Clinical Tools for ME/CFS, POTS and Fibromyalgia Care

FMF
Family Medicine Forum
Forum en médecine familiale

THE COLLEGE OF FAMILY PHYSICIANS OF CANADA
LE COLLÈGE DES MÉDECINS DE FAMILLE DU CANADA

Presenters:
Kathleen Walsh, MD CCFP
Farah Tabassum, MD FCFP

Family Medicine Forum - November 5, 2025 (Winnipeg)

Join Poll Everywhere: **pe.app/mecfs2025**

Presenter Disclosure

Presenter: Dr Farah Tabassum

- Family physician for 15+yrs in a collaborative team environment
- Certificant member of the MDPAC; prior practice in psychotherapy
- PGY-3 Enhanced Skills Program: Clinical Environmental Health
- Institute of Functional Medicine Certified Practitioner
- Staff Physician - Environmental Health Clinic, Women's College Hospital
- ICanCME, e-Consults

Relationships with financial sponsors:

Any direct financial relationships, including receipt of honoraria:

- CareNow Ontario - honoraria for development of base presentation
- CEP - honoraria for role as Clinical Lead
- ICanCME - honorarium for meetings

- Membership on advisory boards or speakers' bureaus: none
- Patents for drugs or devices: none

ICanCME

WCHH
WOMEN'S COLLEGE HOSPITAL
Health care for women REVOLUTIONIZED

eConsult
Ontario eConsult

Presenter Disclosure

Presenter: Dr. Kathleen Walsh

- Early career family doctor in North Bay
- Locum in clinics and hospital
- Has loved ones affected by ME

Relationships with financial sponsors:

- Any direct financial relationships, including receipt of honoraria:
  - ICanCME - honorarium for meetings
- Membership on advisory boards or speakers' bureaus:
  - CFPC First FIve Year Committee (Ontario Representative)
- Patents for drugs or devices: none
- Other: none

Disclosure of Financial Support

- This program has received **financial support from the Interdisciplinary Canadian Collaborative ME (ICanCME)** research network in the form of funding of presenters to attend this presentation.

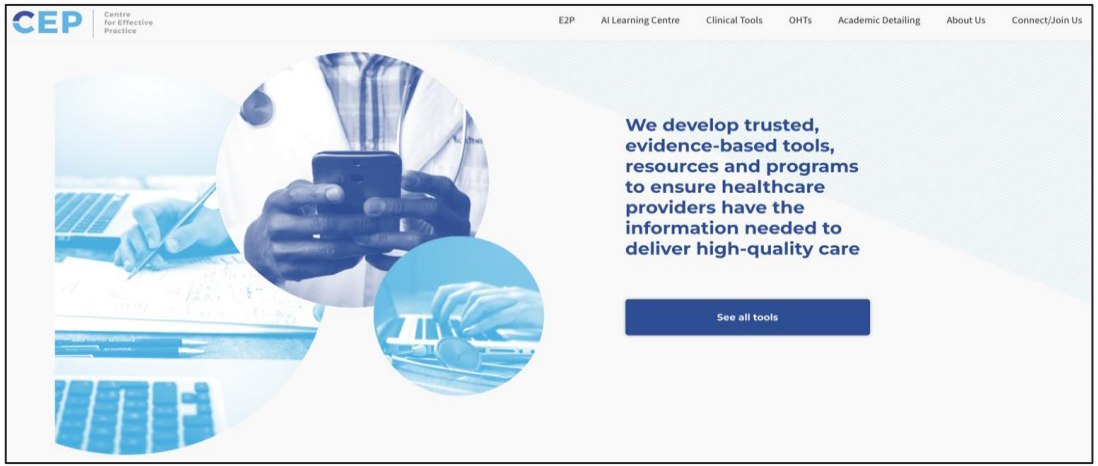
- This program has received no in-kind support.

- There are no other potential for conflict(s) of interest.

ICanCME

How this presentation was developed

CEP Centre for Effective Practice

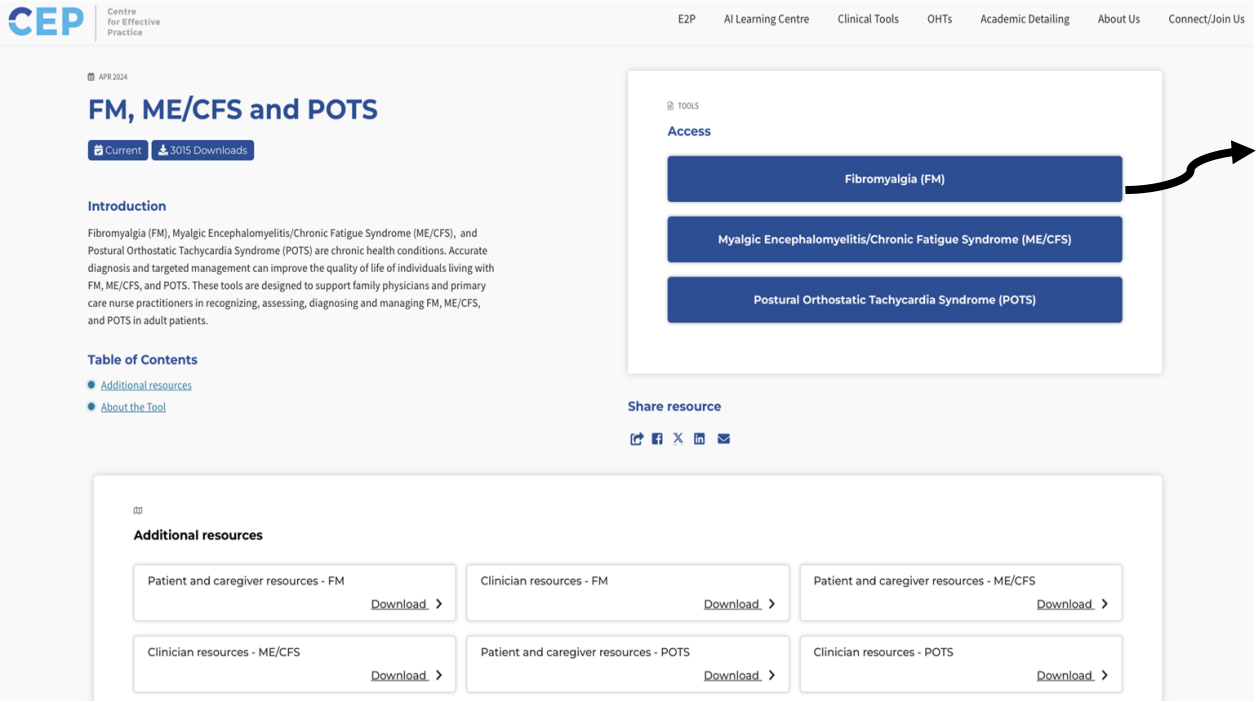


CareNow ONTARIO

ICanCME

Center for Effective Practice - Tools for Primary Care

Can be found at: www.cep.health/tools



Clinical presentation and diagnosis

Assessment

Management

References

Acknowledgement and legal

Objectives

1. Determine how to diagnose and prioritize management for ME, Fibromyalgia, and POTS
2. Differentiate ME, Fibromyalgia, and POTS from other common causes of chronic fatigue
3. Apply the tools from the Center for Effective Practice to support diagnosis, and management of ME, Fibromyalgia, and POTS

Overall goal:
Add ME, FM and POTS to your differential diagnosis list

Join in for polling!

POLL EVERYWHERE LINK

pe.app/mecfs2025

Cases to guide our discussion today

CASE 1 - Asha

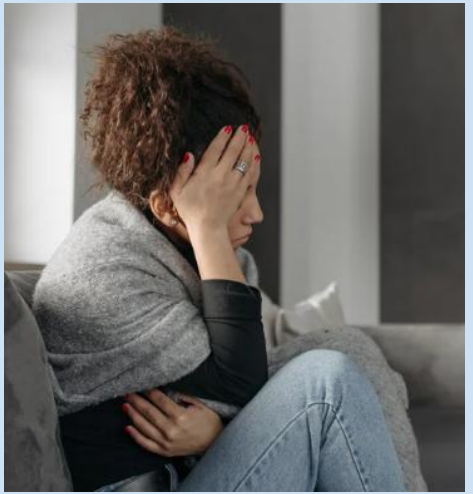
- 40 year old female who was **previously healthy** and worked out regularly.
- Experienced **flu-like illness** 6 months ago
- Off for one week and then attempted to return to work. She has been unable to re-engage in her prior physical activity routines.
- She is having very hard time functioning due to debilitating fatigue, poor sleep, dizziness and mental fogginess.

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

Poll:

Q1. CIHR is Canada’s main healthcare research funder. What percentage of funding goes towards research for conditions that predominantly impact women?

a) <10%
b) 20%
c) 30%
d) 50%

*Respond at **pe.app/mecfs2025***

Poll:

Q2. How many of Canada's 13 provinces and territories have specialty clinics that provide diagnosis and management for patients with ME and comorbid conditions?

a) All 13 provinces/territories

b) Most (6-7) provinces/territories

c) Few (2-3) provinces/territories

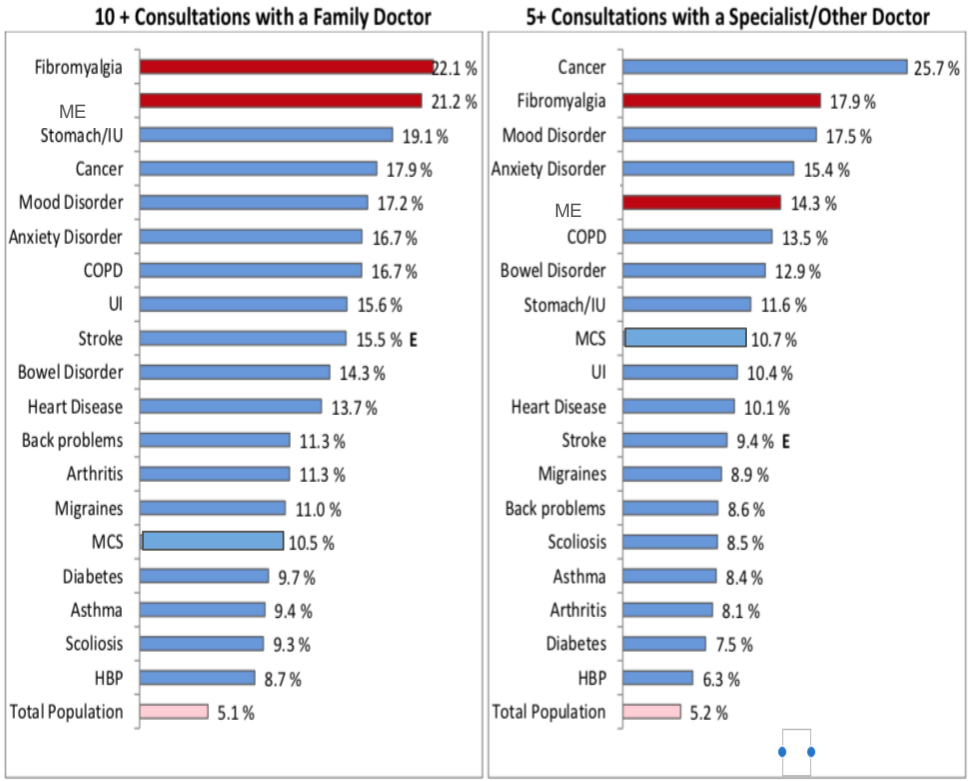
d) Very few (1) province/territory

e) None (0) province/territory

Respond at ***pe.app/mecfs2025***

HEALTH CARE UTILIZATION

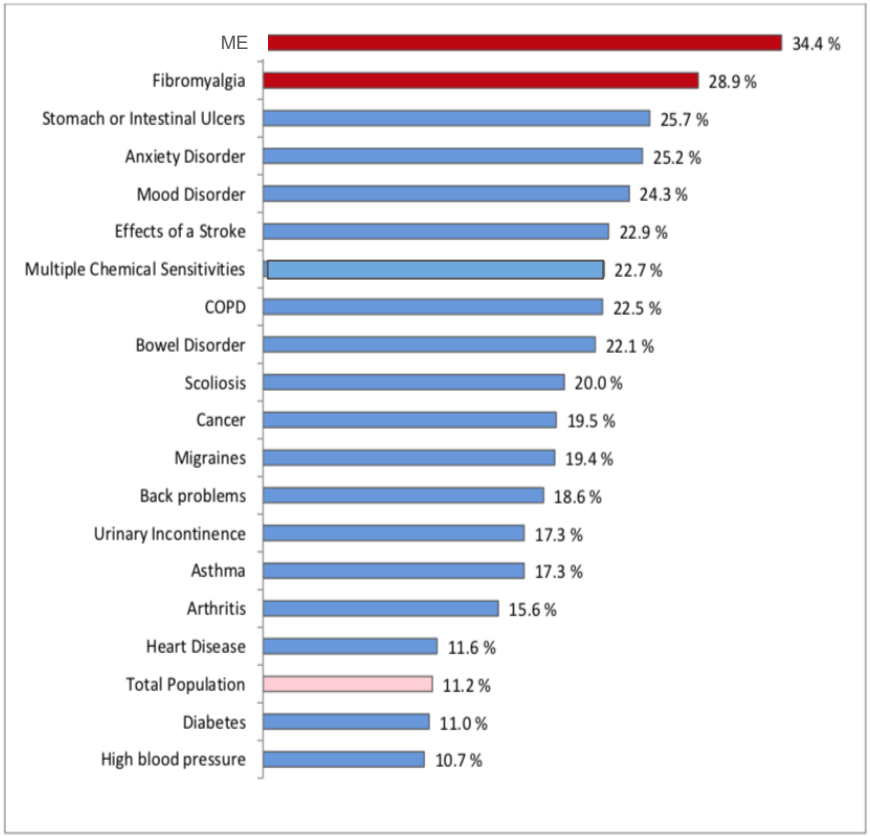
Health Care Consultations by Canadians Aged 12 and Older in the Previous 12 Months According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File

UNMET HEALTH CARE NEEDS

Canadians Aged 12 and Older Reporting Unmet Health Care Needs According to their Chronic Health Condition, 2014



Source: Statistics Canada, Canadian Community Health Survey, 2014, Public Use Microdata File

Adapted from National ME/FM Action Network mefmaction.com/docs/CCHS_Stats_2014.pdf

What are ME, FM and POTS?

- **These 3 conditions are commonly comorbid**
- **All 3 conditions are more common in women**

Myalgic Encephalomyelitis (ME)

- Previously known as CFS (chronic fatigue syndrome)
- 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)

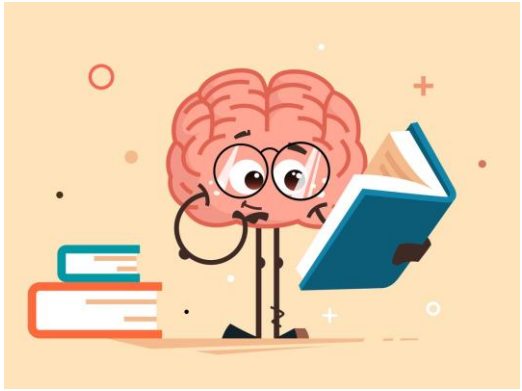
- Widespread musculoskeletal pain and other associated symptoms (sleep disturbances, fatigue, and impaired cognitive and physical function).
- Symptoms vary from person to person and may fluctuate from day to day

Postural Orthostatic Tachycardia Syndrome (POTS)

- Form of dysautonomia
- Excessive orthostatic tachycardia and orthostatic intolerance

Why learn about this?

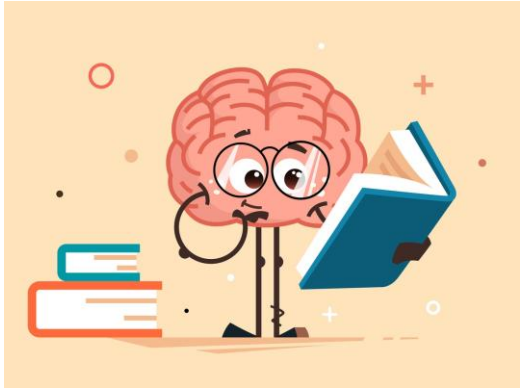
- These illnesses are **not commonly taught** in medical school or residency
- Many patients are **undiagnosed and poorly managed**
- These conditions can lead to **severe disability** and poor quality of life
- These conditions are often **post-infection sequelae**
  - For example, for COVID infections - 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?

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 three of the 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

Poll:

Q3. Tender points examination is required for the diagnosis of Fibromyalgia.

a) True
b) False

Respond at ***pe.app/mecfs2025***

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
  - ☐ WPI 4-6 and SSS ≥ 9
- ☐ **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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Total: _____ WPI score (add up boxes checked, 0-19)

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

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

you been bothered by any of the following?

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	☐	☐
er abdomen	☐	☐
	☐	☐

12)

you have EITHER
SS ≥ 5 OR
SS ≥ 9
het if you checked pain in 4/5 regions (not including items in italics)
≥ 3 months

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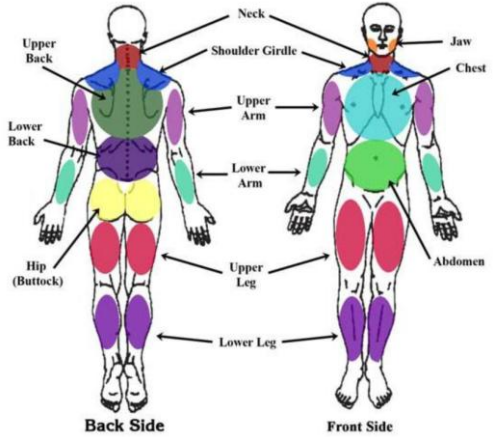

Clinical Pearl

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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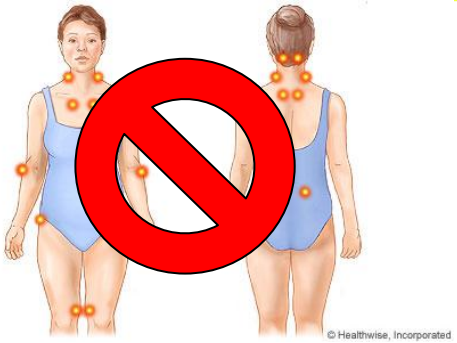
Pain or cramps in lower abdomen	☐	☐
Depression	☐	☐

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 pearl**
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)
- 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 | Takeaways

Poll:

Q4. What percentage of ME patients are unable to work?

a) 100%
b) 75%
c) 50%
d) 25%

Respond at pe.app/mecfs2025

ME - Background

- WHO has classified ME as a neurological disease since 1969
- Affects **more women than men (4:1)** (CIHR, 2021).
- Affects all ages and backgrounds (including children)
- Approx 2/3 patients note the onset of their symptoms **after an infectious illness**
- Underdiagnosed by clinicians (In USA, 90% of patients not diagnosed (CDC, 2021))

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)

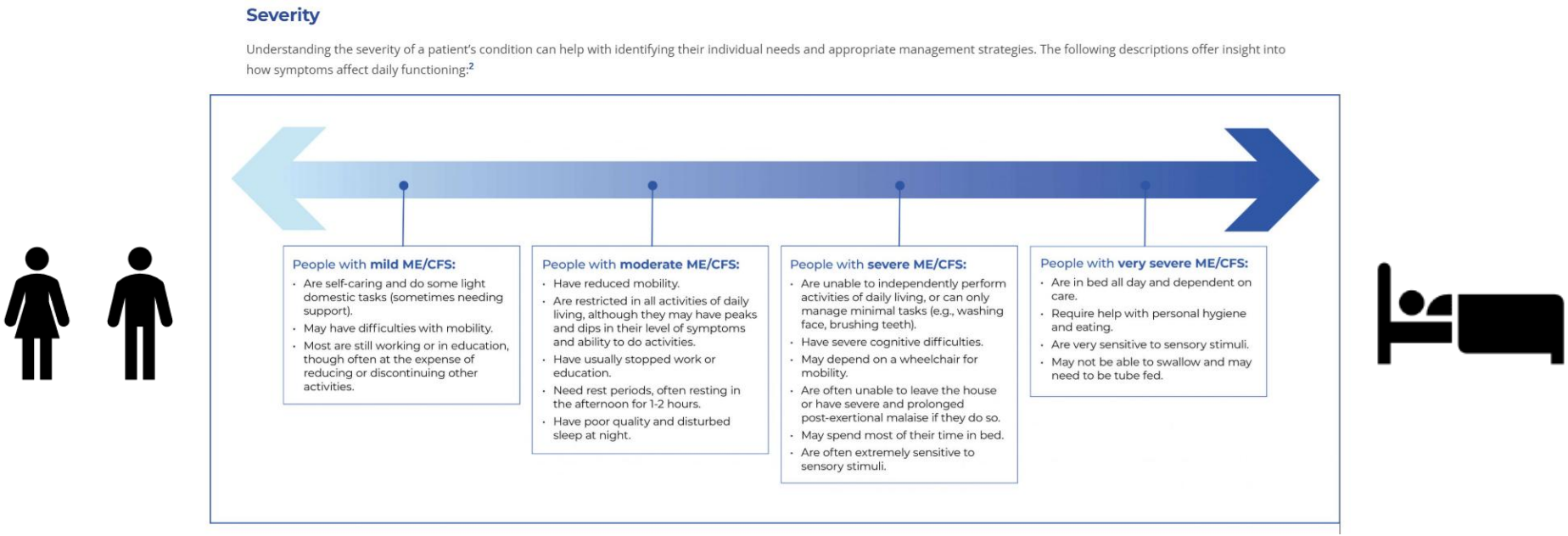


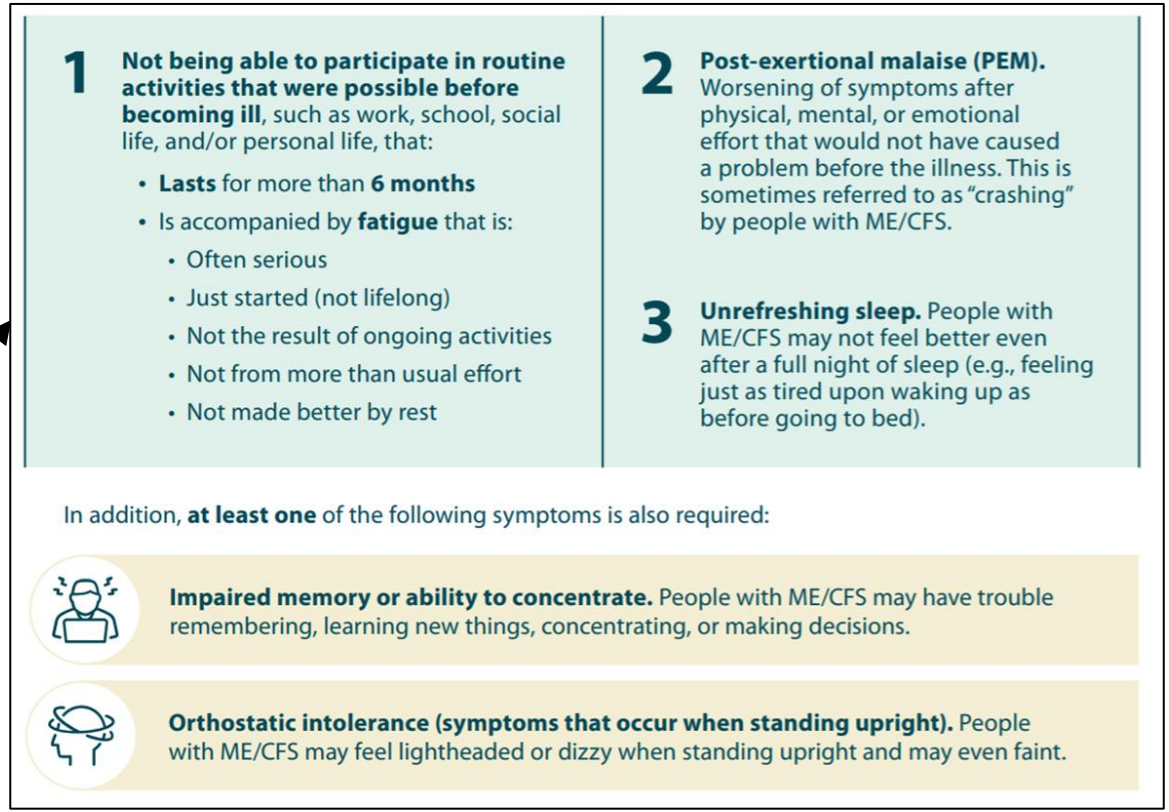
Image adapted from: CEP - ME CFS tool

ME - 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 - Characterizing the Symptom of Fatigue

- Profound, debilitating, resulting in a reduction of activity (occupational or social) (mild vs severe in this context)
- 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**
- PEM after physical / cognitive / emotional demands
- Differs from fatigue of 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]

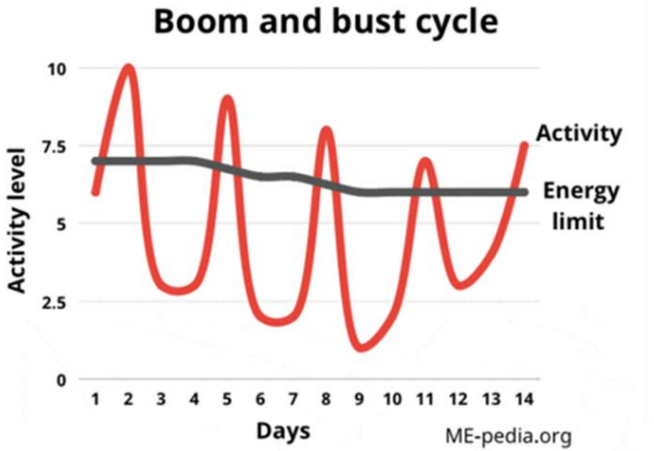
Management - Pacing (Energy Management)

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…)



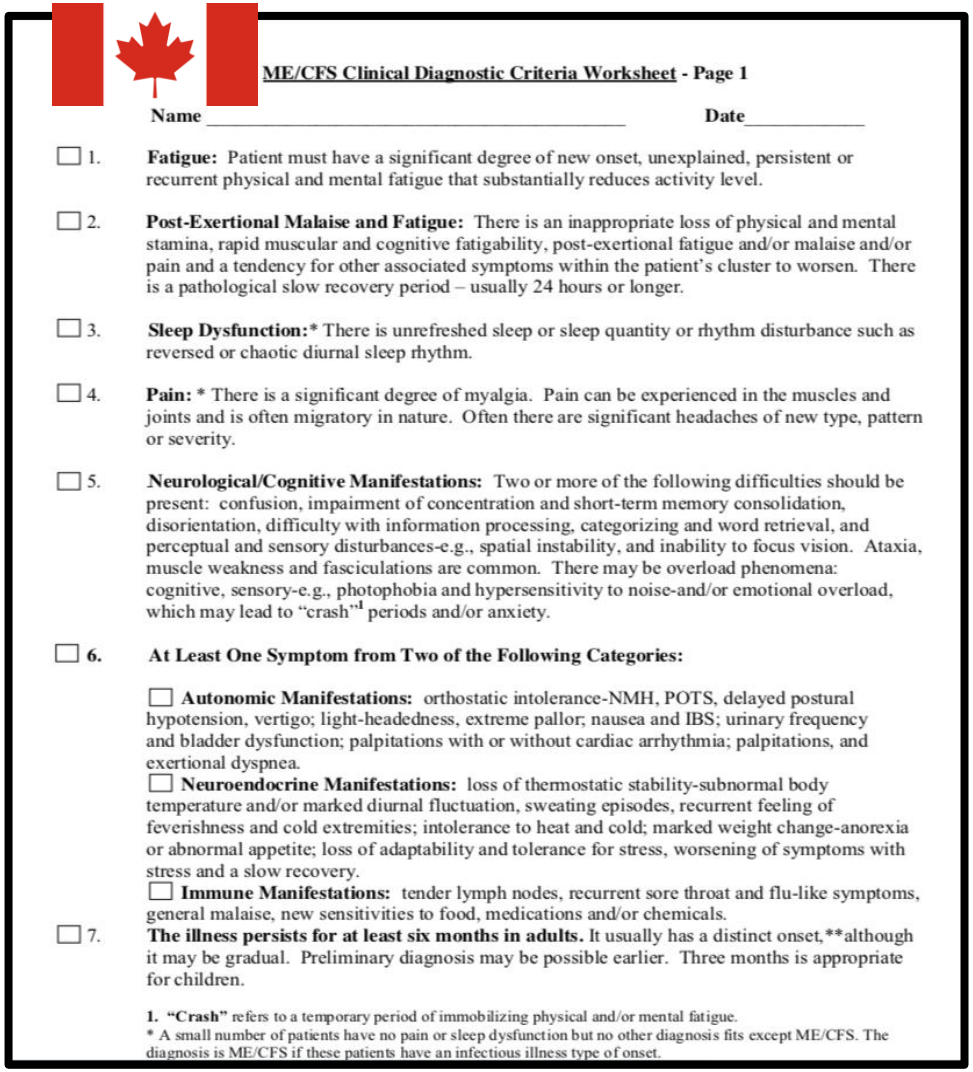
Why GET is not pacing

- **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 | Takeaways

Poll:

Q5. What percentage of patients with Fibromyalgia also have ME?

a) <10%
b) 25%
c) 50%
d) 80%

Respond at pe.app/mecfs2025

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 PAIN plus other symptoms	**Severe chronic fatigue with PEM** plus other symptoms
Patients benefit from moderate **EXERCISE**	Patients benefit from **PACING**

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…e Chronic Fatigue …PEM …us …mptoms
Patient… 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 | Takeaways

Poll:

Q6. You can diagnose POTS in your office.

a) True
b) False

Respond at pe.app/mecfs2025

POTS - Clinical Presentation and Diagnosis

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

Diagnosis

- **Confirm with active stand test/NASA Lean**

Bateman Horne Center
RESEARCH | CLINICAL CARE | EDUCATION

Conducting the 10-Minute NASA Lean Test:

- Ask the patient to remove shoes and socks and lie supine (comfortably) on a bed or full exam table in a quiet room for 15-20 minutes to reach circulatory equilibrium[1].
- After the 15-20 minutes, record the patient's BP and HR.
- Repeat a minute later. If repeat vital signs are not similar, retake until two consecutive readings are relatively consistent. The goal is to determine the average resting supine BP and HR.

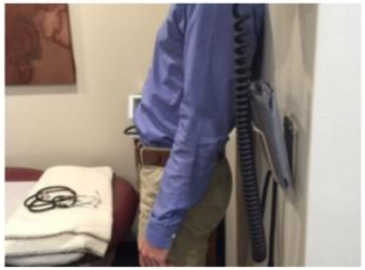
Next:

- Ask the patient to sit on the edge of the table/bed, then stand straight up, and lean against a nearby wall with only their shoulder blades touching the wall.
- Heels should be approximately 6" from the wall.
- Coach the patient to relax as much as possible.

Once the patient is leaning against the wall:

- Start a timer and record the first standing BP and HR.
- Repeat BP and HR measurements every minute for the next 10 minutes.
- Instruct patient not to shift, move, talk/chat, except to report symptoms of discomfort.
- Observe patient for lightheadedness or signs of pre-syncope. **Stop the test and have the patient lie down if about to faint.**
- Observe skin and extremities for changes in color and temperature.
- Assess cognition.
- Document any comments/patient symptoms as applicable.
    - See page 2 for a sample template that can be used to record blood pressure and pulse.

The 10-Minute NASA Lean Test can also be repeated while <u>on all OI treatments and interventions</u> to assess efficacy and determine next steps of treatment.

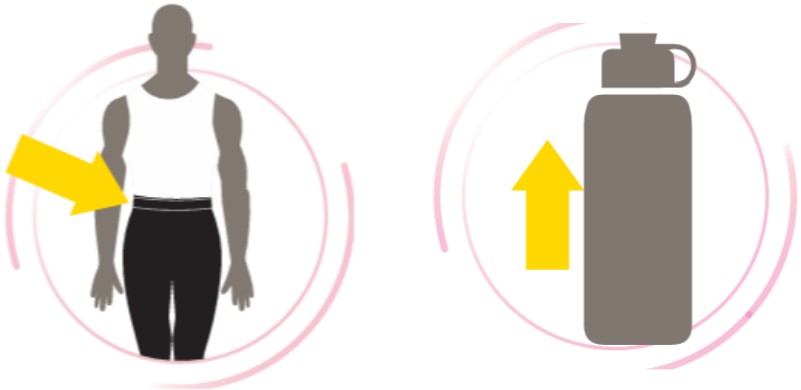


Orthostatic Vital Signs/The 10-Minute NASA Lean Test

	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

Cases

CASE 1 - Asha

40 year old with ongoing fatigue and poor functioning after a flu-like illness

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
- **Amanda meets criteria for ME**
- **Educate on pacing** (start early!!!)
- Assess and treat common comorbidities (use CCC)
  - **Amanda 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 noted 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.
- **Family medicine has 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!

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