# Long Covid

## *Current Understanding and Best Practices*

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# Learning Objectives

1. Describe Post-COVID conditions, risk factors, and basic epidemiology
2. Describe the basic pathophysiology
3. **Be familiar with the commonly presenting symptoms and conditions**
4. **Perform a medical evaluation and develop individualized plan of care**
5. Understand the impact to well-being and importance of healthcare disparities
6. **Be familiar with the clinical toolkit necessary to support your practice**

# Patient Story

Angela is 55-year-old black female, works in tech-industry, divorced, lives with her adult daughter.

Prior to getting COVID-19 in April 2020, she worked 50 hours a week and enjoyed travelling. Now she feels like she is wearing a lead weight on her body, after doing household chores she suffers profound exhaustion for days, and her heart races on occasion. She has an altered sense of smell that is slowly improving. She has difficulty finding words, staying focused, multi-tasking, and is mentally exhausted from going to the market. She has unrestful sleep every night. Her past medical history is otherwise unremarkable.

She has had extensive medical studies (blood, urine, radiology) all without significant findings. She was seen by a pulmonologist and a cardiologist who diagnosed her condition as anxiety-based and told 'think happy thoughts.'

She is unable to work, feels like a burden on her daughter and dismissed by the medical community, doesn't understand what is wrong with her, she is scared she could die, and contemplates if life is worth living.

# Angela's Long COVID Footprint

## HPI

- Wearing a lead weight on her body, after doing household chores she suffers profound exhaustion for days
- Heart races on occasion
- Difficulty finding words, staying focused, multi-tasking, and is mentally exhausted when going to the market
- She has unrestful sleep every night
- Scared she could die, and contemplates if life is worth living

## Long COVID Manifestations

- Post-Exertional Malaise
- Dysautonomia - POTS
- Brain Fog
- Sleep Disturbances
- Depression; PTSD

# Basic Epidemiology

# What is Long COVID?

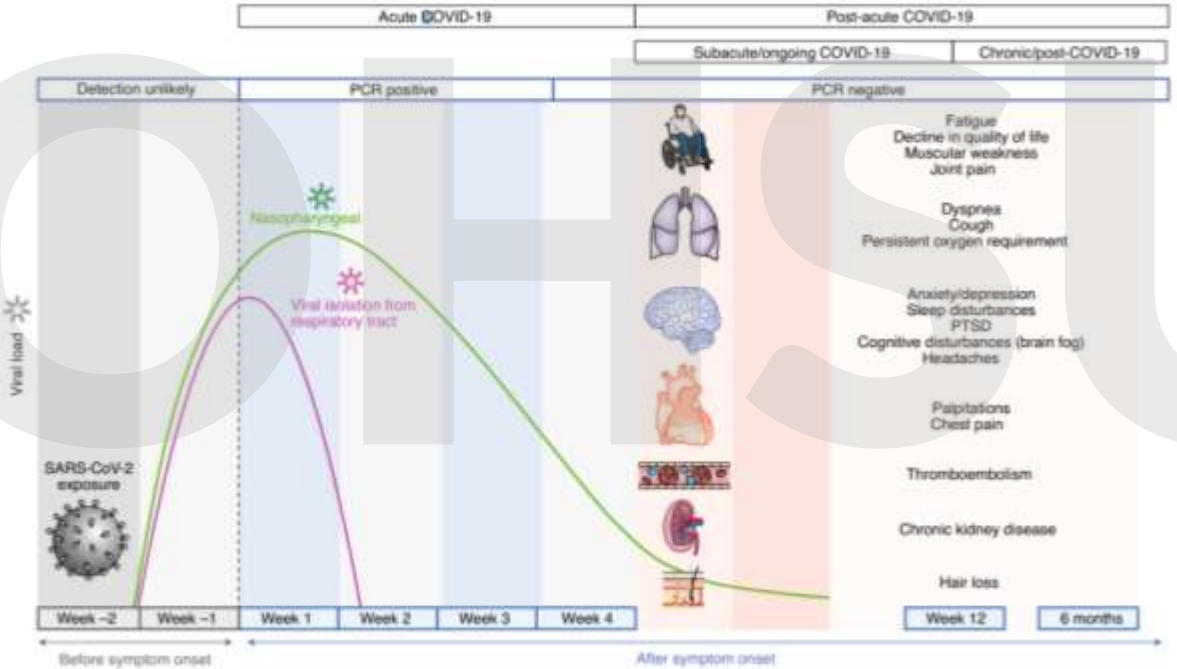
## Post-COVID Conditions

- CDC: Range of new, returning, or ongoing health problems people can experience four or more weeks following initial SARS-CoV-2 infection
- Also be known
  - **PASC** = Post Acute Sequela of SARS-CoV-2 (Research term)
  - **PACS** = Post-Acute Covid Syndrome
  - Chronic COVID
  - Long-haul COVID

# Post-COVID Conditions

- **Some conditions are specific** to effects of SARS-CoV-2
  - e.g. anosmia, brain fog, POTS, post-exertional malaise…
- **Some conditions are not-specific** to effects of SARS-CoV-2
  - E.g. deconditioning, treatment side effects, bereavement, effects of isolation, Post-ICU syndrome, etc.
- All the above = **Post-COVID conditions**

# Disease Course



# Epidemiology

- COVID-19
  - US: 80 million infected 1 million deaths
  - Globally: 500 million infected 6 million deaths
- Long COVID prevalence may range from 10-30% of all COVID-19 cases
  - US: **8 - 24 million**
  - Globally: **50 - 150 million**
- Small percentage of COVID, yet significant impact on public health

# Who is Likely to Get Long COVID?

- True frequency and severity unknown
  - **Occurs with mild acute illness or even asymptomatic**
  - Affects all ages; Most common ages 35-69; Females > Males
- Risk-factors and biological associations are not well understood
  - SARS-CoV-2 RNAemia, EBV viremia, autoantibodies, T2 DM
  - > 5 symptoms during initial infection and/or severity
  - No associations with racial or ethnic backgrounds but **Minorities are disproportionately affected by COVID**

# COVID Vaccination

- **The risk of long COVID is half in fully vaccinated patients!**
- Side effects typically more pronounced and last a few days longer than than general population
- After Vaccination:
  - Most report no change in symptoms
  - Minority get better
  - Smaller minority get worse
- **Reinfection relapses are significant & profoundly demoralizing**

# Clinical Presentation

- Broad symptom overview
- Uniquely important conditions
- Recovery & prognosis

# What are the Characteristic Symptoms?

- **Fatigue / Post-Exertional Malaise**
- Breathing Pain
- **Brain Fog**
- **Palpitations / tachycardia**
- **Sleep disruption**
- GI problems
- **Depression / Anxiety / PTSD**
- **Anosmia**
- Headache
- Paresthesias
- Rashes / urticaria / flushing
- Joint & muscle pain
- Many others – less frequent



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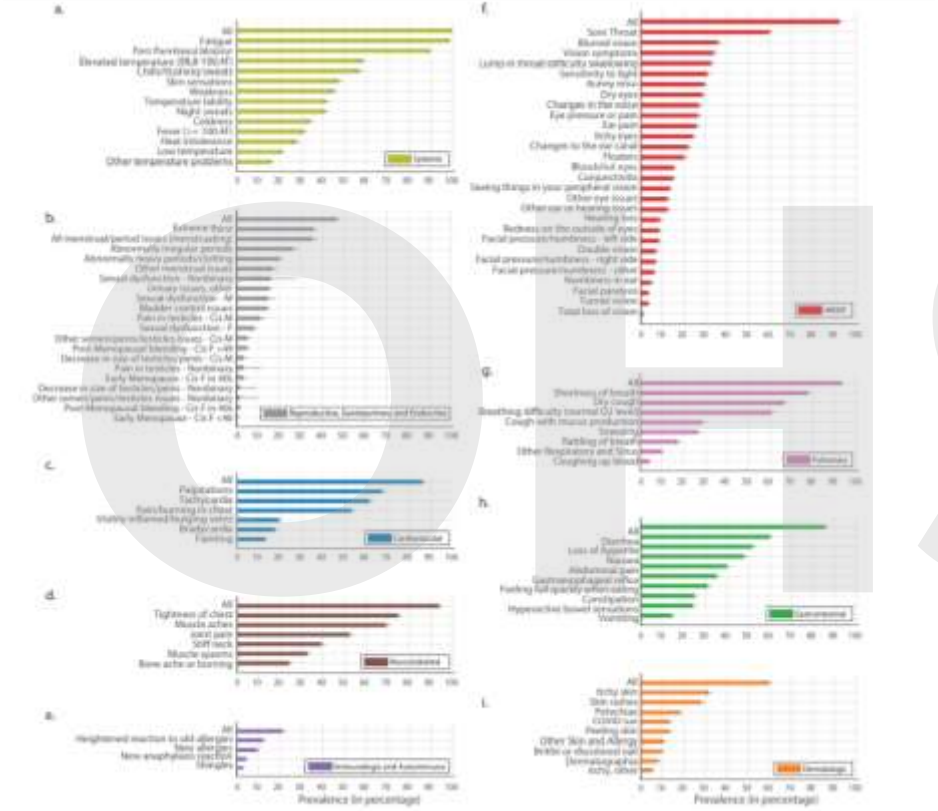
# What are the Characteristic Symptoms?

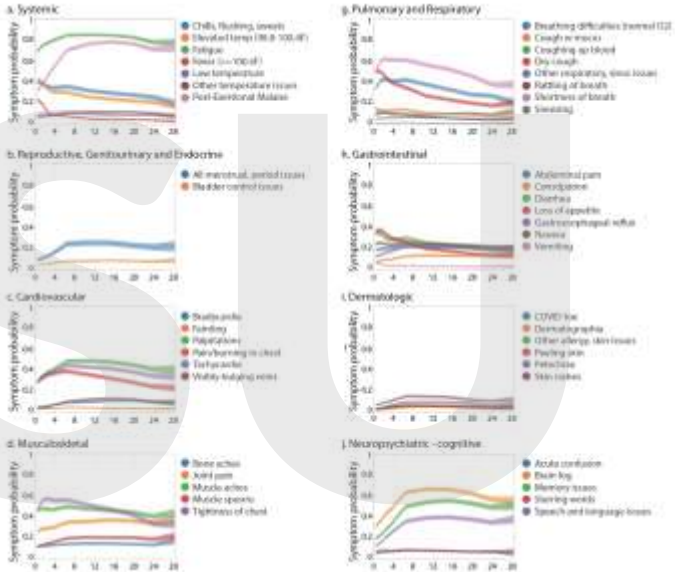
- **Fatigue / Post-Exertional Malaise**
- **Breathing Pain**
- **Brain Fog**
- **Palpitations / tachycardia**
- **Sleep disruption**
- **GI problems**
- **Depression / Anxiety / PTSD**
- **Anosmia**
- **Headache**
- **Nerve abnormalities**
- **Joint & muscle pain**
- **Many others - less frequent**

# Full Inventory of Symptoms

## Patients Researchers Leading the Way!

- A global network of citizen scientists connected by technology
  - March 2020, the founder of BodyPolitic became sick with COVID and started a patient support group
  - Then a world-wide patient-led research group was formed
- They conducted unprecedented research on patient symptoms
  - 3,752 participants from 56 countries.
  - Questionnaire included 205 symptoms over 9 organ systems.




Davis H et al. Characterizing Long COVID in an International Cohort: 7 Months of Symptoms and Their Impact. July 15, 2021: https://www.thelancet.com/journals/eclinm/article/PIIS2589-5370(21)00299-6/fulltext

# Post-Exertional Malaise (PEM)
## A Hallmark Symptom

- **Increased physical or mental exertion on a 'good day' followed by severe exhaustion & worsening of sx requiring several days / weeks of recovery**
- Disabling exhaustion disproportionate to the effort exerted
- Triggered by physical activities (e.g. bathing), cognitive activities, and stress.
- **Onset is delayed 12 to 72 hours** followed by an unpredictable severity of sx
- Different from fatigue = feeling of weariness, tiredness, or lack of energy
- Patients with Long COVID can meet criteria for ME/CFS*



** See references for dx criteria*

# Dysautonomia


- Several different medical conditions causing malfunction of the ANS
- POTS (Postural Orthostatic Tachycardia Syndrome) *
  - Lightheadedness, tachycardia, chest pains, sob, GI upset, shaking
  - Increase HR ≥ 30 bpm, or > 120 bpm, within first 10m of standing
- Other dysautonomia conditions and they can be secondary to other diseases
- Long COVID pts. often have clustering of sx suggestive of some level of dysautonomia



** See references for dx and treatment considerations*

# Cognitive Impairment (Brain Fog)

- Primary cognitive symptoms include difficulty with:
  - Word retrieval
  - Working memory
  - Reasoning
  - Problem solving
  - Attention
  - Executive functioning
  - Spatial planning
- Presents similarly to patients with Post-Concussion Syndrome

# Mast Cell Activation Syndrome

Irregular mast cell activation leading to episodic multisystem symptoms:

- Hives and flushing
- Non-pitting and angioedema
- Nausea, vomiting, diarrhea, and abdominal pain
- Conjunctivitis, rhinitis, and sore throat
- Wheezing
- Palpitations and anxiety
- Hypotension
- Headache and brain fog

# Small Fiber Neuropathy (SFN)

Damage to the small diameter unmyelinated C-fibers and the thinly myelinated A-delta fibers

- Mediate pain, thermal sensation, and autonomic function
  - Pain: Burning, prickling, shooting, and/or aching
  - Autonomic: Dizziness when standing, palpitations, abnormal sweating, dry mouth, eyes, or skin, gastrointestinal & urinary dysfunction, sexual dysfunction

- Different Flavors
  - SFN without dysautonomia
  - Dysautonomia without distal or non-length dependent neuropathy
  - Late SFN with small fibers being burned (numb) without biopsy evidence

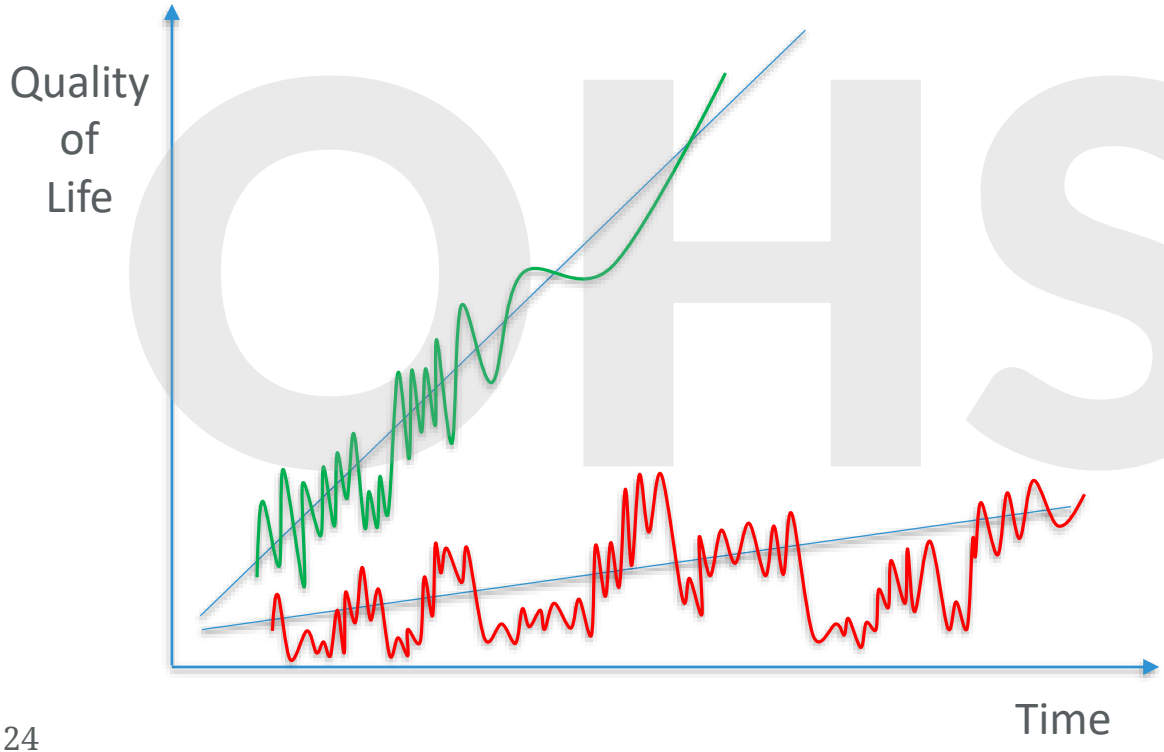
# All Symptoms Flow with the Tide

- Symptoms tend to cluster together during cycles of improvement or worsening
- Worsening of all symptoms characteristically follows patterns of post-exertional malaise & stress
- Challenging to discern the complex of overlapping symptoms and conditions

# Recovery & Prognosis

- Most patients improve and will recover in time
  - Symptoms are unpredictably remitting and relapsing
- Recovery timeline is variable
  - Weeks - Months
  - Beyond 12 Months = ‘Long Long Haulers’
- Unable to predict the recovery timeline
- Recovery is often prolonged with complex pre-existing comorbidities
- **Pacing is essential to a faster recovery!!!**

# Improving Recovery Trajectories




Goals:

- Accelerate and smoothen improvement trajectory
- Decrease number of relapses
- Empower patients with a vision of recovery



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# Impact on Well-Being

*Understanding the Impact of Long COVID at a Personal Level*

# Angela's Story Revisited

## Reported Problems

- Wearing a lead weight on her body, after doing household chores she suffers profound exhaustion for days
- Heart races on occasion.
- Difficulty finding words, staying focused, multi-tasking, and is mentally exhausted when going to the market.
- She has unrestful sleep every night.
- Scared she could die, and contemplates if life is worth living.

## Manifestations of Long COVID

- Fatigue / Post-Exertional Malaise
- Dysautonomia (Dysregulated Heart rhythm)
- Brain Fog
- Sleep Disturbances
- Depression & PTSD

# Angela's Well Being

- **Physical well-being**: PEM, tachy, brain fog, insomnia
- **Economic well-being**: No money, savings, dependents
- **Social well-being**: isolated, discrimination
- **Emotional well-being**: overwhelmed, scared
- **Psychological well-being**: depressed, traumatized
- **Life satisfaction**: Not worth living

- **It is not all in their head, but suicidal ideation might be!**

# Validation is Paramount

- Validation, empathy, and trauma informed patient-centered care is truly the best medicine
- Universally confirmed by veritably every patient

# Evaluation and Management

*Knowledgeable clinicians, earning trust, providing thoughtful, high-quality care*

1. *Pathophysiology*
2. *Best Practices*
3. *Management for Characteristic Symptoms*

# Pathophysiology of Long Covid?

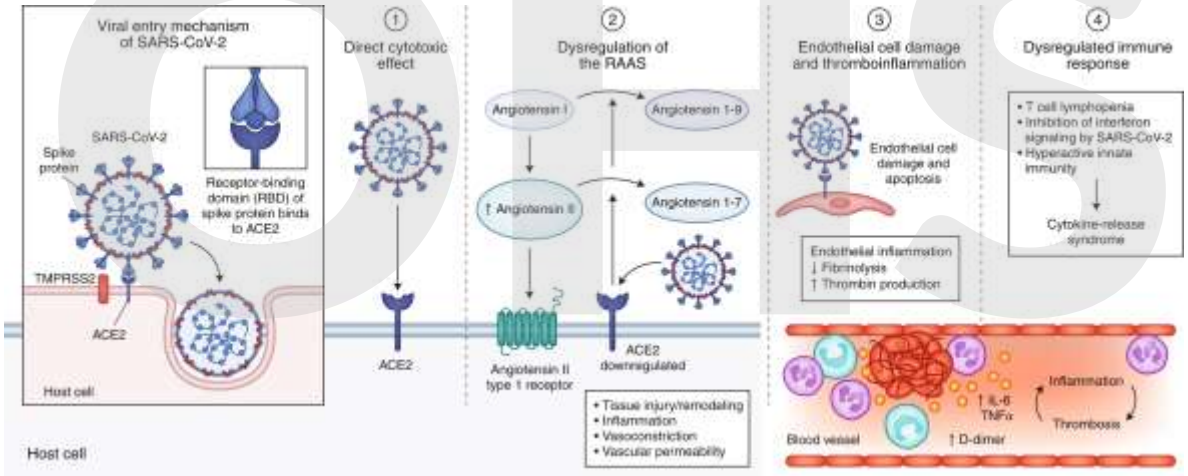
**Viral-dependent mechanisms**

- Persistent hyperinflammatory state
- Immune dysregulation or inadequate antibody response
- Persistent viral replication (reservoir)

**Viral-independent mechanisms**

- Residual organ damage from acute infection
- Unmasking of underlying comorbidities after infection
- Post-hospital or post-ICU syndromes

# The Lock and Key?
# ACE2 Receptor and Spike Protein




Divergence of SARS-CoV-2 from SARS Co-V-1 include mutations in the spike protein which enable more effective binding to the ACE2 receptor.



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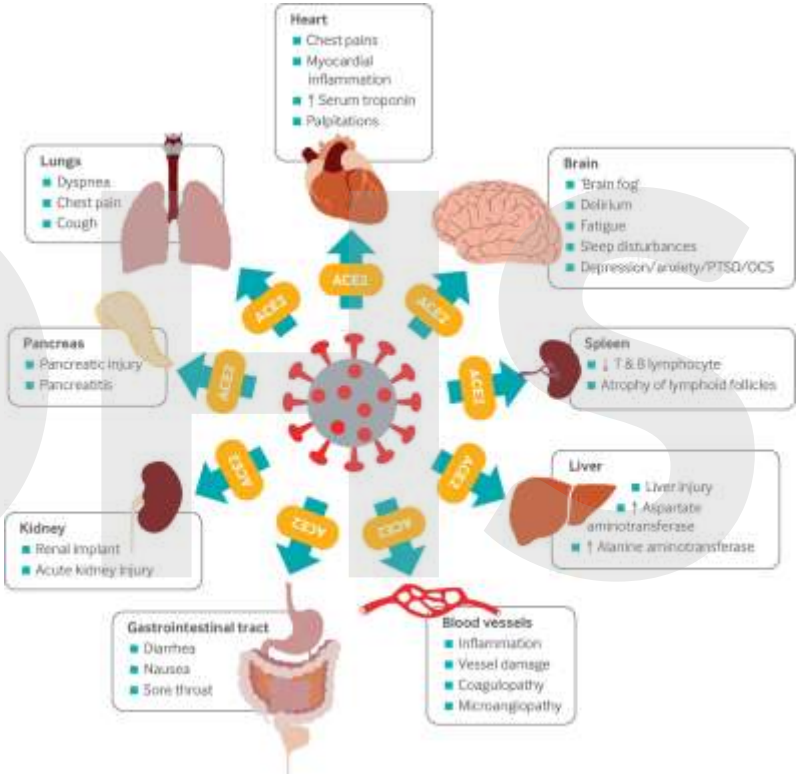
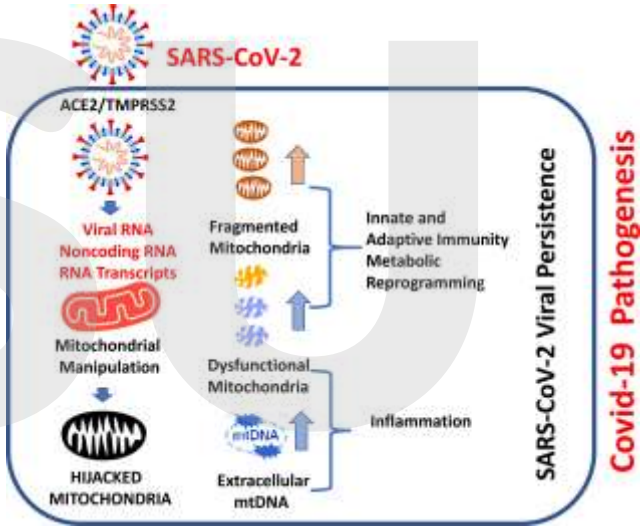
# Multi-organ complications of covid-19 and long covid.




Harry Crook et al. BMJ 2021;374:bmj.n1648

# Mitochondrial Dysfunction

- Majority of SARS-CoV-2 genomic and structural RNA are targeted for mitochondrial matrix and disrupts normal function
  - Decreases energy production
  - Decreases anti-viral signaling and immune response
  - Hijacked for viral replication and proliferation
  - Increases inflammatory responses and reactive oxygen species
  - Impairs ability to support immune response
  - Loss of mitochondrial integrity and death



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# Best Practices

## This is not the first or last post-viral syndrome

**Early Stage**

- Yet, there is a distinct lack of evidence and clinical pathways
- CDC – Interim guidelines; APM&R clinical consensus statements
- Most States have at least one Long COVID clinic

**Supportive Care**

- Majority of issues can be well-managed without drugs and procedures
- We can improve the trajectory and severity of their recovery
- Transparent, well-coordinated, trauma-informed care is essential



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# Considerations for the Evaluation and Management of Long Covid

- Most conditions can be diagnosed by history and exam
- Ordering of laboratory tests and imaging is guided by
  - Duration and severity of complaints
  - Presenting symptoms or conditions.
- It is not uncommon to find symptoms not explained by or out of proportion to objective findings.
  - Listen and validate even when diagnostic testing and exam is normal.

# History of Present Illness

- Method of confirmed testing or if presumed clinical dx
- Symptoms that impact quality of life the most
- Onset, timing, and intensity of sx relative to dx
- Patterns of physical exertion, cognitive exertion, and stress
- Correlation of exertion on symptom intensity

# Review of Systems

- Requires comprehensive review of all symptoms
- Mild or less common symptoms
  - Often not reported
  - Can identify important conditions (e.g. dysautonomia, MCAS)
  - Earn trust by exploring overwhelming barrage of unpredictable sx
  - E.g. Flushing, phantom smells, hair loss, parasthesias, orthostaic intolerance, sensory overload, dental findings

# Past Medical History

- Prior Conditions that can impact the severity of COVID-19 disease and symptoms of Long Covid
  - ***Asthma, mood disorders, headache, sleep disorders, orthopedic, chronic pain, truama***
  - Allergies, COPD, diabetes, fibromyalgia, autoimmune disorders, kidney disease, oncology, orthopedic, etc.

# Social History Considerations

(Pre / Post COVID)

- Baseline daily activities (ADLs, iADLS)
- Social support, empathic partners, caretaker responsibilities
- Unavoidable life stressors (e.g. work, family, SDoH)
- Family-related COVID-19 illness or death, bereavement
- ***Finances, employment disability (FMLA)***

# Medication Review

- Drugs that cause side effects similar to reported symptoms e.g. sedating, psychogenic side effects
  - BEERS
  - Polypharmacy

# Surveys

- Respiratory: mMRC
- Neuro: MoCA, MMSE, Compass 31, Neurobehavioral Symptom Survey
- Psych: GAD-7, PHQ-9, PTSD Screen
- Fatigue: Modified Fatigue Impact Scale, Fatigue Severity Scale
- Insomnia - Insomnia Severity Index (ISI)
- Quality of Life: PROMIS, PCFS, EQ-5D

# Physical Exam

- Vital Signs:
  - BP, HR, Respiratory rate, oxygen saturation, Temp, BMI
  - Orthostatic vitals (POTS protocol), oxygen saturation after activity
    - HR and BP taken in the supine position and then in the standing position at 2, 5, 10 minute intervals.
- Focused Exam:
  - Pulmonary (interstitial lung disease, RAD)
  - Cardiovascular (dysautonomia)
  - GI (bloating, mild-mod pain; dysautonomia, MCAS, IBS)
  - Neurologic Exam (vestibular, sensation; SFN, Central sensitization)
  - Skin (rashes, urticaria, flushing, vascular abnormalizes; telogen effluvium, dysautonomia, MCAS)
  - Psych (difficulty finding words, memory; Mood)

# Exercise Capacity Assessments

## Can play important role in evaluating and monitoring

- Examples include
  - 1 minute sit to stand
  - 2 minute step test
  - 6 minute walk test
  - 10 meter walk test
- Be mindful of post-exertional malaise, prepare home supports

# Diagnostic Studies

- **Positive COVID test is not required to establish the diagnosis**
- Review all prior records in advance
- Establish clear goals as most studies are normal
  - Diagnostic testing may be of limited value and harmful (e.g. anxiety, costs)
  - Absence of findings does not mean symptoms have no functional impact

# Basic Lab Testing

## Screening for treatable conditions

- CBC, CMP, UA
- CRP, ESR, Ferritin
- TSH and free T4
- Vit D, Vit B12
- Chest X-Ray, EKG

# Directed Laboratory Testing

- Further testing directed towards history, exam, ruling out specific etiologies:
  - CV: Echo, BNP
  - Dysautonomia / SFN:  Autonomic reflex testing, heart rate monitor
  - Pulmonary: Spirometry
  - Endo: Cortisol, A1c
  - MCAS: Tryptase (baseline, episodic), 24h urine studies
  - Rheum: ESR/CRP, ANA, RF, anti-CCP, anti-cardiolipin, CPK
  - Coag: D-Dimer, PT/INR, CK, fibrinogen

# Advanced Imaging

- **Not** routinely recommended unless:
  - MRI Brain (red flag headache symptoms, not brain fog)
  - CT Chest (abnormal CXR, PFTs, O2)
  - Cardiac MRI (abnormalities in echo, consider in consultation with specialty care)

# Documentation Framework

**Assessment and Plan:**

**@DIAGMED@**

**Care Navigation / Management**

**Follow - Up**
@FOLLOWUP@
Patient can reach out to Long COVID nurse navigator (833-OHSU-CCC), number provided. In addition, send appropriate MyChart communications as needed.

**History:**
**Onset**
Symptoms began on:
Patient was hospitalized for COVID-19 infection:
Persistent symptoms that impact quality of life:

**Post Acute Sequelae of COVID-19 (PASC)**
**Fatigue & Exertional Malaise**:
**Cardiopulmonary Impairment**:
**Cognitive Impairment**:
**Neurologic:**
**Neuropsychiatric impairment:**
**Sleep Impairment**:
**Other sequelae**: GI, Skin, etc.

**Other Health & Well-Being**
Functional Impairment:
Social support:
Employment status:
Nutrition & Hydration:

**Past Medical History & Prior Studies:**
PMHx, PSHx, Fhx, Shx was reviewed and updated per discussion with patient.

Precovid Conditions of significance include:

Specialty consultations:

Prior labs:
Significant for:

Prior Procedures:
Significant for:

**Allergies:**
@ALLERGY@

**Vitals and Physical Exam:**
@VSREF@

**Clinical Location and Coding Statement:**

Provider: @ME@

# Management & Treatment

- Fatigue / PEM
- Brain Fog
- Notable Sx & Conditions
- Most other Sx & Conditions

# Fatigue and Post- Exertional Malaise

## Pacing! Pacing! Pacing!

The Key to a Stable Recovery Trajectory = The Four P's*

- Pacing
- Prioritization
- Posture
- Planning

**STOP, REST, PACE**



** See references*

# Return to Activity Program
## Carefully Implemented Physical Therapy*

- **Not an 'aerobic exercise' or graded exercise program!**
  - Individualize the optimal level of activity and exertion
  - Systematically titer the progression of activity
- It is a function of
  - Breathing test: Awareness of understanding how breathing patters link directly to maximal effort
  - Heart Rate parameters
  - Most patients have dramatically reduced capabilities



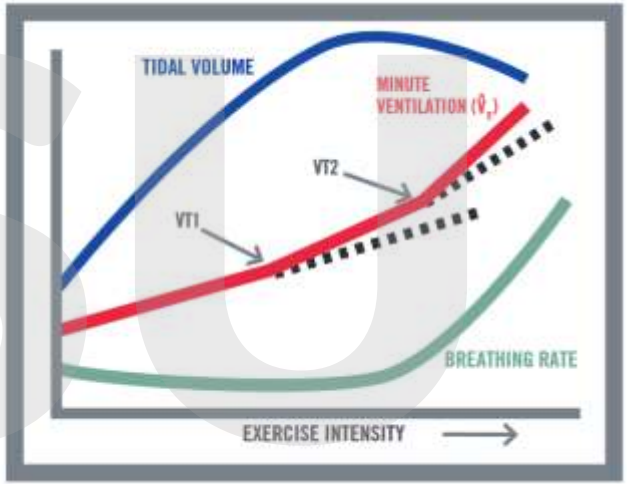
** See references for details*

# Ventilatory Threshold

- During incremental exercise, there are two distinct changes in breathing patterns:
  - VT1 - first ventilatory threshold
  - VT2 - second ventilatory threshold

- VT1 represents the breathing correlate of the body beginning to engage anaerobic fermentation in addition to oxidative metabolism
  - Can be identified using the “talk test.” (Point at which it becomes **difficult to speak in complete sentences**.”
  - Pushing past VT1 can lead to PEM
  - Above VT1 Blood lactate levels begin to rise from baseline but if work levels are held steady a lactate plateau may be held for a time as the body has some ability to clear lactate.”

- VT2 occurs at the point the body must rely almost entirely upon anaerobic fermentation to deal with further increases in workload




*Note:* VT1 = First ventilatory threshold; VT2 = Second ventilatory threshold

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# PT Program

- Long COVID patients should not exceed VT1!!
- Activity levels (exercise) below VT1 can improve recovery
- Patients learn the breathing test as best gauge of appropriate level of activity and avoid going over VT1
  - We also couple with ranges of heart rate (Easily monitored)
- Patients gradually titer their level of exertion as VT1 improves

# Brain Fog

- Speech Language Therapist*
  - Initially 1x / week then biweekly
- Evaluate: Language, attention, memory, energy, sleep, other
- Measure repeatable outcomes: Memory, attention, executive functioning, visuospatial processing (e.g. RBANS, MoCA)
- Monitor: Processing speed, word errors, metacognition
- Recommendations: sleep, diet, exercise, brain / body connection



** See references*

# Other Important Conditions

- **POTS / Dysautonomia**:
  - Salt, compression garments, small frequent meals
  - Rx: propranolol, fludrocortisone, ivabradine, pyridostigmine, midodrine
- **MCAS**: H1 and H2 blockers, cromolyn
- **Anosmia**: Smell training with 4 essential oils, 15-20m BID. (unproven)
- **Small Fiber Neuropathy**: Anti-depressants, gabapentionoids
- **Breathing pain**: Breathing exercises (stasis.life), pulm rehab, return to activity program

# Other Symptoms / Conditions

- **Most managed routinely or with supportive care**
  - Alopecia areata, headache, mood disorders, vertigo, light-headedness, parasthesias, insomnia
- **Pre-existing managed routinely without significant changes**
  - Asthma, diabetes, HTN, CHF, IBS, chronic pain
- **Referral when not-improving, severe, highly-complex**
- Start medications at lower doses than normal

# The Journey to Recovery

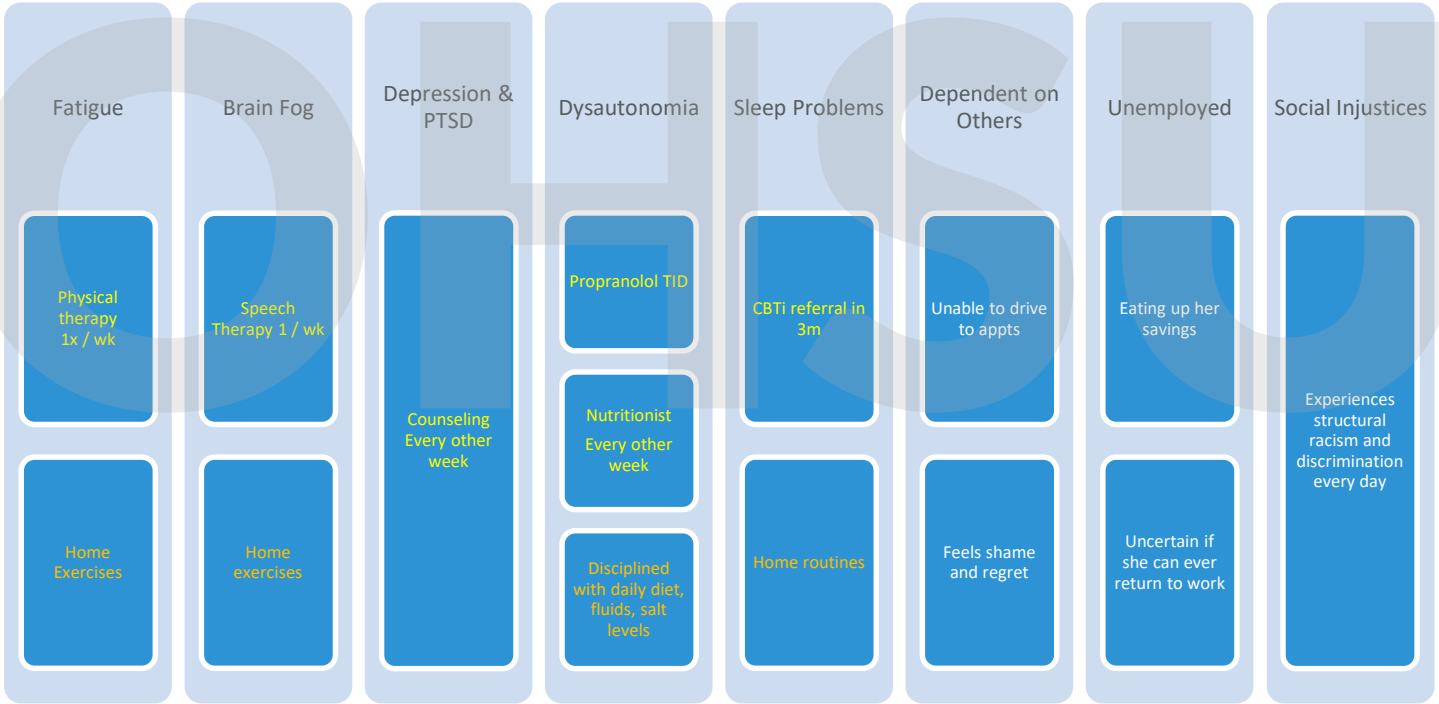
"Participants described feeling physically and emotionally exhausted from the burden of trying to access services, be believed, navigate incomplete and inadequate care pathways, gain knowledge, organize their own recovery plan, and integrate their own care across a disjointed and siloed service. Some talked of a profound breakdown of trust in a previously valued family doctor service."



Ladds, E., Rushforth, A., Wieringa, S. *et al.* Persistent symptoms after Covid-19: qualitative study of 114 "long Covid" patients and draft quality principles for services. *BMC Health Serv Res* **20,** 1144 (2020). https://doi.org/10.1186/s12913-020-06001-y

# Angela's Journey

## She is unequivocally overwhelmed!!



# Care Navigation is Critical for her Well-Being

- She has brain fog!
- She is lost without someone to help her put it all together: organize appointments, access social services, provide education, monitor her action items, connect her to other providers, advocate for her needs.
- Thus, well-resourced programs have some form of nurse navigation, social work, and behavioral health support

# Patient Experiences with Health Systems

- Early on highly unfavorable
  - Clinicians not familiar with Long COVID
  - Patients feeling “dismissed,” “gas lit”
  - Complex for anyone, yet alone with brain fog
- Few Long COVID recovery clinics, long wait times
- Some improvements over time

# Establishing Therapeutic Partnerships

- Holistic, trauma-informed care, with goal to improve QOL and functioning
- Identifying achievable goals and setting expectations for recovery timeline
- Leverage telemedicine whenever possible
- Specialty partnerships should be recruited as needed
- Patient support groups and social media*

# Support For Disability & Work Accommodations

## Likely the 2nd most important thing we can do!

- All patients need to time to recover
- Relapses are common
- Working, stress, pushing themselves too hard is the most common trigger for relapses and PEM
- Facilitating respite and / or reasonable reentry back to work is enormously beneficial for quality of life faster recovery

# Accommodations & Disability for Fatigue & Brain Fog

## Return to 100% work will fail 100% of the time!

Possible Disability Accommodations:

- Work from home
- Limited hours
- Alternating work days
- Frequent breaks
- Avoid standing
- Temporary disabled parking permits
- Limit tasks with divided attention
- Optimize range of movements
- Limit environments with multiple sensory inputs
- Graduated return to work activities

For Disability Applications, Document

- Activity levels pre/post infection
- Symptoms that are remitting and relapsing
- Specific work activities will result in physical and mental fatigue
- Environmental settings that result in sensory overload (markets, etc)
- Work-ups that rule out other associated causes including pre-existing conditions



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# Final Considerations

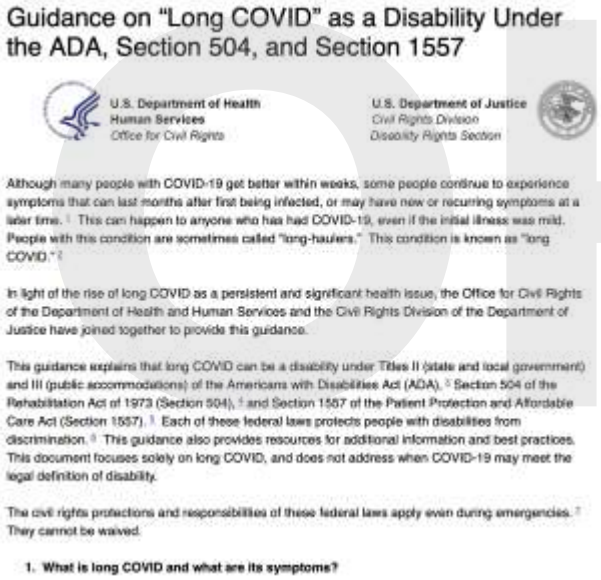
# 100,000 Ft View

- Pacing is the foundation to recovery
- Return to activity program is not exercise
- Remember PEM, POTS, MCAS, SFN
- Directed workup with established goals
- Provide supportive routine care, expect relapses
- Validation, transparency, empathy, patience

# Long Covid Now Has Some Investment

- ***$1.15 billion NIH funding over four years to support PASC research***
- **White House Orders Federal Action Plan, "Whole of Government Response" on Long COVID.**
  - Interagency national research action plan on Long COVID
- **Legislation Introduced to Expand Access to Multi-D Care & Treatment**
  - Targeting Resources for Equitable Access to Treatment for Long COVID (TREAT Long COVID) Act
  - Increase access to Multi-D care and treatment
  - Expansion of existing Long COVID clinics and development of new
  - Empower healthcare providers—including CHCs & local PHD to treat Long COVID patients in their own communities

# Long COIVD is now a Disability Under ADA



Guidance on "Long COVID" as a Disability Under the ADA, Section 504, and Section 1557

U.S. Department of Health Human Services
Office for Civil Rights

U.S. Department of Justice
Civil Rights Division
Disability Rights Section

Although many people with COVID-19 get better within weeks, some people continue to experience symptoms that can last months after first being infected, or may have new or recurring symptoms at a later time. [1] This can happen to anyone who has had COVID-19, even if the initial illness was mild. People with this condition are sometimes called "long-haulers." This condition is known as "long COVID." [2]

In light of the rise of long COVID as a persistent and significant health issue, the Office for Civil Rights of the Department of Health and Human Services and the Civil Rights Division of the Department of Justice have joined together to provide this guidance.

This guidance explains that long COVID can be a disability under Titles II (state and local government) and III (public accommodations) of the Americans with Disabilities Act (ADA). [3] Section 504 of the Rehabilitation Act of 1973 (Section 504), [4] and Section 1557 of the Patient Protection and Affordable Care Act (Section 1557). [5] Each of these federal laws protects people with disabilities from discrimination. [6] This guidance also provides resources for additional information and best practices. This document focuses solely on long COVID, and does not address when COVID-19 may meet the legal definition of disability.

The civil rights protections and responsibilities of these federal laws apply even during emergencies. [7] They cannot be waived.

1. What is long COVID and what are its symptoms?

- Requires > 1 yr of disability
- Accepted ICD-10 Codes
  - B94.8 Sequelae of other specified infectious and parasitic diseases
  - **U09.9 Post COVID-19 condition, unspecified**



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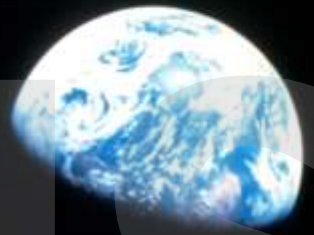
# Managing PASC in Your Practice

## Top 10 Essential Components

1. Knowledge Toolkit – CDC Guidelines, AAPM&R Guidelines, Pacing, PT protocol
2. Empathetic clinicians with committed interest - Neuro, Dysautonomia, Allergist, Behavioral Health, Sleep medicine
3. Rehabilitation team familiar with tittered, individualized treatment coupled with breathing test (PT/SLT/PM&R)
4. Extended visit for a dedicated comprehensive assessment with records in advance
5. Screening instruments for your practice
6. Documentation template or clinical approach for initial assessment
7. Patient instructions for most common symptoms
8. Team members to support SDoH, care navigation, FMLA
9. Whenever possible, access to virtual visits
10. Patience and reassurance

# HOPE

An MyChart (EMR) Message from Angela



This long-hauler clinic and all the resources I now have access to, has improved my life, my outlook on life and my livelihood. I am grateful for you first and foremost believing me that I know my own body better than anyone, listening to all of my concerns and having a thorough knowledge of my post-Covid medical history. Every provider should be willing to listen and care for minorities and any person seeking help. After all, if a doctor will not help someone in need, what other options are there??"



*Image Credit: NASA*

Eric Herman, MD
Chief Primary Care & Population Health Officer
hermaner@ohsu.edu

# Thank You

# Appendix

# Patient Resources

- Patient handout in separate document
- OHSU Long Covid Clinic: OHSU COVID-19 Connected Care Center hotline at 833-OHSU-CCC, or 833-647-8222.

# Patient Support Groups

- Body Politic
- Survivor Corps
- Long COVID Alliance
- Long COVID Kids

# Provider Resources

- CDC - Evaluating and Caring for Patients with Post-COVID Conditions: Interim Guidance
  https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/post-covid-index.html
- American Academy of Physical Medicine & Rehabilitation
  https://www.aapmr.org/members-publications/covid-19/physiatrist-resource-center/long-covid-pasc-resources
  https://pascdashboard.aapmr.org

# POTS Dx

- Measure blood pressure and heart rate at regular intervals
  - Ideally at **1, 3, 5, and 10 minutes**, in standing position
  - After patients lies quietly in supine position for at least 10 minutes
- Criteria for POTS diagnosis includes
  - Increase in heart rate ≥ 30 beats/minute within 10 minutes of upright posture from supine position (increase in heart rate > 40 beats/minute required for patients < 20 years old)
  - Absence of orthostatic hypotension
  - Standing heart rate is often ≥ 120 beats/minute, typically higher in morning than evening
- Increases in orthostatic heart rate gradually decrease with age in patients with POTS
- **Sx often detected during PT program**
- Also consider tilt table testing, Quantitative Sudomotor Axon Reflex Test, Thermoregulatory Sweat Test (TST), skin biopsies looking at the small fiber nerves

# POTS Conservative Tx

**Salt**

- 10 grams of salt per day total, 2-3 grams added to hydration.
  - Drink mix options: LMNT™ electrolyte replacement, Re-Lyte™ electrolyte replacement, Nuun™ electrolyte replacement, Dr. Price's Electrolyte Mix™, Normalyte™. Drip Drop ORS™. Liquid IV™
  - Tablet/capsule Options: Salt Sticks Vitassium™ electrolyte capsules, Hi-Lyte™ , Thermotabs™ (1000mg sodium)
  - AVOID the following: Gatorade, Powerade, other sugary sports drinks

**Hydration**

- Finding the perfect amount of water can challenging. Drink 2-4 liters of water per day.
- Drinking water quickly rather than sipping helps expand blood volume more rapidly, mimicking the effects of IV saline.

**Compression Garments**

- Knee high compression socks come in variable strengths. The weakest strength is 15-20mmHg. Pick the most tolerable and helpful for you. Beware of socks too tight just below the knee.
- Waist high compression garments may work best for you
- Wear compression socks during all times with activity, especially standing for longer periods of time.
- Wear compression hose full time if it makes you feel better.
- Custom made garments are made for the “hard to fit” and are generally covered by insurance.
- Abdominal binders or Spanx may be helpful for abdominal compression.
- Abdomen to thigh compression is recommended for patients due to excessive splanchnic blood pooling.

**“Zero Gravity reclining chairs”**

- A reclined position can greatly improve energy and digestive symptoms.
- “Zero gravity” chairs range in price starting at about $45.
- Consider getting into zero gravity for 30 minutes prior to and during meals.

**Digestive support**

- Eat meals slowly and chew food thoroughly in a low stress environment.
- Drink at most, small amounts with meals.
- Over the counter digestive enzymes may be taken with meals to improve digestion and absorption of nutrients.
- Iberogast: This is an over the counter herb blend that can be found online and comes in both capsules and liquid. By improving digestive motility, nausea, bloating, and pain may be decreased. Take 20-30 drops by mouth 2-3 times daily, or as needed.

**Heat Intolerance**

- Ice packs to the face and neck
- Cold showers
- Koldtec ice towels
- Embr wave bracelet
- ChiliPAD for sleep support

**Bed Risers**

- Raising the head of the bed 4-6 inches with bed risers may lead to increased volume expansion and improve orthostatic intolerance.

# General Attributes of Individually Titrated, Symptom-guided Program of Return to Activity Program

- Goal is to restore previous levels of activity and improve quality of life.
- Until goals are achieved, patients should not initiate high-intensity aerobic exercises or heavy weight training.
- If program is advanced too quickly, it can worsen symptoms and trigger PEM.
- Patients are directed to perform activities at sub-maximal levels.
- Activities are adjusted in response to symptoms that develop both during and after activity.
- Patients are educated on how to recognize perceived exertion and use other metrics such as heart rate or validated exertion scales.
- Activity recommendations depend on level of severity and progress according to symptom tolerance.
- An example of program progression could be bedside mobilization, range of motion exercises, tolerated household activities, stretching of extremities, limited community activities, submaximal exercise, and eventual higher intensity activities.
- Consider referral to a medical professional (physiatrist or physical therapist) who is knowledgeable with Long COVID care and can monitor the course of the program.

Survey Instruments For Long COVID

Post-COVID-19 functional status scale
https://gp-website-cdn-prod.s3.amazonaws.com/topic-downloads/1602682348-5fc74b64deceab6b45c679772acab0f4.pdf

Modified medical research council (mMRC) dyspnea scale
https://www.mdcalc.com/mmrc-modified-medical-research-council-dyspnea-scale#evidence

Montreal cognitive assessment (MoCA)
https://www.mdcalc.com/montreal-cognitive-assessment-moca#evidence

Patient health questionnaire (PHQ-9)
https://www.mdcalc.com/phq-9-patient-health-questionnaire-9#evidence

Generalized anxiety disorder scale (GAD-7)
https://www.mdcalc.com/gad-7-general-anxiety-disorder-7#evidence

Modified fatigue impact scale (MFIS)
https://www.mdcalc.com/modified-fatigue-impact-scale-mfis#evidence

Fatigue severity scale (FSS)
https://www.sralab.org/sites/default/files/2017-06/sleep-Fatigue-Severity-Scale.pdf

Insomnia severity index (ISI)
https://www.ons.org/sites/default/files/InsomniaSeverityIndex_ISI.pdf

Snoring, tiredness, observed apnea, high BP, BMI, age, neck circumference, and male gender (STOP-BANG) questionnaire:
https://www.mdcalc.com/stop-bang-score-obstructive-sleep-apnea

Geriatric Depression Scale (GDS)
https://web.stanford.edu/~yesavage/GDS.html

PTSD Checklist for DSM-5 (PCL-5)
https://www.ptsd.va.gov/professional/assessment/adult-sr/ptsd-checklist.asp#obtain

10-item DePaul Symptoms Questionnaire – Post Exertional Malaise (DSQ-PEM)
https://csh.depaul.edu/about/centers-and-institutes/ccr/myalgic-encephalomyelitis-cfs/Pages/measures.aspx?

# National Academy of Medicine's Proposed Diagnostic Criteria for Myalgic Encephalomyelitis / Chronic Fatigue Syndrome (ME/CFS)

| |
|---|
| **Diagnosis requires that the patient has the following three symptoms:** |
| **1. A substantial reduction or impairment in the ability to engage in preillness levels of occupational, education, 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**<br>**2. Postexertional malaise***<br>**3. Unrefreshing sleep*** |
| **At least one of the following:** |
| **1. Cognitive impairment* or**<br>**2. Orthostatic intolerance** |
| ***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.** |



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# Energy Conservation – 4Ps

- **Pacing**: reasonable, short, more time, breaks, avoid push and crash
- **Prioritization**: What to do on specific days, left for time with more energy, uncessary. Avoid overexertion and crash
- **Positioning**: Modify activities to make easier. Sitting, workspace optimization, shower chairs,
- **Planning**: plan day / weeks / energy windows. Diary of good/bad/energy windows. Plan rest breaks, preparing tasks ahead of time, plan out completion of tasks. Plan out return to activities like work. Accomodations: limited hours, adjust work activities, breaks, parking. Voc rehab counselor
- https://www.hackneycitizen.co.uk/wp-content/uploads/Post-COVID-19-information-pack-5.pdf

# Example Strategies in SLP

| | |
|---|---|
| Memory | • WRAP (write, repeat, associate, picture), associating word lists<br>• Calendars, important items in the same place, follow directions |
| Attention | • Limit multitasking and distractions<br>• Self-talk and self-cues and goal setting<br>• Increase attention from sustained, selective, alternating |
| Communication | • Face speaker, ask for attention, talk the word<br>• Pause / think / speak,<br>• Tell others how they can help ('give me a second or can you offer a guess') |
| Sleep | • Avoid caffeine, alcohol, fatty meals, screentime<br>• Bedtime rituals, sleep environment, sunlight |
| Language | • Extra time to think, describe what you're thinking, scan alphabet for start letter<br>• Draw, gestures, words with same meaning |
| Exec Function | • STOP (Stop, Think, Organize, Plan)<br>• Self-talk, repetition, visualization, self-monitoring, puzzles, logic tasks |