Over the Long Haul:

An Approach to Post-Covid Conditions

AAPA WE ARE FAMILY (Medicine) Conference
San Diego, California 2023

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POST COVID CARE CLINIC
HOUSTON, TEXAS

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OBJECTIVES

At the conclusion of this session, participants should be able to:

- Identify ***common physical*** *and* ***psychological manifestations*** of Long Covid in the primary care setting
- Develop ***clinical evaluation*** *and* ***monitoring plans*** based on emerging evidence-based approaches
- Implement ***individualized medical management plans*** to ***optimize*** patient function and quality of life
- Recognize the ***value of interdisciplinary care-teams,*** including Long Covid Clinics, and ***when to refer***

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DISCLOSURES:

I have no relevant relationships with ineligible companies to disclose within the past 24 months.

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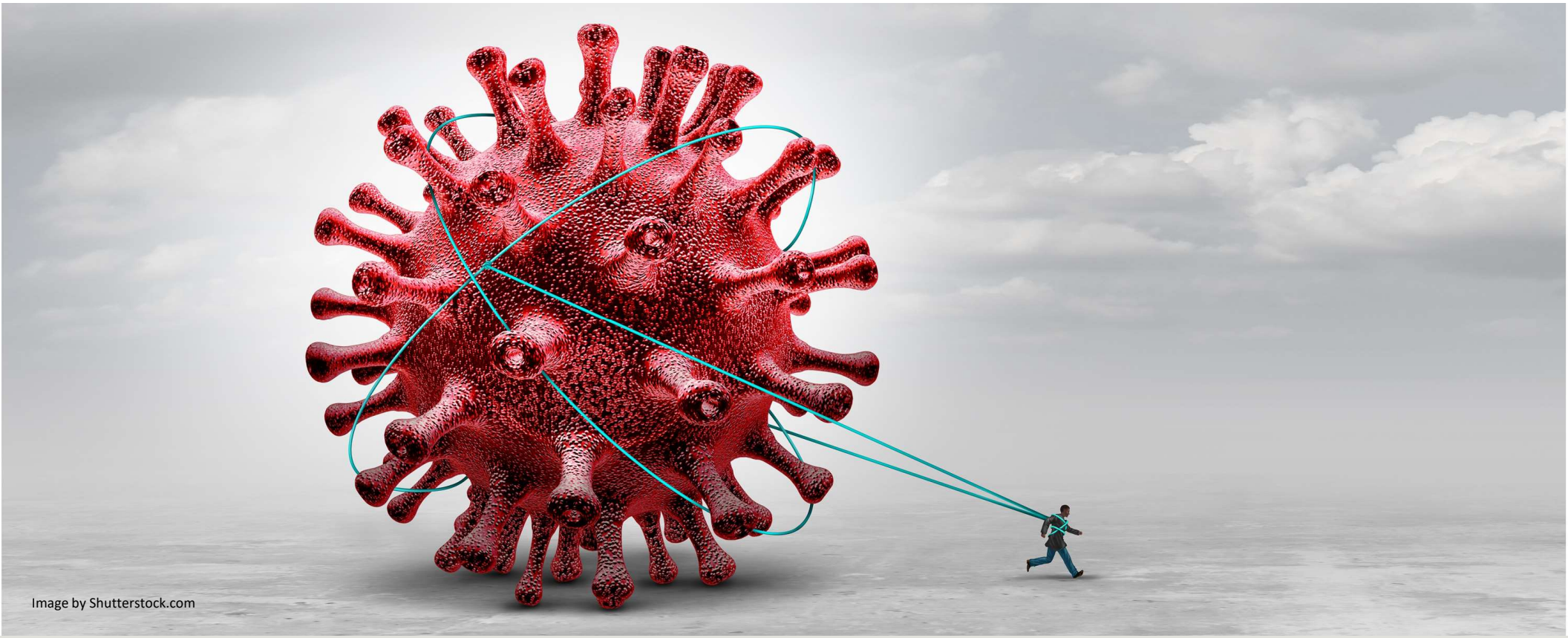

"**Long Covid (Post-Covid Conditions)** - associated with a spectrum of **physical, social,** and **psychological** consequences **+ functional limitations** that can present **substantial challenges** to patient **wellness** and **quality of life**." *(CDC)*

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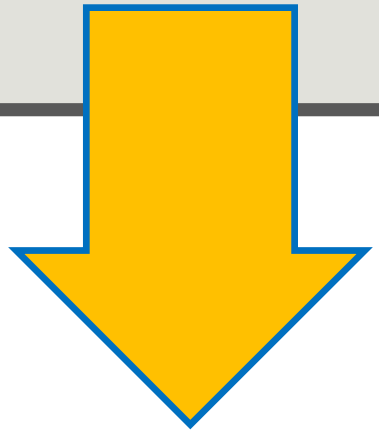

Keep in mind that **Long COVID is a 'continuously evolving landscape.'
There's still A LOT of answers we don't have – yet.

Information discussed today will undoubtedly be modified as research advances.**

- Anticipated to **substantially alter lives of millions** globally
- Associated with **significant disability** + heightened **anxiety**

"I don't really have… a life at this point. I'm just trying to manage my symptoms," (patient with Long Covid)

US Census Bureau's Household Pulse Survey →

- **~16M** (8%) working-age Americans (18-65) have Long COVID
- Of those, **2-4 million out of work**
- **ECONOMIC BURDEN OF LOST WAGES APPROACHING $200 BILLION/YR**

"I would give anything if I could have a day in the life of working as who I was before," (patient with Long COVID)

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OVERVIEW

History of Long Covid Reports in the *Popular Press*

HEALTH

Long-Term Symptoms Of COVID-19

May 23, 2020 · 5:17 PM ET
Heard on All Things Considered

What It's Like When COVID-19 Lasts For Months

August 10, 2020 · 5:00 AM ET
Heard on Morning Edition

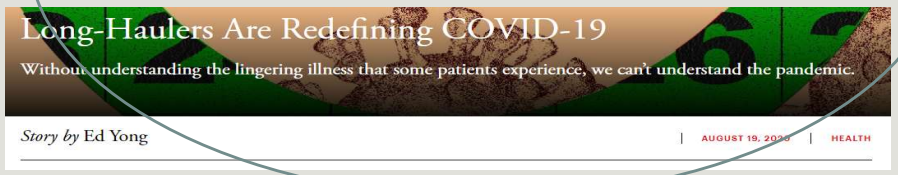
HEALTH

What We Know About COVID-19 Long Haulers

October 18, 2020 · 7:47 AM ET
Heard on Weekend Edition Sunday

What's It Like To Be A COVID-19 'Long Hauler'

November 9, 2020 · 4:00 AM ET



For Long-Haulers, Covid-19 Takes a Toll on Mind as Well as Body

"It makes you depressed, anxious that it's never going to go away."

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Early *Scientific Reporting* of Long Covid

Research Letter

July 9, 2020

Persistent Symptoms in Patients After Acute COVID-19

Angelo Carfì, MD[1]; Roberto Bernabei, MD[1]; Francesco Landi, MD, PhD[1]; et al

143 patients in **Italy** followed post-hospitalization

All patients PCR-negative at time of follow-up

At a mean of **60 days** after onset of symptoms:

- 87% had ≥1 persistent symptom
- Fatigue (53%)
- Shortness of breath (43%)
- Joint pain (27%)

55% of participants had ≥3 symptoms

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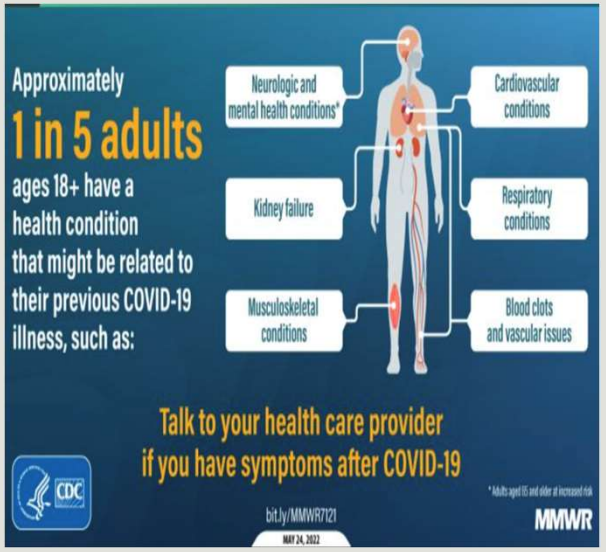
Prevalence of Long COVID

True Prevalence Unknown: CDC estimates prevalence ranging widely **(5–30%)**

Reasons for these wide-ranging estimates include:

- differing symptoms or conditions investigated
- the temporal criteria used (three weeks up to many months following SARS-CoV-2 infection)
- the study settings included (outpatient vs. inpatient)
- how symptoms and conditions are assessed (e.g., self-report vs. electronic health record database)



More commonly observed in:

- Female Sex
- Ages 36-50

https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects/index.html

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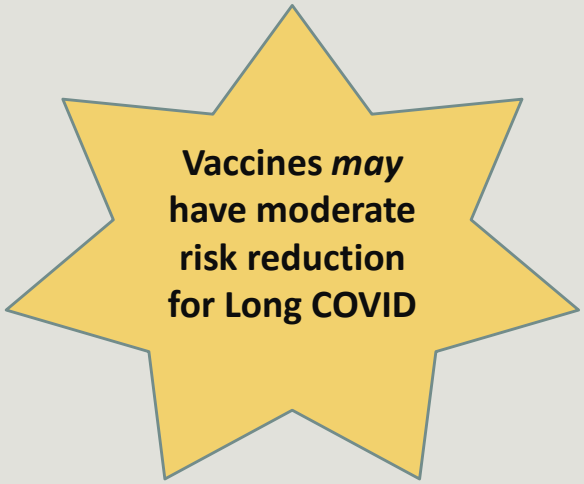
? Risk Associations

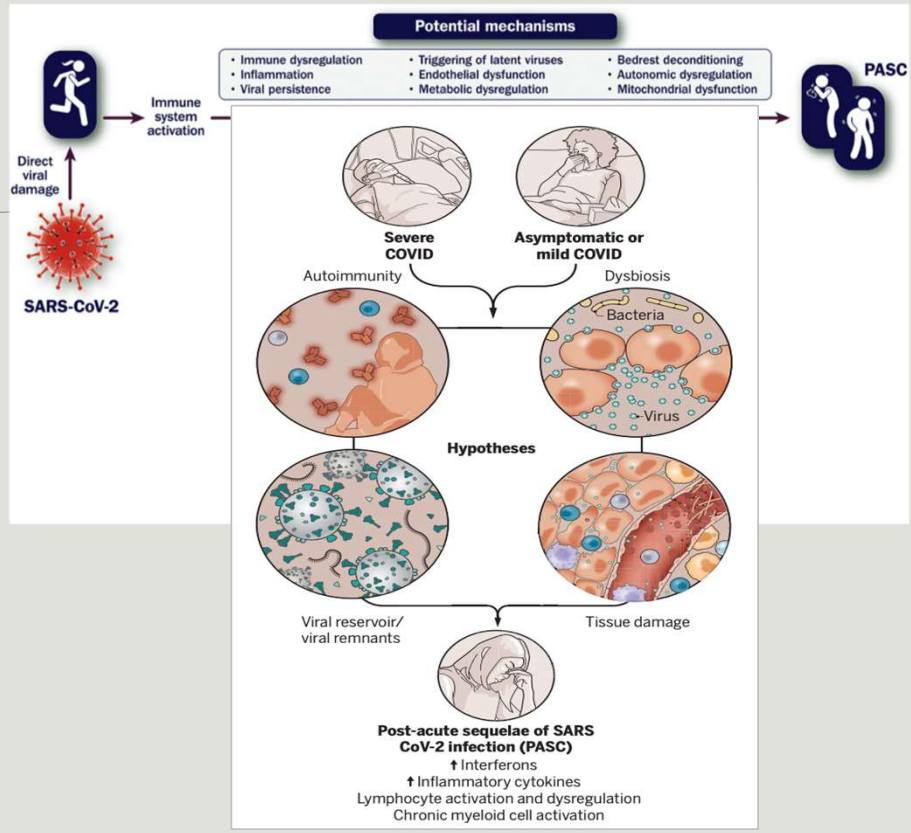
- **Emerging Data indicates *Possible* Risk Association:**
  - **Female Sex**
  - **Mid-Older Age**
  - Obesity
  - Pre-existing conditions: Asthma
  - Poor pre-pandemic general + mental health
  - Lower socio-economic status (health inequities)
- **Research has shown certain groups *MAY* be affected more by Long Covid**
  - Experienced more severe COVID-19 illness, especially those who were hospitalized or needed intensive care
  - Unvaccinated
  - Experienced multisystem inflammatory syndrome during or after COVID-19 illness



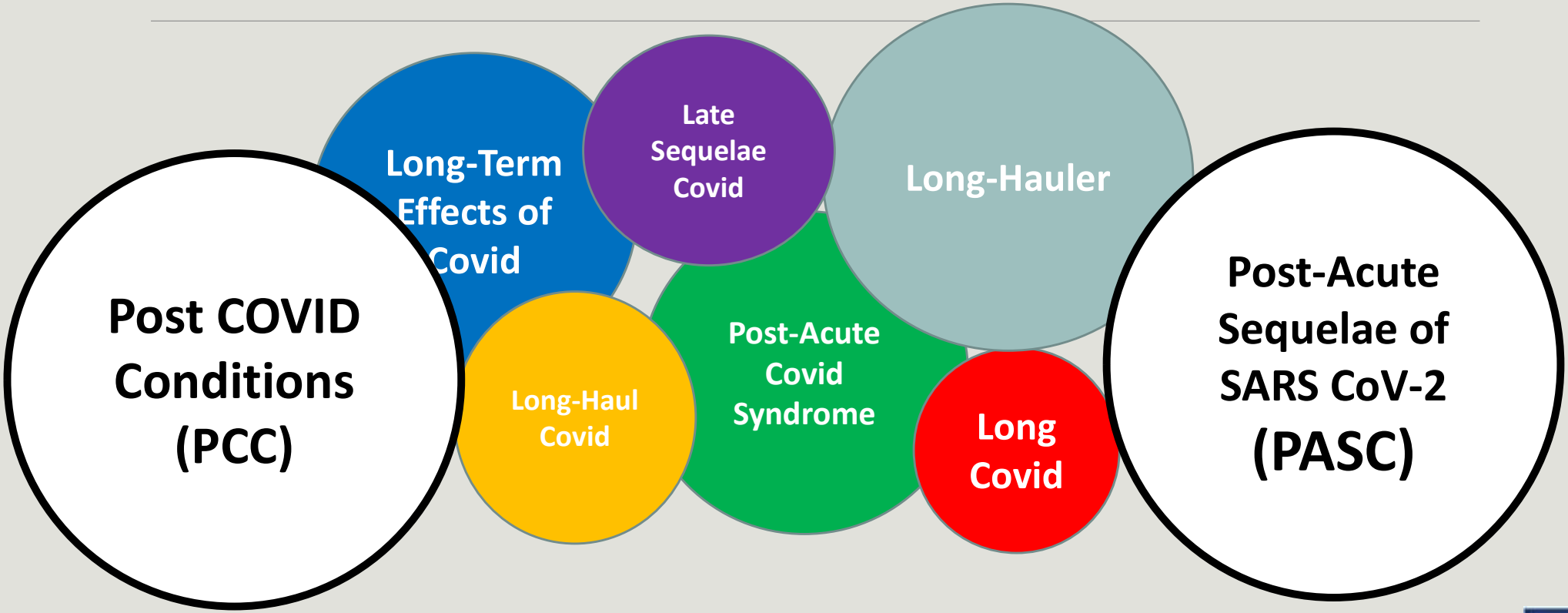
Pathophysiology

- Direct viral induced tissue injury
- Endothelial injury
- Immune system dysregulation/ stimulation of a hyperinflammatory state
- Hypercoagulability often leading to thrombosis
- Maladaptation of the angiotensin-converting enzyme 2 (ACE2) pathway

VERY GENERALLY TRANSLATED:
- Organ damage from acute-phase infection
- Complications from dysregulated inflammatory state
- Autoimmunity
- On-going viral activity



What's The *Name*?



https://www.covid.gov/longcovid

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Definition(s)

- *There is **NO** unanimous definition just yet*
- *In the broadest sense, post-COVID conditions can be considered **a lack of return to a usual state of health following acute COVID-19 illness**.*

- **CDC:** defines "post-COVID conditions" (PCC) as an umbrella term for the **wide range of health consequences** that can be present **four or more weeks** after infection with SARS-CoV-2, the virus that causes COVID-19

- **WHO:** Post COVID-19 condition occurs in individuals with **a history of probable or confirmed SARS-CoV-2** infection, **usually 3 months from the onset of COVID-19 with symptoms that last for at least 2 months and cannot be explained by an alternative diagnosis.**

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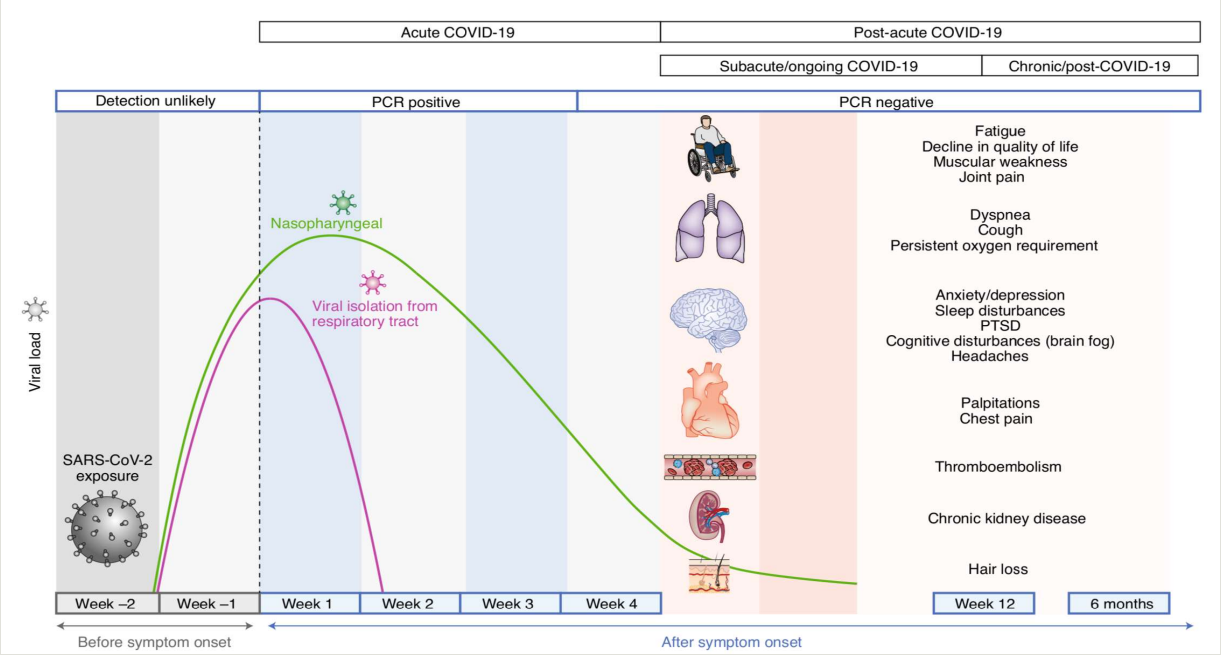
Post-Acute COVID *Timeline*



Post-Acute Recovery Period 4-12 weeks → Chronic Period > 12 weeks

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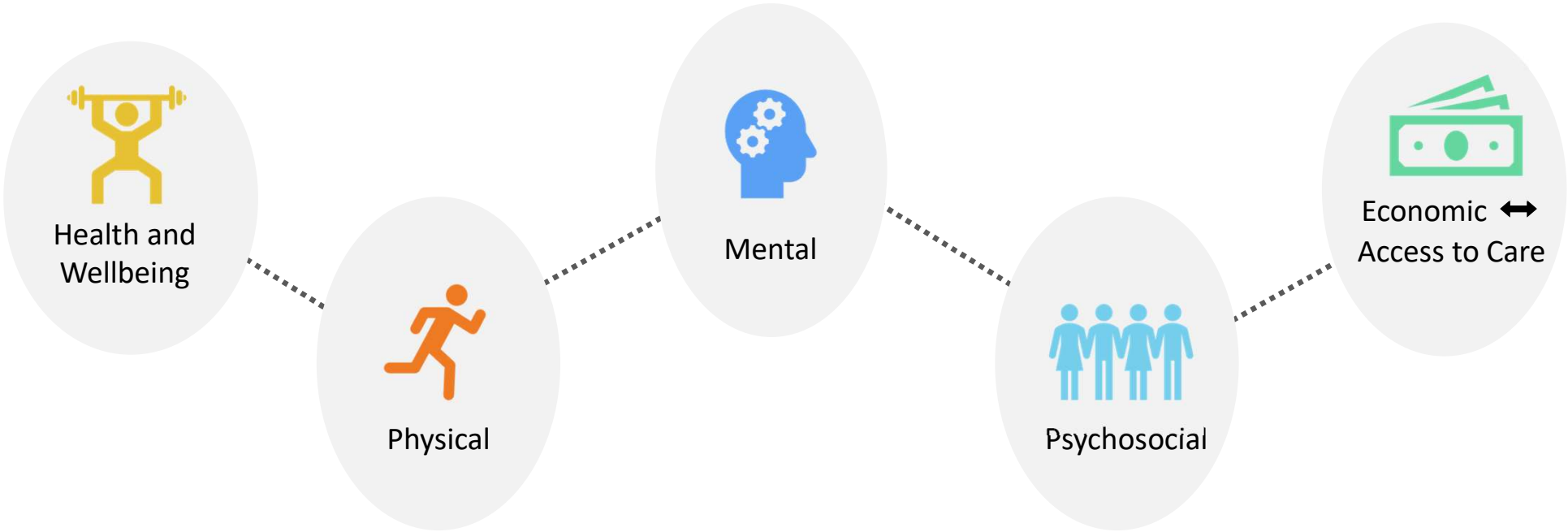
“Recovered” ≠ Healthy



Graphic courtesy of Fidaa Shaib, MD, BCM Post-Covid Clinic

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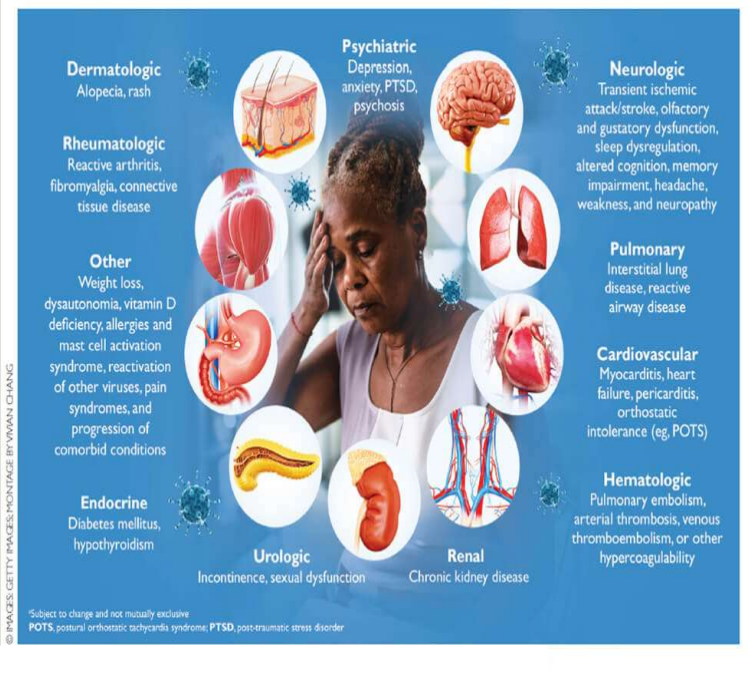

CLINICAL PRESENTATION

https://www.clinicaladvisor.com/home/topics/infectious-diseases-information-center/long-covid-diagnosis-treatment/2/

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How might ***PCC*** present?

Different patterns of symptom/condition presentation that exemplify heterogeneity:

- **Persistent** - since acute illness
- **New-onset** - after resolution of acute illness or following asymptomatic disease
- **Returning** - following a period of recovery
- **Evolution** of symptoms/conditions including **persistent symptoms** with **addition of new** symptoms/conditions over time

Can occur in people who had **asymptomatic, mild or severe** Covid infection
May not have had a positive Covid test

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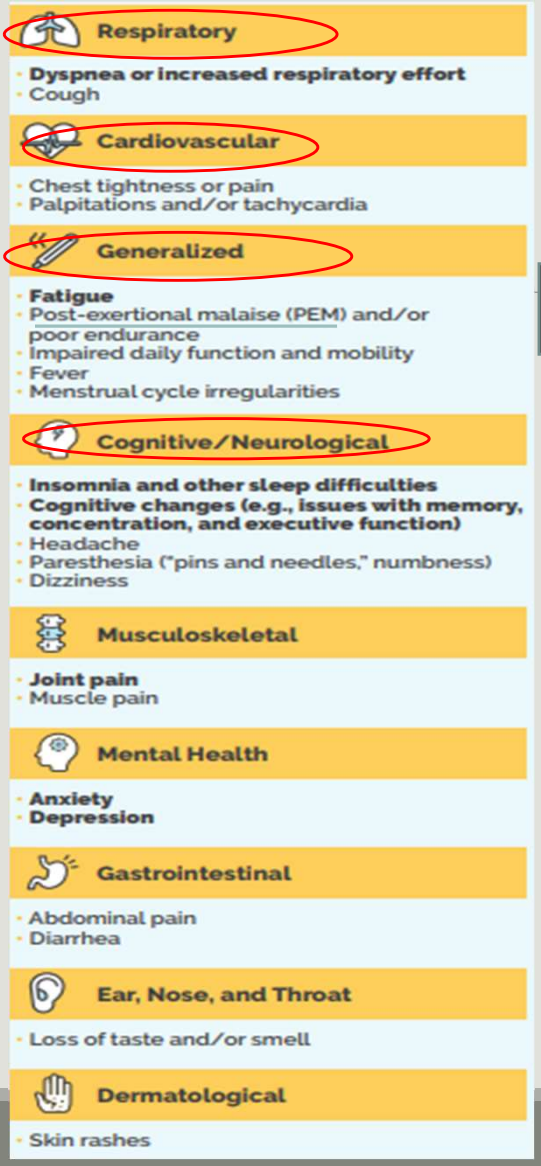
Other **Presentation** Considerations

- **Symptom presentation**
  - Uniqueness of presentation and combination of symptoms
    - Most often present with >1 symptom – often in clusters
  - Involve multiple-organ systems
  - Severity of symptoms is variable
- **Additional observations**
  - Worsening of pre-existing conditions
  - Unmasking of new illness
- **Complicating factors**
  - Pre-covid comorbidities
  - Baseline physical deconditioning
  - Physical + mental health consequences of long-complicated disease course



Symptoms (100+ identified)

PEM (Post-Exertional Malaise) : worsening of symptoms following mental/physical exertion **("PUSH/CRASH" Cycle)**

Recovery Timeline

- **Time course variable** and may be **dynamic**
- **Those with mild-moderate illness:**
  - **Majority** with persistent post-acute sx at 4 weeks **will recover by 12 weeks**
  - Beyond 12 weeks, persistent illness becomes more likely
    - Many continue to recover within 1 year
- **Most common symptoms/conditions persisting beyond 12 months:**
  - Unrelenting fatigue
  - Post-exertional malaise
  - Cognitive impairment
  - Autonomic dysfunction (POTS)

Long covid—an update for primary care | The BMJ

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Associated *Conditions*

Dysautonomia

- POTS most common manifestation

Myalgic Encephalomyelitis/Chronic Fatigue Syndrome (ME/CFS)

- May meet criteria for ME/CFS if extreme fatigue-related symptoms 6+ months

Depression/Anxiety

- Increased risk of mood disorders during recovery

Post-ICU Syndrome (PICS)

- Range of physical, cognitive and psychiatric illnesses following critical illness
- Often include severe weakness, PTSD, neurocognitive deficits

Different *Phenotypes*

Patient 1: 32-year-old who experienced ***mild*** COVID-19 with 3 days of fever, sore throat and poor appetite → develops "brain fog" with new difficulty concentrating 3 months later

Patient 2: 56-year-old with hypertension who had ***severe*** COVID-19 requiring 3 days of hospitalization with supplemental oxygen and treatment with dexamethasone → shortness of breath that improved after 2 months, fatigue persists and developed diabetes at 4 months

Patient 3: 76-year-old admitted to ICU with ***acute respiratory distress syndrome*** (ARDS) for 6 weeks → generalized weakness, significant dyspnea, nightmares, and depression

*SARS-CoV-2 may have very different presentations and **outcomes***

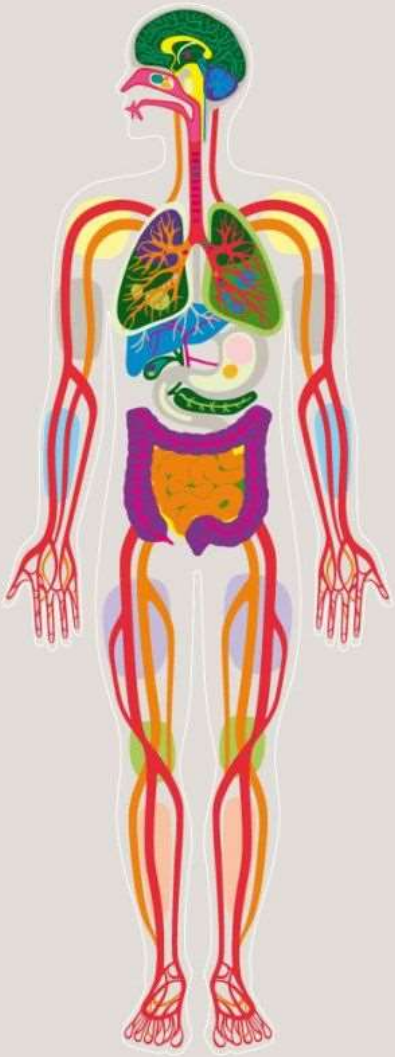
Covid-19 Pneumonia requiring intubation in ICU

Survival + Recovery

Long COVID Syndrome

Mild respiratory presentation not requiring hospitalization

Complete Recovery



EVALUATION and MANAGEMENT

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Evaluation/Management *Guidelines*

- Approach to evaluation can be complex due to heterogeneity of disease.
- There are no established evidence-based practice guidelines

CDC
CENTERS FOR DISEASE CONTROL AND PREVENTION

CDC PCC Guidance Providers Link

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AAPMR PCC Guidance Link

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Evaluation *Considerations*

No single laboratory test definitively distinguishes PCC from other conditions

1. Many PCC can be **diagnosed clinically** - others may **require directed diagnostic testing**
   - *Goal: Identify symptoms that can be managed + conditions that can be treated*
2. Remember that other **new, unrelated conditions can develop/persist**
   - ***Keep wearing your "Primary Care Hat"***
     - Orthopnea, dyspnea on exertion, + paroxysmal nocturnal dyspnea → evaluate for new-onset heart failure
     - Morning joints stiffness + low-grade fevers → consider rheumatoid arthritis
     - Hoarse voice in a patient with ongoing tobacco use disorder → consider head and neck cancer
3. Avoid over-investigation early **(first 4-12 weeks)** if symptoms **NOT** worsening/or new – **consider conservative approach.**
   - Diagnostic work-up can prove to be arduous – sometimes creating **financial burden** for patient
4. Some testing/assessments **might be uninformative** – does not negate patient's suffering

Initial Evaluation - General **Approach**

- **Frequency of Visits**
  - Depends on severity of initial disease + current, persistent symptoms
    - Post-hospital discharge – see within a few days
    - Persistent, on-going symptoms – see at 4-6 weeks
  - Continue f/u every 2-3 months pending symptoms/illness progression
- **History**
  - **Acute Covid-19 Illness**– dates, PCR/Rapid Test? (or epidemiological link to known case), timing/duration/nature/severity of symptoms, hospitalization (course), diagnostics, treatments (including O2 therapy), vaccine status
  - Current symptoms – full ROS*
  - PMH – comorbidities, current medications
  - SDOH
- **Physical Exam**
  - Standard vital signs including pulse ox. **Orthostatic vitals** (if postural symptoms)
  - Full physical examination

***Special Focus on Current Symptoms:**

1. **Frequency, severity, change**
2. Cognitive/psych symptoms warranting further screening
3. **Impact** of symptoms on **quality of life/daily functioning**

Evaluation – Diagnostic Testing

Goals of testing should be clear. Lab testing guided by history, exam, clinical findings.

SYMPTOMS/CONDITIONS	EVALUATION
Symptoms **Improving** →	No testing. **Monitor**
Ongoing symptoms (between **4-12 weeks**)	**Baseline testing** *(CBC, CMP, UA, TSH, Vit D)*
New or **worsening** symptoms (**4 weeks+**) *(for example: pulmonary embolism)*	**Specialized testing** *(D-dimer, CT-PE Protocol)*
Advanced symptoms especially **persisting beyond 12 weeks** *(for example: arthralgias, pain)*	**Specialized testing** *(arthralgias – ESR, CRP, ANA, anti-CCP)*
Red Flag Symptoms (*New confusion or focal weakness, SI*)	***Referral*** acute-services (ED)

Evaluation – Inventory/Assessment Tools

- Use **assessment/screening tools** to further assess symptoms
  - *brain fog/memory loss → MoCA*
  - *non-restorative sleep → ESS*

ASSESSMENT/SCREENING TOOLS	
Functional Status or Quality of Life	Post-Covid 19 Functional Status Scale (PCFS)
Respiratory Conditions	Modified Medical Research Council (mmRC) Dyspnea Scale
Cognitive/Neurologic Conditions	Montreal Cognitive Assessment (MoCA)
	Mini Mental Status Examination (MMSE)
Mental Health Conditions	Generalized Anxiety Disorder (GAD-7)
	Patient Health Questionnaire (PHQ-9)
Sleep Disorders	Insomnia Severity Index (ISI)
	Epworth Sleepiness Scale (ESS)

- Use **functional testing tools** to provide objective measures:
  - *fatigue, dyspnea → 6MWT*

FUNCTIONAL TESTING TOOLS	
Exercise Capacity	1-minute sit-to-stand (STS); 6-minute walk test (6MWT)
Balance and Fall Risk	BERG Balance Scale
Other	Orthostatic HR Assessment

Addressing ***Most Common*** Symptoms/Conditions

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- FATIGUE
- BREATHING DISCOMFORT
- CARDIOVASCULAR SYMPTOMS/COMPLICATIONS
- AUTONOMIC DYSFUNCTION (POTS)
- NEUROCOGNITIVE SYMPTOMS

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Eval/Mgmt Focus: ***FATIGUE***

History: -Assess patterns, **impact on activity or exercise**, changes in **daily functioning**
-Focus on pre-existing conditions / meds as exacerbating factors

Exam: -Assess physical functioning – 6 MWT
-Evaluate for **contributing system-based conditions** that may warrant further eval/referral
Sleep
Cardiopulmonary (ie) →
Autoimmune
Endocrine
Mood

	Common Symptoms and Signs	Further Studies to Consider in addition to basic laboratory evaluation	Referral
Cardiovascular	**Symptoms:** Chest pains, palpitations, sweating, nausea, fatigue, leg swelling, shortness of breath – at rest / on exertion / lying flat / waking up at night, dizziness on standing, feeling feint / feinting **Signs:** Pallor, tachypnea, tachycardia, diaphoresis, pulmonary rales, lower extremity edema, hypotensive sitting / standing – orthostatic hypotension, pre-syncopal / syncopal, poor activity tolerance / endurance	B-type natriuretic peptide (BNP), Troponins, D-dimer, chest-x-ray (CXR), electrocardiogram (EKG), echocardiogram (ECHO), exercise stress test/ cardiopulmonary exercise test (EST/CPET), Holter monitor, Cardiac Magnetic Resonance Imaging	Cardiology

-If unrelenting fatigue x 6 months, may meet criteria for **ME/CFS**

Treatment: -**Titrated**, structured **return to work/activity**
-*If **PEM**, manage with **Pace Training** (4 P's)
- Optimize other confounding issues: *sleep disorders (CPAP), mood issues (medication, psych), etc.*
- Referral if unrelenting

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Eval/Mgmt Focus: ***BREATHING DISCOMFORT***

- **History:**
  - **COVID Illness** – dx (PNA), oxygen requirements, diagnostics (CXR, CTs), admission (including ICU – mechanical ventilation)
  - **Current symptoms** – cough, dyspnea → **trajectory of sx** (improving, worsening, unchanged)
- **Exam:**
  - Pulse ox (rest, walking)
  - Exercise Tolerance (6MWT)
- **Diagnostics**
  - CXR – **new, worsening** sx/findings - **OR** - **h/o PNA or ICU stay** (repeat 12 wks)
  - CT – **worsening** SOB → CT-PE protocol - **OR** - **persistent sx + abnormal PFT** → **HR-CT**
  - PFT – if **persistent SOB** or radiographic abnormalities (12 wks+)
  - ECHO – in context of associated sx (CV)
- **MGMT**
  - **Breathing exercises**
  - Referral: abormal imaging/exam, sx persisting beyond 12 weeks

PFT Pearl:
Order PFT with
Spirometry
+ Volumes
+ **DLCO**

Dyspnea DDX *: Neuromuscular weakness, Post-ARD Fibrosis, PE, Bacterial superinfection, Dysautonomia, Cardiac*

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Eval/Mgmt Focus: ***CARDIOVASCULAR COMPLICATIONS***

- **History:**
  - **COVID Illness** – severity, hospitalization (diagnostic testing), new COVID-related CV dx
  - **Current Symptoms** (CP, palpitations, SOB, Syncope, Exercise intolerance, Fatigue) → **New/worsening**? (including frequency, intensity)
  - PMH: pre-comorbidities or CV events, medications
- **Exam: Vitals, CV, Pulm**
  - If postural dizziness/lightheadedness/palpitations + fatigue/sob – **chest orthostatics** (abn → eval dysautonomia)
- **Diagnostics:**
  - Labs - based on **symptoms** (CBC, CMP, Troponin, BNP, D-dimer)
  - Diagnostics (EKG, ECHO, Holter) consider based on **active symptoms**
- **MGMT:**
  - Cardiology referral: **uncertain** dx -OR- **progressive** symptoms -OR- **new/worsened dx** (arrhythmias, structural disease, CAD, Ventricular disease) -OR- **known COVID-related cardiac injury**
  - Risk Factor/Lifestyle modifications

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Eval/Mgmt Focus: *AUTONOMIC DISORDERS (POTS)*

- **History:**
  - **ID disabling s/s** that may be **autonomic** → *dizziness, lightheadedness, palpitations, (pre)syncope, orthostatic intolerance, exercise intolerance, cognitive dysfunction, fatigue*
  - **Characterize** sx: → new/chronic, frequency, intensity, **impact on function**
  - Meds (esp anti-HTN, anti-cholinergic, stimulants)
- **Exam**
  - Vitals (including **orthostatics**), pulse ox + CV, neuro exams
- **Diagnostics:**
  - **10-minute stand test**; Consider TTT (tilt table test)
  - Baseline labs (CBC, CMP, TFT, ANA)
  - **Holter monitor** or event monitor (palpitations, tachy)
- **MGMT:**
  - If dysautonomia (and **no CV contraindications**) → **Increase fluids, salt, compression garments, lifestyle modifications, small frequent meals**
  - Meds if refractory (beta-blocker, etc)
  - Consider autonomic rehab

POTS Criteria:
- *HR increase >30bpm or HR>120 on standing (per 10-minute test)*
- *No OH*
- *Sx of orthostatic intolerance x 6 mo*
- *Exclusion of other causes*

Of note → Systems impacted by dysautonomia: **Gen, CV, Neuro, Resp, GI, GU, Thermoreg (Endo), Ocular**

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Eval/Mgmt Focus: ***COGNITIVE SYMPTOMS***

- **History:**
  - Identify symptoms and **screen** for **cognitive deficits** → **validated tools** (MMSE, MoCA)
  - Assess <u>impact on daily activity, functioning</u>
  - Review preexisting conditions, meds
- **Exam:**
  - Thorough Neuro exam (**focal neurological deficits**) → if positive, neuro imaging
  - Evaluate for **contributing system-based sx/conditions** that warrant further testing/referral

    Sleep Impairment →
    Mood (anxiety, depression, PTSD)
    Fatigue
    Endocrine abnormalities
    Autoimmune disorders

Sleep disorders	**Symptoms:** Poor sleep - hard to get to sleep/wakes frequently/wakes early, nonrestorative/refreshing sleep -"tired" on waking, snoring, frequent urination at night, bad dreams/nightmares, falls asleep during the day **Signs:** snoring, restless legs, observed apneic episodes, hypertension, arrhythmias, narcolepsy, congestive heart failure, impaired cognition, poorly controlled mood disorder, metabolic dysfunction: glucose intolerance	Restorative sleep can be assessed using the Epworth Sleepiness Scale (ESS), Stanford Sleepiness Scale, PROMIS Sleep, or Sleep Scale Survey, Insomnia Severity Index screen Sleep apnea evaluation: STOP-BANG questionnaire; overnight sleep study with oximetry to assess for obstructive or central sleep apnea, benefit of CPAP/BIPAP, and oral appliances	Pulmonology - sleep medicine

- **Diagnostics:** Consider labs (CBC, CMP, B12, Vitamin-D, TSH)
- **MGMT:**
  - If positive screen → **referral to specialist** (SLT, OT, Neuropsychologist)for neurocog testing
  - **Optimize** sleep, mood disorders + reduce pain
  - **Titrated return to activity** plan (including work) – may need modified work schedule

Pt's may report symptoms as : *brain fog, deficits with attention/processing/memory/language/decision making*

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Of *(Important)* Note

DISABILITY → PCC can **qualify as a disability**

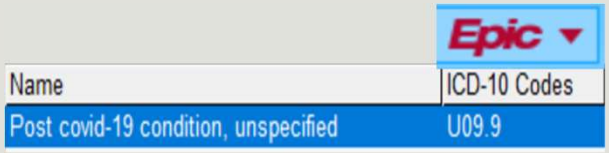
- Under the ADA, Section 504, and Section 1557
- If substantially limits one or more major life activities

NOTE DOCUMENTATION → Once diagnosis established, PCC should be documented:

Official ICD-10-CM: *U09.9 Post COVID-19 condition, unspecified*

Additionally assign codes for specific conditions/sx identified:

1. *R53.83 Other Fatigue*
2. *U09.9 Post COVID-19 condition, unspecified*



Management – General Approach

LONGTERM GOAL: Optimize function and quality of life

1. Provide **Patient-Centered, Holistic Care** →
   - Set **realistic goals** through shared decision making
   - Provider **transparency** via communication is important
   - **Whole person care** (including well-being, psychosocial)
     - **Validate** the impact of illness
     - Provide resource **assistance for hardships** (disability/accommodations for work/school)
     - Provide resources for **support groups**, research opportunities if patient interested
2. **Symptom management** →
   - Provide **medications** (*eg. headaches, anxiety, etc.*)

Management – General Approach

3. Provide **Rehabilitative Services** as indicated →
   - PT, OT, PMR, SLT, neurocognitive
     - ***Pacing for post-exertional malaise***

4. **Optimize** health co-morbidities and health behaviors →
   - Counseling on lifestyle components such as restorative sleep, nutrition, ensuring proper hydration, reducing stress (*eg meditation*), and restorative exercise

5. **Monitor** progress →
   - Encourage diaries and calendars to document change in conditions and symptoms severity

6. Provide **referrals** to specialists →
   - Mental support, persistent/severe symptoms, marked functional impairment, not improving)

7. **Vaccinate!**

Kari Moden image

Evaluation – *Referrals*

- **Interdisciplinary Care can be vital for those with PCC**
- **Consider dedicated <u>Long Covid Care Clinics</u>**
  - **Multi-disciplinary**, coordinated, collaborative care
    - Specialty providers (Cardiology, Pulmonology, Neurology, etc)
    - Rehabilitation services (Psychology, Neuropsych, PMR, PT, SLT)
  - **Research** Centered (data collection)
  - Collaborative with community providers

  - *Mostly at larger academic institutions*
  - *Located in every state*
  - *Wait can be lengthy*

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Patient *RESOURCES*

***ENERGY CONSERVATION/ PACING (Ps):**
Royal College of OT Energy Conservation Instructions

***BREATHING EXERCISES:**
American Lung Association Breathing Exercises Link

***SUPPORT GROUPS:**
Survivor Corps Link

***RESEARCH OPPORTUNITIES:**
NIH Recover Study Link
CDC Covid Inspire Study Link

TAKE HOME POINTS

- Long COVID is **common.**
- Long COVID is characterized by **varied persistent symptoms** after an initial COVID-19 infection.
- **Different definitions exist.**
- PCC can l**ast weeks, months, or years.**
- **Evaluation** should focus on impact of symptoms on **quality of life/daily functioning** and detection of treatable complications
- **Normal laboratory/imaging** does **not invalidate** the existence, severity, or importance of a patient's symptoms/conditions.
- The mainstay of **management** is **supportive, holistic care**, symptom control, and rehabilitation.
- Long COVID care will often require care delivered by **interdisciplinary** teams.
- Patient **validation**, counseling, and education cannot be underemphasized.
- Long COVID qualifies for **disability** according to the ADA.
- **Understanding** of Long COVID is **incomplete**. The approach to caring for these patients will **likely change** over time as evidence accumulates.

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- Negative test results do not mean the patient is OK.
- Optimize the optimizable (especially sleep). **Small Victories are BIG wins!**
- Help **prioritize goals** with the patients -- remember **they are using their** (often very few) **resources**
- It's okay to not have all the answers. No one does right now. **Your transparency builds trust.**
- Often the **ones that have lost the most** are the ones that **want to help** others – offer them resources.
- Remember that understanding/managing Long COVID is like flying the plane while it's being built!

- ***LISTEN to your patients and VALIDATE their experience/concerns. This will go a LONG way!***

Elissa's Two Cents

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Thank you!

Happy to answer any questions

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