No definitive evidence based recommendations exits
We therefore used a pragmatic approach based in published papers
POST COVID-19
A LONG-COVID PRIMARY CARE TOOLKIT

OBJECTIVES
• Describe the symptoms of Long COVID
• Make a diagnosis of Long COVID
• Compare Long COVID to similar conditions
• Do a basic workup for Long COVID
• Identify co-morbid conditions associated with Long COVID
• Provide advice and resources for patients
• Locate physician resources

PRINCIPLES
• Focus on practical tools to help PCP care for patients
• Help manage patient expectations
• Avoid over-investigation and patient-driven testing
• Focus on patient self-management rather than diagnosis seeking
• Leverage multiple short-visits with specific tasks
• Uncouple patient visits from symptoms
• Leverage existing resources
• 51 yo F - married with 2 kids - triathlete
• Previously well; No H/O CSS
• Presumed COVID Jan 2021
• Bed-bound for a week
• Persistent symptoms - unable to return to work
  • Breathlessness and difficulty taking in a deep breath; chest tightness
  • Fatigue, decreased activity tolerance, post-exertional malaise
  • Widespread aches and pains
  • Unrefreshing sleep; sleeps during the day
  • Brain Fog; mentally drained
  • Orthostatic intolerance
  • Loss of motivation and interest; not “coping”; overwhelmed
  • Feverish; tender lymph nodes; loss of smell
• No cardiac risk factors; no Fax CAD; very physically fit
What to call it?

- Post acute sequelae of COVID19 (PASC) – research term
- Long COVID
- Long-haul COVID
- Post-acute COVID syndrome
- Chronic COVID
- (Myalgic encephalomyelitis/chronic fatigue syndrome?)

Dr. Renée Janssen presentation - “You’ve got this”

How to approach long-COVID patients

- Complete review of systems, screening for common symptoms
- Target investigations to patient symptoms
- Exhaustive investigations are not required to rule out objective end-organ disease
- Validate patient symptoms
- Refer to subspecialty for red flags or objective findings of disease
How to approach long-COVID patients

- Complete review of systems, screening for common symptoms
- Target investigations to patient symptoms
- Exhaustive investigations are not required to rule out objective end-organ disease
- Validate patient symptoms
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Central Sensitization Phenotypes in Post Acute Sequelae of SARS-CoV-2 Infection (PASC): Defining the Post COVID Syndrome

- Mayo Clinic Rochester
- Post acute sequelae of SARS-CoV-2 infection (PASC)
  - Heterogeneous group
  - 3 Groups
    - Tissue damage
      - e.g., lung scarring, myocarditis, anosmia
    - No identifiable tissue damage *
      - Post-viral syndrome
      - CSS (Mayo Clinic)
    - Psychiatric / psychological
Central Sensitization Phenotypes in Post Acute Sequelae of SARS-CoV-2 Infection (PASC): Defining the Post COVID Syndrome

Dates received: 24 May 2021; revised: 17 June 2021; accepted: 18 June 2021.

• Mayo Clinic Rochester
• Post acute sequelae of SARS-CoV-2 infection (PASC)
  • Heterogeneous group - Dr. Jansen Triage Presentation
• 3 Groups
  • Tissue damage
    • e.g., lung scarring, myocarditis, anosmia
  • No identifiable tissue damage *
    • Post-viral syndrome
    • CSS (Mayo Clinic)
  • Psychiatric / psychological

* Messaging
  NOT psychosomatic or somatiform

MEDICAL GASLIGHTING

"How do I know you're not malingering?"
Medical News & Perspectives

As Their Numbers Grow, COVID-19 “Long Haulers” Stump Experts

Rita Rubin, MA

- Medical Gaslighting
  - “Many long haulers never had laboratory confirmation of COVID-19, which, they say, adds to some health care professionals’ skepticism that their persistent symptoms have a physiological basis.”
  - “these mystery diagnoses are real, and they’re not just in patients’ heads.”
- Post-viral syndrome
- Solve ME/CFS Initiative
  - Registry and biobank: COVID-19 long haulers | ME/CFS | healthy controls

Central Sensitization Phenotypes in Post Acute Sequelae of SARS-CoV-2 Infection (PASC): Defining the Post COVID Syndrome

Dates received: 24 May 2021; revised: 17 June 2021; accepted: 18 June 2021.

- Post COVID syndrome (Long COVID)
  - Post-viral syndrome
  - Clinical stabilization or resolution of viral infection
  - > 3 weeks
  - + COVID test NOT required: not tested; false +
  - Some…
    - Go on to meet criteria for ME/CFS, FM, POTS, other CSS
  - Note: excluded patients with pre-existing CSS !!
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  • Note: excluded patients with pre-existing CSS !!

 Messaging

Long COVID ≠ ME/CFS

Central Sensitization Phenotypes in Post Acute Sequelae of SARS-CoV-2 Infection (PASC): Defining the Post COVID Syndrome

Dates received: 24 May 2021; revised: 17 June 2021; accepted: 18 June 2021.

• Post COVID Syndrome (Long COVID): 42/465 (9%)
  • ⅓ male - ⅔ female (2:1 female)
  • Age 21 - 74 (average 46)
  • Most common symptoms
    • Pain (90%)
    • Fatigue (74%) - ?? PEM
    • Dyspnea (43%)
    • Orthostatic intolerance (38%)
• “high degree of similarities between long COVID and ME/CFS”

• 25/29 ME/CFS symptoms were reported by at least one long COVID study

• NOT Reported: 1. motor disturbance; 2. tinnitus/double vision; 3. lymph node pain/tenderness; 4. sensitivity to chemicals, foods, medications, odours

• Estimated 10% with COVID-19 may develop ME/CFS

• It may be too early to establish a direct causal relationship between long COVID and the development of ME/CFS

[EDITORIAL]

Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

• Deconditioned?

• Early efforts drove rehabilitation teams to apply exercise-based protocols

• The history of ME/CFS with exercise is one of false hope.

• Post-exertional malaise and worsening of symptoms!
**STOP** trying to push your limits. Overexertion may be detrimental to your recovery.

**REST** is your most important management strategy. Do not wait until you feel symptoms to rest.

**PACE** your daily physical and cognitive activities. This is a safe approach to navigate triggers of symptoms.

**FIGURE.** The “Stop. Rest. Pace” approach to safely manage physical and cognitive activities while recovering from long COVID.

---

**Messaging**

- **Messaging**
  - PEM is a game-changer!
  - Pushing through symptoms
    - Or
    - Boom/Bust
  - Makes things worse
  - Prolongs recovery
  - Reduces chances of remission

- Some patients may benefit from Exercise
Diagnosis and Treatment of
Chronic Fatigue Syndrome

it's mitochondria, not hypochondria

POST-EXERTIONAL MALAISE
Discriminative Validity of Metabolic and Workload Measurements for Identifying People With Chronic Fatigue Syndrome

Christopher R. Snell, Staci R. Stevens, Todd E. Davenport, J. Mark Van Ness

Figure 2
Measurements of workload at peak exercise (A) and at the ventilatory threshold (B) in participants with chronic fatigue syndrome (CFS) and control participants during cardiopulmonary exercise test 1 (blue bars) and cardiopulmonary exercise test 2 (gold bars). Error bars represent 1 standard deviation.
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Day 1

A

B

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Day 2: Crash

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Day 2: Crash

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CHRONIC PAIN – A NEW TYPE

- Pain falls into three categories:
  - Nociceptive – inflammation and damage
  - Neuropathic – damaged or irritated nerves
  - Nociplastic
    - Volume knob for pain is turned up
    - “Central sensitization”
    - e.g., FM
    - “Noci-” is from the Latin for “to do harm”
  - A person might have more than one type of pain
CHRONIC PAIN

Sensitization & Amplification

CHRONIC PAIN: SENSITIVITY SHIFT

[Graph showing the relationship between stimulus intensity and pain sensation before and after injury, illustrating the shift in pain sensitivity.]
Functional Magnetic Resonance Imaging Evidence of Augmented Pain Processing in Fibromyalgia

Richard H. Gracely,1 Frank Petzke,2 Julie M. Wolf,3 and Daniel J. Clauw2

Objective. To use functional magnetic resonance imaging (fMRI) to evaluate the pattern of cerebral activation during the application of painful pressure and determine whether this pattern is augmented in patients with fibromyalgia (FM) compared with controls.

Methods. Pressure was applied to the left thumb-nail beds of 16 right-handed patients with FM and 16 right-handed matched controls. Each FM patient underwent fMRI while moderately painful pressure was being applied. The functional activation patterns in FM patients were compared with those in controls, who were tested under 2 conditions: the "stimulus pressure control" condition, during which they received an amount of pressure similar to that delivered to patients, and the "subjective pain control" condition, during which the intensity of stimulation was increased to deliver a subjective level of pain similar to that experienced by patients.

Results. Stimulation with adequate pressure to cause similar pain in both groups resulted in 19 regions of increased regional cerebral blood flow in healthy controls and 12 significant regions in patients. Increased fMRI signal occurred in 7 regions common to both groups, and decreased signal was observed in 1 common region. In contrast, stimulation of controls with the same amount of pressure that caused pain in patients resulted in only 2 regions of increased signal, neither of which coincided with a region of activation in patients. Statistical comparison of the patient and control groups receiving similar stimulus pressures revealed 13 regions of greater activation in the patient group. In contrast, similar stimulus pressures produced only 1 region of greater activation in the control group.

Conclusion. The fact that comparable subjectively painful conditions resulted in activation patterns that were similar in patients and controls, whereas similar pressures resulted in no common regions of activation and greater effects in patients, supports the hypothesis that FM is characterized by cortical or subcortical augmentation of pain processing.

Fibromyalgia (FM) is characterized by chronic widespread pain (involving all 4 quadrants of the body as well as the axial skeleton) and diffuse tenderness (1). Population-based studies have demonstrated that FM affects 2–4% of the population, with a very similar prevalence in at least 5 industrialized countries (2,3). The etiology of FM remains elusive, although there is support for the notion that altered central pain processing is a factor in the presentation of this disease. The development of functional brain imaging techniques provides an opportunity to examine central pain processing in patients with FM.

Supported in part by the National Fibromyalgia Research Association, by Department of Army grant DAMD 17-00-2-0018, and by the National Institute of Dental and Craniofacial Research, Division of Intramural Research.

1Richard H. Gracely, PhD: National Institute of Dental and Craniofacial Research, NIH, Bethesda, Maryland, and Georgetown Chronic Pain and Fatigue Research Center, Georgetown University, Washington, DC;2Frank Petzke, MD, Daniel J. Clauw, MD: Georgetown University Medical Center, and Georgetown Chronic Pain and Fatigue Research Center, Georgetown University, Washington, DC;3Julie M. Wolf, BA: National Institute of Dental and Craniofacial Research, NIH, Bethesda, Maryland.

Address correspondence and reprint requests to Daniel J. Clauw, MD, University of Michigan Medical Center, 5510 MSRB I, Ann Arbor, MI 48109.

Submitted for publication May 17, 2001; accepted in revised form December 19, 2001.

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- Pain intensity vs. stimulus intensity graph
- Brain images showing regions of increased activation in patients with fibromyalgia compared to controls
- Legend: IPL, SII, STG, Insula, Putamen, Cerebellum

Conclusion.

The fact that comparable subjectively (designed to be in the same levels, but the level at which these stimuli become unpleasant or noxious (pain threshold) is lower than normal, with the same amount of pressure that caused pain in both groups resulting in 19 regions of increased fMRI signal occurring in 7 regions common to both groups, and 12 significant regions in patients. In contrast, stimulation of controls resulted in only 1 region of greater activation in the control group. In contrast, similar stimulus pressures produced greater effects in patients, supporting the hypothesis that FM is characterized by cortical or subcortical augmentation of pain processing.

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Results. Imaging during the application of painful pressure demonstrated increased fMRI signal in 7 regions common to both groups, and decreased signal was observed in 1 region common to controls. In contrast, stimulation of controls resulted in only 2 regions of increased signal, with the same amount of pressure that caused pain in patients (8–11).

Conclusion. The fact that comparable subjectively unpleasant or noxious (pain threshold) is lower in patients with FM and control subjects generally detects 11 of 18 tender points (regions that are painful when manually palpated with 4 kg of pressure), in FM patients processing in patients with FM.

The etiology of FM remains elusive, although there is support for the notion that altered central pain processing is a factor in the presentation of this disease. The prevalence in at least 5 industrialized countries (2,3). Population-based studies have demonstrated that FM affects 2–4% of the population, with a very similar prevalence in at least 5 industrialized countries. ME/CFS (Myalgic Encephalomyelitis/Chronic Fatigue Syndrome); FM (Fibromyalgia); MCS (Multiple Chemical Sensitivities); CLD (Chronic Lyme Disease); IBS (Irritable Bowel Syndrome); T-T (Tension Type); TMD (Temporomandibular Disorders); POTS (Postural Orthostatic Tachycardia Syndrome); RLS (Restless Leg Syndrome); Others including: irritable larynx syndrome, PTSD (Post Traumatic Stress Syndrome), non-cardiac chest pain (costochondritis), myofascial pain syndrome, and other pain syndromes.

Adapted from Yunus, Semin Arthritis Rheum 36:339-356
BIRDS OF A FEATHER
CENTRAL SENSITIVITY SYNDROMES

• ME/CFS
• Fibromyalgia
• Myofascial Pain Syndrome
• Migraines
• Tension Type Headaches
• Irritable Bowel Syndrome
• Interstitial Cystitis
• Pelvic Pain Syndrome
• PTSD
• Non-Cardiac Chest Pain (Costochondritis)
• Temporomandibular Disorder
• Irritable Larynx Syndrome
• Central Abdominal Pains Syndrome (AKA Functional)
• Other Pain Syndromes

POTS : POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

• Associated symptoms
  • Fatigue
  • Sleep disturbance
  • Cognitive symptoms
  • GI symptoms
  • Headaches
  • Other autonomic phenomena

• POTS Dx criteria
  • 1st thing in the AM
  • HR before getting out of bed
  • HR upon standing: time 0, 1, 3 5, 10 min
  • HR > 120 or ↑ 30 BPM
Sleep is un-refreshing: disturbed quantity - daytime hypersomnia or nighttime insomnia and/or disturbed rhythm - day/night reversal.

A significant degree of new onset, unexplained, persistent or recurrent pain and tenderness.

Rarely, there is no pain.

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.

Post-exertional Malaise* and Unrefreshing Sleep* at least one of the two following:

Cognitive Impairment* or Orthostatic Intolerance

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

The illness has persisted for at least 6 months.
**Myofascial Pain Syndrome (MPS)**

- Myalgias
- Fatigue
- Sleep disturbance
- Cognitive symptoms
- Unexplained dizziness
- Autonomic phenomena

- ? Localized FM

**Amplification & Distortion**
LONG-COVID PRIMARY CARE TOOLKIT

• Overview
• Dysautonomia & POTS
• Mental Health
• Pain
• Central Sensitivity Syndromes
• Approach to Common Symptoms
• New or Changing Symptoms
• Work/Disability/Paperwork
• Principles of CBT

PRINCIPLES — YOU GOT THIS

• Patient centred
• Trauma-informed care
  • www.cdc.gov/cpr/infographics/6_principles_trauma_info.htm
• Shared decision making
• Optimization of quality of life and function
• Self-management strategies
• Symptom focused
  • Red flags & risk factors
• Patient education
• Transparency - incomplete/changing knowledge
• Standardized care
• Uncoupling of symptoms with medical visits
## PHYSICAL SYMPTOMS

### Long COVID Symptom Inventory

<table>
<thead>
<tr>
<th>Symptom</th>
<th>Description</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Fatigue</strong></td>
<td>Physical fatigue, Mental fatigue, Decreased activity tolerance, Decreased exercise capacity, Post-exertional malaise</td>
</tr>
<tr>
<td><strong>Pain</strong></td>
<td>Muscle pain, Joint pain, Headaches, Chest pain, Chest tightness</td>
</tr>
<tr>
<td><strong>Sleep problems</strong></td>
<td>Unrefreshing sleep, Difficulty falling asleep, Difficulty staying asleep</td>
</tr>
<tr>
<td><strong>Brain fog</strong></td>
<td>Poor memory, Difficulty concentrating, Difficulty finding words, Easily overwhelmed</td>
</tr>
<tr>
<td><strong>Unexplained symptoms</strong></td>
<td>Lung: Shortness of breath, Difficulty taking a deep breath, Cough, Wheezing</td>
</tr>
<tr>
<td></td>
<td>Digestive: Loss of appetite, Nausea, Vomiting, Significant weight change</td>
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<tr>
<td></td>
<td>Nervous system: Loss of taste or smell, Blurry vision, Vertigo</td>
</tr>
<tr>
<td></td>
<td>Immune: Sore throat, Tender lymph nodes, recurrent flu-like symptoms</td>
</tr>
<tr>
<td></td>
<td>Other: Hair loss, Rash, Menstrual cycle irregularities, Urinary frequency</td>
</tr>
<tr>
<td><strong>Psychiatric</strong></td>
<td>Depression, Anxiety, Mood swings, PTSD</td>
</tr>
</tbody>
</table>

### Other Symptom Inventory

- Resp
- Autonomic
- CNS
- GI
Do you have any of the following pre-existing Central Sensitivity Syndromes?

- None
- Chronic Fatigue Syndrome (ME/CFS)
- Fibromyalgia
- Headaches (tension type)
- IBS (irritable bowel syndrome)
- Interstitial Cystitis
- Irritable larynx syndrome
- Migraines
- Myofascial pain syndrome
- Non-cardiac chest pain
- Pelvic pain syndrome & related disorders
- POTS (postural orthostatic tachycardia syndrome)
- PTSD (post-traumatic stress disorder)
- Restless leg syndrome
- Temporomandibular disorders (TMD/TMJ)
- Multiple chemical sensitivities/environmental sensitivities
- Other:

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<tr>
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<td>- Chest pain</td>
<td></td>
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<td>Sleep disturbances</td>
<td></td>
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<tr>
<td>- Difficulty taking a deep breath</td>
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<td>- Fainting</td>
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<td>- Low blood pressure</td>
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<td>- Palpitations</td>
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<td>- Racing heart</td>
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<td>- Irregular heart</td>
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<td>- Heat/cold intolerance</td>
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<td>- Nervous system</td>
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<td>- Loss of taste or smell</td>
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<td>- Blurry vision</td>
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<td>- Diminished vision</td>
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<tr>
<td>- Muscle weakness</td>
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<tr>
<td>- Hypersensitivity to light or sound</td>
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<td>- Problems with balance and coordination</td>
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<tr>
<td>- Immune</td>
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<td>- Sore throat</td>
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<td>- Fever</td>
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<td>- Ringing in the ears</td>
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<tr>
<td>- Sensitivities to food/medications/chemicals</td>
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<td>- Other</td>
<td></td>
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### Long COVID Symptom Inventory

**Name:**

**Date of COVID onset:** Jan 2021

**Positive COVID test:** Yes [ ] No [ ]

Please circle all symptoms that apply.

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</tr>
<tr>
<td>Difficulty falling asleep</td>
</tr>
<tr>
<td>Difficulty staying asleep</td>
</tr>
<tr>
<td>Other pain</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Brain fog</strong></td>
</tr>
<tr>
<td>Poor memory</td>
</tr>
<tr>
<td>Difficulty concentrating</td>
</tr>
<tr>
<td>Difficulty finding words</td>
</tr>
<tr>
<td>Easily overwhelmed</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Unexplained Symptoms</strong></td>
</tr>
<tr>
<td>Lung</td>
</tr>
<tr>
<td>Shortness of breath</td>
</tr>
<tr>
<td>Difficulty taking a deep breath</td>
</tr>
<tr>
<td>Cough</td>
</tr>
<tr>
<td>Wheezing</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Autonomic</strong></td>
</tr>
<tr>
<td>Lightheadedness</td>
</tr>
<tr>
<td>Dizziness</td>
</tr>
<tr>
<td>Fainting</td>
</tr>
<tr>
<td>Irregular heart</td>
</tr>
<tr>
<td>Low blood pressure</td>
</tr>
<tr>
<td>Heat/cold intolerance</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
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</thead>
<tbody>
<tr>
<td><strong>Digestive</strong></td>
</tr>
<tr>
<td>Loss of appetite</td>
</tr>
<tr>
<td>Nausea</td>
</tr>
<tr>
<td>Vomiting</td>
</tr>
<tr>
<td>Significant weight change</td>
</tr>
<tr>
<td>Diarrhea</td>
</tr>
<tr>
<td>Constipation</td>
</tr>
<tr>
<td>Abdominal bloating</td>
</tr>
<tr>
<td>Abdominal cramps</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Nervous system</strong></td>
</tr>
<tr>
<td>Loss of taste or smell</td>
</tr>
<tr>
<td>Blurry vision</td>
</tr>
<tr>
<td>Vertigo</td>
</tr>
<tr>
<td>Problems with balance and coordination</td>
</tr>
<tr>
<td>Tinnitus</td>
</tr>
<tr>
<td>Muscle weakness</td>
</tr>
<tr>
<td>Hypersensitivity to light or sound</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Immune</strong></td>
</tr>
<tr>
<td>Sore throat</td>
</tr>
<tr>
<td>Rashes</td>
</tr>
<tr>
<td>Recurrent flu-like symptoms</td>
</tr>
<tr>
<td>Sensitivities to food/medications/chemicals</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Other</strong></td>
</tr>
<tr>
<td>Hair loss</td>
</tr>
<tr>
<td>Rash</td>
</tr>
<tr>
<td>Menstrual cycle irregularities</td>
</tr>
<tr>
<td>Urinary frequency</td>
</tr>
</tbody>
</table>

<table>
<thead>
<tr>
<th>Symptom</th>
</tr>
</thead>
<tbody>
<tr>
<td><strong>Psychiatric</strong></td>
</tr>
<tr>
<td>Depression</td>
</tr>
<tr>
<td>Anxiety</td>
</tr>
<tr>
<td>Mood swings</td>
</tr>
<tr>
<td>PTSD</td>
</tr>
</tbody>
</table>

---

### Do you have any of the following pre-existing Central Sensitivity Syndromes?

- [ ] None
- [ ] Chronic Fatigue Syndrome (ME/CFS)
- [ ] Fibromyalgia
- [ ] Headaches (tension type)
- [ ] IBS (irritable bowel syndrome)
- [ ] Interstitial Cystitis
- [ ] Irritable larynx syndrome
- [ ] Migraines
- [ ] Myofascial pain syndrome
- [ ] Non-cardiac chest pain
- [ ] Pelvic pain syndrome & related disorders
- [ ] POTS (postural orthostatic tachycardia syndrome)
- [ ] PTSD (post-traumatic stress disorder)
- [ ] Restless leg syndrome
- [ ] Temporomandibular disorders (TMD/TMJ)
- [ ] Multiple chemical sensitivities/environmental sensitivities
- [ ] Other:
BASIC WORKUP FOR LONG-COVID

- Long-COVID does NOT require an exhaustive workup
- EBM recommendations do not exist
- Appropriate but limited workup
- Using the pre-printed Symptoms Inventory helpful
  - DDx and coexisting conditions needing workup
- Initial evaluation should include:
  - Identification of Red Flags and Risk Factors requiring further evaluation
  - Limited medical work-up

Messaging
Long COVID is NOT diagnosis of exclusion
BASIC WORKUP FOR LONG-COVID

• Long COVID does NOT require an exhaustive workup
• Appropriate but limited workup
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  • DDx and coexisting conditions needing workup
• Initial evaluation should include:
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  • Limited medical work-up

Case
Breathlessness and difficulty taking in a deep breath; chest tightness
No cardiac risk factors; no FHx CAD; very physically fit

Screening Blood work:
• CBC + diff
• S.potassium, creatinine
• Mg, Phe, Ca
• Fasting blood sugar
• CRP
• Liver tests: AST, ALT, GGT, ALP, bilirubin, albumin
• CK
• Thyroid
• Ferritin (slightly elevated associated with fatigue even in the absence of anemia)
• Hgb, Hct
• TSH
• VES
• +/- FISH test (age-appropriate screening)
• +/- anti-TTG (symptoms)

Note: ANA is not recommended as a screening test

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What is the efficacy and safety of rapid exercise tests for exertional desaturation in covid-19?

What is the efficacy and safety of rapid exercise tests for exertional desaturation in covid-19?

A 3% drop in pulse oximeter reading on exercise is cause for concern in covid-19. The 1-minute sit-to-stand test (patient goes from sit to stand as many times as they can) has been validated; the unvalidated 40-step test (take 40 steps on a flat surface) is in widespread use. Neither should be attempted outside a supervised care setting if oximeter reading is < 96%.

#EvidenceCOVID Trisha Greenhalgh, Babak Javid, Matthew Knight, Matt Inada-Kim 21st April 2020

What is the efficacy and safety of rapid exercise tests for exertional desaturation in covid-19?

- Home pulse oximetry can be helpful in monitoring breathlessness
- Useful in the assessment and reassurance of patients

What is the efficacy and safety of rapid exercise tests for exertional desaturation in covid-19?

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#EvidenceCOVID Trisha Greenhalgh, Babak Javid, Matthew Knight, Matt Inada-Kim 21st April 2020
### Long COVID Worksheet

<table>
<thead>
<tr>
<th>Pre-existing Central Sensitivity Syndromes</th>
</tr>
</thead>
<tbody>
<tr>
<td>☐ Long COVID (ME/CFS)</td>
</tr>
<tr>
<td>☐ With features of ME/CFS</td>
</tr>
<tr>
<td>☐ With features of FM</td>
</tr>
<tr>
<td>☐ With features of orthostatic intolerance</td>
</tr>
<tr>
<td>☐ With loss of taste or smell</td>
</tr>
<tr>
<td>☐ Other</td>
</tr>
</tbody>
</table>

### Co-morbid psychiatric problems

- Depression
- Anxiety
- FTSP
- Other

### Differential diagnosis and co-existing conditions that need to be worked up

- OSA
- Chest pain
- Neurological symptoms
- OSA
- POTS
- Other

### Investigations ordered

- Routine Long COVID bloodwork
- CRS
- MR
- Periostal MIBI (avoid exercise stress test)
- Holter
- Overnight oximetry
- Age-appropriate malignancy screening
- MRI
- Pap
- PSA
- Other

### Referrals

- Post COVID Clinic
- Respiratory
- Cardiology
- Neurology
- Other

### Patient Handouts

- Long COVID Patient Resources
- POTS home test
- Other

### Plan for next visit

- Review investigations
- Rapid exercise tests for exertional desaturation
- Review POTS home test
- Other

### Notes

- √
- √
- √
- √
- √
- √
- √
- √
- √
- √
Long COVID – Patient Resources

BC Provincial Health Services Authority
www.phsa.ca/health-info/post-covid-10-care-resources

US Centre for Disease Control

BC Women’s Hospital Complex Chronic Diseases Program
www.bcwomens.ca/health-info/living-with-illness/living-with-complex-chronic-disease

<table>
<thead>
<tr>
<th>TABLE</th>
<th>Online Resources to Support People Living With Long COVID and ME/CFS</th>
</tr>
</thead>
<tbody>
<tr>
<td>Source</td>
<td>Organisation/T opic Resource</td>
</tr>
<tr>
<td>-------</td>
<td>-------------------------------------------------------------</td>
</tr>
<tr>
<td></td>
<td>“How to manage post-viral fatigue after COVID-19: practical advice for people who have been treated in hospital” <a href="https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19">Website</a></td>
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<td>“How to conserve your energy” <a href="https://www.rcot.co.uk/conserving-energy">Website</a></td>
</tr>
<tr>
<td>Dialogues for ME/CFS</td>
<td>“Activity and energy management – pacing” <a href="https://www.dialogues-mecfs.co.uk/films/pacing/">Website</a></td>
</tr>
<tr>
<td>Physios for M.E.</td>
<td>“Pacing” <a href="https://www.physiosforme.com/pacing">Website</a></td>
</tr>
<tr>
<td></td>
<td>“Heart rate monitoring” <a href="https://www.physiosforme.com/heart-rate-monitoring">Website</a></td>
</tr>
<tr>
<td></td>
<td>“Heart rate monitoring” podcast <a href="https://www.physiosforme.com/post/new-podcast-heart-rate-monitoring">Website</a></td>
</tr>
<tr>
<td>Emerge Australia</td>
<td>“Pacing” <a href="https://www.emerge.org.au/Handlers/Download.ashx?IDMF=2a2287ee-b84d-428f-b72e-00da812ddd7c">Website</a></td>
</tr>
<tr>
<td>Long Covid Physio</td>
<td>“Resources” <a href="https://longcovid.physio/resources">Website</a></td>
</tr>
<tr>
<td>Physiopedia</td>
<td>“Long COVID” <a href="https://www.physio-pedia.com/Long_COVID">Website</a></td>
</tr>
<tr>
<td></td>
<td>“Myalgic Encephalomyelitis/Chronic Fatigue Syndrome” <a href="https://physio-pedia.com/Myalgic_Encephalomyelitis/Chronic_Fatigue_Syndrome">Website</a></td>
</tr>
</tbody>
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POTS (Postural Orthostatic Tachycardia Syndrome – Home Test

**What is POTS?**

POTS is a medical condition where the heart races when a person stands up. It is part of the family of conditions called dysautonomias – problems with the autonomic (i.e., automatic) nervous system. In addition to a racing heart, symptoms include lightheadedness, dizziness, and fainting.

**How do you test for POTS?**

You can easily test for POTS at home. The home test is as good, if not better, than specialized testing like tilt-table testing.

1. First thing in the morning, before getting out of bed, take your heart rate: _________
2. Take your heart rate immediately upon standing: _________
3. Repeat your heart rate after:
   - 1 minute _________
   - 3 minutes _________
   - 5 minutes _________
   - 10 minutes _________

Note: Lie down immediately if you feel like you’re going to faint.

Bring the results to your next visit with your family doctor.

You may have POTS if your heart rate spikes to more than 120 beats per minute or increases by more than 30 beats per minute at any time during the 10 minutes. You can stop the test.

**Where Can I learn more about POTS?**

- POTS – Recognitions for Patients
- Diagnosing from a Medical Journal
- Link for POTS
- Exercise for POTS
- Dysautonomia International: POTS
- Lifestyle Adaptations for POTS
- Exercises for Dysautonomia Patients
- Medical Journal Articles on POTS
PROGNOSIS - RULES OF THUMB

• Anecdotally - most patients get better

• Poorer prognosis
  • ? Pre-existing CSS – more = worse
  • ? More severe & greater number of symptoms
  • ? Longer duration of symptoms
  • ? Psychiatric comorbidities

• Transparency
  • We don’t really know
  • More will be revealed…

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Messaging
Most patients recover spontaneously (if slowly) with holistic support, rest, symptomatic treatment, and gradual increase in activity
Long-COVID Primary Care Toolkit

- Overview
- Dysautonomia & POTS
- Mental Health
- Pain
- Central Sensitivity Syndromes
- Approach to Common Symptoms
- New or Changing Symptoms
- Work/Disability/Paperwork
- Principles of CBT