



# Massachusetts ME/CFS & FM ASSOCIATION

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### ***PT/OT for ME/CFS and Similar Chronic Illnesses***

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## ***Sunday Conversations***

***with MassME***

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# What Is ME/CFS in 2022?

- There are multiple case definitions of ME/CFS
- The case definition most used by clinicians in 2022 is the IOM case definition which relies heavily on Post Exertional Malaise (PEM)
- PEM is defined as the worsening of symptoms following even minor physical or mental exertion, with symptoms typically worsening 12 to 48 hours after activity and lasting for days or even weeks. [1]



# Proposed Diagnostic Criteria for ME/CFS

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Diagnosis requires that the patient have the following three symptoms:

1. A substantial reduction or impairment in the ability to engage in pre-illness levels of occupational, educational, social, or personal activities, that persists for more than 6 months and is accompanied by fatigue, which is often profound, is of new or definite onset (not lifelong), is not the result of ongoing excessive exertion, and is not substantially alleviated by rest, and
2. Post-exertional malaise,\* and
3. Unrefreshing sleep\*

At least one of the two following manifestations is also required:

1. Cognitive impairment\* or
2. Orthostatic intolerance

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\* Frequency and severity of symptoms should be assessed. The diagnosis of ME/CFS should be questioned if patients do not have these symptoms at least half of the time with moderate, substantial, or severe intensity.

# Severity Range of ME/CFS

- ME/CFS ranges in severity from mild to severe.
- The severity scale does not appear to be in the published literature.
- Severity scale published by the ME Association of the U.K. [2]
  - Very Severe – bedridden
  - Severe – housebound
  - Moderate – unable to work; requires help with personal care
  - Mild – able to care for self; able to work part-time



# Is ME/CFS A Unique Illness?

- There is such overlap of symptoms between ME/CFS and Longhaul COVID that Longhaul patients are currently being diagnosed with ME/CFS [3]
- One study of COVID-19 patients, 1/3 developed Longhaul COVID. [4]
- Wong & Weitzer (2021) looked at 21 studies of Longhaul COVID symptomology to determine the overlap of symptoms with ME/CFS using meta-analysis. [5]





# Longhaul COVID Symptoms Overlap ME/CFS

What Wong & Weitzer found:

- Out of 29 listed ME/CFS symptoms all but 4 were reported by at least one long COVID study.
- All three major ME/CFS criteria symptoms (fatigue, reduced daily activity and PEM) were reported in multiple studies
- Fatigue was reported in 12 of 21 studies making it the predominant symptom of Longhaul COVID found in their study.



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## Similar Onsets of ME/CFS & Longhaul COVID-19?

- Anthony Fauci, M.D., the White House COVID-19 Response Team's chief medical adviser said during a the White House briefing:  
"Many of you are now aware of what had long been called Long COVID. But actually, what that really is is post-acute sequelae of SARS-CoV-2 infection, which we're now referring to as 'PASC,' or P-A-S-C." [6]
- Thus, the onset of PASC is similar to the onset of ME/CFS in many patients.



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# Are ME/CFS and Longhaul COVID The Only Post Infectious Illnesses?

- No! Post infectious viral and bacterial syndromes have been recognized for at least fifty years. [7]
- Prior to the proposed PASC illness, PAPIS (Post Active Phase of Infectious Illness Syndromes) was published in the journal *Medicina*. [8]
- The difference between the current category of Post Viral Syndromes (PVS) and PAPIS are: 1.PAPIS is more inclusive (onset triggered by a viral, parasitic or bacterial infection), and (2) PAPIS has overlap of symptoms with ME/CFS and Longhaul COVID-19.





# Additional Hypotheses of the PAPIS Proposal

1. Regardless of trigger or original source of infection, each symptom will have a similar pathophysiology.
  2. Similar pathophysiologies are most likely to be ameliorated by similar treatments.
- Therefore, healthcare providers need to be knowledgeable about the treatments which have been successful for other PAPIS's.



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# Impact of PASC on Healthcare [9]

- In a systematic review of 57 studies comprising more than 250, 000 survivors of COVID-19:
  - More than half of COVID-19 survivors experienced PASC 6 months after recovery.
  - Most common PASC involved functional mobility impairments, pulmonary abnormalities, and mental health disorders.
- These long-term PASC effects occur on a scale that could overwhelm existing health care capacity.



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## Who Currently Treats ME/CFS and Longhaul COVID?

- There are relatively few physicians with the expertise to treat ME/CFS – U.S. ME/CFS Clinical Coalition. 22 members listed [10]
- ME/CFS patients are currently underserved. [11]
- As of August 3, 2021, 44 Longhaul COVID clinics have been launched. [12]
- Will Longhaul COVID clinics treat ME/CFS patients or other PAPIS patients?
- We need a strategy to overcome the increasing healthcare worker shortage. [13]



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# Propose A More Active Role of PTs & OTs in ME/CFS Healthcare Management

- PT's concerned with restoring bodily function
- OT's concerned with restoring abilities to perform needed tasks.
- Both needed. A blend of the two.
- Example: Staci Stevens and the Workwell Foundation
  - Stay below your anaerobic threshold: Cardiopulmonary Exercise Testing – CPET. (PT)
  - Dividing tasks into blocks with intervals of rest. (OT)



# What Does the Literature Tell Us About PT/OT for ME/CFS? (1/2)

- Amy Mooney conducted a PubMed literature search. (Thank-you Amy!)
- There are few quality PT/OT for ME/CFS studies.
- Most recent study performed in 2021 [14]: There is no scientific evidence [data does not demonstrate a statistically significant improvement] when it comes to effective physiotherapy for ME patients.



## What Does the Literature Tell Us About PT/OT for ME/CFS? (2/2)

- An online survey of ME/CFS patient outcomes with rehabilitation [15] found both positive and negative experiences of rehabilitation
  - Positives: supportive communication, the benefits of a routine linked with baseline setting and pacing, the value of goal setting, increasing confidence associated with exercise
  - Negatives: poor communication, feeling pushed to exercise beyond a sustainable level, no plan for setbacks, feeling blamed for rehabilitation failing





## Difficulties In Providing Care To PAPIS Patients [16]

- When “standard” laboratory tests come back normal, there is no diagnosis.
- The choices are to:
  - Order more tests
  - Say I don’t know/I can’t help you?
  - Provide treatment based on symptoms?
  - Conclude there is nothing wrong with this patient.
- A large literature now suggests abnormalities in five areas: brain, immune system, energy metabolism, autonomic nervous system, G.I. microbiome.
- Lesson to be learned: Do not dismiss a patient’s symptoms because you cannot explain them.



# Guiding Principles for Healthcare Providers (1/3)

The Primary Care Provider guidelines published for the treatment of ME/CFS are appropriate for all therapists treating PAPIS [17]:

- Educate your patient to minimize post-exertional malaise (PEM) by pacing her/his activities.
- Propose small amounts of work, between periods of rest. (It may be possible to accomplish more by working in spurts with periods of rest than by working for a longer period of time.)



## Guiding Principles for Healthcare Providers(2/3)

- Advocate the use of activity monitoring devices: activity logs, heart rate monitors, step counters. Patients should attempt to understand the relationship between activities and energy limits.
- Identify and treat pre-existing (now co-morbid) conditions in an effort to improve the patient's overall health.
- Ask which symptom is the most troublesome or which symptoms your patient would like treated first (and attempt to do so).



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## Guiding Principles for Healthcare Providers (3/3)

- ME/CFS patients have reported pain relief from acupuncture, chiropractic, pilates and massage. (Ad hoc, no formal studies) Worth a try?
- No specific treatment for symptom relief works for all patients. (There is a high degree of variability among patient responses.)
- For evaluating a patient and developing a treatment plan, healthcare providers will find the DePaul Symptom Questionnaire useful. [18]



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# Chronic Illness Healthcare Is a Partnership

- Both patient and provider should treat each other with respect.
- There may be frustration and disappointment on both sides.
- Be articulate in explaining your perceptions of treatments and your feelings.
- Confrontation, anger, and/or accusations rarely improve healthcare.



# Conclusion & Proposal (1/3)

- An estimated up to 2-2.5 million ME/CFS patients in the U.S. (IOM) [19]
- As of October 2, 2021, there were an estimated 146.6 million COVID cases in the U.S. [20]
- An unknown percentage of Longhaul COVID patients will satisfy the ME/CFS case definition.
- Currently few, if any, published studies of PT/OT improvement for ME/CFS patients.





# Conclusion & Proposal (2/3)

- If we classify ME/CFS and Long COVID under the proposed PAPIS classification, what PT and OT therapies can be provided to improve patient outcomes?
  - Generate a list of projected, helpful therapies.
  - Articulate suggestions in a theoretical journal article.
  - Create a mechanism for data collection & reporting results.
  - Write a manuscript indicating the therapies that have helped patients with PAPIS.



# Conclusion & Proposal (3/3)

- The journal *Healthcare* has agreed to establish a topical collection for PAPIS.
- Papers can be submitted to the journal for publication within that series going forward.
- I and others will be guest-editing that collection.
- We would be pleased to receive, consider and submit to peer review PT and OT manuscripts.



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