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# Documenting Long COVID for Disability Determination

Substance Abuse and Mental Health Services Administration  
(SAMHSA) SOAR Technical Assistance (TA) Center  
Policy Research Associates, Inc.

December 8, 2022



**SAMHSA**  
Substance Abuse and Mental Health  
Services Administration

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# Purpose and Objectives

- Learn about the impact of COVID-19 infection and how it can lead to Long COVID disability impairment (physical and mental)
- Understand the impact of Long COVID impairment on the usual disability determination process
- Know how to represent SOAR applicants with Long COVID related impairment(s)

# Agenda

## Presenters

- **Dr. J. Scott Pritchard**, D.O., Lead Medical Consultant, Oregon Disability Determination Services (DDS), Salem, Oregon
- **Jessica Stoudmire**, MSW, SOAR Benefits Service Coordinator, Veterans Leadership Program (VLP), Pittsburgh, Pennsylvania
- **SOAR-assisted SSI Beneficiary**, Pittsburgh, Pennsylvania
- **Julie Kujath**, Nevada DDS Claims Examiner, Las Vegas, Nevada

## Questions and Answers

- Facilitated by the SAMHSA SOAR TA Center

# COVID-19 Long Haul: A Twenty-First Century Post Viral Syndrome

J. Scott Pritchard, DO  
Lead Medical Consultant  
Division of Disability Determination Services  
Salem, Oregon

December 8, 2022



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# What is COVID-19

- Novel (Co)rona (Vi)rus – (ID) in 2019
- SARS-CoV– 2 -
  - a family of Coronavirus typically present with upper respiratory symptoms including;
    - sore throat, sinus infections, mild cough to severe PNA and respiratory failure.
    - Coronavirus is a large family of viruses that infect specifically humans or animals. They are named for their corona-like(crown) appearance.
    - CoV – 1 &2 are pathogenic and cause Severe Acute Respiratory Syndromes.



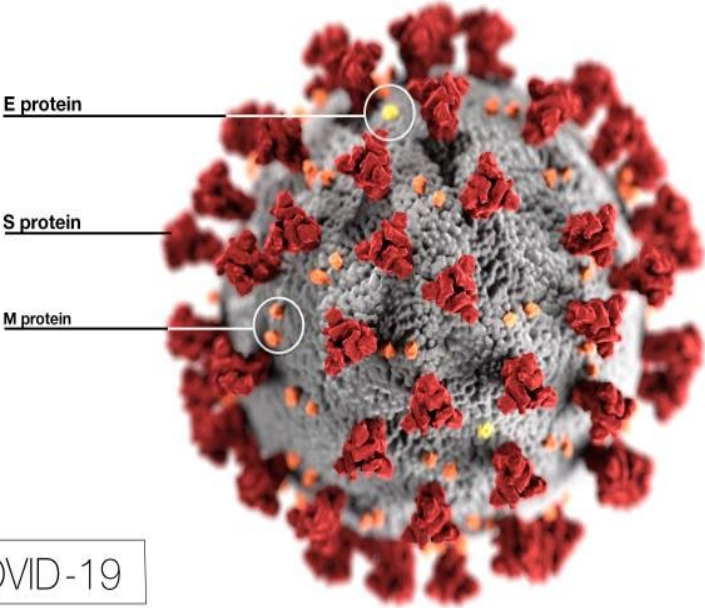
# Symptoms

## Onset:

2 – 14 days after  
exposure to virus

- Fever or chills
- Cough
- Shortness of breath
- Fatigue
- Myalgias (muscle aches and pains)
- Sore throat
- Congestion or runny nose

# COVID-19 Cell



# What is Long COVID?

- CDC definition – a range of new, recurrent or ongoing health problems people can experience four or more weeks after initial SARS – CoV- 2 infection.
- NICE – UK – symptomatic individuals from 4 – 12 weeks. Post COVID syndrome – 12 weeks after acute infection.
- Long COVID is now a condition protected by the Americans with Disability Act(ADA)

## United States

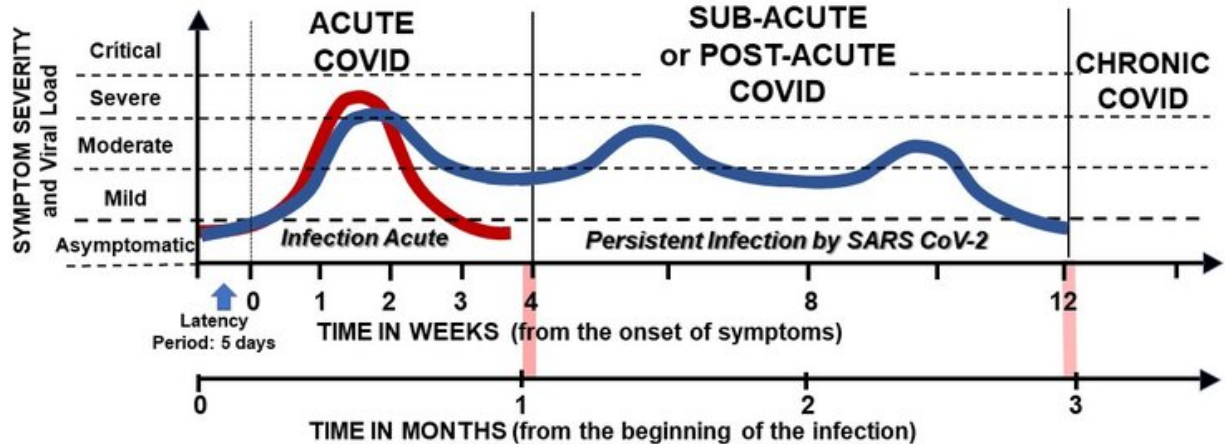
- 80 million infected
- 1 million deaths
- Long COVID prevalence
  - 10% to 30% of COVID cases
  - 8 to 24 million

## World

- 500 million infected
- 6 million deaths
- Long COVID prevalence
  - 10% to 30% of COVID cases
  - 50 to 150 million

# Acute COVID and Sub-Acute Graph

Figure 2  
ACUTE COVID AND SUB-ACUTE OR POST-ACUTE COVID



Source: Aguirre Chang, Gustavo and Trujillo, Aurora. Sub-Acute and Chronic COVID. Research Gate. September 15, 2020.

# Who is Likely to Get Long COVID?

- The true frequency and severity is unknown
  - Occurs with mild acute illness or even those that were asymptomatic
  - All ages: most common ages 35 to 69
  - Women > Men
- The risk factors and biological associations are not well understood, i.e.) SARS – CoV – 2, Epstein Barr Viremia (EBV), Type 2 Diabetes Mellitus, Coronary Artery Disease (CAD), reactivation of other viruses and autoantibodies

# Pathophysiology

- Persistent virus or viral remnants causing chronic inflammation
- Autoimmunity – an acute respiratory infection(s) can induce autoimmunity in some. This is difficult to reduce.
- Dysregulated gut microbiome, dysbiosis and latent reactivation of viruses such as Epstein-Barr (Myalgic Encephalomyelitis (ME)/Chronic Fatigue Syndrome (CFS). [See Social Security Ruling (SSR) 14-1p for evaluating CFS]
- Persistent viral replication
- Residual organ damage from acute infection
- Post-hospital or ICU syndromes
- Mitochondrial disease impact

# Characteristic Persistent Symptoms

## Exertional/Physical

- Pain (muscle, chest, joint, head)
- Fatigue
- Chest tightness
- Palpitations/Tachycardia
- Cough
- Breathlessness
- Gastrointestinal issues
- Anosmia (loss of smell)
- Nerve abnormalities

## Non-Exertional/Mental

- Depression
- Anxiety
- Memory issues
- Loss of concentration
- Brain fog
- Sleep disruption
- Post-trauma



# What is Known About COVID Symptoms?

- Intermittent in nature
- Often very difficult to discern the complex of overlapping symptoms from other impairments
- Tend to cluster during periods of improvement or worsening
- Worsening of symptoms typically occurs after periods of PEM (post-exertional malaise) and stress.
  - Malaise (feeling uncomfortable, ill, or lack of energy that can't be explained)

# COVID Vaccination

- The risk of long haul COVID is 50% less in individuals who are fully vaccinated
- Side effects are typically more pronounced and last longer than the general population
- After vaccination
  - Most report no change in symptoms
  - Minority of those receiving the vaccine improve
  - Smaller minority get worse



# Common Disorders Related to Long COVID Syndrome

- Post-Exertional Malaise (PEM)
- Cognitive Impairment (Brain Fog)
- Dysautonomia (Automatic Nervous System)
- POTS (Postural Orthostatic Tachycardia Syndrome)
- Small Fiber Neuropathy (SFN)
- Mast Cell Activation Syndrome
- Mitochondrial Dysfunction

# Post-Exertional Malaise (PEM)

Hallmark symptoms  
of syndrome  
impacting multiple  
body systems

Increased or mental exertion on a “good day” followed by severe exhaustion or worsening, requiring several days/weeks to recover

Disabling exhaustion out of proportion to the effort exerted

Triggered by physical activity (bathing, stress, cognitive activities)

Onset delayed by 12 to 72 hours. Severity unpredictable.

Not fatigue – feeling of weariness, tiredness, or lack of energy

Individuals can meet criteria for Chronic Fatigue Syndrome (CFS)

# Cognitive Impairment (Brain Fog)

- Primary cognitive symptoms
- Presentation like post-concussion syndrome

Word retrieval

Working memory

Reasoning

Problem solving

Attention

Executive functioning

Spatial planning

# Dysautonomia

- Dysfunction of the autonomic nervous system
- POTS (Postural Orthostatic Tachycardia Syndrome)
  - lightheadedness, chest pain, dyspnea, shaking
  - heart increases  $> 30$  beats per minute or  $> 120$  beats per minute within the first 10 minutes of standing (tilt table test)
- Individuals with long haul COVID often have symptoms suggestive of dysautonomia

# Small Fiber Neuropathy (SFN)

- Small unmyelinated C fibers and thinly myelinated A-delta fibers
- Mediate pain, thermal sensation, autonomic burning, prickling, shooting/aching pain
- Dizzy when standing
- Abnormal sweating, palpitations, dry mouth, and urinary dysfunction

# Mast Cell Activation Syndrome

Irregular mast cell  
activation with  
episodic symptoms

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



# Mitochondrial Dysfunction

- SARS CoV -2 RNA targets the mitochondrial matrix and disrupts normal function:
  - decreased energy production
  - decreased anti-viral signaling and immune response
  - hijacked for viral replication
  - increases inflammatory response
  - impairs the ability to support immune response
  - loss of mitochondrial integrity and death

# Thank You

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# SOAR Provider Perspective: Assisting Veterans with Long COVID Impairment

Jessica Stoudmire, MSW  
SOAR Benefits Service Coordinator,  
Veterans Leadership Program (VLP)  
Pittsburgh, Pennsylvania

December 8, 2022



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Substance Abuse and Mental Health  
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# What is Veterans Leadership Program (VLP)?

- VLP is a non-profit organization that was established 40 years ago.
- VLP assists over 7,200 veterans annually with housing, wellness, career development, and supportive services
- Services are offered throughout 30 counties in Pennsylvania, New York, and Ohio
- SOAR has been an offered service since 2017
  - 100% success rate on 20+ applications!
  - To date, 2 SOAR-assisted applications with Long COVID impairment, i.e.) worsening of existing conditions, Post-hospital or Intensive Care Unit (ICU) syndromes
  - The SOAR process works!
  - We help DDS connect the dots!

Conversation  
with  
Veteran, Rob

- Life before COVID-19
- COVID-19 diagnosis and treatment
- Long COVID and daily life
- SOAR application process
- Final outcome

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Jessica Stoudmire

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# Long COVID and Disability Determination Process Considerations

Julie Kujath

Claims Examiner

Division of Disability Determination Services

Las Vegas, Nevada

December 8, 2022



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Substance Abuse and Mental Health  
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# SSA Emergency Message: 21032

- Purpose: [SSA Emergency Message \(EM\) 21032](#) provides guidance to evaluate claims with coronavirus disease 2019 (COVID-19)
- Establishing an Impairment:
  - Report of a positive viral test for SARS-CoV – 2
  - Diagnostic test with findings consistent with COVID-19, e.g.) chest X-ray with lung abnormalities
  - Diagnosis of COVID-19 with signs consistent with COVID-19, e.g.) fever, cough
  - Note: Positive antibody test does not establish COVID-19 as an impairment because a positive test could reflect other infections with Coronavirus or prior vaccination



# SSA Emergency Message: 21032

- Definition of disability must be established
- COVID-19 may meet the durational requirements
  - Long-term effects of COVID-19
  - One or more new impairments secondary to COVID
  - Worsening of existing impairments
- COVID-19 as a stand-alone impairment cannot meet a listing. It potentially can equal a listing as an unlisted impairment (primarily secondary to other body systems affected)

# SSA Emergency Message: 21032

- For example, we cannot medically equal listing 3.14 (Respiratory Failure)
  - COVID-19 causes acute respiratory failure
  - It cannot be substituted for a chronic respiratory impairment
  - 3.14 “Respiratory failure resulting from any underlying chronic respiratory disorder except Cystic Fibrosis (CF).”
- Prophylactic restrictions or limitations intended to limit exposure to COVID-19 cannot be included in the Residual Functional Capacity (RFC), e.g.) recommendation to a claimant to telework as they are at high risk for COVID-19
- Established Onset Date (EOD) may be established before or after the onset of a COVID-19 infection
- Diaries: Do not apply criteria mechanically. Use judgment to establish a longer or shorter diary for review based on the severity of impairment/restrictiveness of RFC

# Disability Determination: Long COVID Case Example

Dr. Pritchard and Julie Kujath will take us through an evaluation of an applicant with post COVID-19 signs and symptoms



# Disability Determination Process : Long COVID Evaluation

- Prior to getting COVID-19, in April 2020, the claimant reported working 50 hours per week and enjoyed traveling.
- Now she feels like she is wearing a “lead” weight around her body; after doing household chores she suffers profound exhaustion for days and her heart races on occasion.
- She has trouble finding words, staying focused, multi-tasking, and is mentally exhausted going to the store.
- She has undergone an extensive workup by a cardiologist and pulmonologist.
- She was told her symptoms were anxiety based and told: “think happy thoughts.”

# Claimant Story

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

**Does she have Long COVID syndrome?**

**What is your decision based on the evidence  
and guidance of EM 21032?**

# Thank You

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Julie Kujath

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# Questions and Answers

Please type your  
questions into the  
Q&A box.



# Additional Resources

- [SSA Emergency Message \(EM\) Evaluating Cases with Coronavirus Disease 2019 \(COVID-19\)](#)
- [SAMHSA COVID-19 Resources](#)
- [CDC Long-COVID Information and Resources](#)
- [SSA COVID-19 Updates and FAQs](#)
- [Post COVID Care Centers \(PCCCs\)](#)
- [Impact of COVID on Vulnerable Populations](#)



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