pain when initially asked. It is important to ask directly about pain felt elsewhere in the body.



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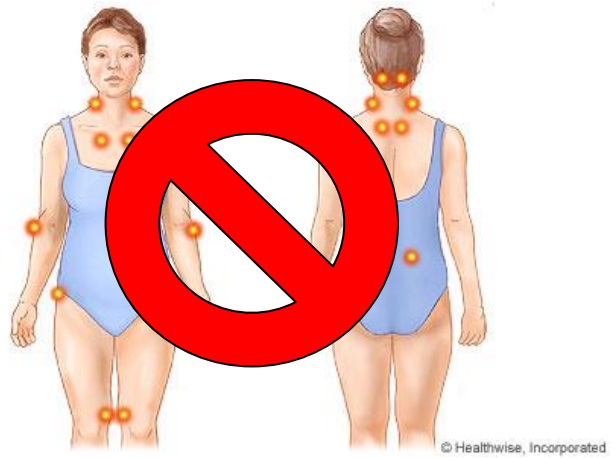
Clinical Pearl

Presence of tender points are **not** needed to confirm a diagnosis of FM.



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Clinical Practice Pearl

If a patient notes anything more than mild fatigue you need to screen for ME as it changes management

Fibromyalgia - **Management**

Non pharmacological

- Patient education
- Support for mental health and wellbeing
- Complementary and alternative therapies (e.g. acupuncture, massage)
- **Physical and occupational therapies

****Clinical ALERT****
In patients with co-existing conditions such as ME, functional and exercise limitations **must** be considered in program design.

Pharmacological

- Antiepileptic agents/ anticonvulsants (e.g. gabapentin, pregabalin)
- Serotonin noradrenaline reuptake inhibitors (e.g. duloxetine)
- Tricyclic antidepressants (e.g. amitriptyline)
- Opioid analgesics (e.g. tramadol)
- Off label medications (e.g. low dose naltrexone)

Clinical pearl
Start with a low dose and up-titrate slowly to efficacy based on tolerance limitations.

Myalgic Encephalomyelitis (ME)

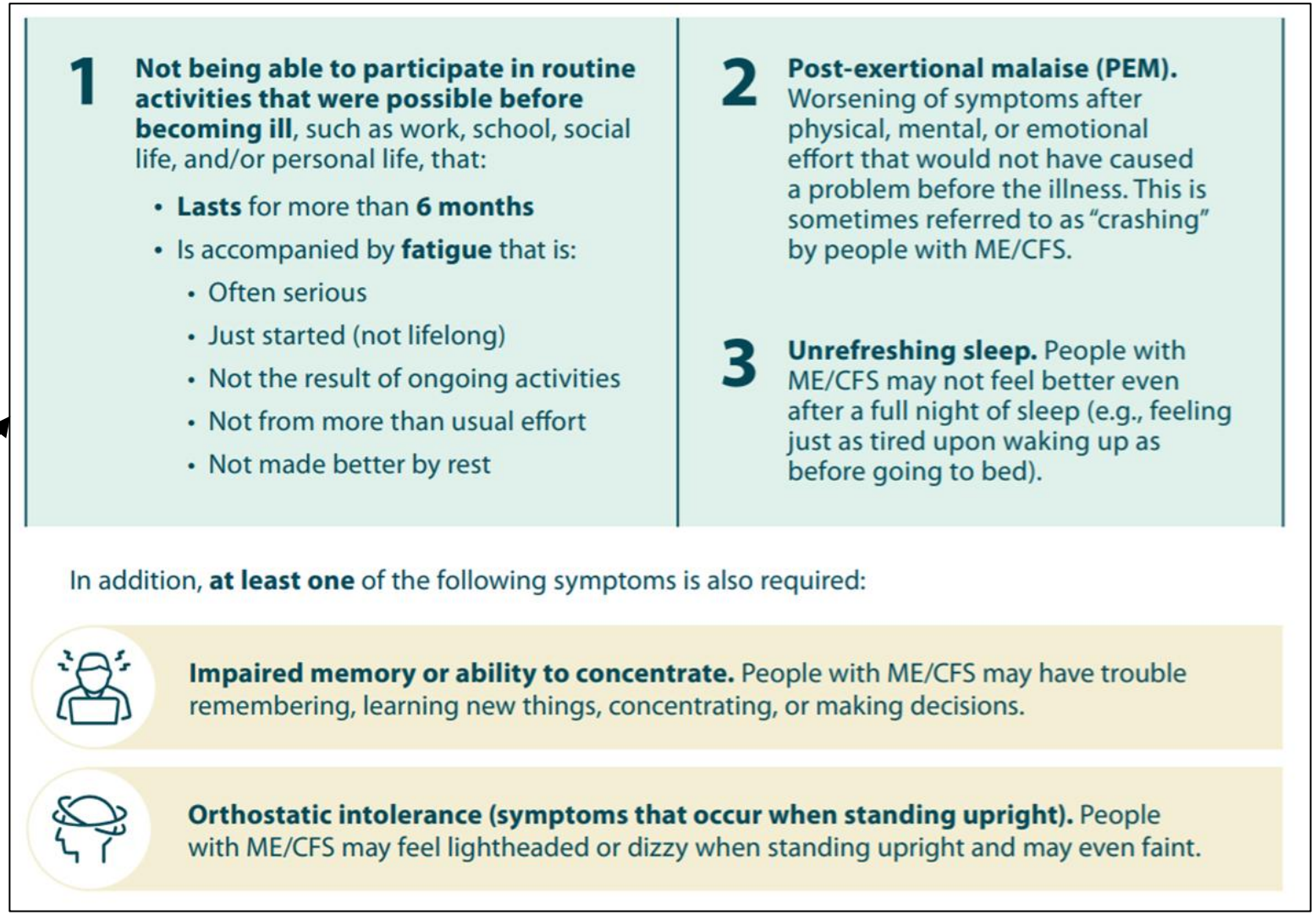
Background | Fibromyalgia | ME | ME + Fibro | POTS | Team Support | Takeaways

ME - **Diagnosis**

- There is **no** specific biomarker to diagnose ME at this time

Diagnostic criterias:

- ***Institute Of Medicine (USA) (2015) - most commonly used**
- Canadian Consensus Criteria (2003)



1 **Not being able to participate in routine activities that were possible before becoming ill**, such as work, school, social life, and/or personal life, that:

- **Lasts** for more than **6 months**
- Is accompanied by **fatigue** that is:
  - Often serious
  - Just started (not lifelong)
  - Not the result of ongoing activities
  - Not from more than usual effort
  - Not made better by rest

2 **Post-exertional malaise (PEM).** Worsening of symptoms after physical, mental, or emotional effort that would not have caused a problem before the illness. This is sometimes referred to as "crashing" by people with ME/CFS.

3 **Unrefreshing sleep.** People with ME/CFS may not feel better even after a full night of sleep (e.g., feeling just as tired upon waking up as before going to bed).

In addition, **at least one** of the following symptoms is also required:

Impaired memory or ability to concentrate. People with ME/CFS may have trouble remembering, learning new things, concentrating, or making decisions.

Orthostatic intolerance (symptoms that occur when standing upright). People with ME/CFS may feel lightheaded or dizzy when standing upright and may even faint.

Symptoms must be **moderate to severe** and present **>50% of the time**

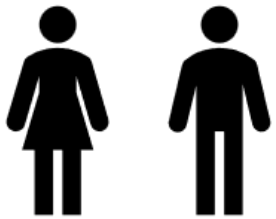
Infographic from Center for Disease Control

*Institute of Medicine is now known as "National Academy of Medicine"

ME - **Severity**

Wide spectrum of ME severity (Montoya et al., 2021)

- **75% are unable to work** (CDC, 2016)
- 25% are homebound or bedridden (Valdez et. al, 2019)



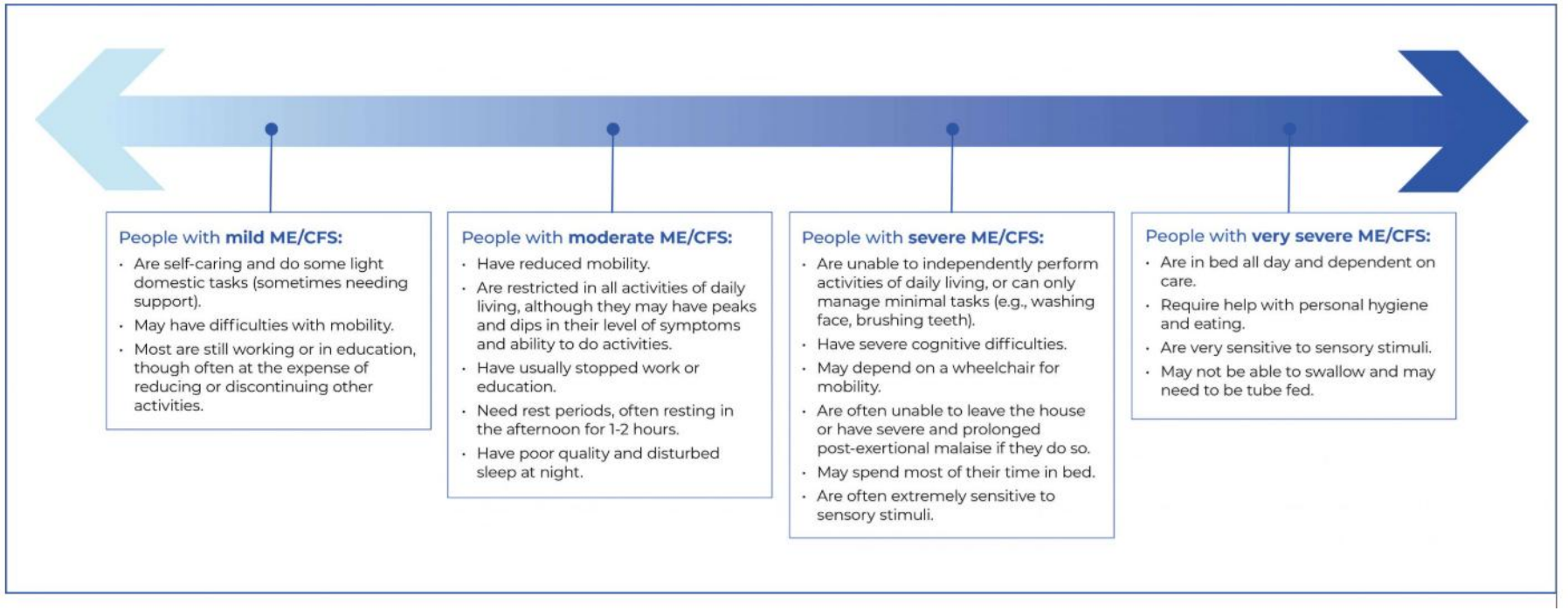


Image adapted from: CEP - ME CFS tool

ME - **Characterizing the Symptom of Fatigue**

- Profound, debilitating, resulting in a reduction of activity (occupational or social)
- Need to characterize fatigue and determine if patient is experiencing **Post Exertional Malaise (PEM)**
  (*can use DePaul PEM Questionnaire)
- **PEM is the hallmark symptom of ME**
- Differs from fatigue from other causes (thyroid, anemia, depression)

Post Exertional Malaise (PEM)

- Hallmark symptom of ME
- Worsening of symptoms and function after exertion (physical, cognitive, emotional) that were previously tolerated before disease onset.
    - For many, basic activities of daily living can cause PEM (*showering).
- Onset is most often delayed (by hours or days).
- Takes days, weeks or months to recover (or may never return to baseline).

- **Repeated PEM can lead to more severe symptoms and long term functional decline**

Clinical Pearl INESSS (Quebec) has an excellent resource on PEM

Assessing PEM

The DePaul Symptom Questionnaire - PEM (DSQ-PEM)

Appendix B

DSQ-PEM Scoring

Scoring Step 1

Items 1–5: A frequency and severity score of 2, 2 on any items 1–5 is indicative of PEM.

Scoring Step 2

Items 7, 8: Either item 7 or 8 must have an answer of yes to indicate an ME and/or CFS dx.

Item 9: A response of >14 h is needed to indicate an ME and/or CFS dx.

Items 6, 10: Neither item indicates an ME and/or CFS diagnosis, but provides a description of patient PEM for clinical evaluations.

Appendix A

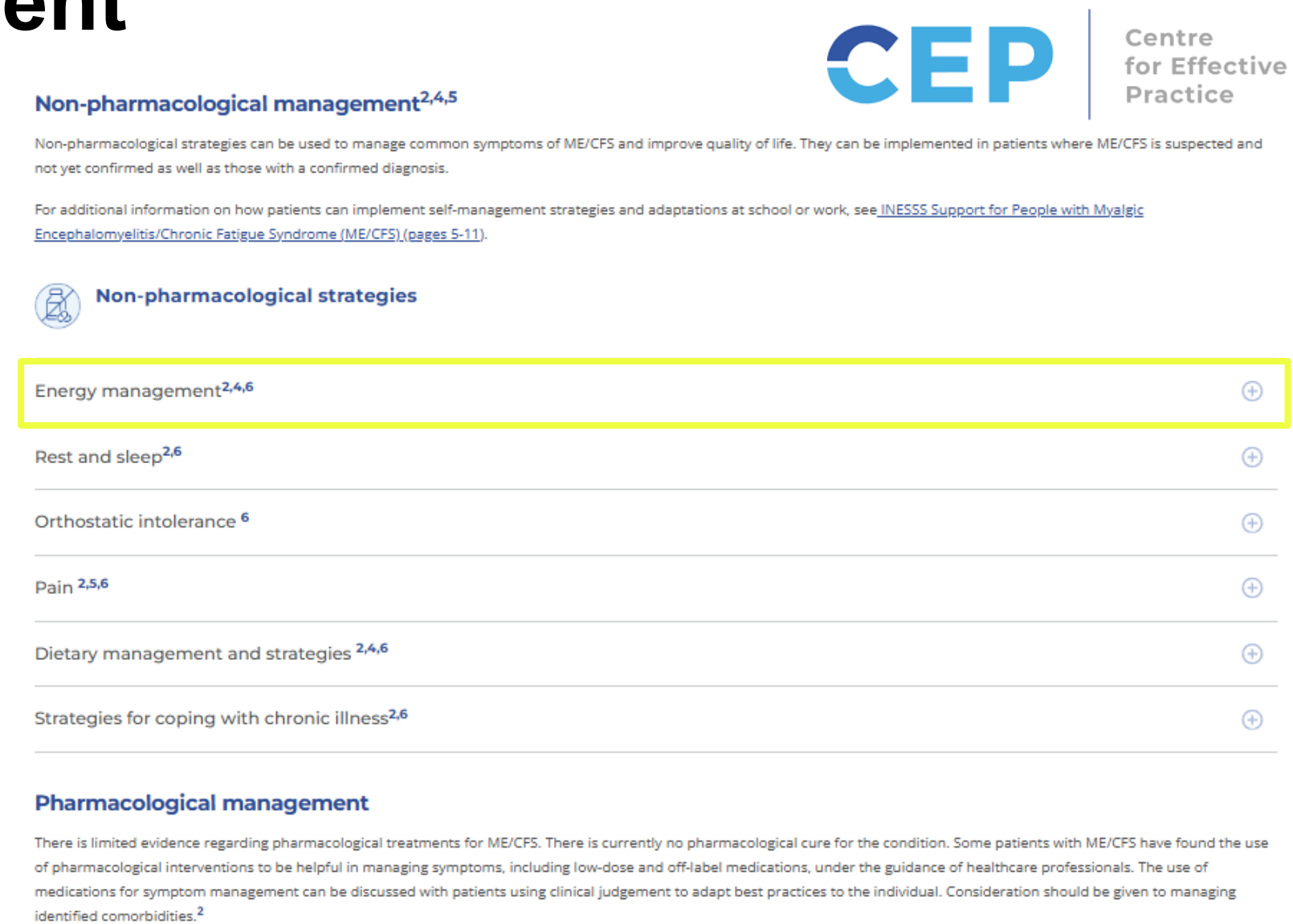
For each symptom below, please circle one number for frequency and one number for severity:

Please complete the chart from left to right.

Symptoms	Frequency: Throughout the **past 6 months**, **how often** have you had this symptom? For each symptom listed below, circle a number from: **0 = none of the time** **1 = a little of the time** **2 = about half the time** **3 = most of the time** **4 = all of the time**	Severity: Throughout the **past 6 months**, **how much** has this symptom bothered you? For each symptom listed below, circle a number from: **0 = symptom not present** **1 = mild** **2 = moderate** **3 = severe** **4= very severe**
1. Dead, heavy feeling after starting to exercise	0 1 2 3 4	0 1 2 3 4
2. Next day soreness or fatigue after non-strenuous, everyday activities	0 1 2 3 4	0 1 2 3 4
3. Mentally tired after the slightest effort	0 1 2 3 4	0 1 2 3 4
4. Minimum exercise makes you physically tired	0 1 2 3 4	0 1 2 3 4
5. Physically drained or sick after mild activity	0 1 2 3 4	0 1 2 3 4
6. If you were to become exhausted after actively participating in extracurricular activities, sports, or outings with friends, would you recover within an hour or two after the activity ended?	Yes	No
7. Do you experience a worsening of your **fatigue/energy related illness** after engaging in minimal physical effort?	Yes	No
8. Do you experience a worsening of your **fatigue/energy related illness** after engaging in mental effort?	Yes	No
9. If you feel worse after activities, how long does this last?	≤1 h 2–3 h 4–10 h 11–13 h 14–23 h ≥ 24 h	
10. If you do not exercise, is it because exercise makes your symptoms worse?	Yes	No

ME - **Management**

- See CEP tool for details
- Cornerstone of ME management is Pacing (Energy Management)
- Address and manage common comorbidities
- Consider PEM in the management approach of comorbidities



CEP Centre for Effective Practice

Non-pharmacological management[2,4,5]

Non-pharmacological strategies can be used to manage common symptoms of ME/CFS and improve quality of life. They can be implemented in patients where ME/CFS is suspected and not yet confirmed as well as those with a confirmed diagnosis.

For additional information on how patients can implement self-management strategies and adaptations at school or work, see INESSS Support for People with Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS) (pages 5-11).

Non-pharmacological strategies

- Energy management[2,4,6]
- Rest and sleep[2,6]
- Orthostatic intolerance [6]
- Pain [2,5,6]
- Dietary management and strategies [2,4,6]
- Strategies for coping with chronic illness[2,6]

Pharmacological management

There is limited evidence regarding pharmacological treatments for ME/CFS. There is currently no pharmacological cure for the condition. Some patients with ME/CFS have found the use of pharmacological interventions to be helpful in managing symptoms, including low-dose and off-label medications, under the guidance of healthcare professionals. The use of medications for symptom management can be discussed with patients using clinical judgement to adapt best practices to the individual. Consideration should be given to managing identified comorbidities.[2]

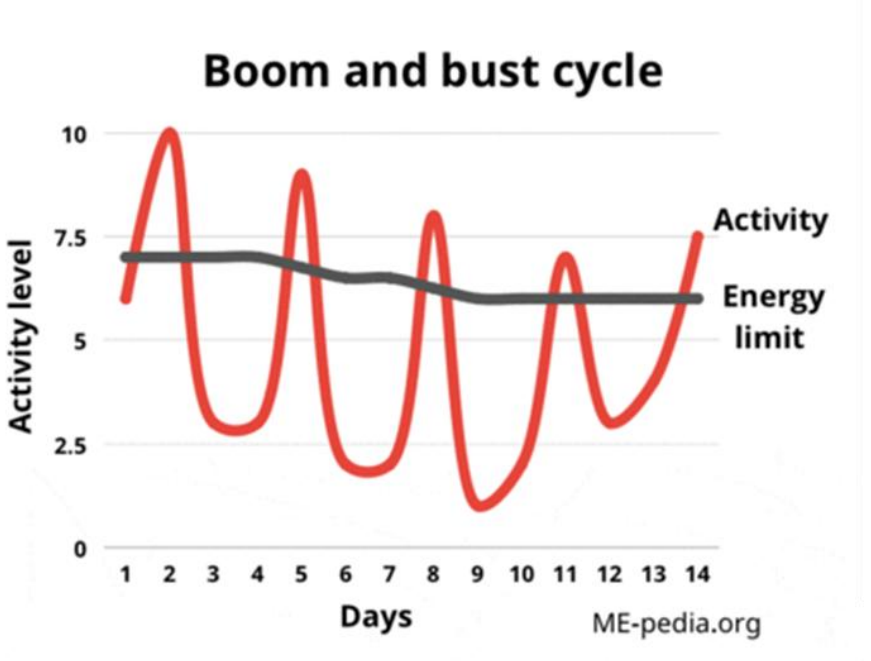
Management **- Pacing (Energy Management)**

Pacing is an activity management strategy to help ME patients **stabilize their energy** and **limit the frequency and intensity of PEM, while remaining as engaged as they feel capable.**

It gives patients the advice to **live within their energy limits,** but they must first determine what those limits are.

Some helpful tools for pacing include:

- Use of activity logs
- Heart rate monitoring
- Pacing techniques (dividing up tasks, regular rest periods, etc…)



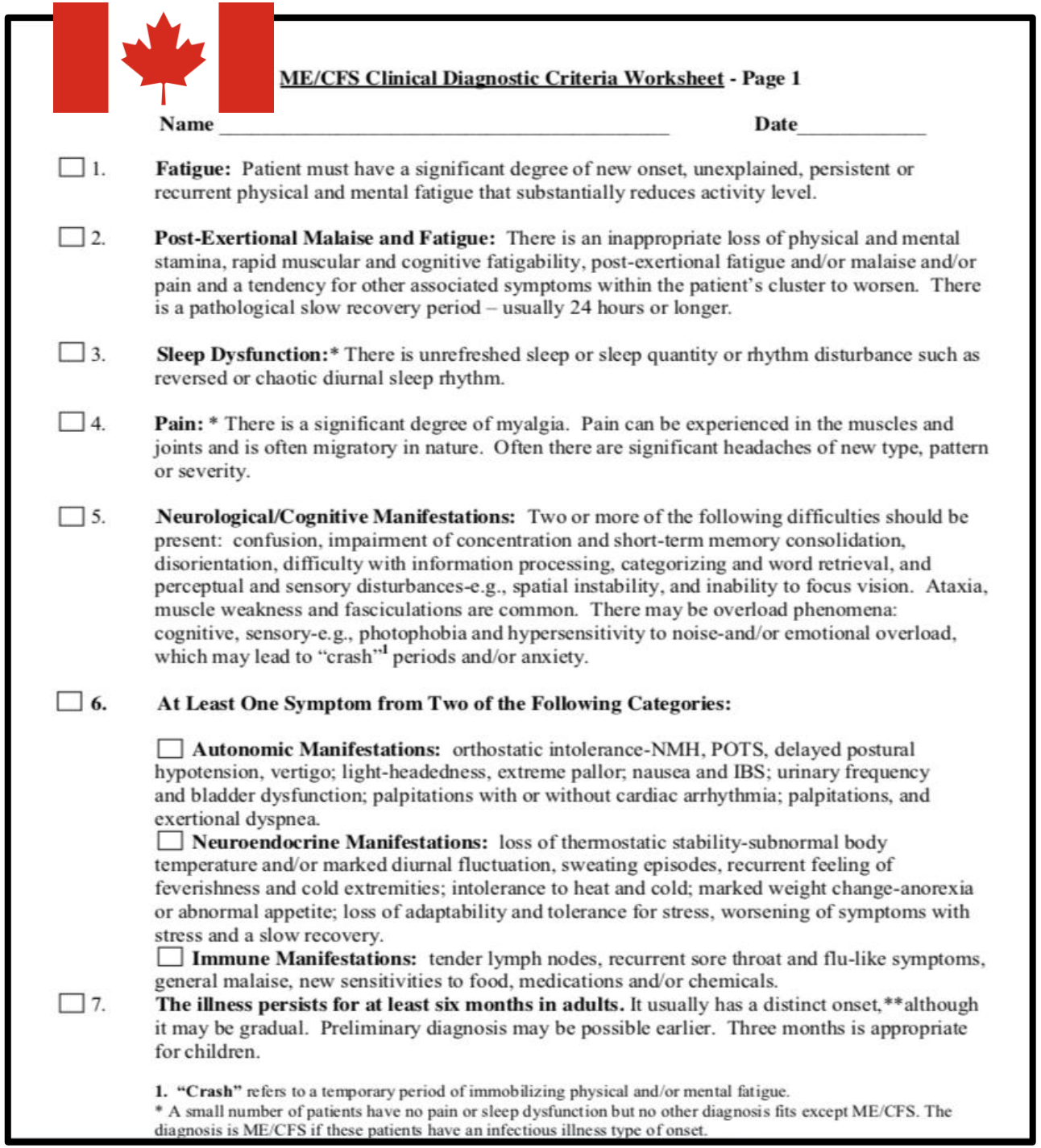
Why Graded Exercise Therapy is **NOT** Pacing

- **Graded exercise therapy (GET) is <u>NOT</u> recommended for patients with ME**
  - GET is different than pacing.
  - GET is defined as fixed incremental increases in physical activity or exercise.
  - GET was historically recommended based on **incorrect theories** about ME (originating from incorrect assumptions that ME was the result of deconditioning and exercise avoidance).
  - GET **<u>can cause harm</u>** due to triggering repeated PEM which can lower baseline functioning
- **There is no therapy based on physical activity that will cure ME**

ME **Comorbidities**

Clinical Pearl
ME is not just about addressing ME alone, but addressing comorbidities. Goal is to improve overall quality of life

- **Canadian Consensus Criteria**
- It is helpful to go through <u>with the patient</u> as it provides a review of systems for commonly comorbid conditions



ME/CFS Clinical Diagnostic Criteria Worksheet - Page 1

Name _____ **Date**_____

☐ 1. **Fatigue:** Patient must have a significant degree of new onset, unexplained, persistent or recurrent physical and mental fatigue that substantially reduces activity level.

☐ 2. **Post-Exertional Malaise and Fatigue:** There is an inappropriate loss of physical and mental stamina, rapid muscular and cognitive fatigability, post-exertional fatigue and/or malaise and/or pain and a tendency for other associated symptoms within the patient's cluster to worsen. There is a pathological slow recovery period – usually 24 hours or longer.

☐ 3. **Sleep Dysfunction:*** There is unrefreshed sleep or sleep quantity or rhythm disturbance such as reversed or chaotic diurnal sleep rhythm.

☐ 4. **Pain:** * There is a significant degree of myalgia. Pain can be experienced in the muscles and joints and is often migratory in nature. Often there are significant headaches of new type, pattern or severity.

☐ 5. **Neurological/Cognitive Manifestations:** Two or more of the following difficulties should be present: confusion, impairment of concentration and short-term memory consolidation, disorientation, difficulty with information processing, categorizing and word retrieval, and perceptual and sensory disturbances-e.g., spatial instability, and inability to focus vision. Ataxia, muscle weakness and fasciculations are common. There may be overload phenomena: cognitive, sensory-e.g., photophobia and hypersensitivity to noise-and/or emotional overload, which may lead to "crash"[1] periods and/or anxiety.

☐ 6. **At Least One Symptom from Two of the Following Categories:**

☐ **Autonomic Manifestations:** orthostatic intolerance-NMH, POTS, delayed postural hypotension, vertigo; light-headedness, extreme pallor; nausea and IBS; urinary frequency and bladder dysfunction; palpitations with or without cardiac arrhythmia; palpitations, and exertional dyspnea.

☐ **Neuroendocrine Manifestations:** loss of thermostatic stability-subnormal body temperature and/or marked diurnal fluctuation, sweating episodes, recurrent feeling of feverishness and cold extremities; intolerance to heat and cold; marked weight change-anorexia or abnormal appetite; loss of adaptability and tolerance for stress, worsening of symptoms with stress and a slow recovery.

☐ **Immune Manifestations:** tender lymph nodes, recurrent sore throat and flu-like symptoms, general malaise, new sensitivities to food, medications and/or chemicals.

☐ 7. **The illness persists for at least six months in adults.** It usually has a distinct onset,**although it may be gradual. Preliminary diagnosis may be possible earlier. Three months is appropriate for children.

1. **"Crash"** refers to a temporary period of immobilizing physical and/or mental fatigue.
* A small number of patients have no pain or sleep dysfunction but no other diagnosis fits except ME/CFS. The diagnosis is ME/CFS if these patients have an infectious illness type of onset.

Examples of common comorbidities:
:

Sleep apnea
Restless leg syndrome
Periodic limb movement disorder

Fibromyalgia
Migraine headaches

POTS
NMH
Orthostatic hypotension

IBS
Overactive bladder
Interstitial cystitis

ME **and** Fibromyalgia

Background | Fibromyalgia | ME | ME + Fibro | POTS | Team Support | Takeaways

Fibromyalgia & ME: Diagnostic Overlap

~ 50%

of Fibromyalgia patients also have ME

47.3% overlap

ME and fibromyalgia diagnoses overlapped in 47.3% of patients

Ramírez-Morales et al, 2022

45.0% of ME/CFS patients

Fibromyalgia was the most common comorbid condition among ME/CFS patients, affecting 45.0% of study patients

Fall et al, 2024

Fibromyalgia and ME are unique conditions but have overlapping symptoms

	Fibromyalgia	ME
Chronic Widespread Pain	+	+/-
Fatigue	+/-	+
Sleep issues	+/-	+
Cognitive Dysfunction	+/-	+/-
Post Exertional Malaise (PEM)	-	+

Simplifying things… looking at these conditions in silo

Fibromyalgia	ME
Chronic widespread <u>PAIN</u> plus other symptoms	**Severe chronic fatigue with <u>PEM</u>** plus other symptoms
Patients benefit from moderate **<u>EXERCISE</u>**	Patients benefit from **<u>PACING</u>**

Fibromyalgia + ME

Fibromyalgia	ME
Chronic othe	Fatigue M oms
Patient moderate **EXERCISE**	fit from **PACING**

What happens if a patient has <u>BOTH</u> FM and ME?

Recall: approximately 50% of patients with Fibromyalgia also have ME

Fibromyalgia + ME

Fibromyalgia	ME
Chronic w… othe…	S… Chronic Fatigue PEM …us …ymptoms
Patients… moderate **EXERCISE**	…enefit from **PACING**

Pacing is prioritized to stabilize energy and avoid states of PEM

Postural Orthostatic Tachycardia Syndrome (POTS)

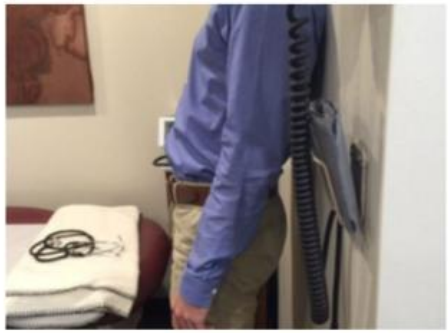
Background | Fibromyalgia | ME | ME + Fibro | POTS | Team Support | Takeaways

POTS - **Clinical Presentation**

- Onset often after an infectious illness
- Symptoms:
  - lightheaded, tachycardia, palpitations, feel pre-syncopal, fatigue, symptoms improve with recumbency, etc.
- Comorbid condition with ME and Fibromyalgia
- May have broader constellation of symptoms, fitting under the umbrella of dysautonomia

POTS - **Diagnostic Criteria**

- **> 3 months** duration of symptoms of orthostatic intolerance that are at least partially relieved by recumbency
- **Sustained** increase in heart rate (30 bpm in adults 19+) from supine position to upright within 10 minutes of standing
- **Absence** of orthostatic hypotension (decrease in systolic blood pressure > 20 mm Hg or diastolic blood pressure > 10 mm Hg)
- **Confirm** with Orthostatic Vital Signs (Active Stand Test or NASA Lean Test)



Orthostatic Vital Signs/The 10-Minute NASA Lean Test

	Blood Pressure (BP)		Heart Rate	
	Systolic	Diastolic	bpm	Comments/Symptoms
Supine 1 minute				
Supine 2 minute				
Standing 0 minute				
Standing 1 minute				
Standing 2 minute				
Standing 3 minute				
Standing 4 minute				
Standing 5 minute				
Standing 6 minute				
Standing 7 minute				
Standing 8 minute				
Standing 9 minute				
Standing 10 minute				

POTS - **Management**

- Lifestyle measures are sometimes enough
- Need to do a review of systems to the determine if one also need to evaluate for ME (very commonly comorbid) and it changes management

Picture from: LIBIN Cardiovascular Institute

POTS Management -1st Line Practical Primary Care Approach
(Non-Pharmacologic)

🧂 Volume Expansion

- Fluids: **2–3 L/day**
- Salt: **8–10 g/day** *(if appropriate)*
- Consider electrolytes

🧍 Orthostatic Support

- Compression garments *(waist-high)*
- Avoid prolonged standing
- Head of bed elevation

🤸 Activity (Individualized)

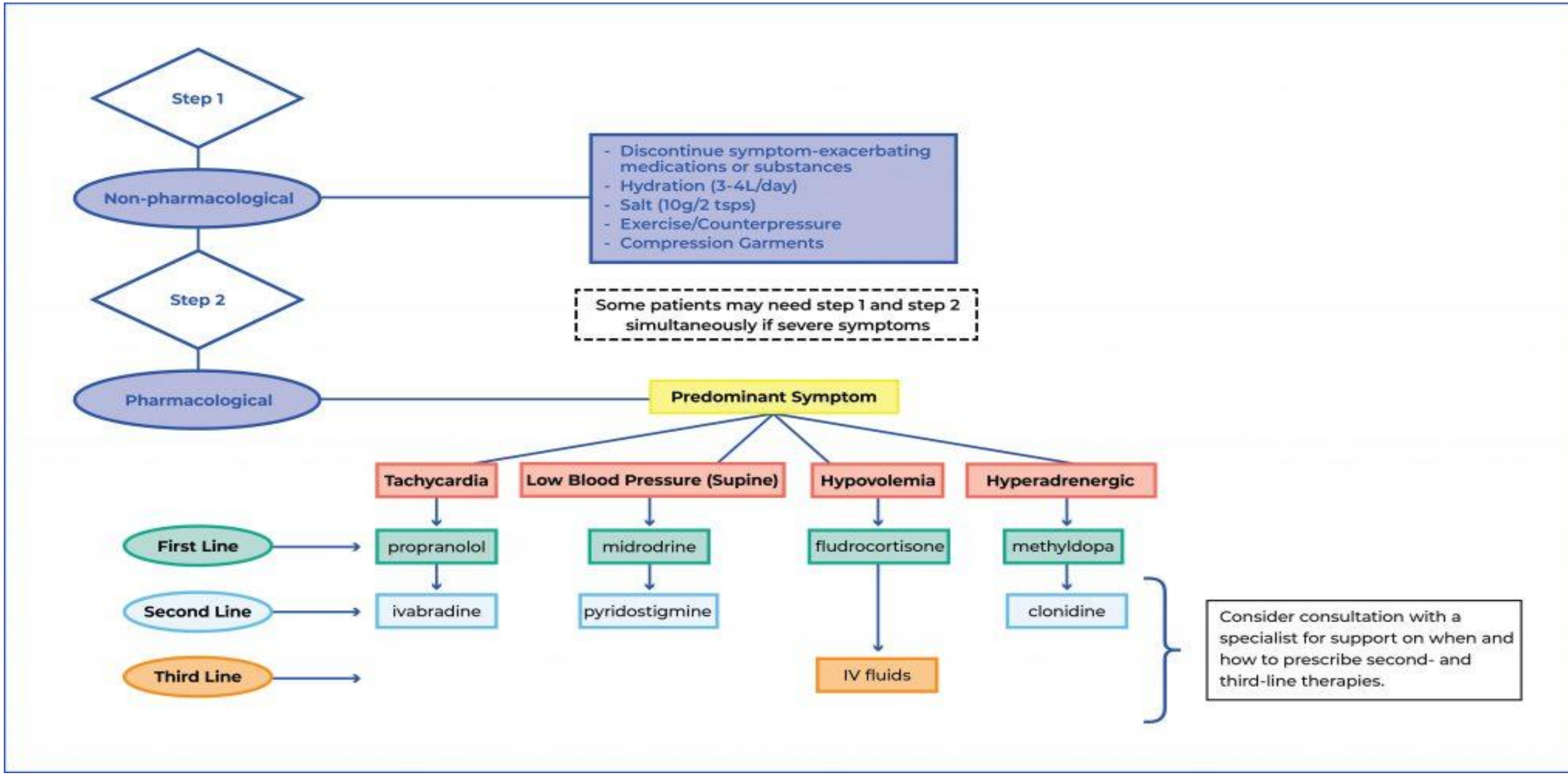
- Start **recumbent** (bike, rowing)
- Gradual progression → upright
- Build tolerance slowly

⚠️ Screen for ME/CFS

If present:

- ❌ Avoid graded exercise approach
- ✅ Use **pacing** to prevent PEM

Proposed 2-step POTS Management Algorithm



Interprofessional Team Support

Background | Fibromyalgia | ME | ME + Fibro | POTS | Team Support | Takeaways

Why Occupational Therapy Is Essential

👉 **Translate medical advice into sustainable living** practical strategies patients can realistically maintain day-to-day

- **Prevent crashes & stabilize function** with energy management, recognizing limits and avoiding PEM
- **Adapt daily life to reduce symptom burden** by modifying ADLs, routines (bathing, cooking, self-care), cognitive load/pacing (screen time, conversations), and upright activity
- **Improve safety, independence & quality of life** such as home/work adaptations, assistive devices, orthostatic support

Physiotherapy Major Roles

- Support safe movement, mobility, pain management, and function
- Use individualized approaches including pacing, energy conservation, and modified exercise
- Help manage orthostatic intolerance and improve tolerance to daily activity
- Refer to a PT who is knowledgeable about these conditions

Key Caution - Always assess for PEM as traditional exercise for traditional exercise and rehab programs for FM and POTS could lead to exacerbations of PEM when co-morbid ME is present.

Role of Social Work

- **Validation & psychosocial support** → Many patients have experienced years of dismissal and disbelief
- **Support with disability forms & benefits** → Disability, income support, tax credits, parking permits, accommodations
- **Connect patients to practical supports** → Home care, meal services, transportation, respite, peer/community supports
- **Help patients navigate healthcare & pacing demands** → Prioritize appointments, conserve energy, coordinate care
- **Facilitate family education & communication** → Support understanding of invisible disability and functional limits

Cases

CASE 1 - Kat

51 with ongoing fatigue and poor functioning after West Nile virus

What are the next steps?

- Characterize the fatigue, and assess for common causes of fatigue
- Review ME diagnostic criteria
  - ✓ Debilitating fatigue x 6 months
  - ✓ **Assess for PEM (DePaul PEM Questionnaire)**
  - ✓ Unrefreshing sleep
  - ✓ Cognitive dysfunction or orthostatic intolerance
- **Kat meets criteria for ME**
- **Educate on pacing** (start early!!!)
- Assess and treat common comorbidities (use CCC)
  - **Kathleen meets criteria for POTS**

*****In a primary care setting, several visits will be needed to complete this*****

CASE 2 - Bridget

52 year old with history of Fibromyalgia with ongoing pain and fatigue.

What are the next steps?

- Confirm diagnosis for Fibromyalgia using 2016 ACR criteria
  - Evaluate fatigue level → If more than mild fatigue, assess for ME
- Review ME diagnostic criteria
  - ✓ Debilitating fatigue x 6 months
  - ✓ **Assess for PEM (DePaul PEM Questionnaire)**
  - ✓ Unrefreshing sleep
  - ✓ Cognitive dysfunction
- **Bridget meets criteria for ME and Fibromyalgia**
- **Pacing is prioritized!**
- Pacing implemented (some improvement in severity and frequency of pain and other symptoms)

Takeaways

Takeaways:

- ME, Fibromyalgia and POTS are **interconnected**

- **Before** implementing a management plan for FM or POTS screen for common comorbid conditions such as ME
- In patients with: Fibromyalgia AND ME **OR** POTS AND ME
  pacing must be prioritized with the goal to stabilize energy and avoid states of PEM.
- I**nterprofessional care** involving OT, PT, and Social Work is essential to support pacing, function, symptom management, mental health, daily living, and quality of life.
- **Primary care clinicians and interprofessional team members have a central role** in diagnosis and management of ME, Fibromyalgia and POTS. The CEP tools on ME, FM and POTS is a new resource to support primary care clinicians

Clinical References

APR 2024

FM, ME/CFS and POTS

Current | 3015 Downloads

Introduction

Fibromyalgia (FM), Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS), and Postural Orthostatic Tachycardia Syndrome (POTS) are chronic health conditions. Accurate diagnosis and targeted management can improve the quality of life of individuals living with FM, ME/CFS, and POTS. These tools are designed to support family physicians and primary care nurse practitioners in recognizing, assessing, diagnosing and managing FM, ME/CFS, and POTS in adult patients.

Table of Contents

TOOLS

Access

- Fibromyalgia (FM)
- Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)
- Postural Orthostatic Tachycardia Syndrome (POTS)

Share resource

Additional resources

Patient and caregiver resources - FM Download	Clinician resources - FM Download	Patient and caregiver resources - ME/CFS Download
Clinician resources - ME/CFS Download	Patient and caregiver resources - POTS Download	Clinician resources - POTS Download

Thank you for watching.

Please take a moment to evaluate this webinar.