



Treating Long COVID: Clinician Experience with Post-Acute COVID-19 Care

Clinician Outreach and Communication Activity (COCA) Webinar

Thursday, January 28, 2021

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- Planners have reviewed content to ensure there is no bias.
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Objectives

- Identify signs and symptoms of long COVID which occur after the acute phase of SARS-CoV-2 infection.
- Identify potential multidisciplinary teams for patient care.
- Describe common challenges to post-acute COVID-19 care.
- Describe examples of patient-centered, interdisciplinary post-acute COVID-19 care.

To Ask a Question

- All participants joining us today are in listen-only mode.
- Using the Webinar System
 - Click the “Q&A” button.
 - Type your question in the “Q&A” box.
 - Submit your question.
- The video recording of this COCA Call will be posted at https://emergency.cdc.gov/coca/calls/2021/callinfo_012821.asp and available to view on-demand a few hours after the call ends.
- If you are a patient, please refer your questions to your healthcare provider.
- For media questions, please contact CDC Media Relations at 404-639-3286, or send an email to media@cdc.gov.

Today's Presenters

- **Alfonso C Hernandez-Romieu, MD, MPH**
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Late Sequelae Unit, Clinical Team
COVID-19 Response
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- **Jennifer Possick, MD**
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- **Allison Navis, MD**
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Icahn School of Medicine at Mount Sinai
Mount Sinai Health System



Treating Long COVID: Clinician Experience with Post-Acute COVID-19 Care

Alfonso Hernandez-Romieu MD, MPH

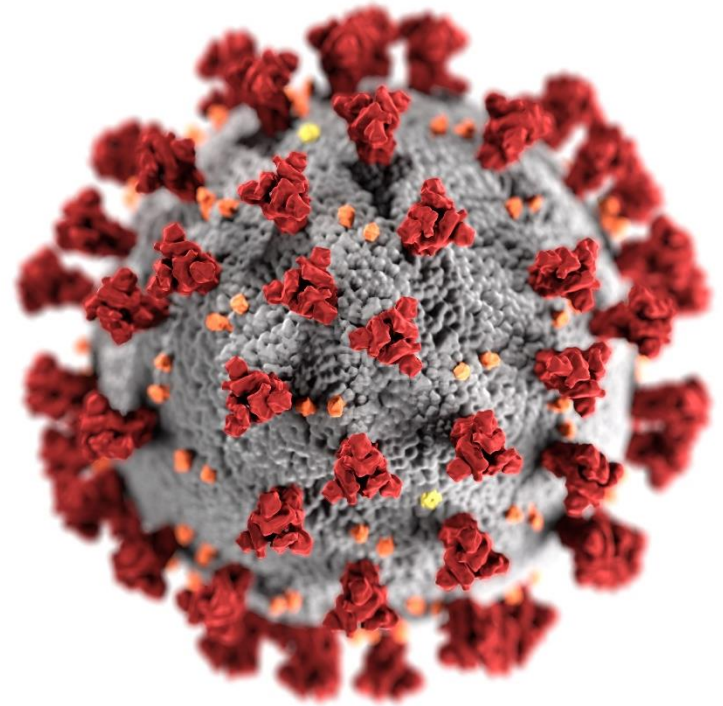
Epidemic Intelligence Service

LCDR, United States Public Health Service

January 28, 2021

Clinician Outreach and Communication Activity

COCA Call



cdc.gov/coronavirus

As reports of long-term COVID-19 symptoms emerged, the need for scientific research about **long COVID** has intensified.

Newsweek

'I Got COVID 9 Months Ago and Still Have Symptoms'

The New York Times

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."

Vox

The many strange long-term symptoms of Covid-19, explained

Long Covid "is a phenomenon that is really quite real and quite extensive," Anthony Fauci said.

By Lois Parshley | Dec 15, 2020, 4:20pm EST

60 MINUTES

PUZZLING, OFTEN DEBILITATING AFTER-EFFECTS PLAGUING COVID-19 "LONG-HAULERS"

Doctors are still searching for answers to why a portion of people who were diagnosed with COVID-19 are still suffering symptoms months later. Anderson Cooper reports.



HEALTH - Published August 23

Coronavirus survivors plagued by long-term ailments

Symptoms include losing sense of smell, dry cough, fever and chronic fatigue

BBC

Long Covid: 'I thought I'd get over this no problem'

By Claire Smyth
BBC News NI

SCIENTIFIC AMERICAN

LOCAL // HEATHER KNIGHT

S.F. Millennial was fit and healthy before COVID-19. He's a disabled 'long-hauler' now

Heather Knight | Jan. 9, 2021 | Updated Jan. 10, 2021 4:30 p.m.

npr

SHORT WAVE

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

November 9, 2020 - 4:00 AM ET

San Francisco Chronicle

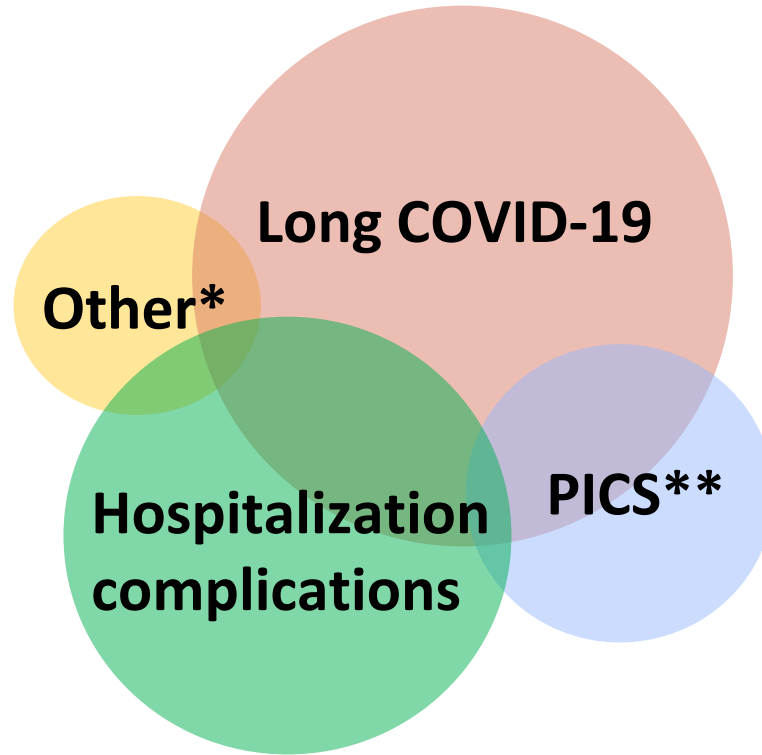
PUBLIC HEALTH | OPINION

The Problem of 'Long Haul' COVID

More and more patients are dealing with major symptoms that linger for months

By Carolyn Barber on December 29, 2020

Long COVID may overlap with other complications of acute COVID-19 illness making it **hard to define**.



*Multisystem inflammatory disorder, Guillain-Barre, among others

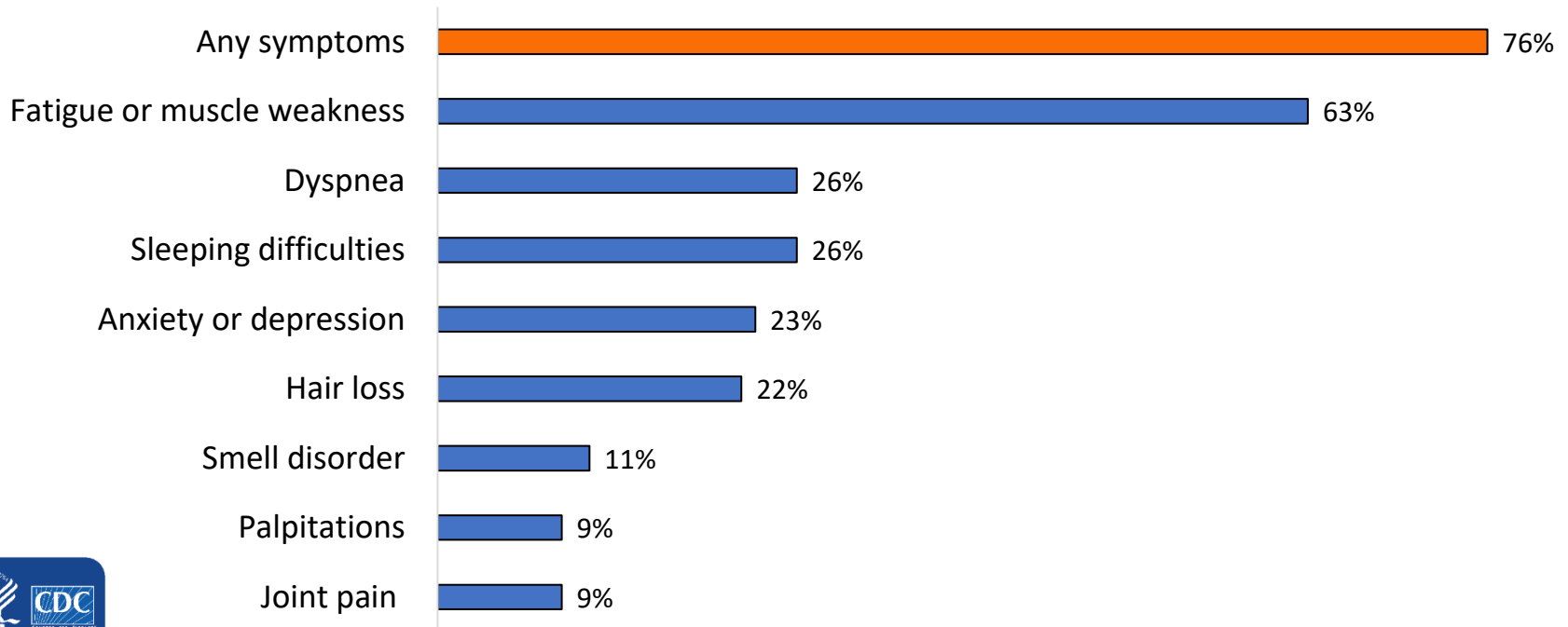
**Post-Intensive Care Syndrome

Long COVID often presents as reported **persistent severe fatigue, headaches, and brain fog (mild subjective cognitive impairment) >4 weeks** after acute illness and may be **independent of acute illness severity.**



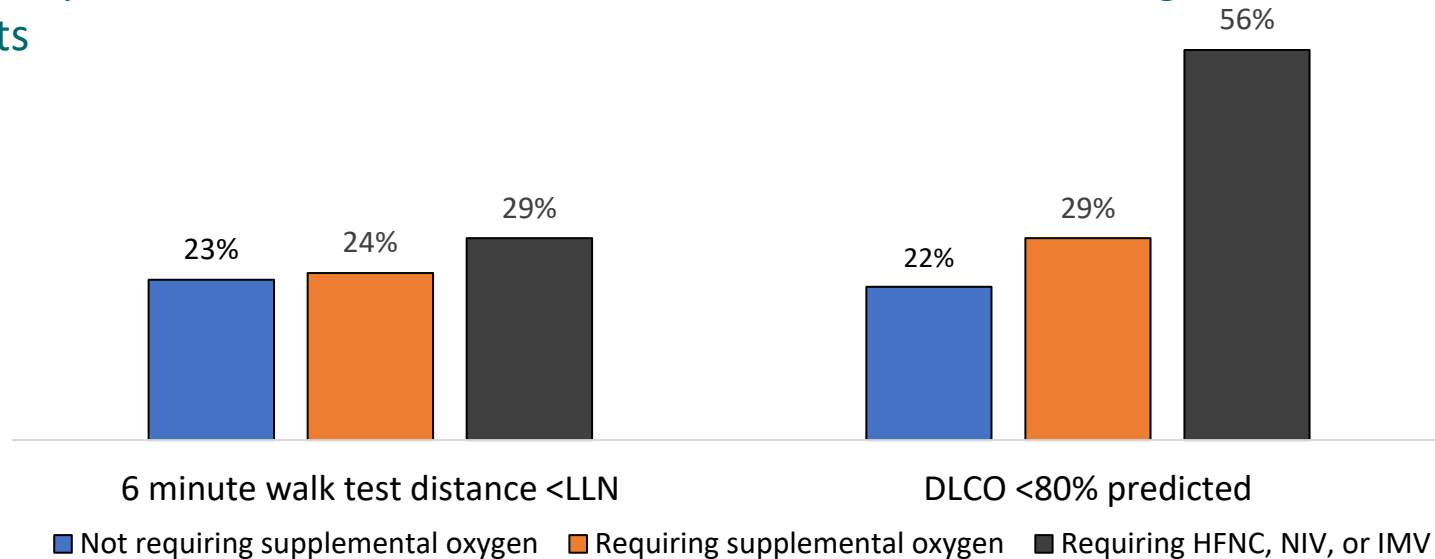
Three quarters of patients hospitalized with COVID-19 had **at least one ongoing symptom** 6 months after their acute illness.

Symptoms among 1,733 patients after hospitalization for COVID-19, China



One in five patients not requiring supplemental oxygen during hospitalization had decreased lung function after 6 months.

Pulmonary function and 6-minute walk test distance results among COVID-19 hospitalized patients



LLN = lower limit of normal; DLCO = diffusion capacity for carbon monoxide



Prolonged symptoms are common among patients with mild COVID-19 disease **not requiring hospitalization.**

- Survey of patients in a post-COVID 19 clinic in France¹ and telephone surveys in the Faroe islands² and Switzerland³
 - 35-54% of patients with mild acute COVID-19 had **persistent symptoms after 2-4 months**
 - 50-76% of patients **reported new symptoms** not present in their acute COVID-19 illness **or symptoms that resolved and reappeared**¹
 - 9% reported prolonged symptoms as **severe**²



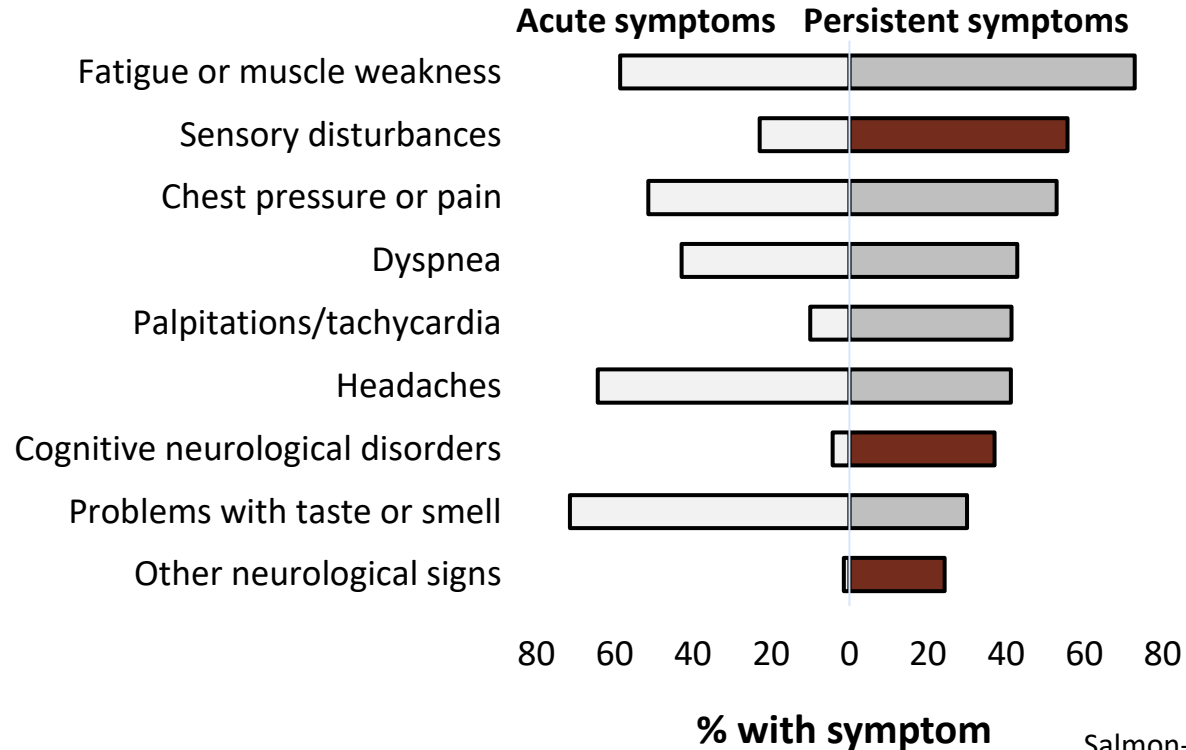
1. Salmon-Ceron et al., J Infect. 2020

2. Petersen et al., Clin Infect Dis. 2020

3. Nehme et al., Ann Intern Med. 2020

More than one quarter of patients developed new neurological symptoms after their acute COVID-19 illness.

COVID-19 symptoms among 70 non-hospitalized patients, France



Key points

- New or persistent symptoms (lasting >4-6 months) may occur among patients with COVID-19 **regardless of acute episode severity.**
- In addition to respiratory symptoms, **patients may present with fatigue, sleeping difficulties, depression, anxiety, and neurological dysfunction.**
- Baseline and serial **comprehensive reviews of systems and physical exams** may better document possible long COVID manifestations and improve management.
- There is still **a lot we do not understand**, and **empathy toward patients** experiencing long COVID is fundamental.

CDC is involved in a multipronged approach to understand and characterize long COVID.

- Cohort studies
- Administrative data and chart reviews
- Patient surveys
- Clinician engagement
- Partnering with other agencies and organizations
- Public and clinical messaging



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YOUR HEALTH

Long-Term Effects of COVID-19

Updated Nov. 13, 2020 [Print](#)

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

HEALTHCARE WORKERS

Late Sequelae of COVID-19

Updated Nov. 13, 2020 [Print](#)

<https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/late-sequelae.html>

Resources

- **CDC webpages on long COVID:**
 - For the general public: <https://www.cdc.gov/coronavirus/2019-ncov/long-term-effects.html>
 - For clinicians: <https://www.cdc.gov/coronavirus/2019-ncov/hcp/clinical-care/late-sequelae.html>
- **NIH Workshop on Post-Acute Sequelae of COVID-19**
 - Day 1: <https://videocast.nih.gov/watch=38878>
 - Day 2: <https://videocast.nih.gov/watch=38879>



References

- Greenhalgh T, Knight M, A'Court C, Buxton M, Husain L. Management of post-acute covid-19 in primary care. *BMJ*. 2020 Aug 11;370:m3026.
- Huang C, Huang L, Wang Y, et al. 6-month consequences of COVID-19 in patients discharged from hospital: a cohort study. *Lancet*. 2021 Jan 8:S0140-6736(20)32656-8.
- Salmon-Ceron D, Slama D, De Broucker T, et al. Clinical, virological and imaging profile in patients with prolonged forms of COVID-19: A cross-sectional study. *J Infect*. 2020 Dec 4:S0163-4453(20)30762-3.
- Petersen MS, Kristiansen MF, Hanusson KD, et al. Long COVID in the Faroe Islands - a longitudinal study among non-hospitalized patients. *Clin Infect Dis*. 2020 Nov 30:ciaa1792.



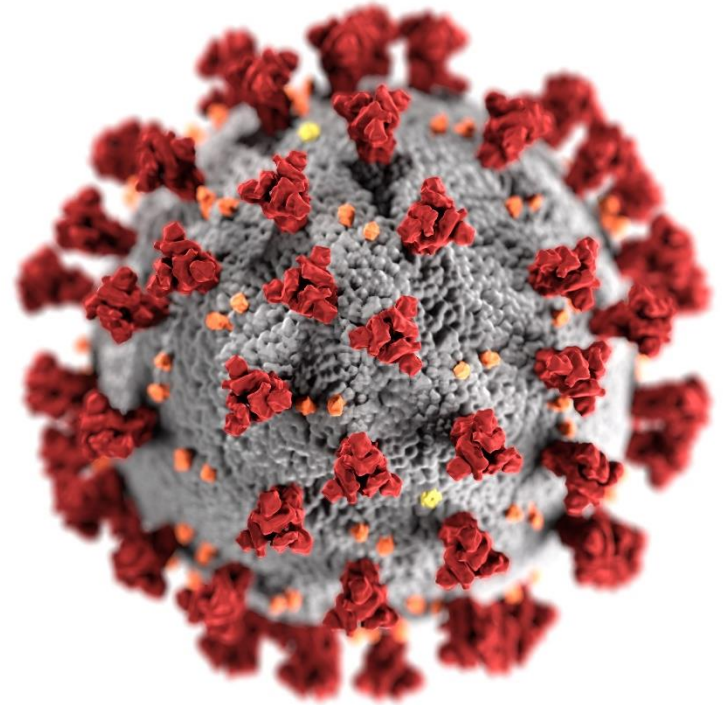
Thank you

CDC COVID-19 Healthcare Systems and Worker Safety Task Force
Healthcare Systems Coordination Unit
eocmcctfhome@cdc.gov



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cdc.gov/coronavirus

Treating Long-COVID: Clinician Experience with Post-Acute COVID-19 Care

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Yale University School of Medicine

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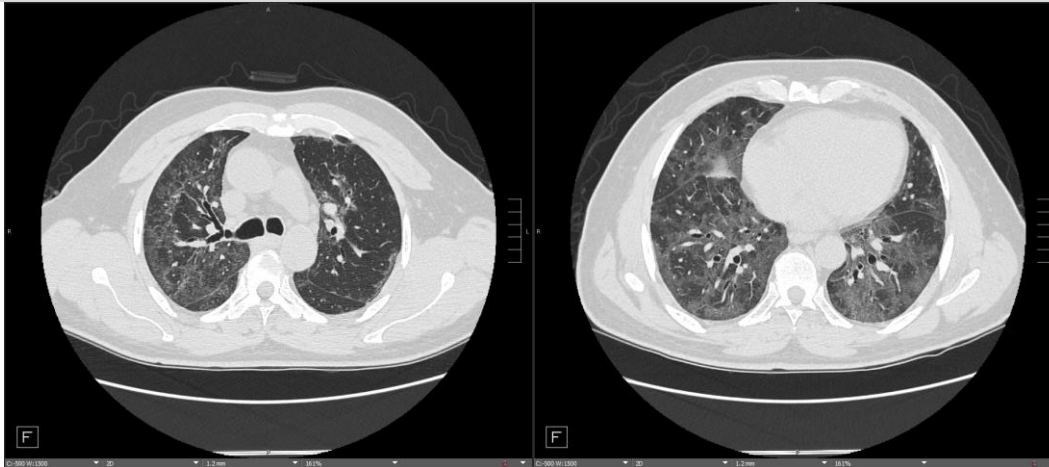
Yale-New Haven Hospital



Objectives

- Review post-COVID-19 respiratory symptoms and potential sequelae
- Explain how experience with other diseases informed our approach to post-COVID-19 pulmonary assessment
- Share our initial framework for providing post-COVID-19 evaluation in a pulmonary specialty clinic
- Discuss how initial observations are shaping the next steps in our approach

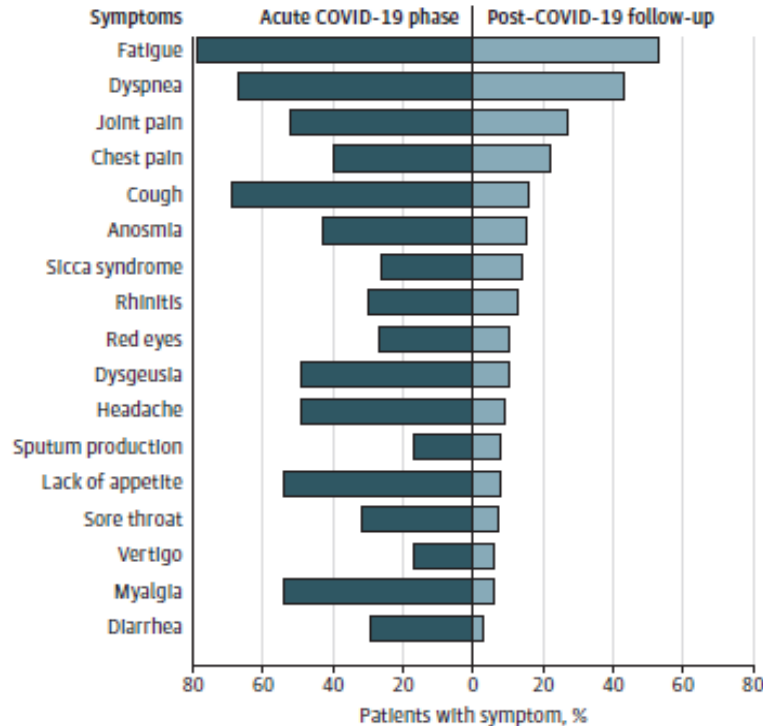
A typical patient:



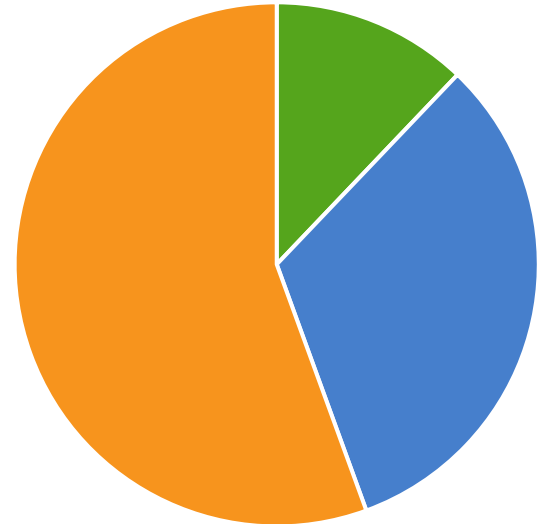
- 50-year-old man admitted in May with hypoxemic respiratory failure requiring high flow nasal cannula and prolonged hospitalization followed by short term rehab
- Initial pulmonary function tests showed severe restriction and diffusion impairment, though now off oxygen
- Follow up compute tomography chest shows clearance of infiltrates with minimal fibrosis
- Ongoing dyspnea and fatigue limiting return to work and hobbies
- Lapses in memory and concentration, increased anxiety and depression

Post-COVID-19 symptoms are common and diverse, with respiratory symptoms a frequent feature:

Figure. COVID-19-Related Symptoms

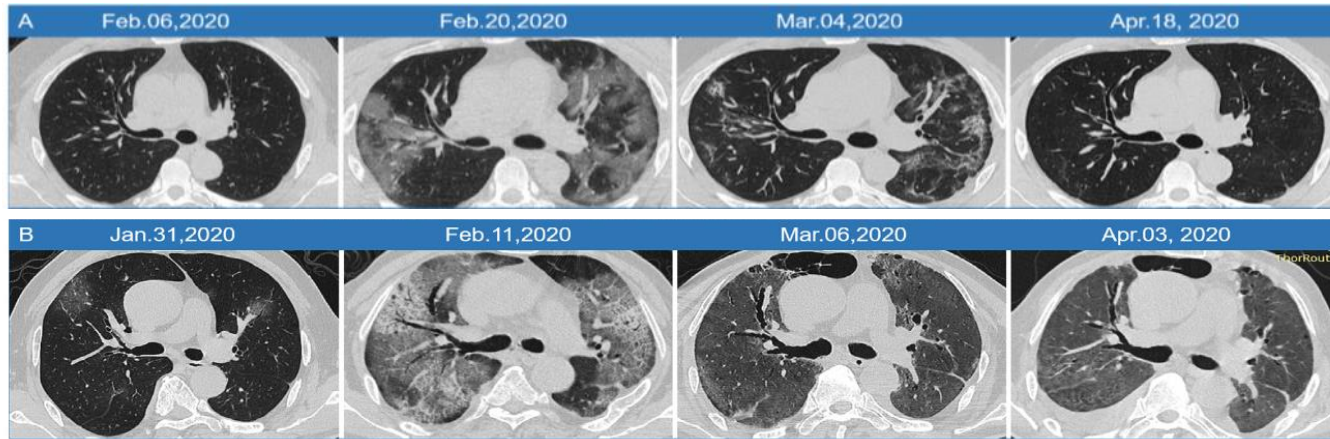


Persistent Symptoms in 87%



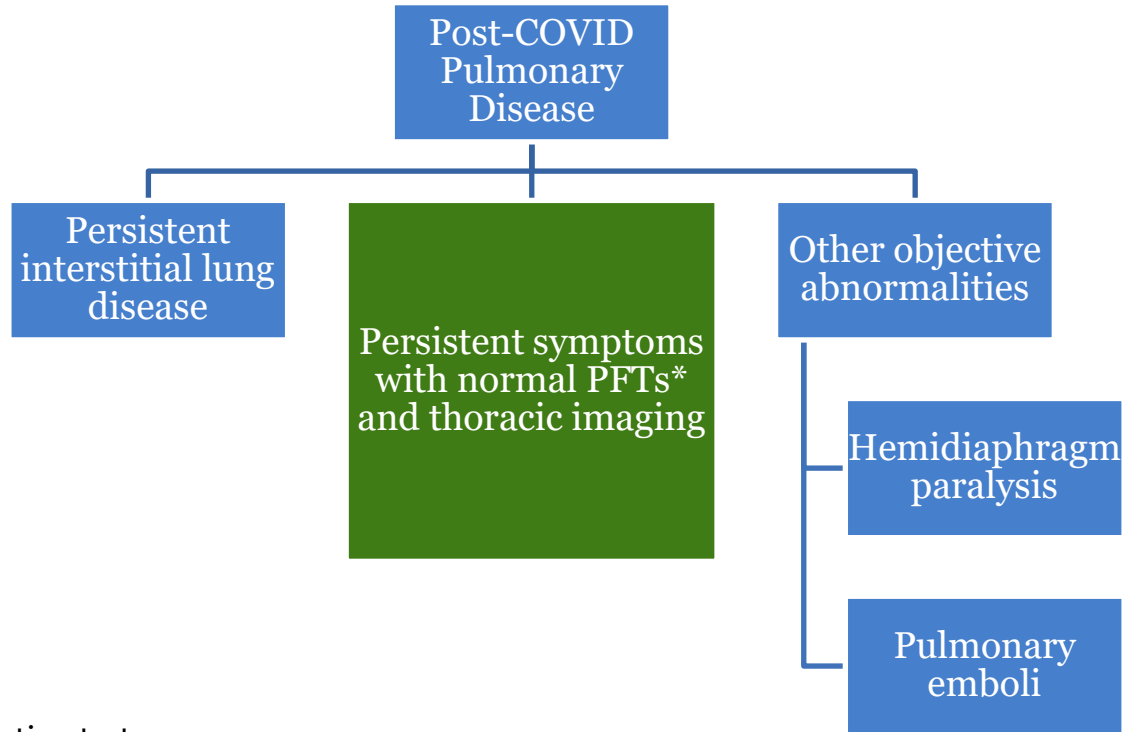
■ None (13%) ■ 1 to 2 (32%) ■ 3 or more (55%)

In addition to persistent symptoms, the potential for persistent interstitial lung disease :



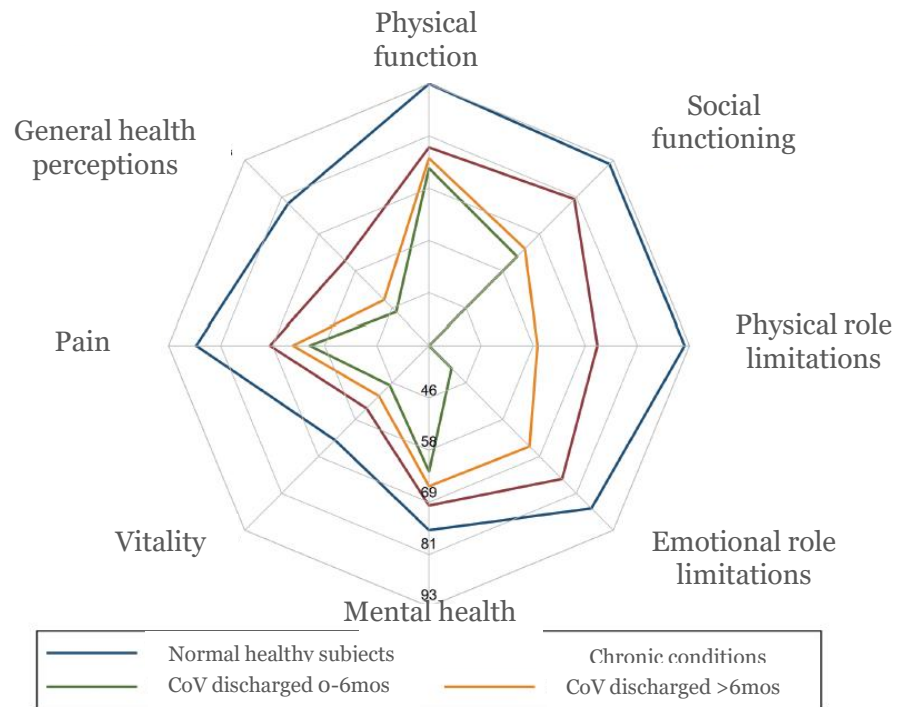
- Subset of patients with residual pulmonary infiltrates and fibrotic lung disease
- Correlates with deficits in pulmonary function (restriction, diffusion impairment)
- Associated with a signature of sustained inflammation through acute/post-acute phase
- Risk factors incompletely understood but associated with age, male gender, and underlying comorbidities

Patterns emerging:

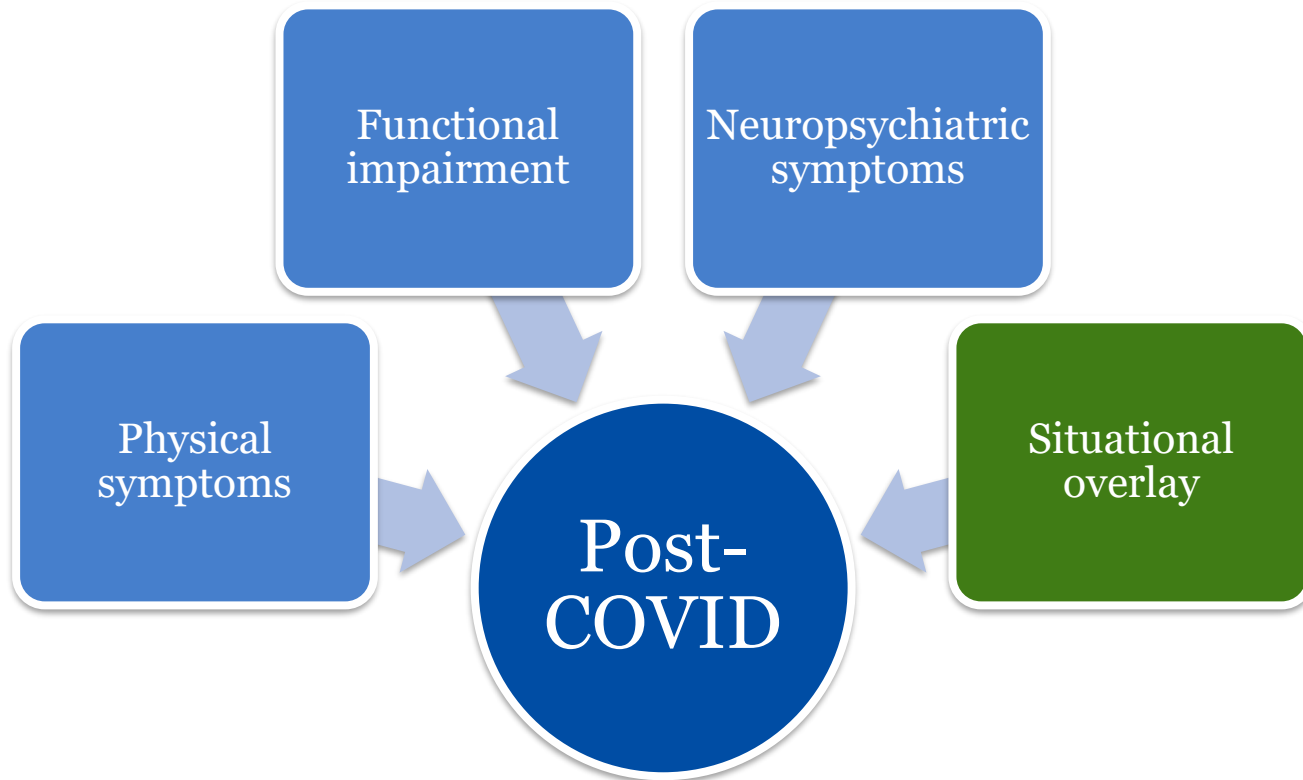


*PFT=pulmonary function tests

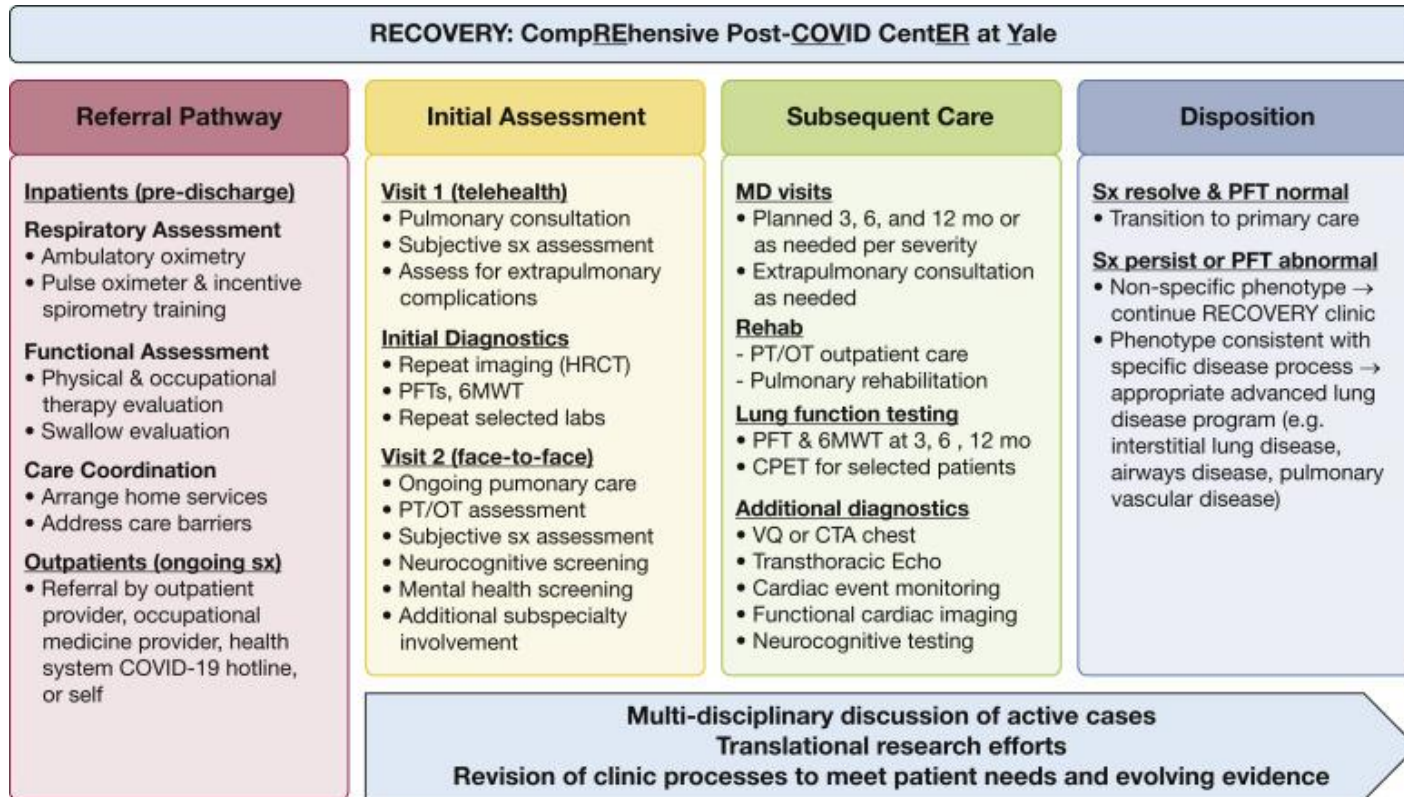
Pulmonary recovery from COVID-19 must be framed in a multi-dimensional context over a long time period:



A familiar constellation of challenges in a COVID-19 context:



Our initial clinical model:



Observations for our next iteration:

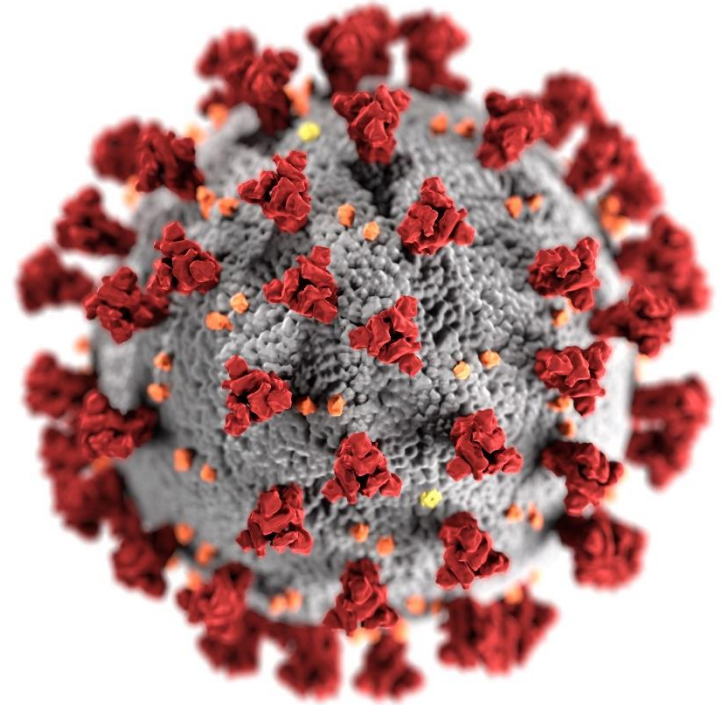
- Imaging most helpful in those with abnormal PFTs or previously extensive abnormalities
- Partnership with PT has been essential, but what is the ideal rehab structure for this population?
- Social work heavily utilized and very effective
- Neurocognitive sequelae have been common
- “Subjective/objective mismatch” is common, optimal diagnostic pathway uncertain
- Most people slowly improving – therefore supportive interventions may be more high value than serial diagnostics

Thank you

- CDC
- Yale School of Medicine, Dept of Internal Medicine, and Section of Pulmonary, Critical Care and Sleep Medicine
- Yale-New Haven Hospital
- Winchester Chest Clinic Post-COVID-19 Recovery Program team
- Collaborators across YSM/YNHH and at other institutions

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Post-COVID Neurological Symptoms: Experiences From Our Center

Allison Navis, MD

Division Neuro-Infectious Diseases

Icahn School of Medicine at Mount
Sinai



**Mount
Sinai**

A COVID Timeline

- ▶ April 2020: redeployed to serve as a medicine attending on an inpatient COVID service
- ▶ May 2020: neurology consult attending
 - COVID encephalopathy, strokes, acute disseminated encephalomyelitis (ADEM), Guillain-Barre Syndrome
- ▶ June 2020: started at the Center for Post-COVID Care at Mount Sinai Hospital
 - Expected: patients who had been hospitalized with moderate-severe COVID
 - Reality:
 - Neurology is top referral, along with pulmonology and cardiology
 - Majority of patients were not hospitalized
 - Wide range of neurological and non-neurological symptoms

- ▶ Concern for widespread neurological process?
 - ACE2 not widely expressed in brain but is expressed on vasculature
 - Case reports of COVID in brains on autopsy, but inflammatory damage greater
 - Is COVID more neurotropic than we expected?

- ▶ Neurological syndromes with objective deficits (e.g., mononeuropathy, brachial plexopathy) are occurring, but less common, and being referred to outside neurologists

*ACE2 (angiotensin-converting enzyme 2) is the functional receptor providing SARS-CoV-2 entry into human cells

Example Post-COVID Patient

- 42-year-old woman, no medical history, had COVID in April. Was sick for 2 weeks with fever, myalgias, headache and anosmia. Not hospitalized.
- Was feeling better but then noted in June she was having trouble with short-term memory and focus. Works at a non-profit, continuing to work but has cut hours and struggles.
- Also notes physical fatigue that worsens with exercise. Gets tingling sensation throughout her body but worst in hands. Also with heart rate elevations, palpitations, and shortness of breath.

Neurological Symptoms--Brain Fog

- ▶ Most common neurological symptom
- ▶ Issues with short-term memory, concentration and word-finding/speech difficulty
- ▶ No clear correlation with severity of COVID infection, age or comorbidities
- ▶ Symptoms often fluctuate, “good and bad days”
 - Fluctuations often correlate with other symptoms like fatigue and dysautonomia
- ▶ Impact on life varies: some able to still work, others on disability
- ▶ Sleep: many patients with poor sleep
- ▶ Mood: many patients experiencing depression, anxiety and/or PTSD

Approach to workup

- ▶ Initially, broad workup undertaken
- ▶ Bloodwork for contributing, reversible causes
- ▶ Neuroimaging
- ▶ Neuropsychological testing
- ▶ EEG if concern for seizures
- ▶ EMG/nerve conduction studies for paresthesias
- ▶ Rare instances, lumbar puncture

Neurological Symptoms--Headaches, Paresthesias and Dysautonomia

- ▶ Headaches
 - Often describes as constant pressure that can fluctuate in severity
 - May have migraine symptoms or not
 - Many don't have a history of headaches
- ▶ Paresthesias
 - Tingling, numbness and/or burning sensation
 - May be focal, diffuse, alternating in locations
 - Sometimes more in distal extremities (stocking-glove distribution)
- ▶ Dysautonomia
 - Fluctuating blood pressure and heart rate
 - Lightheadedness, palpitations, GI disturbances

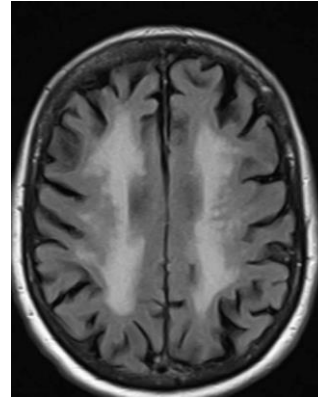
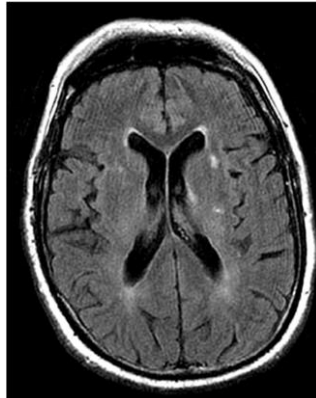
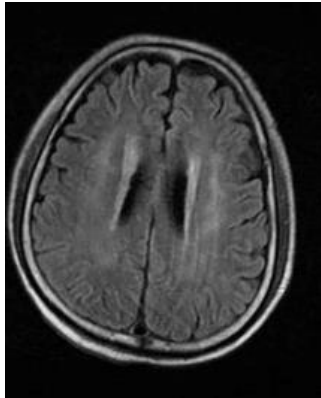
Most patients have multiple chief complaints. Rare to have someone coming in for only one issue

Approach to workup: typical findings

- ▶ Initially, broad workup undertaken
- ▶ Bloodwork for contributing, reversible causes
- ▶ Neuroimaging- **no widespread signs of damage from infection or inflammation**
- ▶ Neuropsychological testing- **variable**
- ▶ EEG if concern for seizures- **seizures do not appear to be a common complication**
- ▶ EMG for paresthesias- **negative for neuropathy in vast majority**
- ▶ Rare instances, lumbar puncture- **no major inflammatory/infectious changes**

Neuroimaging: typical findings

- ▶ Not seeing large inflammatory/infectious appearing lesions
- ▶ Not seeing many strokes, including lacunar strokes
- ▶ White matter changes (i.e., microvascular ischemic changes)
 - Very common imaging finding regardless of COVID
 - Occurs with age, vascular risk factors, migraines
 - Unless severe, often not considered clinically relevant
 - Caution in attributing to COVID without comparison imaging, or, if more severe than expected for age



Cognitive test: typical findings

- ▶ Younger patients: results more often within normal limits
 - May be some decrease from presumed prior level of function
 - May show more issues with attention
- ▶ Older adults: deficits in varying domains
 - No clear pattern, or "post-COVID cognitive profile"
 - COVID unmasking underlying cognitive impairment versus causing
- ▶ Reports often comment on mood (depression, anxiety, PTSD), sleep and fatigue as potential contributing factors
- ▶ **Brain Fog ≠ Dementia** for most people
 - Does not mean cognitive changes are not present and interfering with life

What else may be occurring?
Our evolving understanding

What may be occurring?

- ▶ Damage to central nervous system (CNS)?
 - Lack of evidence to support/refute
 - Unlikely widespread CNS infection. Role of vasculature?
- ▶ Peripheral nervous system may be affected
 - Much more vulnerable to systemic insults than central nervous system
 - Presence of small fiber neuropathy?
 - Small fiber neuropathy leading to dysautonomia?
- ▶ Other, possibilities:
 - Postural orthostatic tachycardia syndrome (POTS)
 - Hyperadrenergic POTS relating to excessive catecholamines?
 - Myalgic encephalomyelitis/chronic fatigue syndrome (MECFS) like process?

▶ Small fiber neuropathy

- Paresthesias
- Dysautonomia/autonomic neuropathy
- Chronic pain syndromes
- Fatigue?

▶ POTS

- Dysautonomia (orthostasis and tachycardia)
- Headaches
- Fatigue/ generalized weakness
- Paresthesias
- Brain fog

▶ MECFS

- Overwhelming fatigue, not improved by rest
- Post-exertional malaise
- Associated with orthostatic intolerance, pain, poor sleep and brain fog

Current Approach to Workup and Management

History

- ▶ Symptoms and their correlation
 - If multiple symptoms, do they fit with a larger diagnosis?
- ▶ Severity of COVID
 - Associated complications, cytokine storm, hypoxia
- ▶ Age and medical comorbidities of patient
- ▶ Impact of symptoms on ability to work and/or activities of daily living
- ▶ FOCAL neurological deficits or symptoms
- ▶ Sleep
- ▶ Mood

Workup--often aimed to look for contributing factors

- ▶ Bloodwork
 - TSH, Vitamin B12 and Vitamin D
 - HIV, RPR, thiamine, folate (if severe cognitive deterioration)
 - Hemoglobin A1c if neuropathy
- ▶ Imaging- MRI Brain (or CT Head)

| Consider Imaging: | Can Consider Holding Imaging: |
|--|---|
| <ul style="list-style-type: none">• Moderate-Severe COVID• Over 50 years of age• Medical comorbidities/risk factors• Impact on job or iADLs• Focal neurological deficits or symptoms | <ul style="list-style-type: none">• Not hospitalized/no complications with COVID• Less than 50 years of age• Otherwise healthy• Correlation with other symptoms, has “good days” |

- ▶ Neuropsychological Testing
 - Can be helpful in highlighting if/what deficits present as well as potential contributing factors

Workup

- ▶ EEG: if episodes of altered consciousness, seizure-like activity
- ▶ Lumbar puncture: only in cases of severe cognitive deterioration or other concerning neurological deficits.
- ▶ EMG: for neuropathy. Normal in small fiber neuropathy
- ▶ Skin biopsy for small fiber neuropathy- confirms diagnosis. Doesn't change management
- ▶ Autonomic function/tilt table testing- if concern for POTS

Likely okay to do a small, focused workup. Extensive testing has not been helpful in vast majority of patients.

Treatment: mostly symptomatic and supportive

- ▶ Brain fog:
 - No specific treatment
 - Address any abnormalities in bloodwork
 - Address contributing factors
 - If attention is major issue: Atomoxetine, dextroamphetamine/amphetamine, methylphenidate, modafinil
- ▶ Dysautonomia:
 - Hydration, increase salt intake, compression stockings
 - Meditation, breathwork
 - POTS: consider adding in midodrine or fludrocortisone
 - Hyperadrenergic POTS: beta-blocker
- ▶ Small fiber neuropathy:
 - Address any abnormalities in bloodwork
 - Symptomatic treatment of paresthesias: gabapentin, pregabalin, tricyclics, duloxetine
 - Dysautonomia as above
- ▶ Fatigue:
 - Treat associated symptoms as above
 - Pacing of exercise: low-impact, short duration exercise with gradual increase. Do not push to recondition quickly

Other critical factors

- ▶ Sleep:
 - Sleep hygiene
 - Assess for possible sleep apnea
 - Sleep aids: melatonin, mirtazapine, gabapentin or amitriptyline (if paresthesias or headaches also present)

- ▶ Mental Health:
 - Critical to address while not being dismissive
 - May be “the result of”, not the primary cause of symptoms.
 - Depression, anxiety and PTSD can affect cognition
 - Something we can act on
 - Anti-depressants like duloxetine or venlafaxine may be beneficial in also treating paresthesias and/or headaches

Conclusion

- ▶ Many neurological symptoms present in post-COVID patients
- ▶ Many symptoms may correlate, important to get broad history
- ▶ So far, diagnostic workup is not providing much information
 - Likely okay to do less testing, unless red-flag symptoms present
 - Important to not over-interpret things like imaging
- ▶ Treatment is supportive and symptomatic
 - We don't have medications to “cure” neurological damage
- ▶ Multi-disciplinary approach with post-COVID experience is critical
- ▶ We don't know what is causing symptoms, but that does not mean this is not real.
- ▶ Reassurance. Patients can/do get better.

To Ask a Question

- Using the Zoom Webinar System
 - Click on the “Q&A” button.
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 - Submit your question.
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- **When:** A few hours after the live call
- **What:** Video recording
- **Where:** On the COCA Call webpage at https://emergency.cdc.gov/coca/calls/2021/callinfo_012821.asp

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CDC Clinician Outreach
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COCA Learn
CDC Clinician Outreach
and Communication Activity

Monthly newsletter that provides information on CDC training opportunities, conference and training resources, the COCA Partner Spotlight, and the Clinician Corner.



The logo for Clinical Action features a red horizontal bar with the text "Clinical Action" in white. To the left of the bar are four square icons: a white eye in a blue circle, a white stethoscope in a red circle, a white syringe in a green circle, and a white biohazard symbol in an orange circle.

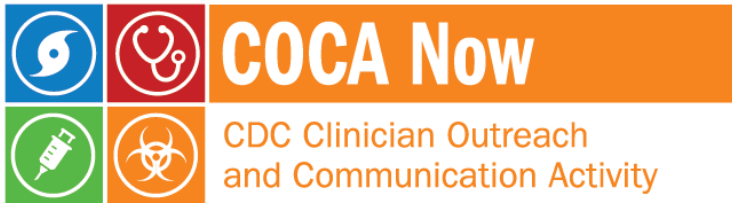
Clinical Action
CDC Clinician Outreach
and Communication Activity

As-needed messages that provide specific, immediate action clinicians should take. Contains comprehensive CDC guidance so clinicians can easily follow recommended actions.

COCA Products & Services



Monthly newsletter providing updates on emergency preparedness and response topics, emerging public health threat literature, resources for health professionals, and additional information important during public health emergencies and disasters.



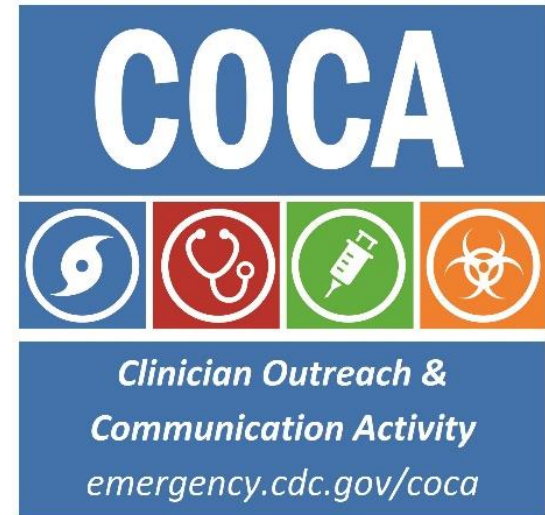
Informs clinicians of new CDC resources and guidance related to emergency preparedness and response. This email is sent as soon as possible after CDC publishes new content.



CDC's primary method of sharing information about urgent public health incidents with public information officers; federal, state, territorial, and local public health practitioners; clinicians; and public health laboratories.

Join COCA's Mailing List

- **Receive information about:**
 - Upcoming COCA Calls
 - Health Alert Network (HAN) messages
 - CDC emergency response activations
 - Emerging public health threats
 - Emergency preparedness and response conferences
 - Training opportunities



emergency.cdc.gov/coca/subscribe.asp

Join Us On Facebook!



The screenshot shows the Facebook profile for COCA (CDC Clinician Outreach and Communication Activity). The profile picture features a group of six diverse healthcare professionals (three women and three men) in various medical attire (scrubs, lab coats, business attire) smiling against a blue background. The cover photo is the same image.

COCA
CDC Clinician Outreach and Communication Activity - COCA ✓
@CDCClinicianOutreachAndCommunicationActivity

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Government Organization in Atlanta, Georgia
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COCA CDC Clinician Outreach and Communication Activity - COCA shared their event.
October 31 at 1:18pm · 🌐

Clinicians, you can earn FREE CE with this COCA Call! Join us for this COCA Call November 7, 2017 at 2:00PM.

Clifton Rd. NE
Houston

Thank you for joining us today!



emergency.cdc.gov/coca