

POST COVID-19

A LONG-COVID PRIMARY CARE TOOLKIT

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No Conflicts of Interest to Declare

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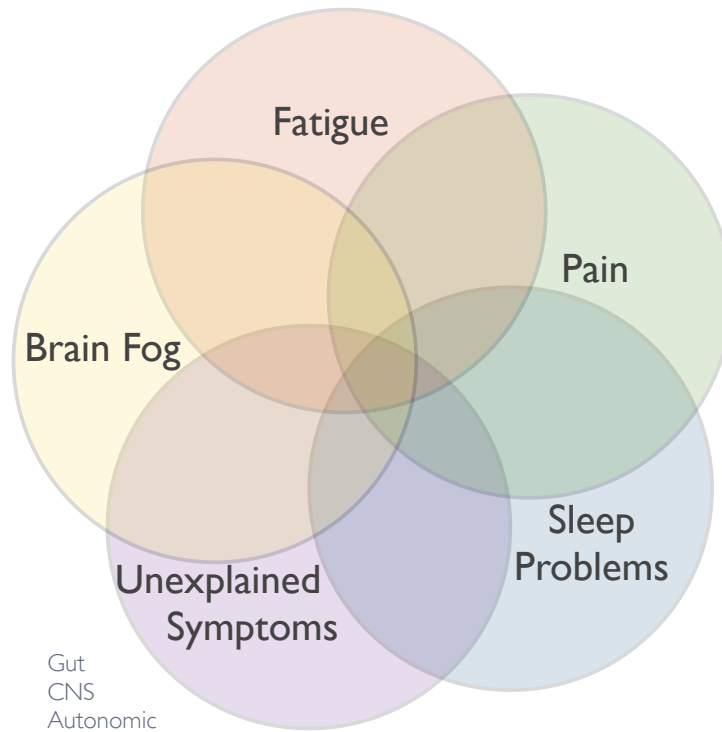
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OVERLAPPING GROUPS



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Research

BMJ

Post-infective and chronic fatigue syndromes precipitated by viral and non-viral pathogens: prospective cohort study

Ian Hickie, Tracey Davenport, Denis Wakefield, Ute Vollmer-Conna, Barbara Cameron, Suzanne D Vernon, William C Reeves, Andrew Lloyd, for the Dubbo Infection Outcomes Study Group

BMJ, doi:10.1136/bmj.38933.585764.AE (published 1 September 2006)

Design Prospective cohort study following patients from the time of acute infection with Epstein-Barr virus (glandular fever), *Coxiella burnetii* (Q fever), or Ross River virus (epidemic polyarthritis).

Results Prolonged illness characterised by disabling fatigue, musculoskeletal pain, neurocognitive difficulties, and mood disturbance was evident in 29 (12%) of 253 participants at six months, of whom 28 (11%) met the diagnostic criteria for chronic fatigue syndrome.

Conclusions A relatively uniform post-infective fatigue syndrome persists in a significant minority of patients for six months or more after clinical infection with several different viral and non-viral micro-organisms. Post-infective fatigue syndrome is a valid illness model for investigating one pathophysiological pathway to chronic fatigue syndrome.

- 11% ME/CFS at 6 mo.
- Consistent across infections
- Related to *host response* rather than pathogen

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Editorial

Post-Ebolavirus disease syndrome: what do we know?

DOI: 10.1586/14787210.2015.1079128

Francisco Javier Carod-Artal^{a,b}
pages 1185-1187

Publishing models and article dates explained

Published online: 13 Aug 2015

Abstract

As the current Zaire ebolavirus disease outbreak in West Africa fades, the health problems of the more than 16,500 survivors have come to light. A wide range of mental and physical symptoms may occur during the convalescence stage. Reported symptoms of “post-Ebolavirus disease syndrome” (PEVDS) include chronic joint and muscle pain, fatigue, anorexia, hearing loss, blurred vision, headache, sleep disturbances, low mood and short-term memory problems. PEVDS has been associated with a decrease in functionality and difficulties to return to work. Further studies are needed to fully categorize the clinical spectrum of PEVDS. Diagnostic criteria and surrogate markers for the early diagnosis of PEVDS, and implementation of specialized health services to treat and follow-up survivors are also needed.

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SPECIAL ARTICLES

Post-Treatment Lyme Syndrome and Central Sensitization

Shweta Batheja, M.B, B.S.
Jenifer A. Nields, M.D.
Alla Landa, Ph.D.,
Brian A. Fallon, M.D., M.P.H.

J Neuropsychiatry Clin Neurosci 25:3, Summer 2013

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No definitive evidence based recommendations exists
We therefore used a pragmatic
approach based in published papers



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**\$1.15 Billion in
Congressional
Funding for Long-
COVID Research
and Clinical Trials**

A circular graphic with a blue border. Inside the circle is a photograph of the United States Capitol building dome, viewed from a low angle. Overlaid on the image is the text "\$1.15 Billion in Congressional Funding for Long-COVID Research and Clinical Trials" in a bold, white, sans-serif font.

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



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A LONG-COVID PRIMARY CARE TOOLKIT

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



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Case

- 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



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Archives of Academic Emergency Medicine. 2021; 9(1): e14
<https://doi.org/10.22037/aaem.v9i1.1058>

OPEN ACCESS

REVIEW ARTICLE

Late Complications of COVID-19; a Systematic Review of Current Evidence

SA. SeyedAlinaghi et al.

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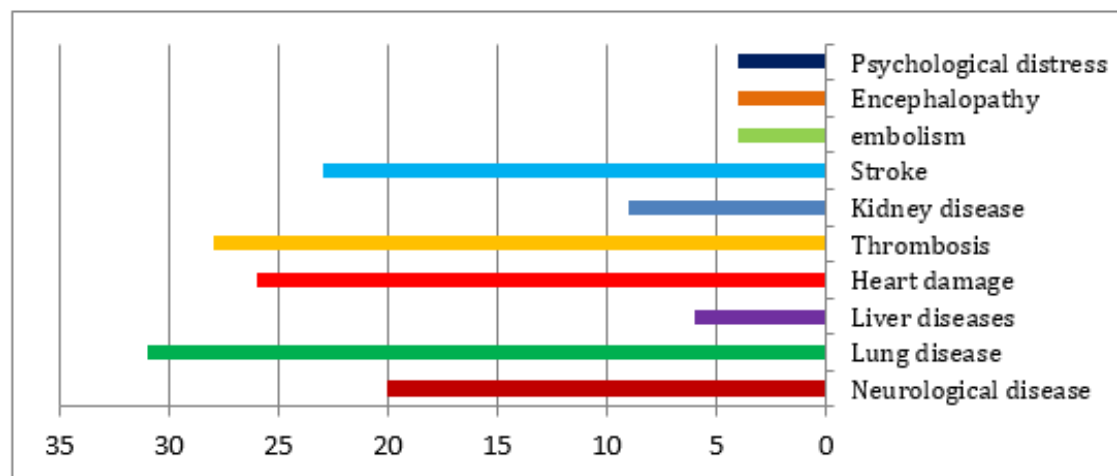


Figure 2: Frequency of identified late complications of COVID-19.

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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?)

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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

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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



RAPID ACCESS TO
CONSULTATIVE EXPERTISE

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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.

Journal of Primary Care & Community Health
Volume 12: 1–8
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- 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

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Long
COVID




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- Mayo Clinic Rochester
- Post acute sequelae of SARS-CoV-2 infection (PASC)
 - Heterogeneous group - Dr. Jansen Triage Presentation
- 3 Groups
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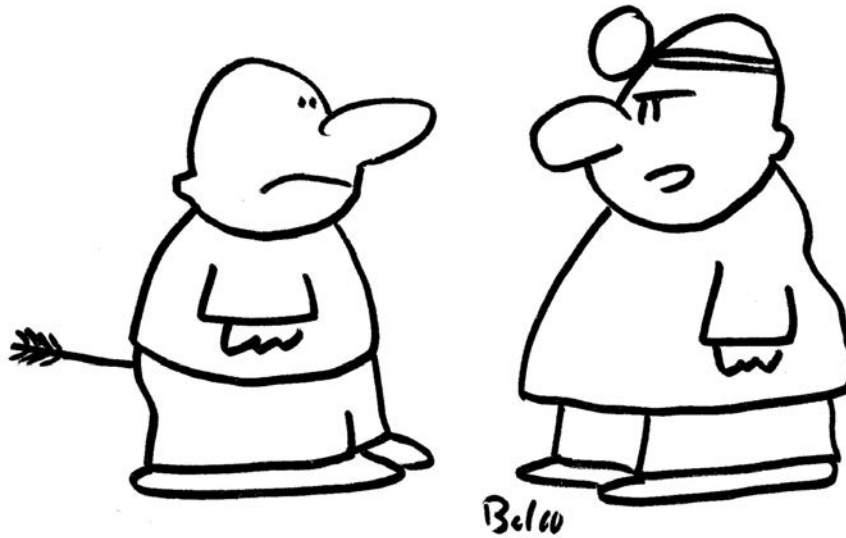
* Messaging

NOT
psychosomatic
or
somatiform

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MEDICAL GASLIGHTING



"How do I know you're not malingering?"

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News & Analysis

Medical News & Perspectives

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

Rita Rubin, MA

JAMA October 13, 2020 Volume 324, Number 14

- 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




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- 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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Messaging
Long COVID
≠
ME/CFS

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- Post COVID Syndrome (Long COVID): 42/465 (9%)
- 1/3 male - 2/3 female (2:1 female)
- Age 21 - 74 (average 46)
- Most common symptoms
 - Pain (90%)
 - Fatigue (74%) - ?? PEM
 - Dyspnea (43%)
 - Orthostatic intolerance (38%)

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Review

Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)—A Systemic Review and Comparison of Clinical Presentation and Symptomatology

Timothy L. Wong * and Danielle J. Weitzer

Medicina 2021, 57, 418. <https://doi.org/10.3390/medicina57050418>

<https://www.mdpi.com/journal/medicina>

- “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

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SIMON DÉCARY, PT, PhD¹ • ISABELLE GABOURY, PhD² • SABRINA POIRIER³ • CHRISTIANE GARCIA⁴
SCOTT SIMPSON, BA, CWC⁵ • MICHELLE BULL, PhD⁶ • DARREN BROWN, MSc, MRes⁷ • FRÉDÉRIQUE DAIGLE, MSc¹

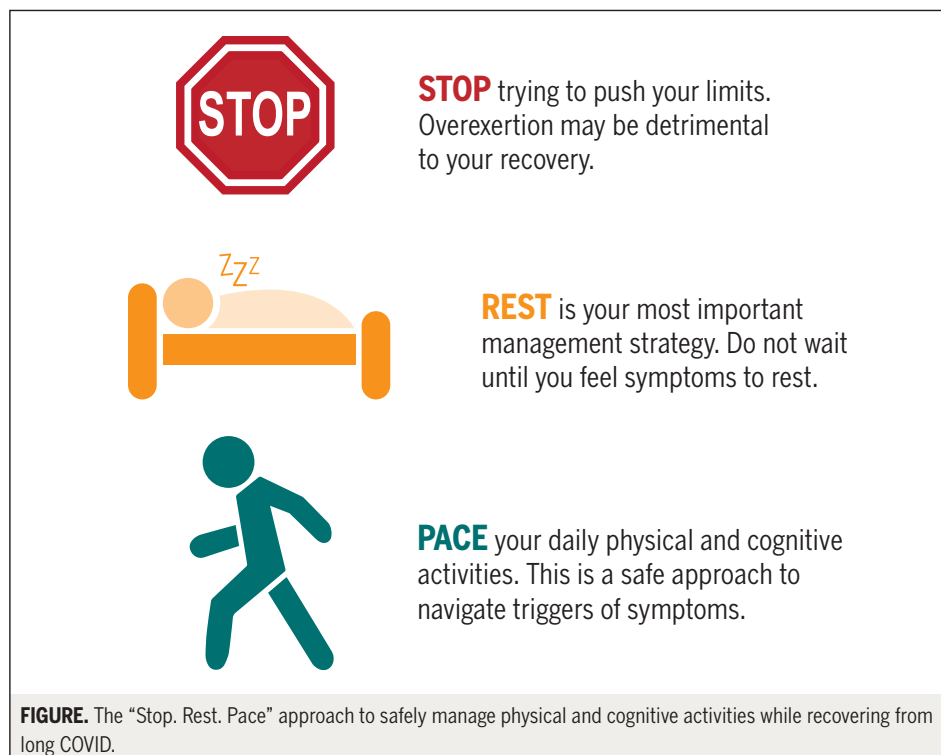
Humility and Acceptance: Working Within Our Limits With Long COVID and Myalgic Encephalomyelitis/Chronic Fatigue Syndrome

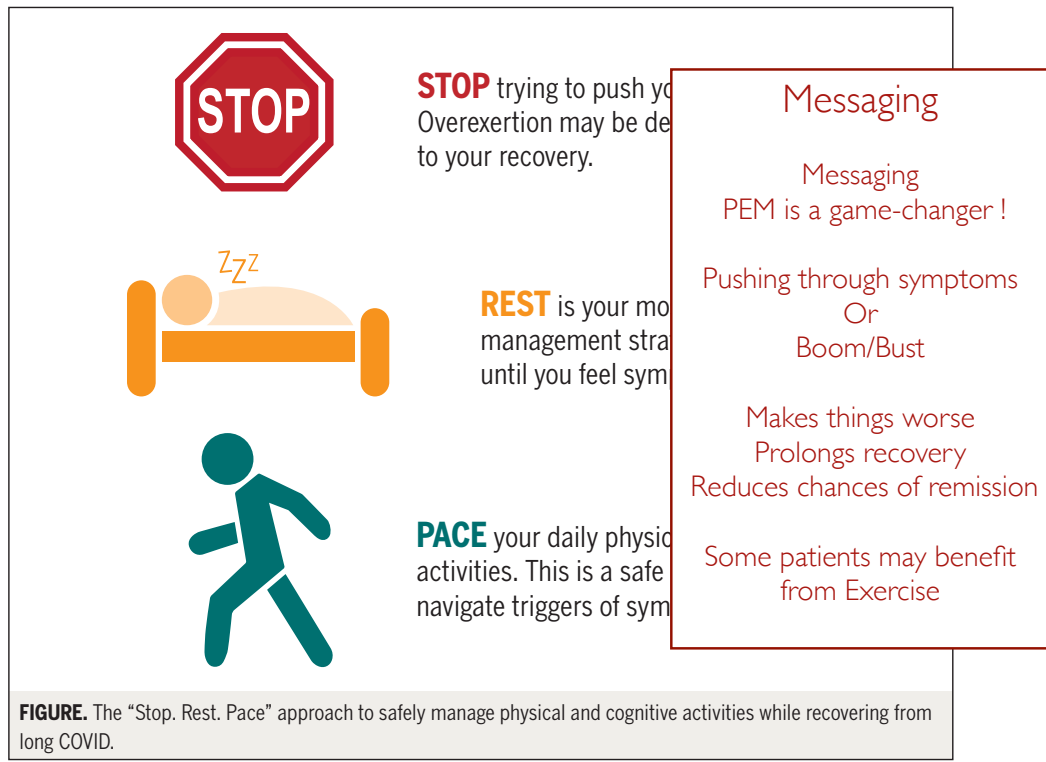
JOURNAL OF ORTHOPAEDIC & SPORTS PHYSICAL THERAPY | VOLUME 51 | NUMBER 5 | MAY 2021 | 197

- 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 !

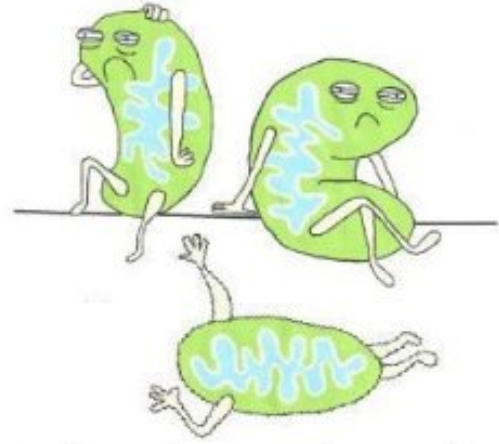
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Diagnosis and Treatment of Chronic Fatigue Syndrome



it's mitochondria, not hypochondria

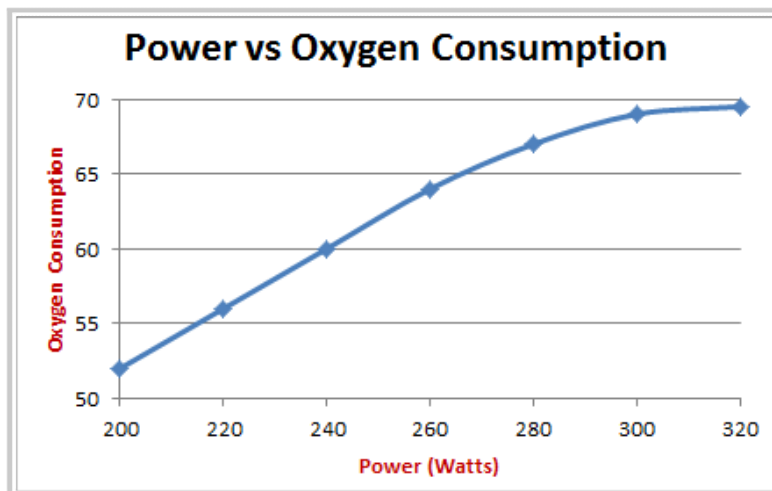
POST-EXERTIONAL MALAISE



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VO₂ MAX



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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

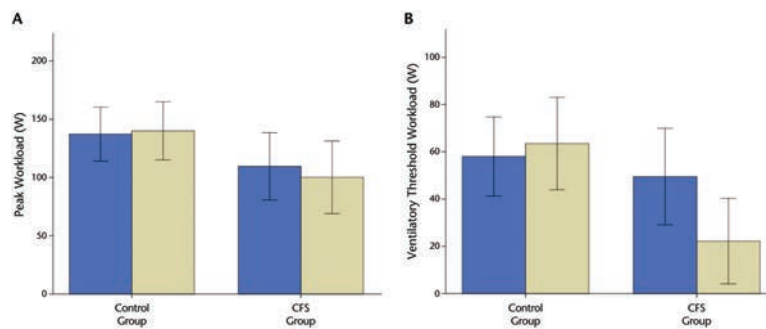


Figure 2. Measurements of workload at peak exercise (A) and at the ventilatory threshold (B) in participants with chronic fatigue syndrome (CFS) and control participants during cardiopulmonary exercise test 1 (blue bars) and cardiopulmonary exercise test 2 (gold bars). Error bars represent 1 standard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

November 2013

Volume 93 Number 11 Physical Therapy 1489

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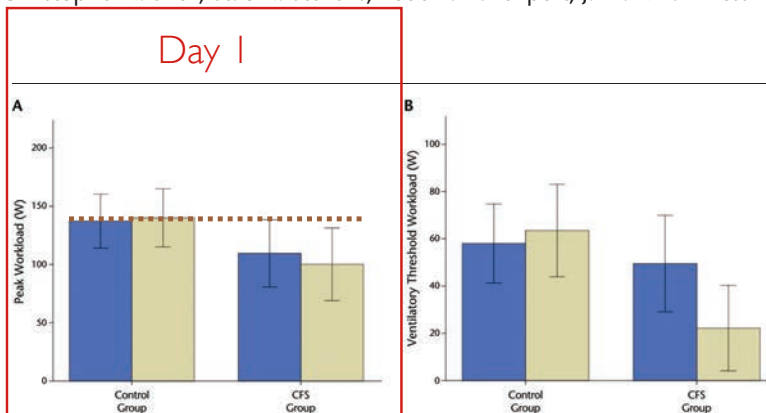


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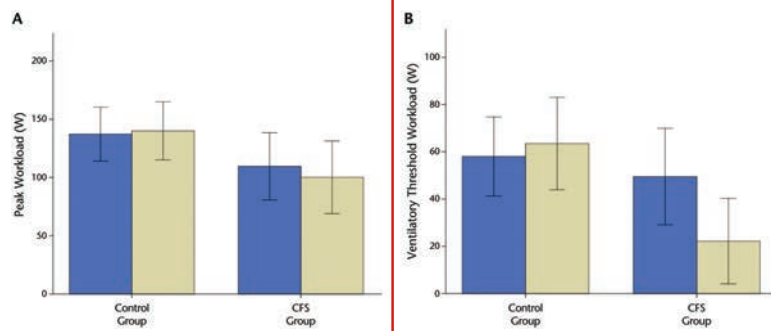


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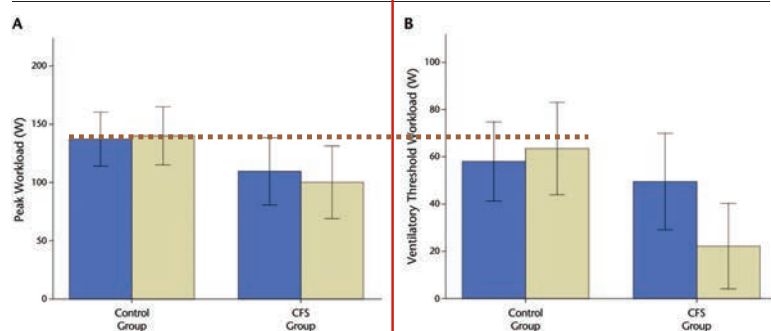


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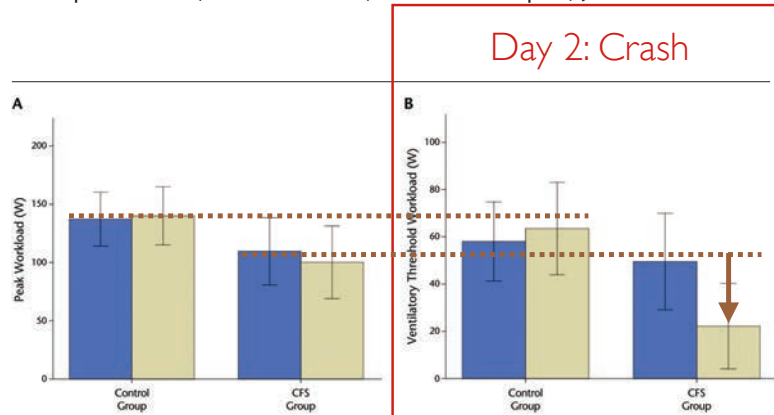


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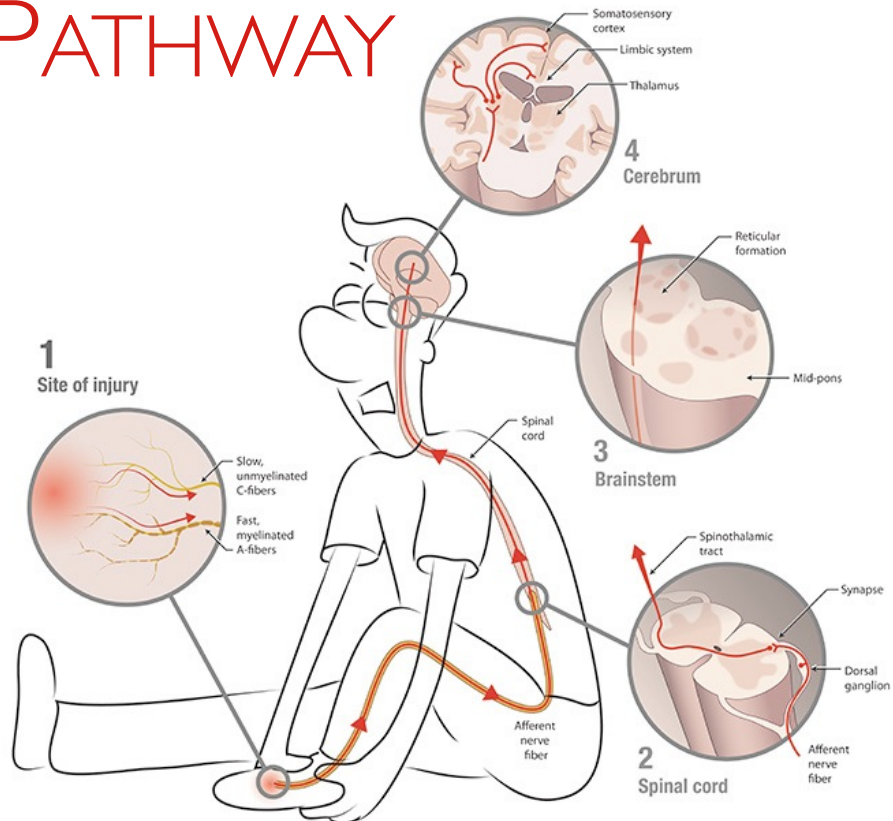
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PAIN PATHWAY



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CHRONIC PAIN – A NEW TYPE

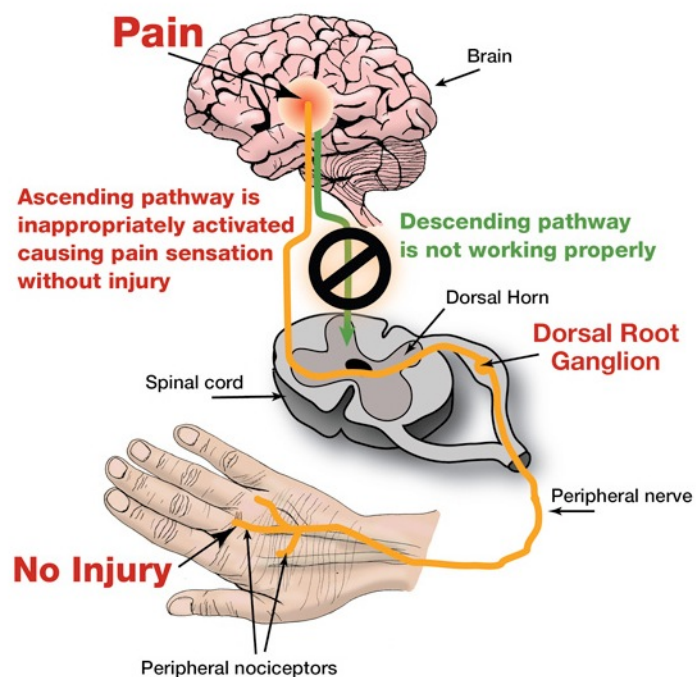
- Pain falls into three categories:
 - Nociceptive – inflammation and damage
 - Neuropathic – damaged or irritated nerves
 - *Nociplastic*
 - Volume knob for pain is turned up
 - “Central sensitization”
 - e.g., FM
- “Noci-” is from the Latin for “to do harm”
- A person might have more than one type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

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CHRONIC PAIN

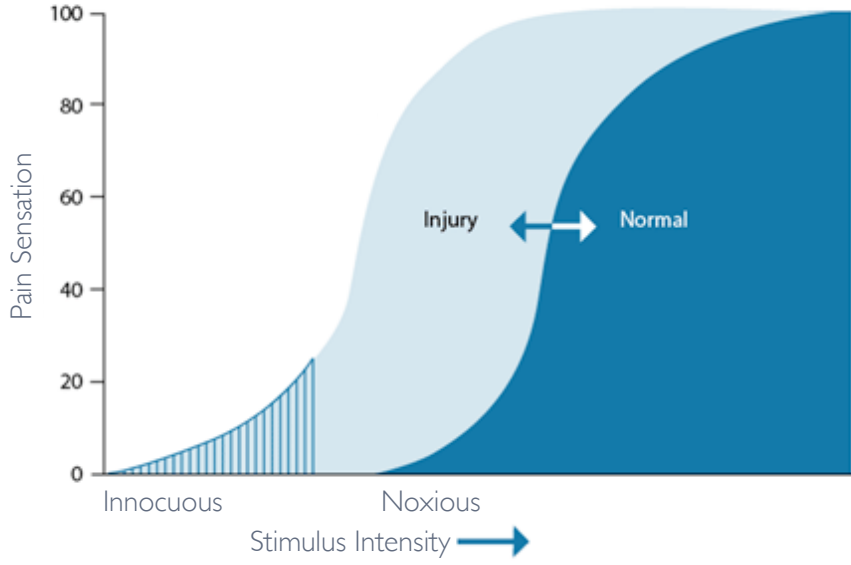
Sensitization
&
Amplification



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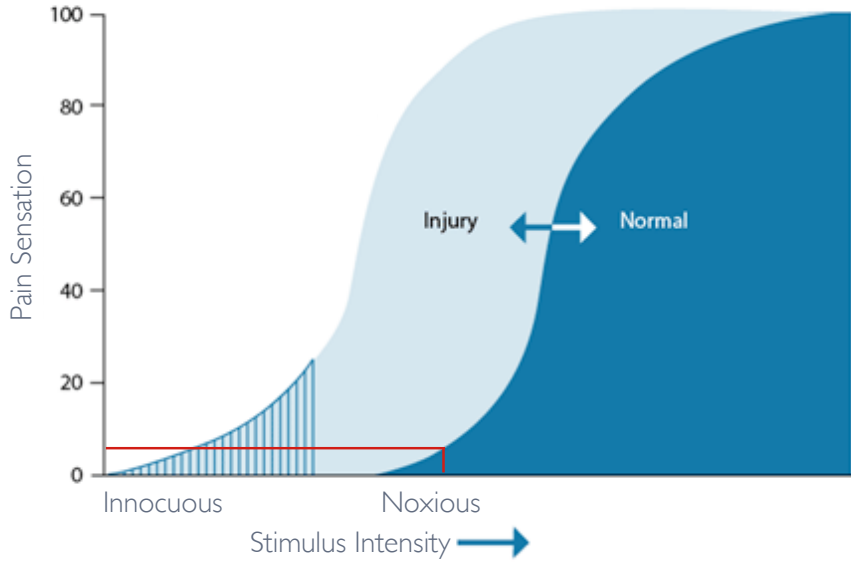
CHRONIC PAIN: SENSITIVITY SHIFT



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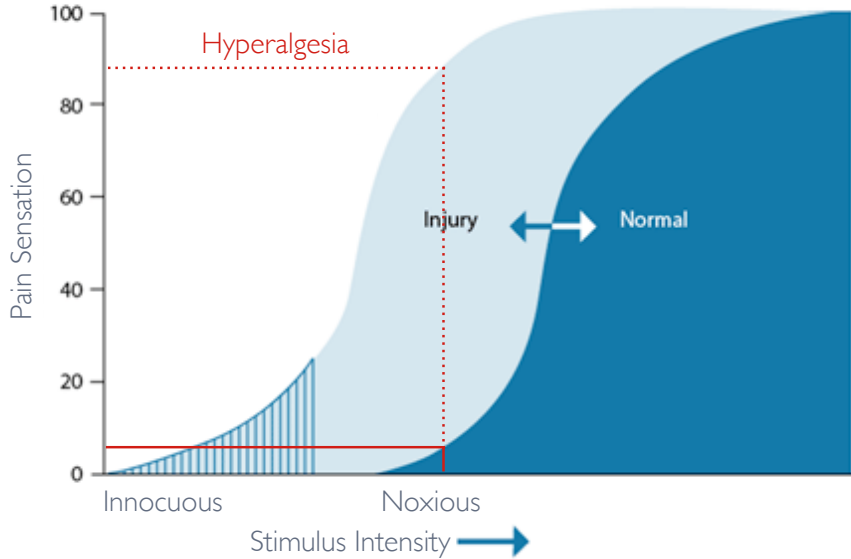
CHRONIC PAIN: SENSITIVITY SHIFT



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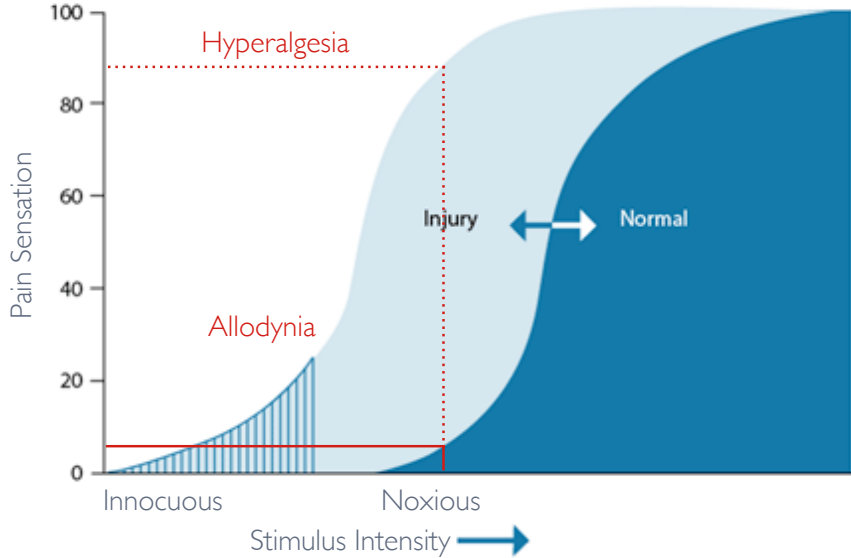
CHRONIC PAIN: SENSITIVITY SHIFT



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CHRONIC PAIN: SENSITIVITY SHIFT

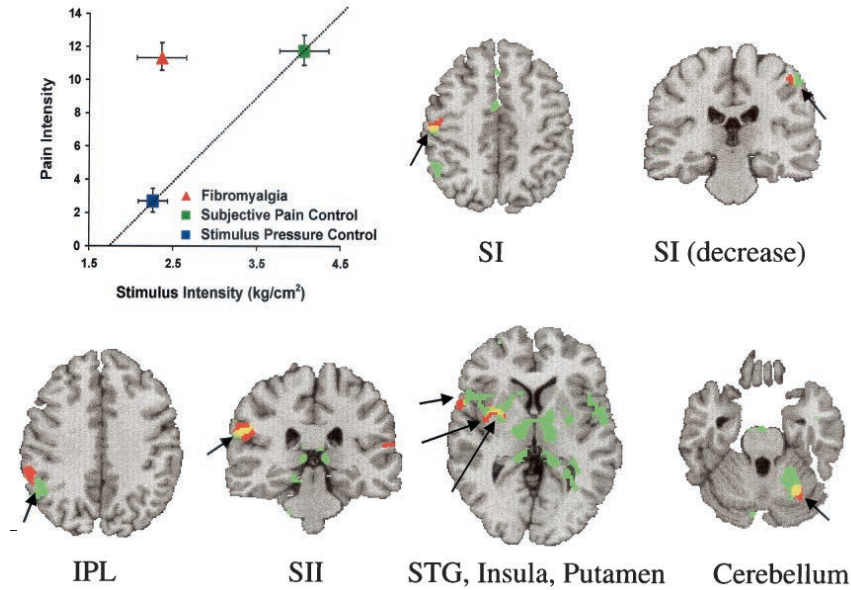


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Functional Magnetic Resonance Imaging Evidence of Augmented Pain Processing in Fibromyalgia

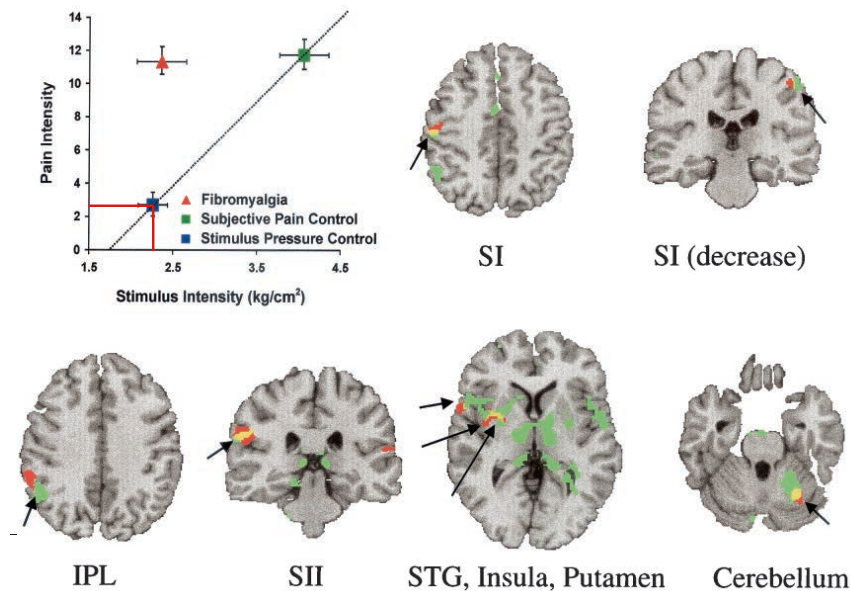
Richard H. Gracely,¹ Frank Petzke,² Julie M. Wolf,³ and Daniel J. Clauw²



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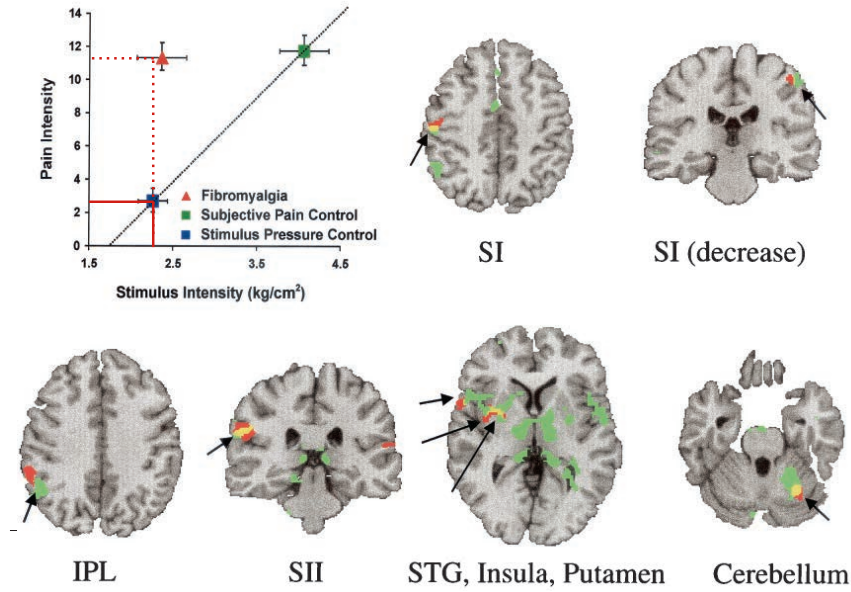
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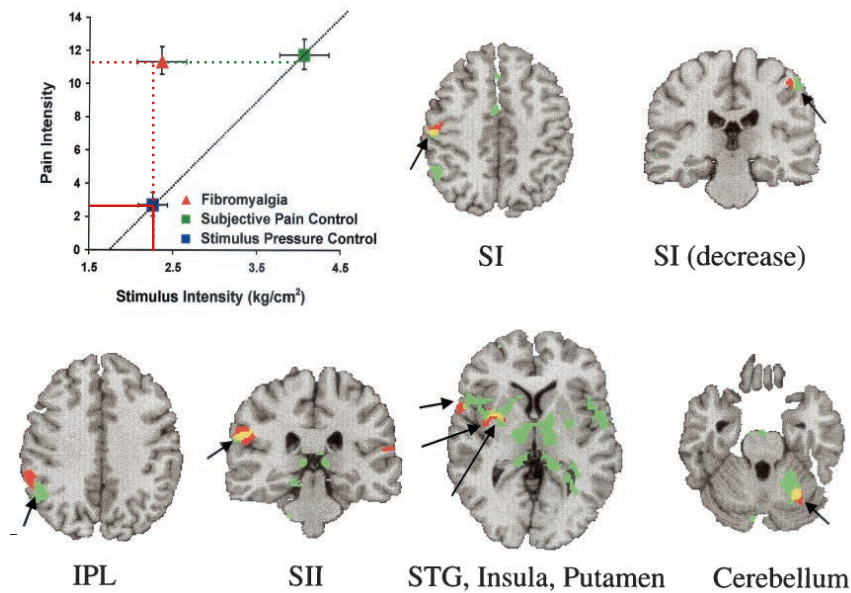
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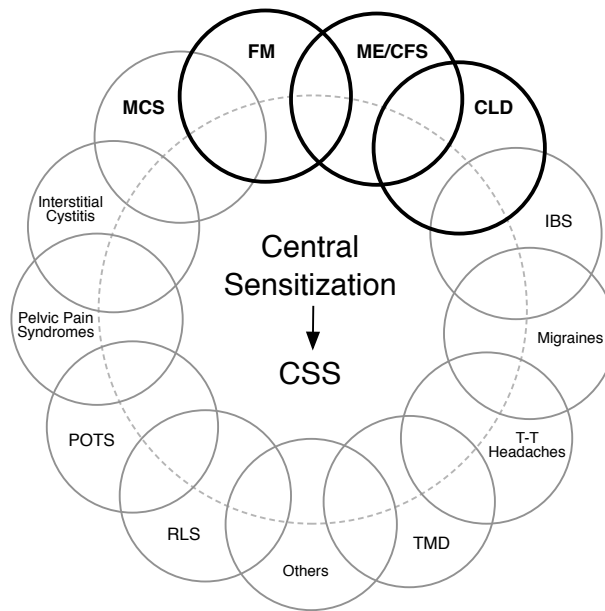
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CENTRAL SENSITIVITY SYNDROMES



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

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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

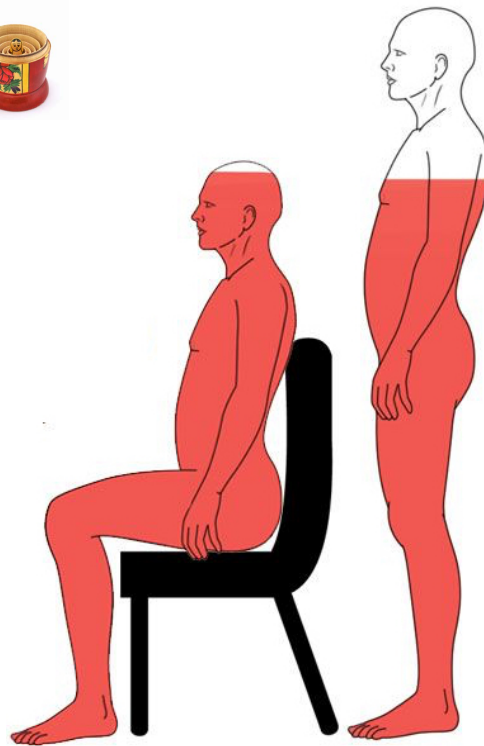


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POTS : POSTURAL ORTHOSTATIC TACHYCARDIA SYNDROME

- 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



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<p>ME/CFS: 2003 Canadian Clinical Working Case Definition</p> <p><input type="checkbox"/> 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</p> <p><input type="checkbox"/> 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</p> <p><input type="checkbox"/> 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.</p> <p><input type="checkbox"/> 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</p> <p><input type="checkbox"/> Neurocognitive Manifestations (2 or more)</p> <table border="0"> <tr> <td><input type="checkbox"/> confusion</td> <td><input type="checkbox"/> impaired concentration</td> </tr> <tr> <td><input type="checkbox"/> short-term memory</td> <td><input type="checkbox"/> disorientation</td> </tr> <tr> <td><input type="checkbox"/> categorizing and word retrieval</td> <td></td> </tr> <tr> <td><input type="checkbox"/> perceptual and sensory disturbances</td> <td></td> </tr> <tr> <td><input type="checkbox"/> ataxia</td> <td><input type="checkbox"/> muscle weakness</td> </tr> <tr> <td><input type="checkbox"/> fasciculation</td> <td><input type="checkbox"/> cognitive overload</td> </tr> <tr> <td><input type="checkbox"/> emotional overload</td> <td><input type="checkbox"/> hypersensitivity to light or sound</td> </tr> </table> <p><input type="checkbox"/> At least one symptom from three of the following categories:</p> <p>Autonomic Manifestations</p> <table border="0"> <tr> <td><input type="checkbox"/> orthostatic intolerance—neurally mediated hypotension (NMH)</td> <td></td> </tr> <tr> <td><input type="checkbox"/> postural orthostatic tachycardia syndrome (POTS)</td> <td></td> </tr> <tr> <td><input type="checkbox"/> delayed postural hypotension</td> <td><input type="checkbox"/> light-headedness</td> </tr> <tr> <td><input type="checkbox"/> extreme pallor</td> <td><input type="checkbox"/> nausea and IBS</td> </tr> <tr> <td><input type="checkbox"/> urinary frequency and bladder dysfunction</td> <td></td> </tr> <tr> <td><input type="checkbox"/> palpitations with or without cardiac arrhythmias</td> <td></td> </tr> <tr> <td><input type="checkbox"/> exertional dyspnea.</td> <td></td> </tr> </table> <p>Neuroendocrine Manifestations</p> <table border="0"> <tr> <td><input type="checkbox"/> loss of thermostatic stability—subnormal body temp; marked diurnal fluctuation</td> <td></td> </tr> <tr> <td><input type="checkbox"/> sweating episodes</td> <td><input type="checkbox"/> recurrent feelings of feverishness</td> </tr> <tr> <td><input type="checkbox"/> cold extremities</td> <td><input type="checkbox"/> intolerance heat and cold</td> </tr> <tr> <td><input type="checkbox"/> marked weight change</td> <td><input type="checkbox"/> anorexia or abnormal appetite</td> </tr> <tr> <td><input type="checkbox"/> loss of adaptability and worsening of symptoms with stress</td> <td></td> </tr> </table> <p>Immune Manifestations</p> <table border="0"> <tr> <td><input type="checkbox"/> tender lymph nodes</td> <td><input type="checkbox"/> recurrent sore throat</td> </tr> <tr> <td><input type="checkbox"/> recurrent flu-like symptoms</td> <td><input type="checkbox"/> general malaise</td> </tr> <tr> <td><input type="checkbox"/> new sensitivities to food, medications and/or chemicals.</td> <td></td> </tr> </table> <p><input type="checkbox"/> The illness has persisted for at least 6 months</p>	<input type="checkbox"/> confusion	<input type="checkbox"/> impaired concentration	<input type="checkbox"/> short-term memory	<input type="checkbox"/> disorientation	<input type="checkbox"/> categorizing and word retrieval		<input type="checkbox"/> perceptual and sensory disturbances		<input type="checkbox"/> ataxia	<input type="checkbox"/> muscle weakness	<input type="checkbox"/> fasciculation	<input type="checkbox"/> cognitive overload	<input type="checkbox"/> emotional overload	<input type="checkbox"/> hypersensitivity to light or sound	<input type="checkbox"/> orthostatic intolerance—neurally mediated hypotension (NMH)		<input type="checkbox"/> postural orthostatic tachycardia syndrome (POTS)		<input type="checkbox"/> delayed postural hypotension	<input type="checkbox"/> light-headedness	<input type="checkbox"/> extreme pallor	<input type="checkbox"/> nausea and IBS	<input type="checkbox"/> urinary frequency and bladder dysfunction		<input type="checkbox"/> palpitations with or without cardiac arrhythmias		<input type="checkbox"/> exertional dyspnea.		<input type="checkbox"/> loss of thermostatic stability—subnormal body temp; 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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.</p>	
<input type="checkbox"/> confusion	<input type="checkbox"/> impaired concentration																																													
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ME/CFS:

2003 Canadian Clinical Working Case Definition

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

At least one symptom from three of the following categories:

Autonomic Manifestations

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

Neuroendocrine Manifestations

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

Immune Manifestations

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

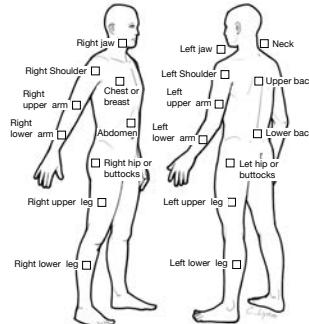
The illness has persisted for at least 6 months



2016 Revised Fibromyalgia Diagnostic Criteria Seminars in Arthritis and Rheumatism 46 (2016) 319 - 329

Widespread Pain Index (WPI score range 0 - 19)

Pain and tenderness during the past week



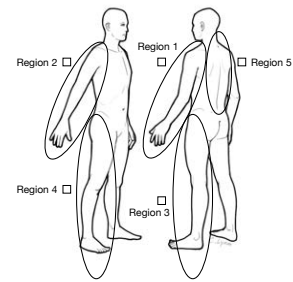
Widespread Pain Index Total (maximum 19) _____

All of the following criteria must be met to make a diagnosis of Fibromyalgia

1. WPI \geq 7 and SSS \geq 5 OR WPI 4 to 6 and SSS \geq 9 No Yes
2. Generalized pain: at least 4/5 regions No Yes
3. Have the symptoms in section 3 and pain been present at a similar clinical level for at least 3 months? No Yes

Fulfills all diagnostic criteria for FM No Yes

Generalized pain - do not count jaws, chest, or abdomen



Generalized Pain Total (maximum 5) _____

Symptom Severity Score (SSS score range 0 - 12)

Over the past week:

No problem

Slight or mild problem: generally mild or intermittent

Moderate problem: considerable problems; often present and/or at a moderate level

Severe problem: continuous, life-disturbing

	No problem	Slight/mild	Moderate	Severe
Fatigue	<input type="checkbox"/> = 0	<input type="checkbox"/> = 1	<input type="checkbox"/> = 2	<input type="checkbox"/> = 3
Trouble thinking or remembering	<input type="checkbox"/> = 0	<input type="checkbox"/> = 1	<input type="checkbox"/> = 2	<input type="checkbox"/> = 3
Waking up tired (unrefreshed)	<input type="checkbox"/> = 0	<input type="checkbox"/> = 1	<input type="checkbox"/> = 2	<input type="checkbox"/> = 3

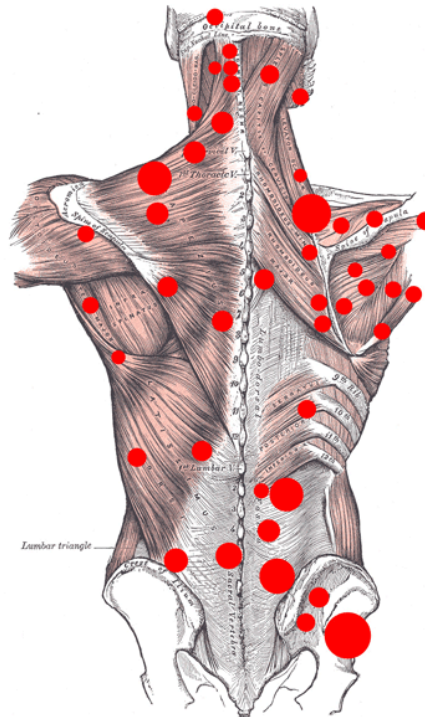
During the past 6 months:

Pain or cramps in the abdomen	<input type="checkbox"/> No = 0	<input type="checkbox"/> Yes = 1
Depression	<input type="checkbox"/> No = 0	<input type="checkbox"/> Yes = 1
Headache	<input type="checkbox"/> No = 0	<input type="checkbox"/> Yes = 1

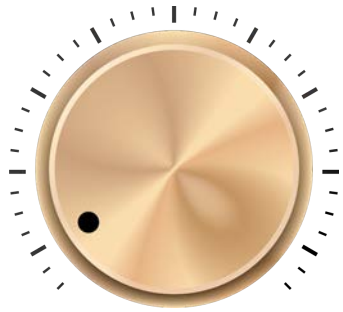
Symptom Severity Score Total (maximum 12) _____

MYOFASCIAL PAIN SYNDROME (MPS)

- Myalgias
- Fatigue
- Sleep disturbance
- Cognitive symptoms
- Unexplained dizziness
- Autonomic phenomena
- ? Localized FM



AMPLIFICATION & DISTORTION



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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



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PRINCIPLES — YOU GOT THIS

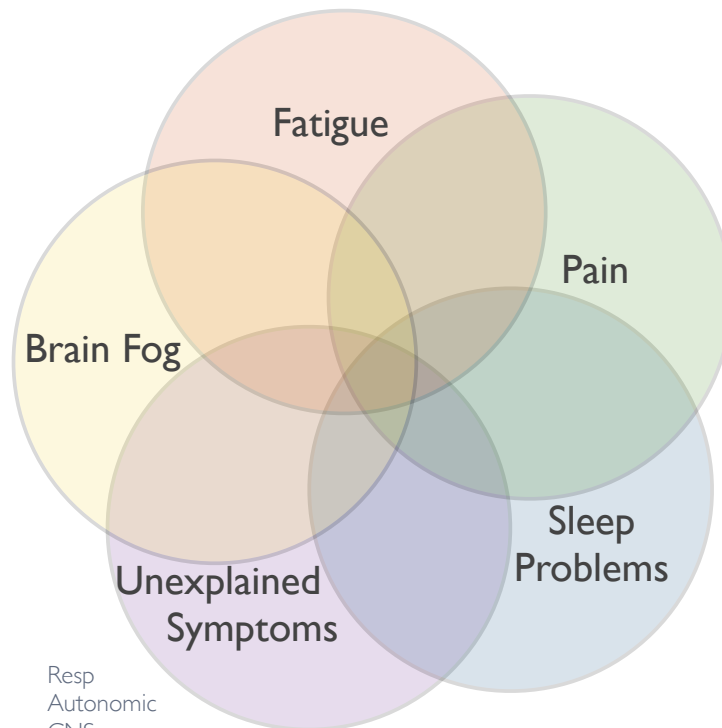
- Patient centred
- Trauma-informed care
 - www.cdc.gov/cpr/infographics/6_principles_trauma_info.htm
- Shared decision making
- Optimization of quality of life and function
- Self-management strategies
- Symptom focused
 - Red flags & risk factors
- Patient education
- Transparency - incomplete/changing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



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PHYSICAL SYMPTOMS



Resp
Autonomic
CNS
GI

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Long COVID Symptom Inventory

Name:

Date of COVID onset:

Positive COVID test: Yes No

Please circle all symptoms that apply.

<i>Fatigue</i>	Physical faigue	Mental fatigue	Decreased activity tolerance	Decreased exercise capacity	Post-exertional malaise
<i>Pain</i>	Muscle pain	Joint pain	Headaches	Chest pain	Chest tightness
	Abdominal pain	Pain all over	Other pain		
<i>Sleep disturbance</i>	Unrefreshing sleep	Difficulty falling asleep	Difficulty staying asleep		
<i>Brain fog</i>	Poor memory	Difficulty concentrating	Difficulty finding words	Easily overwhelmed	
	Diorientation	Confusion			
<i>Unexplained Symptoms</i>	<i>Lung</i>	Shortness of breath	Difficulty taking a deep breath	Cough	Wheezing
		<i>Autonomic</i>	Lightheadedness	Dizziness	Fainting
	Palpitations		Racing heart	Irregular heart	
	Feverish		Night sweats	Heat/cold intolerance	
	<i>Digestive</i>	Loss of appetite	Nausea	Vomiting	Significant weight change
		Diarrhea	Constipation	Abdominal bloating	Abdominal cramps
	<i>Nervous system</i>	Loss of taste or smell	Blurry vision	Vertigo	Ringing in the ears
		Numbness and tingling	Muscle weakness	Hypersensitivity to light or sound	Problems with balance and coordination
	<i>Immune</i>	Sore throat	Tender lymph nodes	recurrent flu-like symptoms	Sensitivities to food/medications/chemicals
	<i>Other</i>	Hair loss	Rash	Menstrual cycle irregularities	Urinary frequency
<i>Psychiatric</i>	Depression	Anxiety	Mood swings	PTSD	

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Long COVID Symptom Inventory

Name:

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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Long COVID Symptom Inventory

Name:

Case

Date of COVID onset: Jan 2021

Positive COVID test: Yes No

Please circle all symptoms that apply.

Fatigue	Physical faigue	Mental fatigue	Decreased activity tolerance	Decreased exercise capacity	Post-exertional malaise
Pain	Muscle pain	Joint pain	Headaches	Chest pain	Chest tightness
	Abdominal pain	Pain all over	Other pain		
Sleep disturbance	Unrefreshing sleep	Difficulty falling asleep	Difficulty staying asleep		
Brain fog	Poor memory	Difficulty concentrating	Difficulty finding words	Easily overwhelmed	
	Diorientation	Confusion			
Unexplained Symptoms	Lung	Shortness of breath	Difficulty taking a deep breath	Cough	Wheezing
	Autonomic	Lightheadedness	Dizziness	Fainting	Low blood pressure
		Palpitations	Racing heart	Irregular heart	
		Feverish	Night sweats	Heat/cold intolerance	
	Digestive	Loss of appetite	Nausea	Vomiting	Significant weight change
		Diarrhea	Constipation	Abdominal bloating	Abdominal cramps
	Nervous system	Loss of taste or smell	Blurry vision	Vertigo	Ringing in the ears
		Numbness and tingling	Muscle weakness	Hypersensitivity to light or sound	Problems with balance and coordination
	Immune	Sore throat	Tender lymph nodes	recurrent flu-like symptoms	Sensitivities to food/medications/chemicals
Other	Hair loss	Rash	Menstrual cycle irregularities	Urinary frequency	
Psychiatric	Depression	Anxiety	Mood swings	PTSD	

Long COVID Symptom Inventory

Name:

Case

Date of COVID onset: Jan 2021

Positive COVID test: Yes No

Please circle all symptoms that apply.

✓ Fatigue	Physical faigue	Mental fatigue	Decreased activity tolerance	Decreased exercise capacity	Post-exertional malaise *
✓ Pain	Muscle pain	Joint pain	Headaches	Chest pain	Chest tightness
	Abdominal pain	Pain all over *	Other pain		
✓ Sleep disturbance	Unrefreshing sleep	Difficulty falling asleep	Difficulty staying asleep		
✓ Brain fog	Poor memory	Difficulty concentrating	Difficulty finding words	Easily overwhelmed	
	Diorientation	Confusion			
✓ Unexplained Symptoms	Lung	Shortness of breath	Difficulty taking a deep breath	Cough	Wheezing
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		Numbness and tingling	Muscle weakness	Hypersensitivity to light or sound	Problems with balance and coordination
	Immune	Sore throat	Tender lymph nodes	recurrent flu-like symptoms	Sensitivities to food/medications/chemicals
Other	Hair loss	Rash	Menstrual cycle irregularities	Urinary frequency	
✓ Psychiatric	Depression	Anxiety	Mood swings	PTSD	

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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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



BASIC WORKUP FOR LONG-COVID

- Long COVID does NOT require an exhaustive workup
- 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

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BASIC WORKUP FOR LONG-COVID

- Long COVID does NOT require an exhaustive workup
- 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



Case

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

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BASIC WORKUP FOR LONG-COVID

Basic Workup for Long COVID

- Long COVID is NOT diagnoses of exclusion and do NOT require an exhaustive workup
- Patients require an appropriate but limited workup
- Using the pre-printed Symptoms Inventory helpful
- Initial evaluation should include:
 - Identification of **Red Flags and Risk Factors** requiring further evaluation
 - Limited medical work-up
 - +/- Rapid exercise tests for exertional desaturation in covid-19
 - Baseline pulse oximeter should be > 96%
 - One minute doing sit-to-stand as fast as they can (supervised)
 - Drop of 3% requires further work-up
 - +/- Age-appropriate malignancy screening
 - +/- OSA screen (e.g., STOP BANG questionnaire)
- The initial evaluation provides a **differential diagnosis** and identifies **possible co-existing conditions**

Screening blood work

- CBC + diff
- Lytes, urea, creatinine
- Mg, Phos, Ca
- Fasting blood sugar
- CRP
- Liver tests: AST, ALT, GGT, ALP, bilirubin, albumin
- CK
- TSH
- Ferritin (< 50 associated with fatigue even in the absence of anemia)
- Urinalysis
- HIV
- HBV
- HCV
- +/- CXR
- +/- FIT test (age-appropriate screening)
- +/- anti-TTG (GI symptoms)

Note: ANA is not recommended as a screening test



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www.cebm.net/oxford-covid-19/

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

Greenhalgh T, Javid B, Knight M, et al. Oxford COVID-19 Evidence Service, 2020.

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

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

Greenhalgh T, Javid B, Knight M, et al. Oxford COVID-19 Evidence Service, 2020.

- 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?

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

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Long COVID Worksheet

Name: _____

<p>Long COVID</p> <ul style="list-style-type: none"> <input type="checkbox"/> With features of ME/CFS <input type="checkbox"/> With features of FM <input type="checkbox"/> With features of orthostatic intolerance <input type="checkbox"/> With loss of taste or smell <input type="checkbox"/> Other 	<p>Pre-existing Central Sensitivity Syndromes</p> <ul style="list-style-type: none"> <input type="checkbox"/> None <input type="checkbox"/> Chronic Fatigue Syndrome (ME/CFS) <input type="checkbox"/> Fibromyalgia <input type="checkbox"/> Headaches (tension type) <input type="checkbox"/> IBS (irritable bowel syndrome) <input type="checkbox"/> Interstitial Cystitis <input type="checkbox"/> Irritable larynx syndrome <input type="checkbox"/> Migraines <input type="checkbox"/> Myofascial pain syndrome <input type="checkbox"/> Non-cardiac chest pain <input type="checkbox"/> Pelvic pain syndrome & related disorders <input type="checkbox"/> POTS (postural orthostatic tachycardia syndrome) <input type="checkbox"/> PTSD (post-traumatic stress disorder) <input type="checkbox"/> Restless leg syndrome <input type="checkbox"/> Temporomandibular disorders (TMD/TMJ) <input type="checkbox"/> Multiple chemical sensitivities/environmental sensitivities <input type="checkbox"/> Other:
<p>Co-morbid psychiatric problems</p> <ul style="list-style-type: none"> <input type="checkbox"/> Depression <input type="checkbox"/> Anxiety <input type="checkbox"/> PTSD <input type="checkbox"/> Other 	<p>Investigations ordered</p> <ul style="list-style-type: none"> <input type="checkbox"/> Routine Long COVID bloodwork <input type="checkbox"/> CXR <input type="checkbox"/> EKG <input type="checkbox"/> Persantine MIBI (avoid exercise stress test) <input type="checkbox"/> Holter <input type="checkbox"/> Overnight oximetry <input type="checkbox"/> Age appropriate malignancy screening <ul style="list-style-type: none"> <input type="checkbox"/> FIT <input type="checkbox"/> Mammogram <input type="checkbox"/> Pap <input type="checkbox"/> PSA <input type="checkbox"/> Other
<p>Differential diagnosis and co-existing conditions that need to be worked up</p> <ul style="list-style-type: none"> <input type="checkbox"/> Dyspnea <input type="checkbox"/> Chest pain <input type="checkbox"/> Neurological symptoms <input type="checkbox"/> OSA <input type="checkbox"/> POTS <input type="checkbox"/> Other 	<p>Referrals</p> <ul style="list-style-type: none"> <input type="checkbox"/> Post COVID Clinic <input type="checkbox"/> Respiriology <input type="checkbox"/> Cardiology <input type="checkbox"/> Neurology <input type="checkbox"/> Other
<p>Referrals</p> <ul style="list-style-type: none"> <input type="checkbox"/> Post COVID Clinic <input type="checkbox"/> Respiriology <input type="checkbox"/> Cardiology <input type="checkbox"/> Neurology <input type="checkbox"/> Other 	<p>Patient Handouts</p> <ul style="list-style-type: none"> <input type="checkbox"/> Long COVID Patient Resources <input type="checkbox"/> POTS home test <input type="checkbox"/> Other
<p>Plan for next visit</p> <ul style="list-style-type: none"> <input type="checkbox"/> Review investigations <input type="checkbox"/> Rapid exercise tests for exertional desaturation <input type="checkbox"/> Review POTS home test <input type="checkbox"/> Other 	<p>Notes</p>



Long COVID Worksheet Name: _____

<p><input checked="" type="checkbox"/> Long COVID</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> With features of ME/CFS <input checked="" type="checkbox"/> With features of FM <input checked="" type="checkbox"/> With features of orthostatic intolerance <input checked="" type="checkbox"/> With loss of taste or smell <input type="checkbox"/> Other <p>Co-morbid psychiatric problems</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> Depression <input type="checkbox"/> Anxiety <input type="checkbox"/> PTSD <input type="checkbox"/> Other <p>Differential diagnosis and co-existing conditions that need to be worked up</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> Dyspnea <input type="checkbox"/> Chest pain <input type="checkbox"/> Neurological symptoms <input type="checkbox"/> OSA <input checked="" type="checkbox"/> POTS <input type="checkbox"/> Other <p>Referrals</p> <ul style="list-style-type: none"> <input type="checkbox"/> Post COVID Clinic <input type="checkbox"/> Respiriology <input type="checkbox"/> Cardiology <input type="checkbox"/> Neurology <input type="checkbox"/> Other <p>Plan for next visit</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> Review investigations <input checked="" type="checkbox"/> Rapid exercise tests for exertional desaturation <input checked="" type="checkbox"/> Review POTS home test <input type="checkbox"/> Other 	<p>Pre-existing Central Sensitivity Syndromes</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> None <input type="checkbox"/> Chronic Fatigue Syndrome (ME/CFS) <input type="checkbox"/> Fibromyalgia <input type="checkbox"/> Headaches (tension type) <input type="checkbox"/> IBS (irritable bowel syndrome) <input type="checkbox"/> Interstitial Cystitis <input type="checkbox"/> Irritable larynx syndrome <input type="checkbox"/> Migraines <input type="checkbox"/> Myofascial pain syndrome <input type="checkbox"/> Non-cardiac chest pain <input type="checkbox"/> Pelvic pain syndrome & related disorders <input type="checkbox"/> POTS (postural orthostatic tachycardia syndrome) <input type="checkbox"/> PTSD (post-traumatic stress disorder) <input type="checkbox"/> Restless leg syndrome <input type="checkbox"/> Temporomandibular disorders (TMD/TMJ) <input type="checkbox"/> Multiple chemical sensitivities/environmental sensitivities <input type="checkbox"/> Other: <p>Investigations ordered</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> Routine Long COVID bloodwork <input type="checkbox"/> CXR <input type="checkbox"/> EKG <input type="checkbox"/> Persantine MIBI (avoid exercise stress test) <input type="checkbox"/> Holter <input type="checkbox"/> Overnight oximetry <input type="checkbox"/> Age appropriate malignancy screening <input checked="" type="checkbox"/> FIT <input type="checkbox"/> Mammogram <input type="checkbox"/> Pap <input type="checkbox"/> PSA <input type="checkbox"/> Other <p>Patient Handouts</p> <ul style="list-style-type: none"> <input checked="" type="checkbox"/> Long COVID Patient Resources <input checked="" type="checkbox"/> POTS home test <input type="checkbox"/> Other <p>Notes</p>
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Case



Long COVID – Patient Resources

BC Provincial Health Services Authority
www.phsa.ca/health-info/post-covid-19-care-recovery

US Centre for Disease Control
www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-resources-future.html

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

TABLE	ONLINE RESOURCES TO SUPPORT PEOPLE LIVING WITH LONG COVID AND ME/CFS
Organization/Topic	Resource
Royal College of Occupational Therapists	
"Recovering from COVID-19 post-viral fatigue and conserving energy"	https://www.rcot.co.uk/recovering-covid-19-post-viral-fatigue-and-conserving-energy
"How to manage post-viral fatigue after COVID-19: practical advice for people who have been treated in hospital"	https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19
"How to manage post-viral fatigue after COVID-19: practical advice for people who have recovered at home"	https://www.rcot.co.uk/how-manage-post-viral-fatigue-after-covid-19-0
"How to conserve your energy"	https://www.rcot.co.uk/conserving-energy
Diagnosis for ME/CFS	
Activity and energy management – pacing"	https://www.dialagues-meds.co.uk/films/pacing/
Physio for ME	
"Pacing"	https://www.physiosforme.com/pacing
"Heart rate monitoring"	https://www.physiosforme.com/heart-rate-monitoring
"Heart rate monitoring" podcast	https://www.physiosforme.com/podcast/heart-rate-monitoring
#MEAction	
"Pacing and management guide for ME/CFS"	https://www.meaction.net/wp-content/uploads/2020/03/Pacing-and-Management-Guide-for-ME_CFS-4.pdf
Action for ME	
"Pacing for people with ME: a detailed guide to managing energy rest and activity for adults with mild/moderate ME"	https://www.actionforme.org.uk/uploads/Action_Pacing_for_people_with_me_booklet_Feb-2020.pdf
Energy Australia	
"Pacing"	https://www.energy.org.au/Handlers/Download.ashx?ID=26289&=5844-4284-420e-010d62646f7c
The ME Association	
"ME: A summary review: assessing PEM (post-exertional malaise)"	https://meassociation.org.uk/wp-content/uploads/ME-Research-Review-Assessing-PEM-in-ME-CFS-25.03.20.pdf
Long Covid Physio	
"Resources"	https://longcovid.physiosources
Physiosforma	
"Long COVID"	https://www.physio-pedia.com/Long_COVID
"Myalgic Encephalomyelitis/Chronic Fatigue Syndrome"	https://physio-pedia.com/Myalgic_Encephalomyelitis/Chronic_Fatigue_Syndrome

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 - Perspectives for Patients](#)
[Review From a Medical Journal](#)
[Salt for POTS](#)
[Exercise for POTS](#)
[Dysautonomia International: POTS](#)
[Lifestyle Adaptations for POTS](#)
[Exercises for Dysautonomia Patients](#)
[Medical Journal Articles on POTS](#)

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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

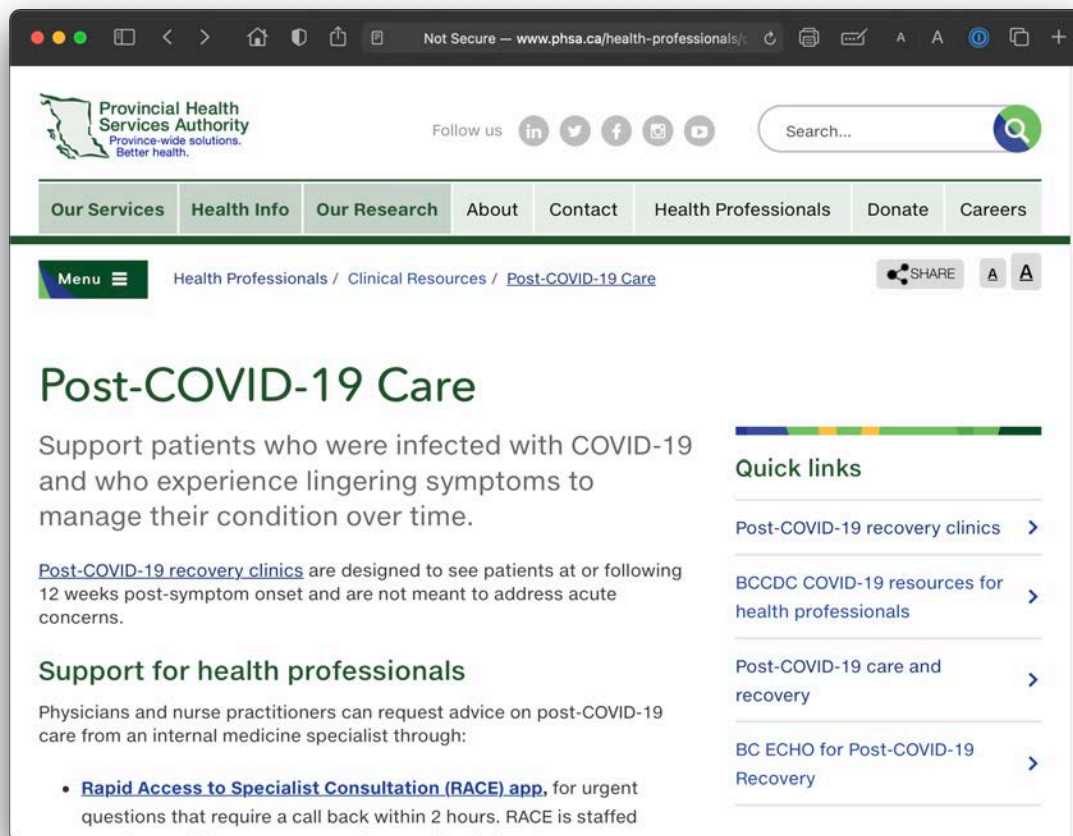
Most patients recover spontaneously (if slowly) with holistic support, rest, symptomatic treatment, and gradual increase in activity



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www.phsa.ca/health-professionals/clinical-resources/post-covid-19-care



The screenshot shows the website for the Provincial Health Services Authority (PHSA). The page is titled "Post-COVID-19 Care" and provides information for health professionals. The main content includes a description of support for patients with lingering symptoms, a section for "Support for health professionals" mentioning the RACE app, and a "Quick links" sidebar with links to recovery clinics, BCCDC resources, and BC ECHO for Post-COVID-19 Recovery.

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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



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QUESTIONS...

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